PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Living with HIV post-diagnosis: a qualitative study of the experiences of Nairobi slum residents
AUTHORS	Coast, Ernestina; Wekesa, Eliud

VERSION 1 - REVIEW

REVIEWER	Cameron Nutt Fellow, Dartmouth Center for Health Care Delivery Science Kigali, Rwanda I declare I have no competing interests.
REVIEW RETURNED	23-Dec-2012

THE STUDY

Medical anthropology and its radically contextualizing methodologies have much to offer researchers, policymakers, and advocates seeking to improve care delivery and ensure that systems truly meet the needs of patients across the life course. This study represents a useful contribution to qualitative research on the lived experience of HIV in resource-constrained urban settings. Several comments regarding background and methodology are below, mostly related to clarifications necessary for readers.

Recommend updating prevalence and antiretroviral therapy coverage figures in the first two paragraphs of the Background section (references 3 and 4). The reports cited are 2 and 4 years out of date, respectively. New data for 2011, including country-level estimates of intervention coverage for key groups discussed in the manuscript such as sex workers, are available at http://www.unaids.org/en/resources/campaigns/20121120_globalreport2012/.

Some kind of comparison or literature review about identity formation in this population prior to widespread availability of antiretroviral therapy treatment would be highly useful. A wide body of mixed-methods literature has found a dramatic reduction in stigmatization of an HIV diagnosis following the availability of ARVs across contexts, and this would seem important to note and explore.

More details on sampling methodology are needed. What is the research design/topic of the larger quantitative study mentioned? How were participants in this sub-study recruited? What was the sampling framework? How was the sample size determined – before data collection began or following response saturation?

How many interviewers conducted the study? The Methodology and Contributors sections make it appear that the first author conducted, transcribed, and translated interviews, but the discussion of social desirability bias later in the manuscript mentions training multiple additional non-clinical community interviewers. This should be clarified in the Methodology section.

I imagine that participant names have been changed for the case studies, but this is not clear from the “Ethical Considerations” section – please clarify in the text.

	The study would have greatly benefitted from the inclusion of perspectives of providers and, if possible, partners of disclosed participants. In future qualitative studies on such complex biosocial topics, would strongly recommend including diverse stakeholder groups in data collection and analysis, whether through individual in-depth interviews or focus groups.
RESULTS & CONCLUSIONS	The paper is a useful and well-written contribution, but would be strengthened by authors considering some of the following suggested revisions. The following sentence in the Discussion is somewhat misleading: “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]”. Readers may conclude from the current wording that distress/depression/low quality of life among PLWHA is more likely due to diminished sexual functioning than to poor health status, which is not what the study cited (Florence et al.) found. Associations between health status and depression were not explored by regression analysis. Would suggest revising syntax to clarify that lower sexual function scores were more likely among women in the study found to suffer from depression/irritability/anxiety, and that sexual function was not associated with indicators of health status. In the section entitled “Reactions to a diagnosis of HIV”, the vignette introducing Malaika’s quote requires more context. What does “inherited by her brother-in-law” mean for risk behavior? Given the sentence structure and its position in the manuscript, readers may be led to assume that this means exposure to forced sex; please clarify in the text. Very little is explored about the context of the two slums where the case study participants live (other than that , or about Kenya more generally (other than that homosexuality and forced sex are stigmatized). Discussion of how social networks, privacy concerns, and other key social determinants of health differ in urban slums compared to other settings where qualitative research on similar questions has been conducted would help to contextualize the findings in important ways. Recommend considering a discussion of the role of social capital in identity formation. A growing body of ethnographic and mixed-methods literature explores social capital's influence on long-term processes for PLWHA (i.e. http://www.sciencedirect.com/science/article/pii/S0277953608000506 and http://www.plosmedicine.org/article/info%3Adoi%2F10.1371%2Fjournal.pmed.1000018). More exploration of the complex decision about whether or not to bear children would be interesting if data and length allow it. Advocates have been pushing for an expansive view of the rights of PLWHA that includes the right to raise their own family and to determine the number of children they want and can provide for. This strikes me as the largest potential contribution of this article, and is relatively new territory in the literature.
REPORTING & ETHICS	Minor comment: as noted in above section, I am sure that participant names have been changed for the case studies, but this is not clear from the “Ethical Considerations” section – please clarify in the text.

REVIEWER	Holzemer, William University of California, School of Nursing
REVIEW RETURNED	17-Jan-2013

THE STUDY	Found reporting on the 41 interviews with just 3 case studies to be

	somewhat limiting; Not sure how representative the three case studies are of the 41 interviews; literature review is quite modest, and could include issues like disclosure, stigma, and ART therapy.
RESULTS & CONCLUSIONS	Felt that the manuscript should do more synthesis and less reporting of case studies; placing the findings in the context of extant literature would strengthen the manuscript.

VERSION 1 – AUTHOR RESPONSE

Reviewers comments	Action
Recommend updating prevalence and antiretroviral therapy coverage figures in the first two paragraphs of the Background section (references 3 and 4).	References updated to (UNAIDS, 2012 and NASCOP, 2011) and text updated to read “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%).” And “Seventy two percent of Kenyan adults and children with advanced HIV infection receive ARVs”
Some kind of comparison or literature review about identity formation in this population prior to widespread availability of antiretroviral therapy treatment would be highly useful. A wide body of mixed-methods literature has found a dramatic reduction in stigmatization of an HIV diagnosis following the availability of ARVs across contexts, and this would seem important to note and explore.	New text introduced, incorporating more extensive literature and relationships between disclosure and stigma pre- and post-ART roll-out. “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].”
More details on sampling methodology are needed. What is the research design/topic of the larger quantitative study mentioned? How were participants in this sub-study recruited? What was the sampling framework? How was the sample size determined – before data collection began or following response saturation?	The following text has been introduced in *Sampling and recruitment* “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].”
How many interviewers conducted the study?	The following text has been introduced in *Sampling and recruitment* “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.”
I imagine that participant names have been changed for the case studies, but this is not clear from the “Ethical Considerations” section – please	We have clarified this with the introduction of new text in *Ethical considerations*:

clarify in the text.	“Our analyses use pseudonyms for the presentation of data.”
The study would have greatly benefitted from the inclusion of perspectives of providers and, if possible, partners of disclosed participants. In future qualitative studies on such complex biosocial topics, would strongly recommend including diverse stakeholder groups in data collection and analysis, whether through individual in-depth interviews or focus groups.	This study did not interview partners of the PLWHA that we interviewed. We did, however, interview (n=14) health service providers. We have introduced this information in the methodology and now refer to these interviews in the results “Key informant interviews (n=14) were conducted with health providers.” And have introduced new text and evidence in the analyses based on healthcare provider data, including: “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.” AND “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.” AND “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.”
Very little is explored about the context of the two slums where the case study participants live (other than that , or about Kenya more generally (other than that homosexuality and forced sex are stigmatized).	New text introduced in *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] .”
Recommend considering a discussion of the role of social capital in identity formation. A growing body of ethnographic and mixed-methods literature explores social capital's influence on	We have introduced discussion of social capital in both the analyses and the discussion. New references have been introduced.

long-term processes for PLWHA	"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]."
More exploration of the complex decision about whether or not to bear children would be interesting if data and length allow it. Advocates have been pushing for an expansive view of the rights of PLWHA that includes the right to raise their own family and to determine the number of children they want and can provide for.	We agree that fertility intentions and decision-making are an under-researched issue in this population. However, for reasons of article focus (identity formation), we will not to explore this issue in-depth in this paper. Analyses of our data relating to future fertility intentions and decision-making are developed in a separate paper. We have removed reference to fertility intentions from this paper in order to focus on sexual behaviour, reflected in the title
In the section entitled "Reactions to a diagnosis of HIV", the vignette introducing Malaika's quote requires more context. What does "inherited by her brother-in-law" mean for risk behavior?	Further text has been added to Table 2 to explain "widow inheritance" "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."
Found reporting on the 41 interviews with just 3 case studies to be somewhat limiting; Not sure how representative the three case studies are of the 41 interviews;	We have introduced new text to justify our use of 3 in-depth case studies for our analyses in this paper. Whilst we agree that a different paper might draw upon evidence from a wide range of respondents, perhaps organised thematically, in this paper the focus is on the ways in which identity formation develops post-HIV diagnosis. By focusing on three purposively selected case studies we are able to develop a comparative narrative in our results that would not be possible if evidence

	were drawn from a wider number of respondents.

VERSION 2 – REVIEW

REVIEWER	Cameron Nutt Fellow, Dartmouth Center for Health Care Delivery Science Hanover, NH, USA I declare I have no competing interests.
REVIEW RETURNED	22-Mar-2013

GENERAL COMMENTS	The manuscript's discussion has been strengthened and the analysis more tightly focused. I am pleased to recommend BMJ Open accept the manuscript for publication. A few minor comments to authors are below: The text could benefit from copyediting where new text was incorporated (subject-verb agreement, etc.). On page 10, the phrase "PLWHA should be assigned a community health worker" should probably read "PLWHA were assigned". On page 13, the phrase about social capital improving treatment outcomes would benefit from a slight clarification. ART adherence is not a treatment outcome, but rather a predictor of positive outcomes. The sentence might read instead, "…facilitates retention in care and adherence to ART [38,66,68], both associated with improved treatment outcomes."