Policy Brief

Medicines for Life: Clients and Providers in Uganda
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Executive Summary

This Ph.D. research describes and analyses clients' and providers' experiences with distribution of and access to ARV in four different treatment centres in Uganda (rural and urban, public and NGO) and suggestions are made concerning improvements of programs, in particular with regard to a) communication and confidentiality, and b) the role of volunteers in ART programs. Treatment programs in Uganda are facing serious challenges concerning counselling and confidentiality, not only with regard to people's sero-status, but even more so with regard to intimate and personal aspects of the clients' lives. Intimate aspects of people's lives are being monitored the staff in the treatment programs, and they are often being debated openly in the treatment centres while other members of staff clients are present. Recommendations are made concerning the physical structure of treatment centres, how to improve on counselling, and how to train volunteers in counselling and respect for confidentiality.

Introduction

Jenipher Twebaze's Ph.D. research focused on the efforts made by people to access and live with lifelong treatment, and how people with different social and economic resources are recognized, supported and hindered by the various care programs distributing ART in Uganda. An analysis is made of clients' and providers' experiences with distribution of and access to ARV and suggestions are made concerning improvements of programs, in particular with regard to a) communication and confidentiality, and b) the role of volunteers in ART programs.

Background

The HIV epidemic has now entered its fourth decade in Uganda. A number of changes and improvements have been made in those years. In particular, there has been a significant increase in the lifespan of people with HIV thanks to ART. The expansion of ART happened dramatically. From 2003 to 2010 there was a tenfold increase in people on ART thanks to resources from many different donors (especially the Global Find to Fight AIDS and PEPFAR) and numerous different treatment programmes, both public, para-statal, NGO and faith-based.

Since the early programmes in Uganda in the late 1980s, secrecy and confidentiality were assured to people who would volunteer to come for HIV counselling and testing. However, as time passed people were told to open up about being HIV positive. Accessing material, medical, social and psychological support also required that one's sero-status was made known to others. As ART started becoming available around the turn of the centre, 'opening up' became even more of a norm. Still confidentiality remains the 'catchword' with which programs attract people to HIV testing. This has created a paradox for health workers as well as clients.

The study was carried out in two districts (one urban and one rural), and two treatment centres in each district (one public and one NGO). The researcher followed both health workers and clients in all locations in these treatment centres: consultation, counselling, laboratory, waiting area, and pharmacy. In addition the researcher lived in the community and interviewed and followed a number of clients in their daily lives outside of the treatment centre.

Results

When following people's experience of trying to access and live with ART, confidentiality turned out to be one of the most important issues, i.e., one of the things that clients in treatment programs were most concerned about. All treatment programs promise confidentiality while at the same time they encourage people to open up about sero-status. Trained health workers and volunteers/expert clients have very different ways of handling this paradox. In reality confidentiality is hardly ever realized in the four treatment programs studied. This paradox of promising confidentiality while encouraging openness and at the same time working in physical surroundings that makes it practically impossible to realize confidentiality, affects clients' trust in health providers. It also influences both health workers' and clients understanding of counselling which only rarely is carried out in accordance with guidelines on counselling. In addition a large proportion of the staff in many treatment programmes are volunteers, who are themselves sero-positive and on treatment, and who also influence how confidentiality and counselling are practiced.

Lack of privacy and confidentiality in treatment centres was manifested in many ways in all treatment locations in the study, starting from the waiting area to exiting the treatment centre. In addition. Outside of the treatment centre, however, people do manage to control information about their situation much more successfully than they do in the treatment centre. In the thesis, these contradictions and dilemmas of confidentiality are described and discussed. More generally speaking the thesis is about clients' and providers' attempts to control information in different settings and social situations.

Choosing to test: In spite of ARV now being widely available to people with HIV in Uganda then it is still an extremely difficult decision to test for HIV. People feel certain that they are facing an uncertain future in case they are HIV positive. Their uncertainty is related fears about the efficacy and sustainability of the treatment. They also still feel uncertain about how people close to them will react and what will happen to their marriages or relationships to partners and other relatives.

Joining a program: The information that people try to control in the early stages of testing and joining treatment programs is on the one hand their sero-status, and on the other hand that they were 'unable' or too weak to prevent themselves from getting infected. The medico-moral discourse of HIV in the first decade of the new century indicates that HIV is something that can be prevented if one chooses to take the right actions. It is therefore still very difficult to face and to open up about the fact that one did not manage to control one's actions.

Being a client: Inside the treatment centre, the secret that people try to control is a different one. The question is no longer simply whether one is HIV positive or not. Instead, a wide range of intimate issues in people's lives is at stake. The limit between what can be said and what cannot be said about that one knows about others is completely different within the treatment centres than outside of the treatment centres and people are made to reveal intimate issues about their lives while many other people are present. An on-going negotiation about what is a 'good' and what is a 'bad' patient is taking place through this exchange of information between providers and clients about people's personal lives. These negotiations are among other things about defining oneself as a good person, who happens to also be HIV positive, and possibly to obtain access to a status as community volunteer of the program with all that this entails in terms of benefits from working for the program.

In the communities: When people return to their communities the content of the secret once more changes. At home people have more control over intimate and personal issues in their lives than they do in the treatment centre. Once more, the secret concerns whether people know they are HIV positive at all. But in addition to this, there are in many cases where the person has not disclosed their HIV status, another important aspect of the secret: Does the other person know that I am consciously betraying him or her?

Conclusions

In conclusion, the study shows that vast improvements can be made with regard to counselling of people on ART. Dilemmas of confidentiality and disclosure, secrecy and openness have not disappeared with ART and in some ways they have even been exacerbated by the availability of ART. The secrets have taken new forms and changed content. In some social situations it has become easier to control information about one's life and health. In other situations it has become more difficult. The secret is no longer necessarily that one is HIV positive. Because of people's lives being monitored closely while they are on ART, other intimate details about their lives end up being revealed in public. Hence, even after the arrival of an efficient medical solution to the fatal outcome of infection with the virus, HIV remains not only a medical, but also a social, moral and ethical challenge in the years to come.

Implications and Recommendations

Two main factors cause the problems of counselling and hence also of confidentiality and disclosure. These are: 1) the role of volunteers with no or limited training and who are furthermore often members of the local community, and 2) the physical facilities of treatment centres which make it difficult to realize confidentiality and carry out counselling.

It is suggested that the following steps be made:

1)

- Developing 'easy-to-understand' HIV counselling guidelines to be used by the 'good patients', i.e. volunteers who provide counselling services.
- Developing an updated counselling manual that includes counselling of clients at their homes and not only at the health facilities.
- Training of the Village Health Teams in counselling skills.

2)

- Improvements of physical facilities.
- Health providers should be encouraged to do counselling in the treatment centre compounds instead of squeezing everybody into small rooms.
- Lack of space in treatment centres can be dealt with by extending counselling services to people's homes or other places approved by Ministry of Health.
- Training of Village Health Team members in counselling skills so that they carry out pre and post ART counselling services while doing health visits. This also avoids having special counsellors visiting homes, which is one of the things that reveal that there is an HIV positive person in the home.