Vaccine preparedness: lessons from Lyantonde, Uganda

Paul Ritvo1*, Dennis Willms2, Robert Meisner3, Laura Brown4, Adam Goldman4 and Nelson Sewankambo5

1 School of Kinesiology and Health Sciences, York University, Chemistry Building 142, 4700 Keele Street, Toronto, Ontario M3J 1P3, Canada
2 Department of Anthropology, McMaster University, Chester New Hall 514, 1280 Main Street West, Hamilton, Ontario L8S 4L9, Canada
3 Department of Anthropology, Harvard University, William James Hall, 33 Kirkland Street, Cambridge, Massachusetts 02138, United States of America
4 University Health Network, Toronto General Hospital, Behavioral Sciences Research Division, 200 Elizabeth Street, Toronto, Ontario M5G 2C4, Canada
5 Faculty of Medicine, Makerere University, Box 7062, Kampala, Uganda
* Corresponding author, e-mail: pritvo@yorku.ca

To explore how to better educate rural Africans about preventive HIV/AIDS vaccine trials, 15 semi-structured, open-ended interviews were conducted with villagers in Lyantonde, Rakai District, Uganda. This study reports on the findings by focusing on the attitudes, knowledge and questions the rural villagers had about HIV/AIDS-preventive vaccine testing. While several interviewees confused preventive vaccines with therapeutic vaccines, most were clear about the distinction and about key questions to ask about vaccine testing. In addition, some subjects manifested high levels of trust in the likely effectiveness of preventive vaccines, even in the testing stages, most subjects demonstrated the potential to be intelligently inquisitive about the likely effects. In sum, these villagers show the potential to be reliable subjects, motivated for appropriate reasons, and willing to play a role in advancing the progress of HIV/AIDS vaccine development in Africa.

Keywords: Africa, ethnography, experimental trials, HIV/AIDS prevention, participatory action research, qualitative interviews

Introduction

When the testing of preventive HIV/AIDS vaccines in Africa reaches a larger scale, individuals from both rural and urban areas will participate. It is thus important to understand the reactions of rural Africans to preventive vaccine trials in order to establish appropriate educational programmes. With this goal in mind, our investigative team conducted open-ended, qualitative interviews with villagers from Lyantonde in the Rakai District of Uganda. In this article we report on our findings and their implications for the ethnographic study of vaccine preparedness in Africa.

Several past studies have focused on the awareness of rural Ugandans about HIV/AIDS and its transmission, and their responses to voluntary HIV testing. Although few have focused directly on possible reactions to vaccine trials, these studies illuminate key issues regarding HIV/AIDS prevention. Several investigations have been undertaken as part of the Rakai Project (RP), one of the most productive ongoing African research programmes related to the AIDS pandemic. Through collaboration between the Uganda Virus Research Institute of Uganda’s Ministry of Health, Makerere University (Kampala), Columbia University (New York) and Johns Hopkins University (Baltimore), this project has addressed a wide range of issues in Rakai District, though most studies have been epidemiological in focus. However, several studies on attitudes, knowledge and behaviour have been undertaken, including one specifically focused on attitudes in relation to HIV risk factors. Baseline surveys and a two-year follow-up survey (1990–1992) were administered to adolescents in a population-based, open rural cohort to estimate the prevalence of HIV and its association with socio-demographic and behavioural risk factors. By the 1992 follow-up, knowledge of sexual transmission of HIV was almost universal, while the number of adolescents reporting multiple partners had decreased and condom use had increased. However, despite these reported changes, HIV incidence remained substantial, and adolescents and young women in particular still appeared vulnerable to HIV infection (Konde-Lule, Wawer, Sewankambo, Serwadda, Kelly, Li, Gray & Kigongo, 1997).

In another qualitatively oriented RP study that involved adult focus group interviews, it was found that most people did not fear casual contact with AIDS patients, but, nonetheless, blamed the spouses of these patients for spreading infection. Many interviewees also believed condoms could
not prevent HIV transmission and some feared they could tear and cause female complications. Most focus group participants did not like injections for treatment purposes, and when injections were necessary they preferred use of disposable needles and syringes. Hospital treatment for AIDS was not a highly trusted option for some focus group participants as many participants believed AIDS patients were being intentionally killed off by doctors (Konde-Lule, Musagara & Musgrave, 1993).

In another behavioural RP study, self-report data was collected on 79 couples discordant for HIV. Findings indicated that in trading centres and intermediate trading villages, women were more likely to be the HIV-positive partner, while in more rural areas the male partner was more often the HIV carrier (in nearly 80% of discordant couples). Altogether, only 17.1% of sero-negative men with HIV-infected wives used condoms in mutual sexual contacts, and likewise only 9.5% of sero-positive men with sero-negative wives. During the one-year study period, the rate of seroconversion was 8.7/100 years of observation for men vs. 9.2 for women. Data from the district as a whole suggested 18.7% of couples had at least one HIV-infected member (Serwadda, Gray, Wawer, Stallings, Sewankambo, Konde-Lule, Laingo & Kelly, 1995).

In two other RP studies, users and nonusers of voluntary counselling and testing (VCT) were compared among 10,950 participants (4,764 males and 6,186 females), and females were found to be significantly less likely to receive VCT than males (31.5% vs. 34.8%, respectively; p < 0.001) — with younger age, HIV-positive status, and having no additional sexual partners in the past five years all associated with lower VCT participation for both genders. Among women, higher VCT participation was associated with AIDS-suggestive symptoms, symptoms of other illnesses, and having a shopkeeper occupation (Nyblade, Menken, Wawer, Sewankambo, Serwadda, Makumbi, Lutalo & Gray, 2001). Lastly, in a specifically rural study involving 56 communities, AIDS counselling programme participants, 15–49 years old, were surveyed, with knowledge, attitude, and behaviour data collected, while blood was obtained from 77% of the recruited participants. Subjects who gave blood received free, unlimited VCT access and could participate on an individual or couple’s basis. Another important project feature was the provision of HIV results in people’s homes by trained, certified resident counsellors. Ninety percent of those providing blood requested HIV testing, although only 64.6% followed up to receive the results. Overall, the proportion of people receiving results increased during six years of project activity, from 35% to 65%, supporting the effectiveness of home-delivered VCT in rural areas (Matovu, Kigozi, Nalugoda, Wabwire-Mangen & Gray, 2002).

Several additional studies are relevant to review, notably a focus group investigation undertaken in four villages in Kigoyera, Uganda. Within these groups, subjects expressed a strong need for VCT services provided by community health workers. Indeed, they felt continual VCT services were necessary to induce consistent precautions in sexual behaviour (e.g., condom use), and wanted a separation of HIV counselling from HIV testing. They confirmed premartial sexual relations were widespread, including relations between married adults and unmarried youth. They also indicated condom use was minimal and that HIV counselling/testing programmes had not yet affected significant changes in sexual risk behaviour (Kipp, Kabagambe & Konde-Lule, 2002).

In still another focus group study conducted in rural southwest Uganda, discussions were held with 208 women about their willingness, in principle, to undergo HIV testing if pregnant, and to disclose their HIV status to clinical maternity staff. These women expressed anxiety about staff keeping communications between them confidential and about medical staff refusing to assist their deliveries if the women tested HIV-positive and their status became known to the staff. They also expressed uncertainties about the reliability of test results and mentioned rumours about medical staff intentionally killing HIV-positive patients to stop the spread of the epidemic. They were also afraid their spouse would blame them for their HIV-positive status and that the blame might escalate to marital separation or domestic violence (Pool, Nyanzi & Whitworth, 2001).

Finally, a RP survey study that assessed villagers’ knowledge and attitudes about vaccination and potential HIV vaccines was undertaken in Uganda among 14,177 participants aged 15–49 years (Kiwanuka, Robb, Kigozi, Birx, Phillips, Wabwire-Mangen, Wawer, Nalugoda, Sewankambo, Serwadda & Gray, 2004). Their willingness to participate in HIV/AIDS-preventive vaccine trials was further assessed during a follow-up survey 10 months later, after a community education programme on HIV vaccines was undertaken. Knowledge of the preventive utility of vaccines was high (71%), higher in men than women (p < 0.001), and higher as education levels increased (p < 0.001). Vaccines were considered appropriate for children and women (99% and 88%, respectively), but not for men (28%). Participants felt adolescents were the most appropriate subjects for HIV/AIDS-preventive vaccine trials (93.7%) but also thought HIV-positive persons were eligible for trials (60.2%). Interestingly, only 20% of this sample thought a preventive vaccine could help control HIV. However, HIV vaccine awareness increased from 68% at baseline to 81% at follow-up (p < 0.001), and willingness to participate in HIV-preventive trials was 77% (Kiwanuka et al., 2004).

Context and methodology

Our inquiry differed from most of those reviewed above in that our study was qualitative and focused solely on the attitudes, knowledge and questions rural villagers had about the testing of HIV/AIDS-preventive vaccines. Our inquiry was assisted by previous work from Willms and Sewankambo, who have conducted participatory action research (PAR) in Lyantonde for 13 years (e.g., Higginsbotham, Willms & Sewankambo, 2001; Sewankambo, Spittal & Willms, 2001; Spittal, Nakuti, Sewankambo & Willms, 1997).

A key opportunity for communicating with townspeople occurred during a meeting of concerned citizens on the future administration of a community development centre. During the meeting, the senior author was introduced as a researcher responsible for preparing an HIV/AIDS vaccine...
trial. The interest was immediate and the group arranged a meeting that evening to discuss the issues that might be relevant if there was trial participation by Lyantonde residents. That meeting involved an extended discussion with 15 Lyantonde residents, conducted primarily in English, with a community translator available. These communications facilitated development of a schedule of interview questions and the subsequent administration of follow-up interviews, which were tape-recorded and transcribed verbatim.

**Interview schedule**

Interviews were conducted by a trained interviewer and included 15 villagers (see Table 1 for the interview schedule). When the spoken English was incomprehensible, a village translator skilled in Lugandan provided assistance. The questions were guided by conceptual dimensions identified in previous survey research regarding attitudes and behaviour concerning vaccines (see Ritvo, Irvine, Klar, Wilson, Brown, Bremner, Rinfret, Remis & Krahn, 2003).

**Results**

**Perceptions of safety and effectiveness issues**

In response to questions about the precautions used in developing vaccines and the potential effectiveness of the preventive vaccines tested in clinical trials, it was obvious that several interviewees confused preventive vaccines with therapeutic vaccines and drugs. Furthermore, while some interviewees attributed significant risks to trial participation, others attributed minimal risks because of the animal testing undertaken prior to human testing (see Table 2).

Several other villagers manifested a high level of trust in vaccine effectiveness, particularly mentioning that vaccine candidates, even in the testing stage, would be highly effective. Attributions of effectiveness were readily transferred from experiences with other well-established vaccines. However, villagers also referred to past difficulties with specific vaccines as indicative of the risks involved, even with frequently used vaccines. Several interviewees referred to a specific past event where several people had died after vaccination, evidently because a vaccine was administered after its expiration date.

**Information delivery and education**

Despite a variety of views on safety and effectiveness, most interviewees were clear about where to obtain more information about vaccine testing. Some mentioned the government health centre as an important source while others preferred information from public and private hospitals, and physicians in the community. Others trusted the community organisation to which they belonged. Most interviewees were articulate about the kinds of information useful to them and their peers (see Table 3).

In terms of commenting on the impact of the information received, some questioned whether the time-line for deriving an effective vaccine was brief enough to encourage people to take safe-sex precautions until an effective vaccine was available. They were also concerned that participation in a vaccine trial might encourage some participants to take fewer precautions.

**Discussion**

Past studies have demonstrated that rural residents of Uganda are responsive to voluntary testing and counselling (VCT) programmes, although perhaps anxious about participation. While the impacts of VCT programmes in Uganda are hard to quantify, residents acknowledge the continued prevalence of high-risk sexual practices, including extramarital practices between adults and youths.

Because VCT is inevitably part of a vaccine trial procedure, the results described above bear some relationship to how residents view trial participation. The attitudes that surface towards vaccine testing, however, appear different from the attitudes that surface towards VCT.

First, vaccine testing evokes the hope of a biochemical solution to the epidemic that appears to be motivating to community leaders and to individual interviewees. The idea of an external agent defeating the virus seems ‘magnetic’. This may explain why some interviewees confused the preventive actions of vaccines with drug treatments for AIDS. Intense emotions are evoked by the epidemic, and the consequent hope of release from its oppression likely activates an emotional pattern of ‘wish-fulfilment’, which glosses over distinctions between therapeutic agents and preventive vaccines. In our sample, this was evident in statements about how the vaccine ‘helped’ when one had the disease ‘in your body’, how vaccines ‘improved’ the status of ‘newly sick people’ and how one would ‘not feel bad’ if infected following vaccination. The notion that the benefits of a preventive vaccine are only for the uninfected seemed hard for some villagers to grasp in contrast to the mistaken notion that it would immediately help infected...
Table 2: Participants’ perceptions of safety and effectiveness issues; sample responses

Perceptions of safety and effectiveness issues

- #002 – “You might have been having disease in your body, maybe suffering from diphtheria... the vaccine helps.”
- #003 – “… some vaccines have proven to be effective because of the improvement of... newly sick people.”
- #004 – “And if you are infected with the virus... you may not feel bad when... infected with the virus.”
- #001 – “Danger could be there... the drugs you are using... may be bad for the person, depending on his blood [and] the strongness of that drug.”
- #006 – “Vaccine experiments may harm... they may even cause death….”
- #001 – “We are told somewhere... they have used it on some animals and then it becomes effective... when there is some agreement, then they give it to human beings.”
- #015 – “… they are tested through animals first and then when found safe... they are introduced to people.”
- #004 – “… in the future, if we bring the vaccine, people can get through it [the epidemic] and stop dying.”
- #015 – “Vaccines are good... when you're vaccinated and when the disease comes, [the disease] won't affect you! ... like measles — when the disease comes, it doesn't become very serious and sometimes you find it's not coming at all.”
- #009 – “Vaccines have been given to people... and some people have died because of the vaccines.”
- #011 – “Some children [who were vaccinated] never got polio... others [who were vaccinated] died.”
- #011 – “I don't know the number of children that died, but it happened around 1996.”

Table 3: Participants’ views on information delivery and education; sample responses

Information delivery and education

- #001 – “I would want some books to read because sometimes I may not be able to be in the workshops or the seminars.”
  Interviewer (I): “Who usually organises these seminars?”
  Respondent (R): “Our counsellors.”
- #003 – “First of all, there are these counsellors who know... we call them counsellors.”
  I: “So you would feel comfortable going to a counsellor to ask questions?”
  R: “Pretty much.”
- #007 – I: “Where would you go in Lyantonde if you wanted to find out more information about HIV/AIDS vaccine testing?”
  R: “… the government health centre... that’s where you could get information... the government centre... I go where they immunise the children... at the government health centre.”
- #011 – “In a government hospital in Lyantonde.”
- #012 – “There are so many hospitals around... you can go there.”
- #014 – “Dr K... the doctor in the private hospital... because he’s a doctor and he can explain everything concerning the vaccine.”
- #009 – “I can go to Y [organisation]; I can get the information.”
- #001 – “We would like to know whether this vaccine has been tried in any other country, and how long these people have tried it... and how better these people are?”
- #006 – “We would like to know whether the vaccine is right for people to use it... that it’s gone through the right channels... that it’s been checked.”
- #006 – “The people must be told that these new vaccines for HIV will not be in their body for their lifetime... that there is a time where it may no longer be in their bodies.”
- #008 – “We will need to know how this vaccine works... what will be the precautions... the risks... the reactions... what guideline shall we be following, and how long would it take.”
- #011 – “The people would want to know how the vaccine is administered and how long does it stay in the human body.”
- #004 – “Explain that this vaccine will help... and there will be less effect when they get this virus.”
- #011 – “I would like to know how long would it take for the drugs to come... so as to see whether [for] that time one could behave well and wait for the vaccine.”
- #011 – “I want to know how long [it will take] for the vaccine [to be ready] for people... because that time is very important for someone to know and behave.”
- #011 – I: “If I’m understanding you, you’re saying that if someone believes the vaccine is coming soon, they are more hopeful and more likely to practice safe sex?”
  R: “Yes.”
- #014 – “It would be better if we explained and emphasised to the younger people that once this blood is introduced, that’s not the end of it, because it is only a test and if you are not 100% safe because you do not yet know the effectiveness of the vaccine, you need to be more careful.”

people. Nonetheless, only a minority of interviewees showed such problems. The majority understood key distinctions between AIDS treatment and a preventive vaccine for HIV.

Perceptions of the potential effectiveness of vaccine candidates and the risks of trial participation varied. Some believed any vaccine that candidates tested would be highly effective, given the laboratory experimentation and animal testing preceding human trials. These expectations of benefit, especially in Phase-I trials, might be overly optimistic. As the intricate uncertainties of experimental vaccine development are difficult to comprehend, even for scientists, we might expect unrealistically optimistic ideas...
among villagers about vaccines. Along these lines, their most common tendency was to over-estimate the degree to which successful animal testing predicted effective human protection. This tendency was reflected in the comments of one interviewee who stated that experimenters use the vaccine in ‘animals’ until ‘it becomes effective’ and ‘then... give it to human beings’. Another conveyed similar optimism with respect to safety, stating that vaccines are ‘tested through animals, first, and then, when found safe, introduced to people’. While neither statement is technically untrue, trial participants would need to be educated about human trials being important precisely because successful animal experimentation does not necessarily predict identical levels of success in humans.

Other interviewees’ attitudes fell at the opposite end of the optimism-pessimism spectrum. They readily associated severe mortality risks with trial participation. Several based their perceptions of risk on past incidents where Ugandans died after receiving a polio vaccine. Although we were unable to trace these adverse events, according to one interviewee, they involved the use of expired agents. In rural cultures, where news frequently travels by word-of-mouth, it is reasonable to expect adverse events to have enduring emotional impact and to be recalled with only partial accuracy. Thus, in educating prospective trial participants, it would be important to consider the individual’s prior beliefs and past experiences, either vicarious or direct, about the risks and benefits of vaccination.

There was still another set of responses about vaccine effectiveness that reflected altruism and civic-mindedness, surfacing in statements that conveyed beliefs that an HIV vaccine ‘can work’ and enable Africans to ‘get through’ the epidemic and ‘stop dying’, with successes paralleling those of the polio and measles vaccines.

In responding to a question about the forms of information that prospective trial participants would require, appropriate critical thinking was demonstrated. An educational checklist emerged from the villagers’ statements. They referred to questions about: what other countries the vaccine had been tried in and with what effects; what experimental checks had been undertaken of the vaccine; how long the vaccine would be expected to remain active and protective, once administered; what precautions would best be taken and what risks would be confronted in the course of testing; and how test vaccines would be administered. These responses reflect critical thinking that could be stimulated and optimized thorough pre-trial education.

There was little ambiguity among interviewees about where to seek further information. Several referred to the government health centre, others to the government hospital in Lyantonde, and to a local doctor on staff at a private community hospital. While most referred to medical personnel and facilities, some mentioned gaining information from the community organisation to which they belonged.

Finally, some interviewees reflected on the potential for vaccine testing to encourage people to reduce sexual risks as people might ‘behave well and wait for the vaccine’, while others were concerned that vaccine testing might be interpreted as a license to take less precaution. The majority of respondents favoured the view that the vaccine tests would encourage precautionary behaviour.

In summary, our study presents the analyses of individual interview responses of 15 Ugandan rural townspeople to issues around HIV/AIDS vaccine trials. Certain study limitations are acknowledged with respect to the convenience sample and the likelihood that a true cross-section of the target population might not be represented. It is likely, however, that the interviewees represent a sector of the village population that is more altruistic and conscientious, and more likely to participate in the first wave of vaccine testing. It is for these same reasons, however, that it is important to understand their responses and propensity for distortion and short-sightedness, as well as their considerable ability to think critically. In the end, these villagers demonstrate the potential to be intelligent, reliable subjects, motivated for appropriate reasons, and willing to play an important role in advancing the progress of HIV/AIDS vaccine development in Africa.

Acknowledgements — This study was supported by a grant from the National Centers of Excellence Programme of Canada, through the Canadian Network for Vaccines and Immunotherapies (CANVAC).

The authors stated that the study sponsors had no role in study design, collection, analysis and interpretation of data; nor in the writing of the report; or in the decision to submit the paper for publication. McMaster Research Ethics Board Approval #2002-023; McMaster University, Hamilton, Ontario.

The authors — Paul Ritvo is Associate Professor, School of Kinesiology and Health Sciences at York University in Toronto, Canada and a Career Scientist at Cancer Care Ontario. He is a Theme Leader in the Canadian Network for Vaccines and Immunotherapies.

Dennis Willms is an Associate Professor in the Department of Anthropology, McMaster University in Hamilton, Ontario, Canada and Executive Director of Salama Shield Foundation, an NGO with projects in Malawi and Uganda.

Robert Meisner is a graduate student in the Medical Anthropology program and a medical student at Harvard University.

Laura Brown is a Post-Doctoral Research Fellow supported by the Canadian Network for Vaccines and Immunotherapies, and a clinical psychology intern.

Adam Goldman is a graduate student in the School of Kinesiology and Health Sciences at York University and a Pre-Doctoral Fellow supported by the Canadian Network for Vaccines and Immunotherapies.

Nelson Sewankambo is one of the first scientists to publish data on AIDS in Africa, the Principal Investigator of the Rakai Project and Dean of the Medical School at Makerere University in Kampala, Uganda. He is Co-Chair of the Academic Alliance for AIDS Care and Prevention in Africa.

References


