HIV/AIDS Research In Developing Countries: Do Participants Have A Choice?

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Developments in science and specifically biotechnology have revolutionized the care of HIV infected patients. The use of highly active antiretroviral drugs has improved the care of HIV infected patients to such an extent that HIV/AIDS is no longer considered a death sentence. Most of the drugs are manufactured in the west where there are fewer patients for both research and treatment.

Every year, thousand of papers are presented on HIV and these help to improve care and treatment. Drugs, however, have to go through several stages before they are finally registered for use in humans.

Because of the urgency and burden of the HIV epidemic on the world in general and specifically on developing countries especially in sub-Saharan Africa where 75% of the HIV burden is, the need for new and better methods of HIV care is an emergency. While drugs developed in the west get dully tested, the effects of these drugs on patients in different environments warrant further research. For this reason and several others, many patients who started life prolonging therapy in developing countries could only get them through research collaborations usually involving a foreign university or pharmaceutical company and local investigators.

What then would be the choices a poor person had in participating in a clinical trial? What would informed consent mean to a person whose vocabulary doesn’t include the word research, trial, and experiment in the local dialects? I could remember a time while recruiting patients for a multinational trail in Uganda which had strict inclusion and exclusion criteria. On one of the clinic days, a young woman who could not qualify for the study started crying to be included in a study. Her mother in her early fifties, also HIV infected but who still looked healthier and had qualified earlier for the trial begged us to have her daughter take her place in the trial. What kind of explanation would convince a woman whose only concern was the health of her daughter? When faced with such challenges, research participation becomes a must rather than a choice.
How then can informed consent be suited to developing countries where participation in a clinical trial is not only a means to avoid death in HIV but better livelihood from some of the financial amenities that accompany research. For example, patients in the west participating in trial are reimbursed, I am tempted to say paid to participate in research. What happens when you pay a similar fee in a developing country? One potentially could bias the entire community because any payment to some body who is not earning will be considered an income and nobody will refuse to earn! When we offered to give a transport refund to participants in a research a fee of US$2 in Uganda, some participants instead offered to walk and save the money for meals.

The next dilemma faced by researchers and participating third world countries is what should happen to the study participants at the end of the trial. Because research trials are designed for a specific purpose and to answer specific questions often when the trial ends, there is no plan for the participants.

Social cultural differences too create challenges for researchers and research subjects. For example, in a study that involved interviewing adult African men and women about their sexual behaviors. For participants above 50 years of age, the questions are not usually sexually appropriate and as such, the answers to them may not be the appropriate answers. Sometimes the interviewer is much younger than the interviewee. How would a 25 year old interviewer ask a 65 year old whether she is sexually active? The answer is very important but how do we get the right response to such social culturally sensitive questions which to the old folk border on obscene.

In terms of benefit, some research projects in AIDS have no direct benefit to the individual but have far important public health implications. It is important for example to find out if antiretroviral therapy reversed strides made in behavioral change in the control of HIV. The answers will help in designing counseling program geared at prevention among positives. Other research projects on the other hand have enormous direct benefit to the individual for example drug trials.

AIDS research among children posses a worse challenge because of issues with confidentiality, disclosure and safety of the various interventions in HIV/AIDS research. While millions of children are suffering with HIV, research ethics does not allow their direct involvement in drug trials. How then can science help children knowing that they are a unique group and not small adults?

In summary, various challenges exist regarding involving HIV/AIDS patients from countries with limited resources regarding accepting to participate in research where choices are limited.

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