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

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Appendix 4: Report of HIV/AIDS Workshop – From Research to Policy to Action

Date: Wednesday, 2nd December 2009

Venue: Engineering Guest House, Kwame Nkrumah University of Science and Technology (KNUST), Kumasi.

Participants: Participants included policy makers, health workers, people living with HIV/AIDS, and people from academia and the media.

The workshop was held over two sessions, one in the morning and one in the afternoon. During the morning session, the three researchers presented some of the main findings of their studies. For the purpose of the workshop, the findings presented were mainly on the influence of stigma on the provision and uptake of VCT and ART.

The afternoon session was used to discuss questions and issues arising out of the presentations from the morning. The discussions were conducted in three parallel groups made up of community members, health workers, and policy makers, in line with the three perspectives of the research design.

Morning session

The programme for the day started with a welcome address by Dr. Frances Owusu-Daaku, Head of the Department of Clinical and Social Pharmacy of KNUST. As the organizer of the workshop, she formally welcomed participants and briefly talked about administrative issues. This was followed by an opening address by Prof. K.A. Senah, Department of Sociology at the University of Ghana. In his capacity as the home (Ghana) supervisor of the researchers, he gave a brief overview of the multi-level perspective research project. He said that the research aimed to look at how the uptake of VCT and ART can be increased in the context of their ongoing scale-up. In order for the objectives of the research topic to be achieved holistically, the three researchers had considered the subject from three different perspectives – the community level, the hospital level, and the policy level. He further explained that the presentations of each of the researchers would centre on their particular perspectives.

Prof. Senah indicated that the rationale for the workshop was to give stakeholders an opportunity to express their views and opinions on the findings of the research before the final reports were made. He therefore entreated participants to freely express their views and opinions on the research findings, alluding to the

fact that their comments would be subsequently incorporated into the final research report. He also asked participants to feel free to speak in any language that they could best express themselves in, including local dialects.

The first presentation

After the welcome address, Mr. Benjamin K. Kwansa was the first researcher to present the findings of his study on the community perspectives on the research topic. Mr. Kwansa's presentation mainly considered the issue of stigma and how it plays out between PLHIV and their spouses, relatives, and community members. He ended his presentation with a number of questions for discussion during the afternoon session.

Reaction to the first presentation

As per the workshop programme, Mr. Assan, a person living with HIV, was invited to respond to issues raised in the first presentation. Mr. Assan thanked Mr. Kwansa for his presentation and also agreed with him on the findings of his study. Mr. Assan pointed out that stigma as a barrier to uptake of VCT and ART is a reality, but he attributed this to the lack of information about HIV/AIDS among most members of the general public. As a result, people spread incorrect information about the disease thereby contributing to the persistent stigma surrounding it. He specifically mentioned people in the media who, according to him, have limited knowledge about HIV/AIDS and often describe the disease as 'disgraceful' and 'deadly'. He also questioned the rationale behind setting aside a particular day(s) for care and treatment for PLHIV in the clinics and hospitals. Mr. Assan explained that this practice exposes the identities of PLHIV because some people find out the days on which PLHIV go to the clinics for care and treatment and are thus able to closely monitor and scrutinize them. When they see clients they know accessing care and treatment on those days, they go to the community and broadcast the news about their HIV positive status, leading to stigmatization.

Mr. Assan further stressed the need for peer educators to be formally integrated into the provision of care and treatment in the clinics. According to him, HIV positive peer educators are in a better position to counsel their peers than health workers who have no firsthand experience of living with HIV. He was also of the view that PLHIV are more likely to believe peer educators with whom they share a common problem than health workers. He did say, however, that the formal integration of peer educators into service delivery in the ART clinics should also be matched by some form of support – either in kind or (especially) in cash – to boost their morale to continue to complement the work of health workers and help their peers.

Participants were allowed to ask a few questions or make comments on Mr. Kwansa's presentation and the response of Mr. Assan. The first comment, from a PLHIV, was that efforts at reducing the spread of the disease often lack political leadership, from the national down to the community level. This, he said, has negatively affected efforts to reduce the spread of the disease in Ghana. A policy maker, however, disagreed (to some extent) with the opinion and rather mentioned that politicians have over the years helped in diverse ways to push forward the fight against HIV/AIDS. He nonetheless agreed to the fact that more needs to be seen from the politicians, especially those at the very top – the President, Vice President, etc. – to make this stance more authentic. “We also must see them openly declaring their status, for instance,” he indicated.

The second presentation

Mr. Jonathan M. Dapaah presented the findings of his study on the hospital perspective of the research, which looked at how the attitudes of health workers and some structural/institutional challenges in the hospitals expose the identity of clients as PLHIV during the uptake of VCT and ART services. He also showed how this has in many cases led to the stigmatization of clients, as a result of which some people refuse to take up VCT and ART.

Reaction to the second presentation

Dr. Maxwell Kankam of St. Patrick's Hospital, Offinso, responded to the presentation on behalf of health workers. Dr. Kankam thanked the presenter and said that the findings of the study were largely a true reflection of the situation in the VCT centres and ART clinics. He said that facts and figures in the facilities show that uptake has increased over the last couple of years. He pointed out, however, that uptake could be much higher if health workers more frequently went on outreach programmes to provide VCT services in the communities. According to Dr. Kankam, experience has shown that most people prefer to undergo HIV testing in their communities rather than walking or travelling all the way to VCT centres in the hospitals. Another reason is the fear that some people have that when they go for the services in VCT centres, they may be observed and/or identified by other people, and thus be stigmatized.

Dr. Kankam also indicated that the attitudes of some health workers in many respects put clients off from accessing VCT and ART. Dr. Kankam explained that the indiscrete utterances of some health workers, for example, have in many cases exposed the identities of clients to people from whom they (the PLHIV) had wanted to conceal their status. He also said that some health workers were not able to keep the status of clients confidential and as a result informed other people about it. He therefore asked health workers to respect the rights of clients

and keep their status confidential, to ensure that they are not stigmatized in their families and communities.

Dr. Kankam further expressed concern about the seeming lack of interest in HIV/AIDS activities by the hospital management. He said that there have been many instances in which the hospital management had refused to release funds for outreach programmes aimed at providing VCT services in the communities. He said that this had constrained the efforts of VCT and ART health workers to reach out to more people for HIV testing, and if tested positive to put them on ART.

When the floor was opened for questions or comments on Mr. Dapaah's presentation and Dr. Kankam's response, a participant (a policy maker) said that the study should acknowledge the progress that had been made in reducing the stigma associated with HIV/AIDS over the years. This was because "the study creates the impression that nothing has been done to reduce stigma over the years." He was of the view that even though stigma is still a problem when it comes to the uptake of services, compared to a few years back the situation has seen some massive improvements.

Another participant (an academic and policy maker) also said that sometimes the reluctance of management to release funds for HIV/AIDS activities in the hospitals and districts is largely due to lack of accountability. She pointed out that in some cases health workers are not able to account for funds released for programmes because they have used such funds for other activities unrelated to HIV/AIDS. According to her, whenever this happens management insists on proper accountability before releasing the next batch of funds for planned activities.

The third presentation

Dr. Owusu-Daaku presented the third perspective of the research: the policy making level. She gave the presentation on behalf of Dr. Rachel Spronk, who had carried out the study but could not attend the workshop due to taking maternity leave. The presentation mainly looked at how HIV/AIDS related policies are formulated, as well as the linkages between policy formulation and implementation. The researcher was of the view that HIV/AIDS policies in Ghana are largely on track but that what is lacking is effective implementation of the policies in the hospitals and districts. The study reported that lack of logistics is also a major factor constraining effective implementation of HIV/AIDS policies in Ghana.

Reaction to the third presentation

Prof. Irene Agyepong responded to Dr. Owusu-Daaku's presentation on behalf of policy makers. She said that the current success in the reduction of HIV infection is largely due to the prevention policy that has been put in place. She said,

however, that future research should focus on how policies are put into action at all levels of the health care delivery system. She also questioned the meaning of the term 'logistics', as it was used in the research findings (as indicated above). According to her, logistics means more than lack of funds, which is often cited as the main constraint to project implementation (often by using the phrase 'logistical constraints'). "It is important that what we mean by logistics should be clarified in research findings," she added. She gave examples where 'logistics' could include funds, means of transport, and personnel, among other things.

Prof. Agyepong also noted that in the Strategic Framework II on HIV/STI Policy, there are no clear guidelines addressing stigma. The reasons for this include the general international lack of guidelines to address stigma, low prevalence fuelling complacency, lack of political will (unlike, for instance, that visible in Uganda), among other reasons. The situation brings to the fore a number of dilemmas; for example, there is more focus on HIV programmes than on HIV within the health system as a whole. Prof. Agyepong therefore noted that the challenge went beyond those in the workshop: "Dialogue should be more up there," she stressed.

In conclusion, Prof. Agyepong raised a number of questions regarding Mobile Counselling and Testing (MCT): what do you do if a particular programme proves successful? Why is it that MCTs are more successful? What is attracting people to MCTs? Maybe the District Assemblies should assist through their share of the Common Fund.

The afternoon session

Participants broke up into three parallel groups based on the three presentations to discuss questions posed in the presentations and other related issues. The presenters moderated each group and a secretary was chosen to record and present proceedings to the larger group. The parallel discussion segment lasted for a little over one hour, after which participants gathered again for the group secretaries to present what they had written down.

Plenary discussion

Community

Mr. Assan was the first to present on behalf of the community group. The group was of the view that the general public still lack adequate information about HIV/AIDS. As a result, many people believe that PLHIV contracted the disease by choice (through 'immoral' behaviour, for instance), and thus they do not deserve sympathy, support, and care. In addition, many people believe the disease to be deadly and that it has no treatment at all. According to the group, lack of information about the disease is the underlying cause for the stigmatiza-

tion of PLHIV in their families and communities. The group was of the view that even though awareness about the disease is near universal in Ghana (about ninety-five percent or more), there is still the need for intensive education about the disease and how it can be managed with ARVs.

The group also pointed out that people in the media – both electronic and print – lack information about HIV/AIDS, and they often show this in the way they report on the disease. Mr. Assan said that they often use ‘bad language’ or dreadful phrases, such as that HIV is a ‘terrible illness that will result in death’ (*yadeε kodi awuo*) to describe the disease and its sufferers, which also feeds into the stigma associated with HIV/AIDS. In addition, some do not even know the difference between HIV and AIDS, so they are not able to explain to the listening public the difference between the HIV infection and the AIDS disease. The group therefore suggested that media men and women also need to be educated properly about the disease in order for them to accurately report on it. This, the group believed, would help reduce the stigma associated with the disease rather than contribute to its persistence.

Mr. Assan further reported that the group called for formal integration of peer educators into the provision of care and treatment in the VCT centres and ART clinics. The peer educators are PLHIV who have been trained in counselling to complement the work of health workers in the VCT centres and ART clinics. The group explained that as people who are also living with the disease, peer educators are in a better position to counsel their peers to accept their HIV positive status and adhere to the ARV medication. This is because they often counsel their peers by sharing their personal experiences of the disease with them, which always impacts positively on them.

The group further suggested that peer educators should be supported financially when they are integrated into the provision of services in the VCT centres and ART clinics. They think that this would motivate peer educators to be committed to the work they do in the health facilities. It is important to mention that this call for formal integration of peer educators into service delivery and the need for them to be supported financially was made following the lack of recognition for their work in one of the ART clinics in which this study was carried out.

In addition, the group called on health workers to try as much as possible to keep information about clients’ status confidential. Any time that they want to disclose information about a client’s status to others, such as spouses or relatives, they should seek the client’s consent before doing so.

Finally, the group suggested that ARVs should be supplied free of charge to clients, because most of them are not able to pay the cost of the drugs every month due to the fact that prolonged illness means that most of them are unemployed. The group contended that even though clients can buy drugs on credit, it

would be better if the drugs were given to clients free of charge to encourage them to come for their refill at the end of every month.

Health workers

The second presentation was by Mr. Samuel Amanor on behalf of the health workers' group. The group generally agreed that the negative attitudes of some of their colleagues towards clients deter many people from taking up VCT and ART. But the group observed that it is mostly health workers who are not directly providing these services who show negative attitudes towards VCT and ART clients. For instance, health workers in the admission wards were said to be putting PLHIV in side wards in order to distance themselves from these clients due to their HIV positive status.

Health workers also admitted that there is a lack of respect for confidentiality among some of their colleagues, as mentioned earlier by the community group. They pointed out that health workers who are not trained professionals are noted for talking about clients' HIV status outside the hospitals, and that this has on many occasions exposed clients as PLHIV in their communities, leading to stigmatization by relatives and community members.

The group also responded to the concerns of some clients that the secrecy they needed to take up VCT and ART is not guaranteed due to open locations of VCT centres and ART clinics in the hospitals. The group suggested that integration of VCT and ART into general health care services would be the best solution to these concerns. But health workers pointed out that isolating VCT centres and ART clinics in the hospitals (as is now sometimes the case) likely results in stigmatization of the sites, because most people do not want to be seen entering or coming out of the centre or clinic, which is often taken as grounds for suspecting someone to be HIV positive. VCT and ART should be included in general care services and be accessed through the OPD like any other disease, rather than being secretly located within the hospitals.

Furthermore, there was the suggestion that health workers should embark on outreach programmes in the communities to provide VCT services. This is because experience has shown that most people prefer to take up VCT outside of the hospital premises, due to the lack of secrecy in terms of the locations of VCT centres. In outreach programmes, clients can avoid being seen at VCT centres, accessing a service which is a justification for being suspected as a PLHIV with its attendant stigmatization. They also proposed using outreach programmes to educate members of the general public about the disease and the availability of ARV drugs to help PLHIV to live longer with the disease.

Health workers contended that inasmuch as stigma has negatively influenced many people not to take up VCT and ART, they believe that something can be

done to reduce its persistence. They admitted that the fight against stigma is a difficult one, yet they do not have to be pessimistic. According to them, they need to assure clients during pre- and post-test counselling that their status will not be made known to other people without their consent. In addition, clients should be assured that information about their status will be kept confidential. Above all, health workers should assure clients that they will endeavour to do their work as professionals so as to provide quality care and treatment. This, they said, would make clients feel that health workers are interested in their welfare beyond the routine provision of services.

Finally, health workers said that they have to find positive ways to encourage PLHIV to accept their status and live with the disease for the rest of their lives. They explained that through ongoing counselling, they could help clients to willingly disclose their status to at least one trusted person, as a coping mechanism to reduce the stress associated with the disease.

Policy makers

The last presentation was by Dr. Raphael Obeng on behalf of the policy making group. This group agreed that even though there is a policy to reduce HIV-related stigma and to encourage more people to take up VCT and ART, there is no clear-cut effort to implement the policy. They therefore suggested that conscious effort should be made at all levels among stakeholders to ensure that the policy for stigma reduction is properly implemented.

Further, the group indicated that one major policy which has boosted the provision of care and treatment for PLHIV is the National Health Insurance Scheme (NHIS). Even though ARVs are not on the list of 'essential drugs' covered by the NHIS, most of the PLHIV can access other health care services almost free of charge. For instance, through the NHIS, the opportunistic infections of PLHIV are treated at little or no cost, which has largely contributed to improvements in their health and welfare.

The group also stressed the need for policy makers to regularly make funds and logistics available to implementers in the districts and hospitals, in order for effective implementation of HIV/AIDS programmes. The group pointed out that without funds and logistics, all the good policies on HIV/AIDS will remain on paper without implementation to benefit the intended target groups.

Conclusion

In conclusion, there was a consensus among the three groups that stigma is the main barrier to increased uptake of VCT and ART. They therefore suggested that efforts should be intensified at all levels to reduce stigma and encourage more people to take up these services. All the groups were of the view that stigma could be reduced through intensive educational programmes and campaigns on

HIV and AIDS for members of the general public, people in the media, and health workers (in the latter case, especially those who do not provide VCT and ART). It was expected that such efforts will help people to understand the disease better and also behave positively towards PLHIV to reduce stigmatization.

Prof. Sjaak van der Geest, the main supervisor of the researchers in Amsterdam, gave the closing remarks for the workshop. On behalf of the research team and organizers of the workshop, he expressed his gratitude to all the participants for making time to attend the workshop. He thanked participants for their good comments and suggestions on the research findings and assured them that they would be incorporated into the final research report. He added that the workshop had shown that it is possible for policy makers, health workers, and PLHIV to sit in one meeting as 'equals' to dialogue and find solutions to the challenges posed by HIV/AIDS. Participants were then paid their per diem and transport costs, after which, at around 4 p.m., they took their lunch packs and left for their respective destinations.