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**Safety in the midst of stigma: Experiencing HIV/AIDS in two Ghanaian communities**

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## Summary

This study is part of a larger research project consisting of three parallel projects that investigated some of the key issues hindering people from taking up voluntary counselling and testing (VCT) and antiretroviral therapy (ART) services in Ghana. While two of the projects focussed on the institutions and the policy terrain (A and C respectively), this project (B) concentrated on those who utilize the services – the general public and people living with HIV (PLHIV). It assessed perceptions of VCT and ART, focused on problems associated with (and motivations for) taking up counselling and care, and looked at issues relating to stigmatization, in the communities accessing the services at Komfo Anokye Teaching Hospital, Kumasi, and St. Patrick's Hospital, Offinso, both in the Ashanti Region of Ghana. Between September 2007 and August 2008, and November 2009 and January 2010, the researcher lived in the same communities as the HIV positive respondents and their families and friends. Through conversations, observations, in-depth interviews, focus group discussions, and a household survey, the experiences of living with HIV and AIDS, and the firsthand knowledge of being affected by the infection, were explored.

Having a good name and thus a positive identity in one's community is of paramount importance to the majority of members of these communities. PLHIV are stigmatized because the disease gives them a bad name. Ordinary members of the general public thus tend to be reluctant to go for VCT because of the fear of being stigmatized if the result is positive. Those who do find out about their HIV positive status try every means possible to conceal it to avoid stigmatization.

Only a few of the participants in this study were tested for HIV after sensitization campaigns or through walking into a VCT centre. The majority found out about their HIV positive status after reporting sick at the hospital, where they were tested, mostly without their knowledge let alone their consent. Furthermore, after the test has taken place, issues and challenges may arise in terms of receiving the test results. Firstly, some counsellors find it difficult to tell clients that they are HIV positive. Thus these health workers often use euphemistic phrases, such as "there are worms/small animals in the blood," which are ambiguous and leave room for the clients to interpret the results in different ways. Secondly, due to fear of the possible consequences of testing HIV positive, many refuse to pick up the test results.

After finding out about their HIV positive status, in most cases these persons consider their next line of action to be to conceal their sero status from those who

they do not want to know it. Death (by suicide) was found to be one of the main considerations at this stage, though only a few went through with it. Considering the public condemnation of suicide in Ghana, the fact that some choose to do so tells of their desperation. Some HIV positive people opt for a concealed form of suicide by refusing to enrol onto an ART programme and thus deciding to die slowly. Most feel lonely and become isolated. A significant number resort to alternative treatments, including local and herbal medicine and 'spiritual therapy', for fear of being discovered using ART.

The PLHIV in this study were preoccupied with feeling safe, in particular safe from the (possible) effects of stigma. Stigma is experienced in two main ways: they anticipate negative reactions from others (perceived stigma) and experience real discrimination and mistreatment (direct stigma). As a result, they generally hide their sero status from their spouses or partners, the family members they live with, and their friends and neighbours. Though HIV positive persons are encouraged by health workers to disclose, especially to their partners, the fear of possible consequences prevents many of them from doing so. Out of fear, people devise strategies to avoid being found out, such as (among other things) finding excuses to explain their frequent visits to the hospital; taking their medicines in secret; circumventing the rule of disclosing to a treatment monitor by using a passer-by from the street; and enrolling in clinics far away from their community.

Of those PLHIV in this study who did start ART, the vast majority claimed that they were relieved when they started treatment and were able to regain their former lives. However, treatment poses its own challenges, such as the initial side effects when starting the medicines, the longer term side effects, and the hassle of the daily intake of drugs. Furthermore, for many of the PLHIV in this study who tested at the hospital when their health condition had become very serious, they were at the end-stage of their HIV trajectory, and this severely impeded the possibility of effective treatment with ART and reduced their chances of living a longer, healthy life in spite of the infection.

In general, the PLHIV on ART took their drugs religiously, but side effects such as nausea, throwing up, and initial lack of appetite prevented proper drug intake, while the huge appetite ultimately brought about by the medicines, as well as mood swings or depression, also restrained proper treatment. Economic constraints further prevented proper treatment when PLHIV had no means to travel to the clinic or maintain a proper diet. Some even discontinued their treatment after having regained their former health, thus ignoring or denying the fact that the treatment is lifelong.

Many PLHIV experience financial problems, which severely impede their adherence to ART. As many do not seek treatment at the ART facility early in their disease trajectory, or only get there after seeking treatment elsewhere (such

as at prayer camps, traditional healers, etc.), they often come to the clinic impoverished. Many have sold their property, such as tools and farming lands, in their pursuit for a cure to their ailment. Their expenditures, however, keep increasing after starting ART, as they need money for food, transportation to the clinic, medical expenses additional to ART that are not covered by the National Health Insurance Scheme (NHIS), as well as for their own private needs. As they are often unable to contribute to the financial upkeep of their household, they can also expect less assistance from their relatives. In cases where they are cared for by family members, once the resources are depleted because of the increasing costs, the whole family suffers economically. This study shows how, for example, transportation costs may prove a heavy burden, forcing infected persons to skip appointments, or how a number of PLHIV are compelled to take their medications without food.

To maintain or regain their dignity and good reputation and to be safe in the midst of stigma, the majority of the HIV positive persons in this study lived as if they were not infected. They continued their lives 'as normal' without informing others. However, this seeming normalcy poses further acute dilemmas, as they are expected to have partners, get married, and have children. The study shows the painful problems that PLHIV face when, for example, they resist marriage proposals for a long time but eventually give in as others start to question their motivations. Knowledge or rumours of such behaviour cause acrimony among community members who feel that HIV positive persons on antiretroviral medicines are intent on deliberately spreading the infection to others. On the other hand, some PLHIV do disclose their status to their family members, though the study found that the majority of those who did so did not receive appropriate assistance. Only a small number of families cared well for them.

As ART is a lifelong treatment, PLHIV must therefore develop new relationships with three new groups of people: the medical staff offering treatment, care, and support; other HIV positive people; and home-based care professionals, including those from PLHIV associations. These groups are therefore crucial for successful adherence to treatment, maintaining successful clinical programmes, and scaling up VCT and ART. ART clinics and PLHIV associations may be important safe havens where PLHIV can share worries, seek advice, and find consolation. Income-generating activities by these associations – such as farming, soap making, and animal husbandry – can help to provide a new course of life. Investing in these supportive circles may seem less direct in terms of offering help and support to PLHIV, but they in fact may prove to be the cement crucial to ensuring the future success of efforts to help people to access HIV testing and counselling services; to access ART if discovered HIV positive; to

regain their health and live positively; and thus to reduce the further spread of HIV.