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

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Our aim was to explore peer counselors’ work and their role in supporting patients’ adherence to antiretroviral treatment (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 organizational 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 are crucial in existing and future ART programs, 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 International Network for the Rational Use of Drugs Initiative on Adherence to Antiretrovirals project (INRUD-IAA) 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 (Asselt, Jerene, Lulseged, Ooms, & van Damme, 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 et al., 2009; Wouters, van Loon, van Rensburg, & Meulemans, 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).

Despite many good examples of the successful employment of peer counselors in ART programs 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.

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 (UNAIDS, 2008). 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: (1) HIV positive; (2) 18 years or older; (3) on ART for six months or more; and (4) willing to give informed consent.

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 six months to six 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 six months to seven 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 were 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 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 and GF) at regular meetings. In addition, the findings were frequently discussed with the other co-authors.

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 antiretrovirals (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 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 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 programs 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.

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 counseled 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 10 kilometers.

Need of support and remuneration

Peer counselors’ positive influence on patients' attitude toward 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 was 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 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 programs 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 vs. 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 to 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 organizational 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 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 & Grénais, 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 to peer counselors are crucial in existing and future ART programs, 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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