Peer counselors' role in supporting patients' adherence to ART in Ethiopia and Uganda

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Abstract

Our aim was to explore peer counselors' work and their role in supporting patients' adherence to ART in resource-limited settings in Ethiopia and Uganda. Qualitative semi-structured interviews were conducted with 79 patients, 17 peer counselors and 22 providers in ART facilities in urban and rural areas of Ethiopia and Uganda. Two main categories with related subcategories emerged from the analysis. The first main category, Peer counselors as facilitators of adherence, describes how peer counselors played an important role by acting as role models, raising awareness and being visible in the community. They were also recognized for being close to the patients while acting as a bridge to the health system. They provided patients with an opportunity to individually talk to someone who was also living with HIV, who had a positive and life-affirming attitude about their situation, and were willing to share personal stories of hope when educating and counseling their patients. The second main category, Benefits and challenges of peer counseling, deals with how peer counselors found reward in helping others while at the same time acknowledging their limitations and need of support and remuneration. Their role and function were not clearly defined within the health system and they received negligible financial and organisational support. While peer counseling is acknowledged as an essential vehicle for treatment success in ART support in sub-Saharan Africa, a formal recognition and regulation of their role should be defined. The issue of strategies for disclosure to support adherence, while avoiding or reducing stigma, also requires specific attention. We argue that the development and implementation of support to peer counselors is crucial in existing and future ART programmes, but more research is needed to further explore factors that are important to sustain and strengthen the work of peer counselors.

Keywords: adherence; antiretroviral therapy; disclosure; HIV/AIDS; peer counselors; support; sub-Saharan Africa; qualitative research

Introduction

Lifelong antiretroviral treatment (ART) has significantly improved life expectancy and turned HIV from a terminal infection to a chronic disease. The progress is however challenged by the demands on the health system to support adherence to ART (Bangsberg et al., 2001; Rosen, Fox, & Gill, 2007), in order to avoid potentially fatal treatment failure and drug resistance (Bangsberg, 2006; Chesney, 2003; Garcia de Olalla et al., 2002). The INRUD-IAA project (The International Network for the Rational Use of Drugs Initiative on Adherence to Antiretrovirals) was initiated to explore the views and experiences of patients, providers and peer counselors on adherence to ART in Ethiopia and Uganda (Gusdal et al., 2009).

The shortage of qualified medical staff in low-resource settings represents a major barrier to a scale-up of HIV services. Deployment of people living with HIV (PLWH) represents one strategy for rapid expansion of the health workforce (WHO, PEPFAR, UNAIDS, 2007). In Uganda, the basic care package of HIV services is delivered by non-specialist doctors or nurses supported by community health workers (CHW) and trained PLWH, i.e., peer counselors (Zachariaha et al., 2009). Similarly, Ethiopia has included trained CHW and PLWH in the workforce (Assefa et al., 2009). In both countries, the peer counselors provide social support and counseling for other HIV patients, mostly on a voluntary basis or with slight financial compensation (Hermann, 2009; Wouters et al., 2009).

While lack of disclosure of HIV-status to near ones is one of the most important factors to negatively affect adherence in sub-Saharan Africa (Mahajan et al., 2008; Mills et al., 2006), the safe environment created by the support of trained PLWH and HIV support groups reduced the fear of possible loss of family support and rejection in relation to disclosure within the family (Wouters et al., 2009; Zachariaha et al., 2009).

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Despite many good examples of the successful employment of peer counselors in ART programmes their role still remains to be defined as well as which factors that are associated with their successful and sustainable service (Celetti et al., 2010). There is also little information on the kind of support peer counselors need in order to pursue their work (Harris & Larsen, 2007; Marino, Simoni, & Silverstein, 2007). Our study aimed at exploring peer counselors' work and role in supporting patients' adherence as viewed by the patients, the providers and the peer counselors themselves.

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Methods

Study context

Ethiopia has 81 million inhabitants with an estimated 980,000 HIV-infected adults in 2007, and 50-100,000 new cases per year. Uganda has a population of 30 million with an estimated 940,000 HIV-infected adults in 2007 and 10-50,000 new cases per year (WHO, UNAIDS, UNICEF, 2006). In 2007, there were 210 facilities providing ART in Ethiopia and 286 in Uganda (WHO, UNAIDS, UNICEF, 2008).

This was a cross-sectional study conducted in six ART facilities in each Ethiopia and Uganda between May and August 2007. The facilities were purposefully selected among 20 facilities in each country participating in a study to determine adherence performance (Chalker et al., 2010). The facilities in Ethiopia were all governmentally run, urban hospitals. Two of them had a community network, which involved collaborations with patients' associations, patient support groups, non-governmental organizations (NGOs) and community-based volunteers. In one facility the peer counselors were particularly well-organized, receiving support both financially and from a coordinator.

In Uganda, there were both governmentally and non-governmentally run facilities, situated in both rural and urban settings. In two of them, the peer counseling programs were well-elaborated, with financial support to the peer counselors, and included a community network.

Participants and eligibility

The research team conducted a total of 118 semi-structured interviews. During two consecutive days, adherence nurses and doctors asked their visiting patients to participate in an interview. Patients were eligible if they were: a) HIV-positive; b) 18 years or older; c) on ART for six months or more; and d) willing to give informed consent.

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In Ethiopia, interviews were held with 38 patients (26 women and 12 men), 12 peer counselors, four adherence nurses and professional counselors, five medical doctors and seven pharmacists. The patients' median age was 36 years (range 24-58), and the mean duration of ART was 19 months (range 6 months-6 years).

In Uganda, 41 patients (20 women and 21 men), five peer counselors, two adherence nurses and professional counselors, two clinical officers and two medical doctors were interviewed. The patients' median age was 35 years (range 26-53), and the mean duration of ART was 23 months (range 6 months-7 years).

Data collection process and ethical considerations

The interviews were performed within the clinics by nine trained interviewers, lasted 30-90 minutes and followed a tested semi-structured guide of open-ended questions with follow-up probes as needed. While interviews with patients continued until saturation was reached in each facility, saturation of interview data from peer counselors and providers was not fully achieved in facilities where their number and availability was limited.

The interview guide (from first author) was designed to elicit information from different perspectives on patients' experiences of ART, and explore the roles of the patient, provider, peer counselor, health system and community in supporting adherence. The interviews were conducted in English, Amharic, Luganda or local languages and were audio-taped and transcribed for subsequent translation into English.

Verbal or written consent was obtained prior to each interview and interviewees' anonymity

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was guaranteed. In Ethiopia the Drug Administration and Control Authority (DACA) gave permission to conduct the interviews as part of their quality improvement processes. In Uganda approval was given by the Institutional Review Board at the Medical Faculty, Makerere University.

Data analysis

Qualitative content analysis (Graneheim & Lundman, 2004) of the interview transcripts was performed using the QSR NVivo software program (NVivo7, 2006). The material was read several times to get a general sense of the content. Coding and categorization were done inductively in several stages. First, meaning units were identified in the text material and codes were assigned to these. Codes were then compared and grouped into tentative subcategories. In the final steps, the emerging categories were further compared, reorganized and merged into two main categories. The first author (AKG) carried out the actual coding and categorization and then reviewed and discussed the emerging codes and categories with two of the co-authors (RW, GF) at regular meetings. In addition, the findings were frequently discussed with the other co-authors.

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Results

We found two main categories and related subcategories. The first main category describes how peer counselors played an important role by acting as role models, raising awareness and being visible in the community. They were also recognized for being close to the patients while acting as a bridge to the health system. The second main category deals with how peer counselors found reward in helping others while at the same time acknowledging their limitations and need of support and remuneration.

Peer counselors as facilitators of adherence

Acting as role models, raising awareness and being visible

An essential part of peer counseling, as told by the providers and peer counselors, was to help patients to create confidence in the treatment and dispel myths about illness and ART through the peer counselors' openness with their HIV-status.

If we are confident and disclose our HIV-status people will respect us. If we are shy to tell people, they will think we have a plan to infect others. In this case therefore they will stigmatize and discriminate us. If we are open, our community will support us. [Peer counselor, Ethiopia]

Several accounts from patients, peer counselors and adherence nurses reported on patients who had disclosed and whose improvement in health status reduced the fear and stigma surrounding the illness and ART in the community. Some patients in Uganda described the community's positive recognition of ARVs as it had not only improved people's health but also increased the awareness of that people did not die from ART. From a learning perspective, patients viewed peer counselors' education as more credible since they had own

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experiences of living with HIV. Peer counselors acted as role models by sharing their experiences of the positive effects of long-term adherence to ART and through their sometimes fearless attitude when being confronted with stigma. Due to ART they could live a healthy life, care for their families and pursue their studies thus challenging any existing beliefs about harmful effects of the medicines.

Being close to the patients while acting as a bridge to the health system

Peer counselors provided patients with an opportunity to individually talk to someone who was also living with HIV, who had a positive and life-affirming attitude about their situation, and were willing to share their personal stories of hope.

I was almost dead and people were preparing to mourn my death. I have risen from that and I am studying to get my first degree. I can be a good example for you. I believe the same thing can happen to you. [Peer counselor, Ethiopia]

Peer counselors shared mutual experiences on how patients felt free to talk to them in confidence as they had already gone through the same difficulties. Adherence nurses in Ethiopia spoke of how peer counselors were thought to better understand and relate on a personal level to patients' worries and practical concerns than providers did. The following account highlights some of the peer counselors' and patients' experiences of how the peer relationship worked as a link between the patients and the providers' understanding of their patients' situation.

We serve as a bridge between the ART clinic and patients. We transfer the feelings and opinions of patients to the ART clinic. Many people could not accept that they are

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HIV-positive. By sharing what we have, we try to change their attitude. [Peer counselor, Ethiopia]

The interviewees' narratives also revealed that peer counselors from the more supportive programs in both countries were engaged in practical aspects such as patients' personal hygiene, household chores, enrolling patients in food support programmes organized by NGOs and lending money to impoverished patients.

According to adherence nurses and peer counselors in less well-organized facilities, patients could feel stigmatized when visiting peer counselors if there was no secluded space to secure confidentiality. Potential stigma associated with peer counselors was also related to the issue of tracing defaulting patients. All adherence nurses in both countries engaged peer counselors when patients had difficulties with adherence or were lost to follow-up. Although peer counselors invested considerable time and effort in looking for defaulting patients, unwillingness of patients to give their right address and phone number in fear of having their HIV-status known when receiving a visit, was repeatedly mentioned by the peer counselors as a limiting factor.

Benefits and challenges of peer counseling

Reward in helping others while acknowledging limitations

The mere fact that the peer counselors were able to help others, created a meaning out of their own illness. Most peer counselors experienced encouragement and gratitude when someone they helped was doing well. In addition, while peer counselors were found to make a distinct contribution to the care and support of others, they also felt empowered to take a greater responsibility of their own care and adherence to ART.

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However, they played a complex role balancing concern and care for others alongside their own struggles living with HIV. The peer counselors frequently mentioned their limitations within a constrained health system. Their sincere concern and compassion for their fellow patients could result in frustration and emotional agony when they observed sick patients not being initiated on ART due to lack of medicines, and how tired and hungry patients waited for long hours to be counselled by a provider. An additional challenge was the narrow geographical scope of the outreach services of the urban facilities making it difficult for peer counselors to look for the defaulting patients from the rural areas, although they were perceived to be in most need of their support. None of the ART facilities extended their outreach services further than ten kilometres.

Need of support and remuneration

Peer counselors' positive influence on patients' attitude towards the illness, ART and improved adherence was recognized and valued by themselves and all adherence nurses, yet they mostly performed their work on a voluntary basis. In Uganda, the facilities were responsible for supervising the peer counselors as well as for creating guidelines and job descriptions for them. In the facilities without a coordinator of peer counselors, providers described inadequate supervision and support because of the overall lack of professional staff. As the peer counselors in Uganda were not officially recognized by the Ministry of Health they did not have a regulatory framework and, as a result, career opportunities were not formally in place. In Ethiopia, the facility or the District Health Office were responsible for the supervision. Good guidelines for team supervision existed but, according to providers and peer counselors, the staff was neither sufficient nor trained to provide good supervision. In the facility in Ethiopia with the best conditions for peer counselors they still had to cover expenses for medication and laboratory tests which were given free of charge to the other

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hospital staff.

Peer counselors in both countries had to look for support and supervision themselves and in doing so they received some training, advice as well as moral support from the staff. This was highly appreciated by the peer counselors, but almost all peer counselors still spoke of high work load, lack of transportation for reaching their patients' homes and the need for more supervision and professional support.

But the main challenge as perceived by the peer counselors was financial. Without adequate pay they could only work for a few hours per week which they saw as a threat to the sustainability of their services. Through their own initiative some of them received extra financial compensation from religious associations and non-governmental organizations when educating on HIV and ART in the community. They questioned why the government and ART programmes did not consider them as any other staff member with a proportional salary.

As long as the benefit of peer education program is recognized, we should be given proper incentive. If other people are to be encouraged to engage in this kind of activity, our problem should be solved. [Peer counselor, Uganda]

Discussion

Our findings showed that the peer counselors were important facilitators of adherence by acting as role models for other PLWH and being visible in the community. Through sharing their positive experiences of ART, they confirmed how HIV patients can live healthy, meaningful lives with HIV and ARVs and helped patients to create confidence in ART. This may reduce stigma and fear of disclosure but the stigma can also be problematic in patients' encounters with peer counselors since they are closely associated with HIV. Thus, peer counselors need to carefully consider their role in reducing versus increasing stigma for their peer patients.

Other evidence suggests that while hiding HIV-status to near ones may negatively affect adherence in sub-Saharan Africa (Mahajan et al., 2008; Mills et al., 2006), disclosure can conversely result in rejection, stigma or other potential harm (Adam, Maticka-Tyndale, & Cohen, 2003; Klitzman et al., 2004). In a study among American HIV patients, it was suggested that patients should be provided with strategies to maintain adherence in situations where disclosure of HIV-status is ill advised, and also taught skills to disclose in a manner that can help avoid stigma and discrimination (Stirrat et al., 2006). Our findings indicate that peer counselors, through their personal background and understanding of the benefits and dangers of disclosure, can support their patients in acquiring such strategies and skills. However, their work may not be effective unless the issue of confidentiality and organisational support are simultaneously attended to.

From this perspective, a concern is the absence of a clearly defined role for peer counselors, as they were not fully recognized as part of the health care team and not granted a secluded space when counseling their patients. The supervisory role of the providers also seemed

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poorly defined as peer counselors rarely received regular supervision and training, and mostly had to rely on themselves and each other when facing problems in their work. These findings are in line with a recent study from Cameroon (Yakam & Gruénais, 2009), which showed that the involvement of peer counselors within an unregulated health system contributed to confusion and conflicts. An important message from our study is thus that peer counselors' role need to be better defined in order to improve their status as member of the staff which can contribute to improved salaries. On the other hand, including peer counselors as team members may change patients' perception of them as peers which may potentially weaken the advantages peer counselors have in their close contacts with patients. This aspect was not explored in our study and has to our knowledge not received attention in previous studies. Further research is thus needed to explore implications of involving peer counselors as part of the staff team.

There are some limitations in the study. We were unable to explore experiences directly from HIV-infected persons who were lost to follow-up, as information was obtained only from patients who actually did turn up at the facility. Saturation of data was not fully reached since we did not have the opportunity to go back to the field for theoretical sampling and testing of data. A consequence of this is that we had to be more careful in our interpretations of the data and stay close to the descriptive level of the text.

Conclusion

While peer counseling is acknowledged as an essential vehicle for treatment success in ART support in sub-Saharan Africa, a formal recognition and regulation of their role should be defined. The issue of strategies for disclosure to support adherence, while avoiding or reducing stigma, also requires specific attention. Development and implementation of support

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to peer counselors is crucial in existing and future ART programmes, but more research is needed to further explore factors that are important for sustaining and strengthening the work of peer counselors.

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27 September 2010

Authors' response to comments from Referee

Re: "Peer counselors' role in supporting patients' adherence to ART in Ethiopia and Uganda"

Comments to the Authors:

I feel this is much improved since the first submission. At this stage, I have a number of specific comments and suggestions. I feel the report does need another round of revision but that overall, it can make a contribution to policy.

The abstract has some questionable logic. For example, I do not think it follows that peer counselors receive negligible financial support BECAUSE their role is not clearly defined. These seem to me separate issues. It is also not clear that they need "formal recognition" -- it seems that their role is recognized, just not fully defined and insufficiently supported. The abstract also repeats an assertion from the results which I think is misstated, regarding the stigma associated with HIV and ART, which I will discuss below. So I think on the whole the abstract needs to be sharper and do a better job of clearly summarizing the results.

Authors' reply:

Thank you for pointing out the problematic causation between negligible financial support and peer counselors' undefined role. In Abstract, as in Results, we now treat them as two separate issues.

In line with changes in Results, changes have also been made in the Abstract.

Comments to the Authors:

P. 3 of the HTML: Spell out INRUD-IAA.

What does "semi-remunerated" mean? Paid very little, I take it. That is what you should say.

Not clear what "the risk of losing family support when disclosing is less important for patients who have the social support . . ." mean? Do you mean, they are less likely to lose family support? Or that, if they do lose family support, they can cope better?

Authors' reply:

INRUD-IAA is now fully spelt out in the introduction: (*The International Network for the Rational Use of Drugs Initiative on Adherence to Antiretrovirals*) (Introduction, 1st paragraph).

"Semi-remunerated" was the term most frequently used among the interviewees but to avoid uncertainty of the word's meaning we have

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changed it into: *on a voluntary basis or with slight financial compensation* (Introduction, 2nd paragraph).

Yes, we mean that PLWH, having the social support of trained PLWH or HIV support groups, cope better with the possible loss of family support as opposed to those who do not have the support of other PLWH. To clarify this we reformulated the sentence: ...*the safe environment created by the support of trained PLWH and HIV support groups reduced the fear of possible loss of family support and rejection in relation to disclosure within the family* (Wouters et al., 2009; Zachariaha et al., 2009). (Introduction, 3rd paragraph)

Comments to the Authors:

You introduce as an issue lack of evidence on "which factors are associated with their successful and sustainable service" but you don't really address the issue of sustainability, although there is perhaps some useful information regarding success. As far as you report, none of your respondents quit or is contemplating quitting. You also raise the issue of "the kind of support peer counselors need," and while you make some assertions about this, I don't see a lot of clear evidence about it. Unless you can rework your analysis to more clearly and specifically address these questions, you should set up your results a bit differently.

Authors' reply:

Please see our reply below on the issues of sustainability and peer counselors' need of support.

Comments to the Authors:

P. 5: You say the facilities you included were "purposefully selected" but don't say how or on what basis. You introduce the concept of a "community network" but don't define or describe these. I'm afraid I don't know what it means. You also say that the peer counselors in one facility in Ethiopia are "particularly well organized" but again, it is unclear to me what this means.

Authors' reply:

In a survey on indicators of adherence within the INRUD-IAA project conducted in both Ethiopia and Uganda, 20 ART facilities in each country were ranked as having high, medium or low performance of adherence, according to defined indicators. Six facilities in each country were purposefully selected, two from each adherence performance level, for this more in-depth study. We have not included this information in the manuscript because of word limits, but we will be happy to do so if it is considered necessary.

By community network we mean collaborations between patients' associations, patient support groups, NGOs and community-based volunteers. These networks were coordinated by the facilities' peer

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counselors and providers. To clarify what we mean by “particularly well-organized” we added the following in the manuscript: *Two of them had a community network which involved collaborations with patients' associations, patient support groups, NGOs and community-based volunteers. In one facility the peer counselors were particularly well-organized, receiving support both financially and from a coordinator.* (Methods section, Study context, 2nd paragraph)

We have also added that in Uganda: *there were both governmentally and non-governmentally run facilities* which is information that we missed to include in the first submission (Methods section, Study context, 2nd paragraph).

The next paragraph speaks of the travelling time and waiting time for patients and of the patient load and human resources of each facility. Since our focus lies with peer counselors' work, we chose to remove the entire paragraph, including its table, in order to comply with the wordlimit: *[Patients' median travel time to the ART facilities was 64 minutes (range 15-169) in Ethiopia, and 89 minutes (range 35-149) in Uganda. The waiting time in the facilities was 99 (range 35-284) and 182 (range 20-392) minutes, respectively. Patient load and human resources per facility are shown in table 1.].*

Comments to the Authors:

"A total of 118 interviews were conducted." I personally don't like the passive voice.

Authors' reply:

We have changed from passive to active voice: *The research team conducted a total of 118 semi-structured interviews.* (Methods section, Participants and eligibility, 1st paragraph)

Comments to the Authors:

P. 6: As before, you say that saturation was not reached with peer counselors and providers, but you do not explain the consequences of this nor is it reflected in the results or discussion. To me, this must mean that there remain unresolved contradictions or ambiguities, but you never tell us what these are. Please explain.

Authors' reply:

We agree with the reviewer's comment and the following have been added to the Discussion section to clarify the consequences: *Saturation of data was not fully reached since we did not have the opportunity to go back to the field for theoretical sampling and testing of data. A consequence of this is that we had to be more careful in our*

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interpretations of the data and stay close to the descriptive level of the text. (Discussion section, last paragraph)

Please see also our reply on themes and theory development below.

Comments to the Authors:

P. 7: The description of data analysis remains cursory, which was an objection I had to the first submission. It is not clear whether this was done by a single person, or a group. You say "a main theme emerged," but I don't discern a single main theme. Perhaps you mean to refer to multiple themes. But I would like to see you take the analysis further and better explicate the relationships among entities, rather than just describing them. Can you begin to develop some theory about how the context in which the counselors live and work, and their experiences as peer counselors and PLWHA, affects their identity formation and the conduct of their work that goes beyond just describing the bits and pieces?

Authors' reply:

We have revised the data analysis section to clarify the analysis and the role of the authors in this process: *The material was read several times to get a general sense of the content. Coding and categorization were done inductively in several stages. First, meaning units were identified in the text material and codes were assigned to these. Codes were then compared and grouped into tentative subcategories. In the final steps, the emerging categories were further compared, reorganized and merged into two main categories. The first author (AKG) carried out the actual coding and categorization and then reviewed and discussed the emerging codes and categories with two of the co-authors (RW, GF) at regular meetings. In addition, the findings were frequently discussed with the other co-authors.* (Methods section, Data analysis)

The reviewer is right about his/her observation that there is not one single theme. In fact, we realize that using the term "theme" can misguide the reader since our analysis deals with the manifest content, i.e. it describes the visible and obvious components in the text (identified as categories), and *not* the latent content, i.e. interpretation of the underlying meaning of the text (identified as themes). We acknowledge that the material did not permit us to actual discern underlying meanings and interrelationships of the data. For this reason we have chosen to use the term "category" instead to clarify that the findings reflect the descriptive (=manifest) content of the text rather than the latent content (this explanation is based on Graneheim's and Lundman's (2004) approach to qualitative content analysis).

We have changed the first paragraph of the Results section accordingly: *We found two main categories and related subcategories. The first main category describes how peer counselors played an important role by acting as role models, raising awareness and being visible in the community. They were also recognized for being close to the patients*

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while acting as a bridge to the health system. The second main category deals with how peer counselors found reward in helping others while at the same time acknowledging their limitations and need of support and remuneration. (Results section, 1st paragraph)

Theory development, as suggested by the reviewer, needs to be discussed in relation to saturation of data (mentioned earlier). According to Strauss and Corbin (1998), creation of a theory requires both inductive and deductive approaches by e.g. theoretical sampling and testing emergent findings with additional data collection. As previously mentioned, we had to recognize certain limitations of the field work and we did not have the resources and time to go back to the field and conduct more interviews. This was the reason for applying qualitative content analysis instead of grounded theory.

Comments to the Authors:

P. 8: You use "disclosed" as an adjective to modify patients. I find this awkward, I think you should say "patients who have disclosed." In this section where you discuss peer counselors as facilitators of adherence you make several assertions about the impact of peer counselors on patients and their communities. I think it behooves you to give us a fuller description of patient perspectives on this phenomenon. It is presented more as a claim the peer counselors make about themselves.

Also, there is a logical problem. You say that it is the improvement in health status of people who have disclosed that reduces fear and stigma in the community. In the next sentence you say that education without real life examples in the community has "little influence on people's understanding, while trained PLWH were thought to have strong influence." But it is not any form of education you have credited with bringing about the change, it is merely the example of people benefiting from treatment. Either what you actually mean to argue is that peer counselors help create understanding in the community by encouraging PLWH to disclose; or you mean to make two largely unrelated points. Or perhaps you mean that the peer counselors themselves are the "disclosed patients" whose example is influential, but that is not what I thought you meant.

Authors' reply:

We have changed "disclosed patients" into *patients who had disclosed* (Results section, 1st main category, 1st subcategory).

Yes, we mean that the peer counselors themselves are the "disclosed patients" whose example is influential.

We agree that patients' experiences are not justly voiced in the manuscript. We have removed the neutral perspective: [*Mere education from providers without any real life examples in the community was considered to have little influence on people's understanding while*

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*trained PLWH were thought to have strong influence. In both the community and in the ART facilities, peer counselors provided health education.] and instead added the following in order to bring forward patients' perspectives: *Some patients in Uganda described the community's positive recognition of ARVs as it had not only improved people's health but also increased the awareness of that people did not die of ART. From a learning perspective, patients viewed peer counselors' education as more credible since they had own experiences of living with HIV.* (Results section, 1st main category, 1st subcategory)*

Comments to the Authors:

P. 10: "peer counselors from the stronger . . . programs . . . were engaged in . . . personal hygiene, various household chores," etc. This is unclear. What is it about the "stronger" programs that makes this possible? And what do you mean by "engagement"? Do the peer counselors actually bathe the people and do household chores, etc. If they lend money, where do they get it from? Ditto for the food support. Is the availability of loans and food necessarily a function of a "stronger" peer counselor program, or are these just separate resources that the clinic happens to have? What's the connection?

Authors' reply:

By stronger peer counselor programmes we mean a functioning community network (described earlier) along with some financial support, although very modest, to the peer counselors.

We would like to clarify that no extra resources in terms of food support and loans were available from the clinics. Instead, peer counselors had to find other solutions, and they sometimes supported patients with money from their own pockets.

By food support we mean that the peer counselors prepared food for those who did not have family and, if needed, helped patients to get enrolled in food support programmes organized by NGOs. However, the programmes were often unable to take on new beneficiaries due to lack of resources, and patients already part of the programmes were not necessarily the poorest ones. An important task for the peer counselors was thus to communicate with the NGOs in the selection procedure of patients to ensure that those in most need got access to the food support programmes.

In the manuscript we have clarified what we mean by food support by adding: *enrolling patients in food support programmes organized by NGOs* and removed a line on other tasks: *[To a varying degree, their care also included referral of PLWH, rapid HIV-testing and dispensing of drugs.]* (Results section, 1st main category, 2nd subcategory)

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Comments to the Authors:

P. 10: It's a bit confusing what you mean by saying the peer counselors are "associated" with the stigma attached to HIV and ART. While it is understandable that people don't want to be counseled without a private space, is it the case that people visiting these clinics can conceal their HIV status UNLESS they are seen speaking with a peer counselor? I would have thought these were specialty clinics in the first place. If that is not correct, please clarify.

Also, in the following paragraph, it is not clear what patients' reluctance to give their correct address and phone number has to do with the "stigma associated with peer counselors." I should think this results from the stigma the patients feel associated with their own HIV status, not any stigmatization of the peer counselors. It wouldn't matter who was assigned to trace dropouts.

Authors' reply:

All of the ART facilities in Ethiopia, and all but one in Uganda, were part of a larger referral, zonal or regional hospital. Patients' HIV status could thus be revealed if speaking to a person known as a peer counselor.

We would like to clarify that the stigma associated with peer counselors tracing dropouts was based on the peer counselors' experiences. Patients included in this study did not talk of home visits since they came to the clinic for treatment. Patients who dropped out of treatment and received home visits were not included. We are aware of that the perspective of the patients who did not visit the clinic is missing here since they were not in the facility for us to interview, but we still believe that peer counselors' experiences on patients' reactions to their calls illuminate important aspects of stigma associated with peer counselors. In the Results section we have added: *mentioned by the peer counselors* so that there is no doubt regarding whose perspectives we describe (Results section, 1st main category, 2nd subcategory).

It should also be added that visits by a nurse or physician were rarely connected with ART since their calls normally concerned other health matters.

The following text on stigma associated with peer counselors has been condensed into fewer words in order to comply with the wordlimit: *[The accounts also demonstrated how peer counseling gave rise to ambivalent experiences. They were acknowledged for their closeness to the patients, but were nevertheless associated with the stigma attached to HIV and ART. In the ART facilities with weak peer counseling programs, they were assigned to share office with the laboratory staff or the data clerks or even counselled their patients outside with other people around. According to the adherence nurses and peer counselors, this lack of confidentiality represented a major obstacle to their work as many patients did not want to be seen with the peer counselors in the open. The stigma associated with peer counselors also became evident when peer counselors and adherence nurses commented on the issue of tracing defaulting patients.]* and is

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replaced with: *According to adherence nurses and peer counselors in less well-organized facilities, patients could feel stigmatized when visiting peer counselors if there was no secluded space to secure confidentiality. Potential stigma associated with peer counselors was also related to the issue of tracing defaulting patients.* (Results section, 1st main category, 2nd subcategory)

Comments to the Authors:

P. 11: I think the term "catchment area" is misused. People from rural areas must be within the facilities' catchment area, or they would not be going there in the first place. What you mean is the narrow geographic scope of outreach services. And why can't the peer counselors travel more than 10 km? Are they forbidden to do so?

Authors' reply:

Yes, by narrow catchment area we mean the narrow geographical scope of the outreach services and we have changed this in the manuscript (Results section, 2nd main category, 1st subcategory).

Patients coming into the facilities could be travelling from further away than 10 km. For the outreach services, peer counselors were instructed to move only within 10 km of the ART facilities, a distance within which transport expenses were covered. If the peer counselors chose to travel further out they had to pay the travelling expenses themselves.

Comments to the Authors:

Again, you report that the peer counselors would like to receive better remuneration, but you fail to make an argument for why funders should make this a priority, since as far as we can tell the peer counselors are doing the work effectively with or without pay. It may seem just to pay them but you do not make an argument that it would make them more effective.

Authors' reply:

To make an argument for the sustainability of peer counselors' services and their need of organizational support and remuneration, we have added: *In Uganda, the facilities were responsible for supervising the peer counselors as well as for creating guidelines and job descriptions for them. In the facilities without a coordinator of peer counselors, providers described inadequate supervision and support because of the overall lack of professional staff. As the peer counselors in Uganda were not officially recognized by the Ministry of Health they did not have a regulatory framework and, as a result, career opportunities were not formally in place. In Ethiopia, the facility or the District Health Office were responsible for the supervision. Good guidelines for team supervision existed but, according to providers and peer counselors, the staff were neither sufficient nor trained to provide good supervision. In the facility in Ethiopia with the best conditions for peer counselors they still had to cover expenses for medication and*

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laboratory tests which were given free of charge to the other hospital staff.

Peer counselors in both countries had to look for support and supervision themselves and in doing so they received some training, advice as well as moral support from the staff. This was highly appreciated by the peer counselors, but almost all peer counselors still spoke of high work load, lack of transportation for reaching their patients' homes and the need for more supervision and professional support.

But the main challenge as perceived by the peer counselors was financial. Without adequate pay they could only work for a few hours per week which they saw as a threat to the sustainability of their services. Through their own initiative some of them received extra financial compensation from religious associations and NGOs when educating on HIV and ART in the community. They questioned why the government and ART programmes did not consider them as any other staff member with a proportional salary. (Results section, 2nd main category, 2nd subcategory)

Comments to the Authors:

P 13: Finally, there are observations which appear for the first time in the discussion. You need to reorganize and get these into the results with proper depth and context. This begins with the second sentence: "They disclosed their status publicly, despite possible discrimination from their own families." Clearly, this calls for presentation in the results. What motivated them to take this risk? Did some of them in fact experience discrimination from their own families? How did they cope with this? Did they win their family members over in time? It seems much too important for a throwaway line.

Authors' reply:

We agree that the line "They disclosed their status publicly, despite possible discrimination from their own families." is too important to wedge into the Discussion without being presented in the Results. It should be emphasized that the "possible discrimination" is an interpretation by the authors, rather than an actual finding, since many patients' accounted of their fear of disclosing to near ones. However, the available data do not allow us to explore this in more depth, so we chose to remove the line [*They disclosed their status publicly, despite possible subsequent discrimination from their own families.*] from the manuscript.

Comments to the Authors:

You also again mention the tension, if that's the word, between the potential for peer counselors to reduce stigma and fear through their example, and the

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potential to "blow people's cover" by being seen with them. Again, I think this calls for more exposition in the results, particularly from the patients' point of view which is generally underdeveloped. You report, in fact, that the bulk of your interviewees were patients, yet you almost entirely neglect this data.

Authors' reply:

Please see our earlier reply on stigma. As previously mentioned we are aware of that patients' perspectives are missing here, and this clearly needs further exploration. For reasons mentioned earlier this was unfortunately not possible in this study, and this has also been mentioned as a weakness of the study (Discussion, last paragraph).

Comments to the Authors:

You claim in the next paragraph that the work of peer counselors in helping patients acquire strategies and skills to manage disclosure and non-disclosure "may not be effective unless the issues of confidentiality and organizational support are simultaneously attended to." You have made some presentation of the confidentiality issue, but none concerning organizational support. What kind of organizational support do they need to be effective in this? I really haven't seen any evidence regarding this question at all.

You also say that "The supervisory role of the providers also seemed poorly defined," and that the PCs receive little supervision and training and have to rely on each other. Again, the discussion is not the place to introduce these issues! They must be presented and elaborated in the results.

Authors' reply:

Please see our previous reply on sustainability and peer counselors' need of organizational support and remuneration.

Comments to the Authors:

You repeat the non-saturation of data but again fail to explain what this means for your results.

Authors' reply:

Please see our previous reply on saturation of data, a paragraph has been added to the discussion.

Comments to the Authors:

So, I appreciate the effort and the progress you have made but I feel you still have work to do. I am left wanting more, so I hope we can have it.

Authors' reply:

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We hope that our revised version of the manuscript will meet these expectations.

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