

Monitoring and Evaluation of National HIV Prevention, AIDS Care and STD Control Programs (Uganda case study)

Introduction

The first documented cases of AIDS in Uganda were reported in October 1985. Early cases, however, were seen in 1982, in the Rakai district (Southwestern Uganda). Since then the AIDS epidemic has spread to all parts of Uganda. In 1988, a national serosurvey was conducted under WHO to establish the extent of HIV infection in Uganda. This survey revealed that about one million Ugandans were HIV positive. The current projected number of HIV infected individuals is about 1.5 million. The average seroprevalance in Uganda is estimated to be about 10% with seroprevalance as high as 50% in some rural towns in the Rakai District.

The March 1998 HIV/AIDS surveillance report indicated that as of 31 December 1997, a cumulative total of 53,306 AIDS cases had been reported, of which 7.3% were children under the age of 12. Results from population based cohorts show that HIV infection is currently the leading cause of mortality in adults aged 15 - 49 years. Mortality rates in HIV positive adults are about 10 times that of HIV negatives. The mortality rate attributable to HIV infection is as high as 50% in Uganda.

Uganda is currently experiencing a mature and generalized HIV EPIDEMIC, as evidenced by a high general population seroprevalance and a high mortality rate from HIV infection.

Uganda has in place a number of intervention programs for the control of HIV infection. Right from the beginning, a health education program targeted to the masses was put in place. Then programs targeted to specific groups were found to be more effective. Currently a program targeted at effective treatment of sexually transmitted diseases and voluntary testing and counseling has been added.

Context of the Uganda AIDS Program and Timeline of Evaluation and Monitoring Activities

In 1982, AIDS cases were reported in the Rakai district of Uganda. The Ugandan government, during that time, did not actively investigate these reports. This was a lost opportunity to initiate surveillance very early and thus start preventive activities. In 1985, documented AIDS cases were reported to the world. President Museveni came to power in 1985. With this new leadership the Ugandan government openly admitted that AIDS was a major health problem. This created a very positive environment to conduct HIV intervention activities. As a result, in 1987 Uganda was one of the first countries in Africa to establish an AIDS Control Program (ACP) within the Ministry of Health. One the aims was to facilitate and coordinate HIV prevention activities. An additional goal was to monitor the HIV epidemic in Uganda.

In 1988, the ACP, as one of its early activities, set about to establish through a national HIV serosurvey the extent of HIV infection in Uganda. In this same year, the European community (EEC) donated funds to refurbish the blood transfusion center, because blood transfusion services were initially involved in the monitoring of HIV seroprevalance in Uganda. The Demographic and Health Survey (DHS) took place in Uganda in 1988. No AIDS module was included, though this would have been a good opportunity to establish baseline sexual behavior in different parts of Uganda at the time

In 1989, the ACP established a sentinel surveillance and, in addition, undertook active surveillance of AIDS patients in hospitals in Uganda. No behavioral surveillance was established at that time. Both

serosurveillance and AIDS patient registers were labor intensive and required a lot of effort from the ACP.

With time, the Ugandan government realized that HIV/AIDS epidemic had a social dimension, and it needed a multisectoral approach in which government and non-government organizations could get involved. In 1990, the Uganda AIDS Commission (UAC) was established to coordinate and set a framework in which government ministries and non-government organizations could function. This, however, created some confusion as to what exactly were the responsibilities of the two organizations, ACP and UAC, and had some impact on funds made available to ACP. On the other hand, it enabled many more ministries to be involved in health (HIV) education activities.

Numerous non-government organizations got involved in HIV activities or were established as funding mechanisms under the coordination of UAC. The Ministry of Economic Development and Planning had the role of monitoring and evaluating their program. There was, however, no linkage of evaluation reports with the ACP in the Ministry of Health. The association of STDs and HIV made it logical to establish closer links in activities between the STD program and the ACP.

In 1994, the STD control program merged with ACP. The ACP HIV/AIDS sentinel surveillance program was, to a limited extent, reporting on STDs trends. The STD manager, however, felt that the HIV/AIDS surveillance report was not comprehensive on STD information.

In 1995, the ACP initiated behavioral surveys in various parts of Uganda in an attempt to understand current changes in sexual behavior. This is still an ongoing activity. In 1996, the UNAIDS program was formed and a UNAIDS theme group created. Its main impact on ACP was a reduction in funds available and limited technical input. Therefore, monitoring and evaluation activities were affected due to reduced resources. The STD control program established its own sentinel STD surveillance program in 1988 using different monitoring sites from those for HIV surveillance.

Data sources for Monitoring & Evaluation

HIV/AIDS Surveillance System

The HIV/AIDS surveillance system was established within ACP in 1989 using antenatal clinics as its testing sites. Initially it started with six sites that have been expanded to 20 antenatal clinics located throughout Uganda. Its aim is to monitor the HIV epidemic in both towns/trading centers and rural areas of Uganda. Initially a one-page form was distributed to the antenatal clinics, and the forms and blood samples were returned to ACP whenever medical officers in charge of the units traveled to ACP. Clearly this method did not allow for timely testing of blood samples. It was changed in early 1990 to a system where forms and blood samples are actively collected by the AIDS control program in each site once every four months. This makes the system more expensive but more reliable. All the blood samples are processed in one central location at the Entebbe Virus Research Institute. A quarterly report is written and disseminated regularly. This has functioned fairly well over the years.

Since 1996, the HIV/AIDS surveillance report has consistently reported a decline in HIV prevalence from its sentinel surveillance sites. A number of reports have examined these trends. There are limitations currently experienced in the present surveillance system. For example, the age grouping in the younger ages is too wide (15-24) to enable ACP examine trends of HIV infection in the young groups, especially the females. As a result, new changes are about to be introduced to oversample younger age groups and break down ages into single units. To cut costs (as large samples will be required), the number of sentinel surveillance sites will be reduced. The usefulness and feasibility of

single year 'groupings' remain to be seen, as in practice, this could be difficult to implement and analyze.

STD Surveillance System

From 1988 to 1997, the STD surveillance system collected data from 13 sites not connected to the HIV/STD surveillance system. The data was analyzed and reported together at the AIDS control program. The STD program, however, felt that not much attention was paid to the information collected about STDs, and the analysis was not exhaustive. In 1997, an evaluation of the STD surveillance system was undertaken by WHO and the Centers for Disease Control (CDC). It was recommended that the STD program use the Health Information Management System (HIMS) to collect the information it needed. After discussion with the Ministry of Health official, this proved to be an impractical option as the STD program needed more information than the HIMS forms could allow them.

Currently the STD program has reestablished the 13 sentinel sites (health units) which continuously report STD patients in these units to the STD control program using centrally designed monthly report forms. The data is analyzed by the STD program and is hoped that a separate surveillance report will be issued quarterly.

In addition a surveillance system for monitoring drug resistance to the recommended STD drug is in place. This, however, is carried out by AMREF and not the STD control program; results are readily available. There is no established separate monitoring and evaluation system for STD drugs. Information about this can be obtained through essential drug monitoring.

Condom Distribution Network.

The following are major importers and distributors of condoms in Uganda: Ministry of Health, Marie Stopes International, Somarc, Family Planning Association and private retailers. Information on the total number of condoms imported and distributed is not easy to obtain. This is mainly because, for some time, there has not been a central place to keep track of data on the number of condoms imported and distributed. Recently the AIDS control program established a condom promotion office that will be able to give more information on trends in condom use in the future.

Records are available from the individual groups that import and distribute condoms. For example, Somarc sales last year were 10 million up from less than one million in 1990. Marie Stopes International distributed 7 million condoms in 1997 as compared to 1.5 million in 1993.

Behavioral Studies in the Country

In 1995, the STD/AIDS control program conducted a WHO funded population-based Knowledge Attitude Behavior Practice (KABP) survey on HIV/AIDS and STDs in the districts of Kampala, Jinja, Soroti and Lira. They were conducted to provide additional data for evaluation of AIDS control efforts. In addition, these surveys were to provide baseline data for the future evaluation of the sexually transmitted infection project, a Ministry of Health/ World Bank funded project. A similar study was conducted in 1989 in Kampala and Jinja, thus it was possible to compare behavior change over time in these two districts. A multistage cluster sampling was used to enroll nineteen households in each district. A total of 5,805 respondents were enrolled in all the four districts with about 1,400 people enrolled per district.

The results of these surveys helped in validating and explaining the trends seen in HIV seroprevalence. There were two significant findings: a) a high proportion of respondents (68%) reported change in sexual behavior, i.e. faithfulness, abstinence and condom use; and b) significant delay in age at first intercourse was observed.

Again in 1997, a similar survey was conducted by the STD/AIDS control program in the Masidi district. In addition to the above mentioned aims of these surveys, the Masidi survey attempted to evaluate prevention indicators (PI) used to monitor HIV/AIDS prevention and control strategies and activities. In all, 1608 respondents were enrolled. Repeat surveys will be carried out in the future to establish if indeed a change in behavior has taken place.

These national behavioral studies were conducted well after seroprevalence surveillance was in place (about six years). Thus, in many areas we lack the temporal relationship between changes in seroprevalence and behavior change. In addition, there is a need to closely link areas where behavioral studies are done and antenatal serosurveillance is carried out.

Behavioral and Seroprevalence Longitudinal Studies

Rakai Cohort

Since 1989, the Rakai project, a collaboration between Columbia University, Johns Hopkins University and the Ministry of Health of Uganda, has conducted a population-based longitudinal study in the Rakai district of southwestern Uganda. This cohort study has been funded by the National Institutes of Health (NIH), Rockefeller Foundation, and World Bank. The main aim of the studies is to evaluate the effect of a number of interventions on HIV transmission. Over the years, the following interventions have been undertaken: extensive health education and mass treatment of sexually transmitted diseases. In addition, in-depth studies on sexual behavior and sexual network groups have been carried out. It has been possible to evaluate the trends of HIV infection over time in the cohort studies. In particular, HIV incidence and prevalence in the general cohort and in special subgroups like pregnant women has been evaluated. This has enabled comparison between trends in HIV in the general cohorts and those in pregnant women within the cohort. Likewise it is possible to evaluate the utility of using sentinel surveillance in antenatal care for general population surveillance.

The sample size for this cohort has grown from 2,591 adults to 12,000 aged 15 - 59. The study population is obtained through stratified, multistage cluster sampling. The significant findings over the years have been as follows:

1. HIV prevalence declined significantly between 1990 to 1992, especially in trading centers. The main factor contributing to reduction of HIV prevalence is the high mortality rate among HIV positives in all ages.
2. Incidence of HIV infection did not change over the same period.
3. In subgroup analysis, pregnant women showed a significant decline in HIV prevalence but no change in incidence. This indicates that changes in HIV prevalence do not reflect changes in incidence in these age cohorts of pregnant women.
4. Mortality among HIV positive adults over 15 years of age is 118.4 per 1000 person-years (PY) compared to 12.4 per 1000 PY in HIV negative people.
5. Mass treatment of STD does not reduce HIV infection despite reductions in STDs.
6. The population attributable risk of STDs for HIV infection is about 22% (Not as high as initially thought).

Notable changes in sexual behavior have taken place over this period such as an increase in condom use and a reduction in STDs and sexual partners. No association between ever use of condoms and

reduction of HIV transmission has been seen. This suggests that in high HIV prevalence areas, consistent use of condoms could be a better marker for reduction of HIV incidence.

Medical Research Council (MRC) Program on AIDS

The Medical Research Council Program on AIDS in Uganda began in 1989 with the establishment of a population-based longitudinal study in Kyamulibwa of the Masaka district of southwestern Uganda. This study enrolled over 10,000 people from 15 neighboring villages in southwestern Uganda. The cohort has been used mainly to evaluate the dynamics of HIV transmission in a rural African village. The project is funded by MRC (UK). The main findings to date include:

1. HIV prevalence fell significantly from 8.1% in 1989 to 7.3% in 1997.
2. Incidence did not drop over the same period.
3. Sexual behavior changed, particularly a reduction of sexual partners and an increase in condom use.
4. Mortality rates among HIV positive people is 115.9 per 1000 compared to 7.7 per 1000 in HIV negative groups.
5. Completion of STD treatment occurs in only 30% of patients.
6. Trained private practitioners are able to use treatment guidelines satisfactorily to treat STD patients.

Longitudinal studies have been particularly useful in the monitoring and evaluation of trends of HIV seroprevalence in the areas in which they operate. Unlike sentinel surveillance, longitudinal studies can account for the impact of mortality and in and out migration of HIV positive and negative individuals.

At the same time longitudinal studies also monitor self reported behavior. In both the Rakai and MRC cohort there is a positive change in reported behavior change. This adds another advantage to longitudinal studies in that behavior change can directly be linked to seroprevalence changes in the same community.

Thus, longitudinal studies can be very useful in validating national serosurveillance trends and, in addition, offer more information on incidence, seroprevalence, behavior change, and mortality. Longitudinal studies, however, are expensive, because one needs to enroll a large number of subjects in order to monitor incidence. Maintaining these cohorts to have meaningful monitoring of HIV trends requires continued and sustained funding. In this respect, the MRC program on AIDS in Uganda has been able to achieve this; the Rakai cohort has not been so lucky. Thus the cohort size has tended to change over time as a result of availability of funds.

The results of these longitudinal studies in monitoring and evaluation in Uganda have not been given the prominence and attention they deserve by the Ministry of Health. Their effect on local policy-making, like other research findings, has not been great.

Demographic and Health Survey (DHS)

The 1995 Uganda Demographic and Health Survey is a nationally representative survey of 7,070 women aged 15-49 years and 1,996 men aged 15-54 years from all districts of Uganda. It is funded by USAID and provides information on fertility, maternal and child health, infant mortality and maternal mortality. For the first time, the 1995 survey included questions on AIDS and other sexually transmitted diseases. This included questions in the area of AIDS/STD knowledge and awareness, risk perception and HIV/STD prevention. In the future these surveys will be useful in validating reported changes in behavior over time at a national level.

The following are the main findings from the 1995 DHS survey concerning AIDS/STD:

1. Close to 100% of males and females are aware of HIV
2. About 60% of respondents knew that reduction of sexual partners can prevent disease spread
3. There are differences in safe sexual behavior between educated and non-educated respondents.

The DHS survey of 1989, however, did not have an AIDS module and took place about a year after seroprevalence surveillance had started. This would have provided an added opportunity to establish a baseline behavioral parameter from various parts of Uganda.

Voluntary Counseling and Testing Centers

AIDS Information Center (AIC)

The AIDS Information Center was established in 1990 with USAID funds to offer voluntary counseling and testing (VCT) in Uganda. Currently it has 4 established sites in Uganda and has tested approximately 350,000 clients. By far it is the largest HIV testing and counseling center in Uganda. Each established VCT center maintains a log on the number of clients that attend and are followed up. Although people who use this service are a self selected group, data collected from these centers can give us trends of HIV prevalence, sociodemographic characteristics of users over time, and dynamics of HIV infection among couples.

In addition, the AIC offers opportunities to assess and monitor over time behavior changes of HIV positive and negative individuals once they know their HIV status. Behavior of HIV positive individuals is a major determinate of HIV dynamics. In study of 3,000 clients evaluated at 3 and 6 months, AIC has demonstrated that testing and counseling does significantly change people's behavior. Monitoring these trends over time within these self-selected individuals and groups at a population level would be useful.

The data from VCT centers, however, cannot be used on a national level for monitoring and evaluation to give us trends over time because of the possible selection bias of the clients that attend.

Other service provider

The Rakai AIDS Information Network (RAIN), working in Rakai district and funded by USAID and DANIDA, has provided HIV testing to over 50,000 clients since 1994. In 1997/8, the Delivery of Improved Services for Health (DISH) opened 10 counseling and testing services in 10 districts in southern Uganda.

The AIDS Support Organization (TASO)

The AIDS Support Organization (TASO) was founded in 1987. It is a voluntary organization that provides psychosocial and medical care support to people affected by AIDS. TASO operates in seven districts in Uganda and is supported mainly by international donors. These include DANIDA, USAID, SIDA, DFID and AusAID. In 1993, it provided counseling, medical care and social support to over 22,795 people living with HIV/AIDS. Since 1996, it is estimated that TASO annually registers 6,000 new clients country wide. In 1994, WHO extensively evaluated the TASO service, and in 1998 DANIDA/USAID did likewise. Evaluation indicates that TASO services have led to the following changes:

1. Helped to promote safer sex practices among clients.
2. Enabled clients to formulate strategies for the present and the future
3. Improved access to treatment of opportunistic infections

4. Increased HIV/AIDS awareness to families with affected members
5. Increased self-reliance among clients through income generating activities funded by TASO.

No evaluation of the UNAIDS provisional care and support indicators have yet been carried out by TASO.

Blood Transfusion Services

In 1986, when the AIDS Control Program started its activities, the blood transfusion services were used to measure the HIV prevalence in the general population. HIV prevalence of up to 25% was reported in 1988. In 1989, the blood transfusion services introduced screening procedures for potential blood donors that helped reduce HIV prevalence among blood donors. In effect, the blood donors are now a selected group. For this reason, the STD/AIDS control program no longer uses the blood transfusion service for monitoring HIV in the country. The amount of blood collected country-wide since 1988 has dramatically increased from less than 5,000 to over 50,000 bottles annually in 1996. In 1997, the blood transfusion services collected 55,000 bottles of blood of which 3% were positive for HIV. This is far below the national HIV seroprevalence of 10%

The blood transfusion service in Uganda collects data on the total number of transfusions carried out in Uganda. It also has information on blood transfusions that have been screened and those that have not. This presents a unique opportunity to monitor and evaluate safe blood transfusions over time. Currently this is not done effectively.

Interaction between Monitoring and Evaluation and Donors / Policymaking

Donors have had a positive impact on monitoring and evaluation of HIV programs in Uganda. This has been due mainly to donors' insistence on using baseline indicators on any project they fund. This makes it easy to establish program impact. In Uganda, USAID funded projects have also been instrumental in providing financial and technical assistance to the ACP HIV/STD surveillance program i.e. WHO GPA. This resulted in heightened awareness of the use and possible impact monitoring and evaluation can have on programs.

The Ministry of Planning and Economic Affairs has a monitoring and evaluation office that monitors all government and non-governmental HIV project funds given to the Ugandan Government through the Ministry of Finance. This apparently excludes projects whose funds are channeled through other mechanisms i.e. directly to the Ministry of Health. Two problems appear to arise a) no comprehensive reports on monitoring and evaluation of HIV projects from the Ministry of Planning appear to be available to the public; and b) no good exchange of information exists between ACP and planning. The net result is that there are numerous projects involved in HIV intervention activities such as health education, training without a good understanding of number involved, process. Information is not readily available.

Monitoring and evaluation information is very useful for policy making. The utility of information collected from has been limited. In the first place, such information is available but not disseminated to policymakers. In other cases, the information is available, but implementation of policy requires money that may not be available. This gives an impression of lack or slow use of available information on.

In Uganda, monitoring and evaluation has assisted in showing a decline in HIV prevalence in the 15 – 20-year age group. As a result, donors pay more attention and provide more money to this age group. This, in turn, has meant that HIV surveillance has intensified for this age group and requires more funding.

Monitoring of Program Inputs and Output

The following tables attempt to indicate what the program inputs and expected outputs are in Uganda. In many cases, actual figures are lacking, because a composite figure of the numerous programs is not available. It requires tremendous effort to collect this information. As highlighted above, there is a need to coordinate these programs. In some cases, different programs collect similar information but just differ on the denominators used or time frame chosen (this makes comparison difficult) i.e. reduction in sexual partners in the last 3 months or use during the last six months.

Brief review of the Ten Prevention Indicators

To date, it is only the ACP/WHO survey in Hoima district that has systematically used the WHO questionnaire for evaluation of national programs. This has enabled the ACP to use the proper numerator and denominator for prevention indicators. Numerous surveys were done in Uganda over the past 10 years that can give us indication of the validity of using the Prevention Indicators (PIs).

PI 1. Knowledge of Preventive Practices

Numerous KAP surveys in Uganda have demonstrated that knowledge of preventive practices is high. The most extensive area coverage was that of DHS that showed that over 60% of respondents know how to prevent HIV transmission. In addition, the ACP/WHO survey, Rakai Project, and MRC have all reported knowledge levels ranging from 60 - 80%.

PI 2. Total Condoms Available for Distribution in Previous 12 Months

The total number of condoms available for distribution in Uganda during the preceding 12 months, PI 2, has proved to be a very difficult figure to determine. Figures for Somarc and Marie Stope International would indicate that at least 17 million condoms were available last year. A conservative estimate from ACP indicates that at least 25 million condoms were available for distribution last year. Lack of a condom monitoring office in the past has been a major handicap, so the ACP recently established one.

PI 3. Condom Availability

The ACP/WHO survey in Hoima, the Rakai Project, and the DHS surveys have all demonstrated that at least 50% of respondents know where they can acquire a condom. This indicator, however, needs to be complemented with condom surveys.

PI 4. Non-regular Sexual Partner

The ACP/WHO survey in Hoima evaluated this indicator and found that 7% of sexually active respondents (1,266) in the last 12 months had non-regular sex partners. While a number of KAP surveys in Uganda have evaluated non-regular sexual partners, they have not used the denominator suggested in the WHO guidelines. In addition, the ascertainment of non-regular sexual partners could be difficult in Uganda due to culture misunderstanding by respondents of what constitutes a non-regular partner.

PI 5. Use of a Condom with a Non-regular Partner

In the Hoima district (ACP/WHO) survey, only 39% of respondents who had sex with a non-regular partner had used a condom in the most recent act of sexual intercourse. A similar figure was obtained in military men in selected barracks in Uganda. In the Rakai cohort, up to 60% of respondents used a condom with non-regular partners.

PI 6/7. STD Case Management

The STD program recently reviewed PI 6/7 in a study carried out in 10 districts of Uganda in 1996. 170 patients presenting with genital ulcers and urethral discharge were assessed. The total score for PI 6 was 5.3% and that for PI 7 was 52.9%

PI 9. Reported STD Incidence, Men

No data is readily available on this prevention indicator. Different questionnaires have used different observation periods and denominators. The Rakai cohort and the MRC cohort did collect information that can be analyzed to examine this indicator over time.

PI 8/10. STD and HIV Prevalence, Women

Although this indicator can easily be obtained from the HIV/STD surveillance system, there is no available figure on this indicator. Similar data can be obtained from population based cohorts.(Rakai & MRC)

Ideas/Requirements to Improve Monitoring and Evaluation.

Results from the evaluation reports of the STD surveillance system and TASO would suggest that the following will be required to improve on monitoring and evaluation:

A. Improve the Quality of Data Collected

1. More education at all levels of the importance of collecting data
2. Training at all levels in the importance of proper recording of data.
3. Adequate supervision to ensure good data quality
4. Periodic evaluation of monitoring and evaluation activities.

B. Policy and Management.

1. Since there are many different HIV/AIDS/STD programs in Uganda (>100), there is a need to have the ACP streamline the collection of key indicators that are used for the monitoring and evaluation of prevention activities.
2. Supervisors/managers must motivate staff to properly collect data
3. The ACP should regularly compile and disseminate information from monitoring and evaluation exercises.

There is a very urgent need for organizations like ACP to educate and disseminate standard, core program indicators that can be collected by all organizations or projects. A mechanism needs to be established to collect, compile, analyze and disseminate this information.

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