GENDER AND HIV/AIDS IN A UGANDAN CONTEXT: A PARTICIPATORY ACTION INQUIRY

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Abstract

The article argues that people and communities perceive and deal with HIV/AIDS as only of the many problems and tensions they experience as affecting their well being. Thus, the intervention for the control of HIV/AIDS through the creative other than the reactive- responsive orientation in the development process is being proposed. It is also noted that the discussion of the issues related to HIV/AIDS and sexuality is blocked by deeply held views that men have about women and sex. This is the reason why the issue of gender is central when discussing with the people to determine the health they truly want including how to manage the HIV/AIDS problem. The study team brought together rural youth of 13-25 years and men and women of 26-45 years and used participatory action research methodologies to reflect and exchange information, knowledge and skills on the issues related to gender and HIV/AIDS. This empowering knowledge was useful for launching advocacy for attitude and behaviour change toward risky sexual behaviours and for supporting communities in developing visions of healthy communities the people truly cherish. The study process generated information, which was used to develop the content for a facilitator's guide on Gender and HIV/AIDS that should be used in all communities in Uganda and elsewhere to adequately manage HIV/AIDS problem.

Introduction

HIV/AIDS has received much international and national attention and in some cases has been presented as a security, political, medical and economic priority by some governments, and as the major cause of increasing morbidity and mortality in countries in Africa. From the beginning it was predicted that the fear of AIDS would tame an African sexuality perceived to be responsible for the high rate of fertility and the spread of AIDS (Caldwell and Caldwell, 1988: 19-28). Yet, more than two decades into the epidemic there is still conflicting evidence that these predictions have been realised and fertility, mortality and sexual behaviour change remain outstanding issues. There is moreover growing evidence that people and communities perceive and deal with AIDS as only one of the many problems and tensions they experience as affecting their well-being. Therefore, over the years, a lot of experience in regard to the spread of HIV/AIDS has been gained and hence the intervention for the control of HIV/AIDS through the creative other than responsive orientation in the development process is being proposed.

The overall aim of the study, therefore, is to undertake an inquiry on how communities in Uganda conceptualise health and ill-health and make sense of gender and HIV/AIDS and related discourses using interactive and collaborative methods to create enabling environment for expression, dialogue and reflection. This, in turn, generates relevant knowledge that can be acted on by the communities and the policy makers as the knowledge creation proceeds.

The study was conducted in five major phases. The first phase was the formation of Village Reflection and Dialogue on Gender and HIV/AIDS Capacity Building Team. The second phase involved the identification of partners in the communities. The purpose of this phase was to identify people that would continue with the interventions to handle the issues of gender and HIV/AIDS that would be identified. The third phase was aimed at building capacity of the identified partners in the issues of gender and HIV/AIDS and matters of sexuality so that they can train or build capacities of people in the communities. The

fourth phase focused on the development of the facilitator's guide, which was developed by the partners together with the study team. This phase was supposed to ensure that the facilitator's guide is translated from English into Runyakitara languages so that it is given a wide publication. Radio programmes were to be cross cutting in all the four phases. Phase five handles the dissemination of the facilitator's guide.

HIV/AIDS and Development

While AIDS is believed to be a new epidemic the situation in Uganda shows that there are other epidemics not yet under control. A recent assessment of infectious disease surveillance found, for example, that only 35% of health facilities had the official standardised case definition booklet and an adequate supply of reporting forms. Only 51% had the laboratory capacity to confirm a diagnosis of malaria and 44% to confirm tuberculosis (Morbidity and Mortality *Weekly Report*, 2000): the major epidemics associated with HIV/AIDS. AIDS is complex because it is not one disease. A recent UNAIDS report made the point that HIV does not cause a single, specific fatal disease and individuals whose immune system has been weakened by the virus fall prey to already common infections and ailments. These common infections, tuberculosis being one of the most serious, are more likely to spread in conditions of overcrowding and malnutrition under which large numbers of people in Uganda live. Distinguishing increasing morbidity and mortality caused by AIDS from the effects of poverty and gender related violence and other infectious diseases are therefore problematic and little has been done to that effect. Addressing the fundamental causes of ill-health, namely: poor nutrition, housing, sanitation, and gender related violence, would seem essential if morbidity from AIDS were to be well understood and reduced.

The underlying assumption of the health education model, which has been the main strategy to combat the epidemic, though largely scare-biased, is that individuals execute their preferences or rational choices once information about health risks is provided to them: an assumption that ignores local contexts and societal dynamics and pressures. In Africa, these inconsistencies are further confounded as African systems that regulated sex behaviour in young people were disrupted by colonialism and colonial education systems that assumed that African sexuality was savage and unrestrained. These assumptions continue to resonate through some aid agencies similarly professing contradictory moral perspectives. Additionally, a stigmatising process has been ingrained in the assumptions, discourses and globalised practices in ways which have debilitated the people and seems no wonder that over two decades in the epidemic very basic questions are still being asked (Pharma-Brief, 2000).

Outside the biomedical reference framework, little has been sought, as to whether people perceive AIDS as the major threat to their well being, or whether the health interventions have improved the quality of their lives. There is increasing evidence that people do not define their well being solely using disease entities, but issues of overwhelming insecurities, for example, loss of employment, loss of social worth and inability to educate and make provisions for children are more important. Whitehead and colleagues describe the poverty trap that includes untreated morbidity, reduced access to care, long-term impoverishment and irrational use of drugs arising from the health reforms including privatisation of health service provision, private financing via user fees and out-of-pocket expenses for private service (Whitehead, 2001).

In spite of the complex context described above it is also clear that communities have wisdom, resources, aspirations and infrastructure, which research and development as currently practised rarely tap or mobilise for action and change. This study is concerned with creating a process or environment that facilitates dialogue or space for dialogue thus enabling people to collectively make sense of the gender and HIV/AIDS and its complex dimensions and to reflect on their experiences and actions to improve their well being.

Study Research Methods

Participatory action-oriented methods that included Focus Group Discussions (FGDs), brainstorming, information sharing, role plays, songs and drama presentations by the groups were used. The groups were three: adult male, adult female and the youth groups that discussed the issues. Out of these groups, participants from each group identified their own facilitator, observer and recorder. Communities have a record of the process, which they can use to facilitate further dialogues and future reference. The plenary sessions were organised because they bring clarity to the groups and some assumptions are openly discussed. Interestingly, no major discrepancy on the topics discussed was observed between the three groups.

Study Findings and Analysis

Combining all the questions that we identified to guide

the study we developed gender and HIV/AIDS areas that the community members should be knowledgeable about in order to mobilise them for action and change. Among the areas, the first, included understanding gender and HIV/AIDS, which concentrated on concepts such as gender, HIV/AIDS and human rights. The second area tackled the relationship between gender and HIV/AIDS by reflecting on gender and HIV/AIDS concepts and establishing the linkage between the two. Introducing visioning in the field of health and well being was the third area that we treated. The whole concept and practice of a good health was handled.

Through brainstorming and focus group discussions and with the facilitator's guidance the participants were able to come up with the meaning of gender and HIV/AIDS.

Gender

This is the social contractual relationship between male and female. It is a broad term that refers to the socially defined masculine and feminine roles and characteristics of men and women. Gender also relates to the different identities assigned by society rather than by nature/biology to men and women namely the masculine identity and feminine identity.

HIV/AIDS

Participants were asked what HIV/AIDS is or what came to their minds when HIV/AIDS is mentioned. Their responses represent what are the likely cause, the impact and the ways of preventing the disease. Under causes of the disease, they gave them as: HIV/AIDS is got if one plays unprotected sex with an infected person, this virus is got through unprotected sex, and this is brought by having sex. Witchcraft, sharing sharp instruments, people going for strip dancing, misunderstandings in homes/families, over drinking alcohol, indecent dressing, poverty in homes, and it is mostly men who bring HIV/AIDS, are other causes of the disease mentioned by the participants.

Under the impact the disease causes, they gave the effects as promoting faithfulness between man and woman. Under prevention measures, participants gave them as using a condom, taking care of persons living with HIV/AIDS and creating harmony in homes. Educating children about AIDS, going for prayers every Sunday and to avoid sharing sharp instruments are other preventive measures mentioned. Promoting dialogue between husband, wife and children and creating an environment where women should always be loving and submissive to their husbands were also other preventive measures the participants mentioned. Enabling a woman and a man to provide for each other, improving nutrition in homes, working together as a family as well as having faith and being truthful to each other are mentioned as other preventive measures. We have to look after the affected, husband and wife should go for HIV/AIDS check up to know their status and parents should give their children condoms as a precautionary measure. Surprisingly, they mentioned a substantial amount of information about HIV/AIDS, which indicated, as earlier noted, that the people are knowledgeable about the disease but the behaviour change is really modest. Moreover, the prevention measures that the participants identify do not only manage the HIV/AIDS problem but also contribute to the health and well being of families and communities.

Human Rights

The rapid spread of HIV/AIDS epidemic has lead to the infringement of human rights of men, women and children affected by the disease. In relation to gender and HIV/AIDS the starting point is to understand what are some of the examples of human rights. Participants were asked about how HIV/AIDS affects the rights of women, men, girls and boys. They responded that the right to dignity for men in their homes is affected when the wife stigmatises the husband pin-pointing that he is the one who brought the HIV/AIDS in the family. The right to marriage is also affected in a way that a girl cannot get married unless she has gone for HIV/AIDS testing. Men and women have a right to sex but due to the prevalence of HIV/AIDS they cannot have sex without using a condom. The right to education for children is affected and children are diverted to look after the sick person in the family due to HIV/AIDS leading to dropping out of school.

Participants were asked about what actions should be taken to address the rights violated. They responded that we should engage in HIV/AIDS mitigation programmes, engage in dialogue on the issue of HIV/AIDS and insist that no marriage should take place unless a man and a woman have undergone HIV counselling and testing. It was also recommended that people's consciousness should be raised and to initiate and establish income-generating activities to raise funds to support the education of the children and the people living with HIV/AIDS in the family.

The Linkage between Gender and HIV/AIDS

In order to establish the linkage between gender and HIV/AIDS participants were asked to brainstorm on the concepts gender and HIV/AIDS, divided into focus groups to discuss the linkage between these concepts and presented their findings in the plenary.

Participants mentioned that it was difficult and complex to dialogue on the crucial issues of sexuality. Dialogue and shared learning stops when men are blaming women and vice versa about such issues as who is or is not using condoms and whose behaviour is causing the spread of HIV/AIDS. They acknowledge that gender related factors shape the extent to which men and women, boys and girls are vulnerable to HIV/AIDS infection. They identified a variety of factors that increase the vulnerability of women and girls to AIDS. They include social norms that deny women sexual health knowledge and practices, which prevent them from controlling or deciding when they should have sex. However, this does not exclude men and young boys who are vulnerable too. Social norms reinforce their lack of understanding of social health issues and at the same time make them celebrate promiscuity. This vulnerability is further increased by the likelihood of engaging in abuse [violence] of alcohol and other drugs that can initiate mobility and family disruption.

The burden of caring for ill family member (s) is placed on the heads of women and girls. As the impact of AIDS epidemic grows girls drop out of school in order to cope up with the task of caring for ill family members. Experience has shown that controlling the epidemic in communities and families demands confronting the gender driven behaviours that increase the chances of infection for girls and boys. This in turn calls for strong and coherent national policies, strategies and plans.

Participants were asked about how HIV/AIDS affects the relationship between husband, wife and children in the family. They responded that HIV/AIDS has caused separation/divorce of spouses in their communities. The member of the community revealed that when a man/woman involves in adultery they start becoming suspicious of each other. This can result into a quarrel hence separation or divorce. They also reported that when a person in a family is HIV positive he or she needs careful attention or special treatment. This special treatment goes with high resource utilisation. A lot of time is spent caring for one person and when one dies a lot of time is required to carry out funeral rites. Funds to buy food (balanced diet) and medicine for the infected person deplete the family resources and hence affecting other members of the family. For example, the children drop out of school followed by early marriage and dishonest people in the communities rob the orphans of their property and as a result they are not well supported resulting in some becoming street children. They also reported that productivity and production is negatively affected. The family members will not have energy to work and will not engage in farming activities and as a result there is food insecurity (not enough food for the families) and low income for families. Such families pick quarrels from time to time leading to family instability or violence. They shared that when one partner dies because of HIV/AIDS, more especially the husband, some members of that family can decide to chase away the widow and deny her ownership/ access to the property of the deceased.

Participants were asked about how they want to manage the above problems. They responded that the gender and HIV/AIDS partners should begin to carry out awareness activities about these issues. They also recommended promoting continuous dialogue on gender and HIV/AIDS in their families and to engage in income generating activities at family level in order to have sufficient funds to meet their domestic needs. Lastly, they suggested that consciousness raising on human rights should commence so that members of the communities can understand their rights and make informed decision, for example, writing a will before one dies in order to minimise chaos or disharmony after death.

What is Good Health?

Focus group discussions, testimonies of those living positively with AIDS, brainstorming and demonstrations were employed by the facilitators to enable the participants to reflect on good health as a human right. The information that was obtained from the participants was guided by these questions: what is good health, how is good health related to human rights and what should be done to live positively with AIDS.

Participants were asked to state what they understood by good health in the context of HIV/AIDS. They mentioned that good health is a state where people with HIV/AIDS infection prolong their life by making good choices to care for their own mental, physical and spiritual health. In addition, they said that everybody has a right to life and this means that a person with HIV/AIDS has this right to live a healthy life. Finally, they mentioned that it also means living responsibly with HIV/AIDS.

The participants were then asked where does the treatment of HIV/AIDS lie in the orientation of the creative/visionary approach. Using the visioning technique the participants were asked to think about the good health they want to be living. Again, the participants were asked to reflect on the health they are currently living in their homes. The participants

were enabled to see the gap between the good health (the vision they uphold) and their poor or fair state of health (current reality). A structural tension is created as a result of the gap between their vision of good health and the state of their current health. This tension created seeks resolution. The resolution can be towards the vision so that the achievement of good health is attained or it can be towards the current reality where energy and momentum is lost and people stay where they are. To bridge the gap between good health and the current status of health, therefore, there should be actionable steps. These steps include using of ARVs correctly and regularly for people who are HIV/AIDS positive, using a condom in case you are to have sex and abstaining from sex (being faithful to each other). Peaceful family discussion, none alcohol drinking and smoking, having adequate and sufficient rest as well as having physical fitness exercises, improved family hygiene and adequate food and nutrition are other actionable steps towards the good health one truly cherishes. There is need to note that the actionable steps, even when they are significant to manage the HIV/AIDS problem, but also important for creating healthy families and communities.

A Note on the Facilitator's Guide on Gender and HIV/AIDS

Through discussion and careful listening the content of the facilitator's guide on gender and HIV/AIDS was put together. However, the content of the guide is not a blueprint, but rather the focus should be more on the process. The guide is meant to share processes with facilitators and civic leaders who intend to promote health at community level. They can adapt it to their own situations deemed appropriate to cause dialogue on gender and HIV/AIDS for reducing on the high infection rate.

The facilitator's guide has been designed to promote Community Action Planning (CAP) at village level to enable members discuss the relationship between male-female power relations, sexuality and the transmission of HIV/AIDS. The process then provides community based resources to help communities understand and plan for activities to decrease the transmission of HIV/AIDS especially among the risky group of young women aged 13 to 25 years.

Conclusion

The study has ably shown that the problem of HIV/AIDS cannot be treated in isolation. For its management it requires the inclusion of all the issues that relate to the creation of well being and healthy being of communities. Therefore, the people's capacities need to be developed so that they can take roles in community action planning. It was for this reason that the study team decided to develop content for the facilitator's guide on Gender and HIV/AIDS to allow the development of people's capacities happen. The guide is an initiative that must be scaled up for use by many communities in Uganda that still grapple with HIV/AIDS problem. Capacities of people will further be developed if we put in place structures that are totally committed to the health of the community. Facilitating the process of forming men and women's groups to which members can turn to in case they get problems related with gender and HIV/AIDS is another way of building people's capacities. In addition, designing school programmes that treat issues dealt with in the study in order to empower teachers and children. Finally, developing women's empowerment programmes that would enable them to be autonomous so that they can begin conversations with men on the possibility of creating an end result that they truly cherish.

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