Community-based AIDS prevention and care in Africa: Workshop report

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The Population Council, an international, nonprofit organisation established in 1952, undertakes social and health science programmes and research relevant to developing countries and conducts biomedical research to develop and improve contraceptive technology. The Council provides advice and technical assistance to governments, international agencies, and nongovernmental organisations, and it disseminates information on population issues through publications, conferences, seminars and workshops.

The Wellcome Foundation Limited is an international pharmaceutical company dedicated to the discovery and marketing of products which promote human health and quality of life. The company has been at the centre of the medical response to HIV and AIDS since its development in the mid 1980s of zidovudine (AZT) for the management of HIV infection.

Through its “Positive Action” programme, Wellcome is committing funds, expertise, and facilities in support of its fundamental belief that its activities in the field of HIV and AIDS should go beyond the traditional roles and responsibilities of commercial organisations. Positive Action is an international programme of HIV education, care and community support, and comprises a series of different initiatives, each focusing on a different area where there is most need. There are currently five main initiatives: HIV Community Support, Children and Young People, Developing Country, The Workplace, and Information and Policy.
Representatives from community-based AIDS prevention and care programmes in five sub-Saharan African countries (Kenya, Tanzania, Uganda, Zambia, and Zimbabwe) spoke about their programmes' strengths, shortcomings and hopes for the future at a meeting entitled “Community-Based AIDS Prevention and Care in Africa: Building on Local Initiatives”, organised by The Population Council with the support of the Wellcome Foundation's Positive Action Programme. The meeting took place on June 5, 1993 in Berlin just prior to the IXth International Conference on AIDS. The participants' experiences and insights demonstrated the tremendous ingenuity and imagination that communities have generated to prevent the spread of HIV and AIDS and how they have taken action where governments' activities have fallen short. The workshop brought representatives of these programmes together with the staff of governmental and nongovernmental organisations, funding institutions, technical assistance agencies, and national and international AIDS prevention programmes to present their experiences. Discussion focused on strategies to strengthen community-based AIDS prevention and care in Africa.

The meeting was the culmination of the first year of a three year project established by The Population Council as part of the Positive Action Programme's Developing Country Initiative. The Population Council is an international non-profit research organisation applying science to the problems of population and health. The Wellcome/Population Council initiative aims to identify the successful elements of community-based AIDS prevention and care programmes and promote a global exchange of expertise that will build upon the lessons learned from these local initiatives.
Dr. Colette Dehlot, director of The Population Council's project based in Nairobi, Kenya, explained how this epidemic has altered the social and economic fabric of the community, stressing the devastating consequences for families. For example, AIDS is leaving an increasing number of orphans whose parents have either died of AIDS or who are too sick to take care of their children any longer. Unfortunately, the epidemic has arrived in concert with severe economic crisis in many countries. Economic stress has caused family members to separate from one another, thus weakening the traditional family structure, draining community resources, and leaving families and the community further at risk due to consequent changes in social and sexual behaviour.

The eight programmes highlighted in the workshop were divided into four themes:
1) The role of counselling in HIV/AIDS prevention and care programmes; 2) The exploration of home-and community-based care; 3) The reorganisation of traditional institutions within the community to meet the needs for AIDS prevention and care; and 4) The impact of the changing socio-economic environment of AIDS on women and children.

EIGHT COMMUNITY-BASED INITIATIVES

1. The role of counselling in HIV/AIDS prevention and care programmes.

Community-based programmes often involve the provision of counselling to individuals, couples, or groups. From Kenya, Ms. Jane Murago-Munene, producer and director of Cine Arts Productions, an organisation that creates films for international development agencies, reported on the work of the Know AIDS Society (KAS) of Kenya. KAS employs people living with AIDS (PLWAs) as counsellors in the belief that they are in the best position to understand individuals' and families' concerns about HIV and AIDS. The goal of KAS is to reduce the disability and stigma associated with HIV infection. To realise this goal, KAS mobilises PLWAs to respond to their own health problems in a positive way and uses its members to inform the community at large about AIDS prevention and how to live with the disease.

The primary activities of the programme include recruitment of clients through counselling outlets in dispensaries and hospitals; media and educational campaigns; provision of education and information for patients, their partners and friends; and a 24-hour telephone hotline. KAS counsellors also make home visits and provide community outreach and health education/counselling on "positive living," i.e., disease management and behavioural risk reduction. KAS is also actively involved in advocacy in support of the rights of PLWAs.

KAS utilizes one mechanism of counselling services; other organisations use volunteers from the community or, as in the case of the Ministry of Labour and Social Security in Zambia (MLSS), employees of large companies. According to Dr. Mubiana Macwang'i, a research fellow at the Health Promotion Research Programme of the University of Zambia's Institute for African Studies, the overall goal of the MLSS AIDS prevention initiative is to reduce the transmission of HIV infection among the workforce. The programme's specific objectives are to: 1) create awareness about and prevention of HIV/AIDS among employees; 2) reduce behavioural risk through promotion of condom use; and 3) encourage "positive living" among those infected with HIV. This programme concentrates on training educators, motivators, counsellors, paramedical personnel, and trainers of trainers from participating industries.

The MLSS has initiated this project in 65 companies, including the INDENI Petroleum Refinery Company. MLSS has been working with INDENI by offering the company's clinic staff and workers seminars on population, family planning, and HIV/AIDS prevention. INDENI then provides the personnel, drugs, information and education, and other materials needed for AIDS prevention and care to all its employees.
At the Berlin workshop, participants questioned how counselling programmes could be made more effective, given that so many initiatives use counselling as their primary method of AIDS education and prevention. Participants concurred that PLWAs should be recruited more frequently as counsellors given their experience with AIDS. Some participants believed that group therapy might be more effective than individual counselling because people meeting together to share information and experiences discover a sense of belonging. In any case, participants agreed that the counselling process, whether used among groups or individuals, provides an environment in which people feel safe enough to talk about taboo subjects such as sex.

2. The exploration of home and community-based care.

Traditionally, women are primary caretakers of sick and elderly family members and, in recent years, they have taken on most of the responsibility for caring for family members affected by AIDS. This additional burden often stretches their meagre household resources to the breaking point and adds another responsibility to women's already heavy workload. Home-based care is often the only practical form of care in many African societies in the absence of extensive hospital-based or alternative care services.

The workshop moderator, Dr. Geeta Rao Gupta, Project Manager of the Women and AIDS Project of the International Centre for Research on Women in Washington D.C., pointed out that women have various roles within the family and society, each one having different degrees of power. She noted that women in all parts of the world demonstrate a remarkable ability to maintain families with only meagre resources at their disposal. Social policies often take advantage of women's good management by diverting resources to meet other community needs. Just because they have proven to do so well with so little, women are often deprived of resources that could help them better handle their various tasks and reduce their enormous workload.

In Uganda, the National AIDS Programme, located within the Ministry of Health, has initiated a community outreach effort for combined home-and institution-based care. Ms. Mary Amanyire, a social worker and health educator from the National Aids Programme reported that the programme uses trained counselling aides for AIDS prevention. The aides provide home and community support for people with HIV/AIDS and their families and have set up a two-way referral system between the community and local health care facilities.

In Pakanyi subcounty, where this project was initiated in 1991, extensive AIDS education now occurs in public places such as churches and the health centre, and both the counselling aides and medical assistants make home visits. The result appears to be increased referral of patients to the local health unit. When AIDS patients are released from the hospital, they are followed up by a counselling aide under the supervision of the district health team. These aides provide counselling and other services in the patients' homes.

In Tanzania, an NGO known as “The People in the Fight Against AIDS in Tanzania” (WAMATA) was founded by a small group of men and women concerned about the plight of individuals and families and the need to overcome the stigma of HIV/AIDS infection. Dr. Esther Mwaikambo, Head of the Department of Child Health at the Muhimbili University College of Health Sciences in Dar es Salaam, described WAMATA's specific objective as reaching individuals, families, and grassroots groups in rural and urban areas with AIDS prevention education.

WAMATA provides community-based care and treatment to its clients through home-based drug management, nursing, counselling, education, and to a lesser degree, disease management. It also gives referrals for out-patients and services for drop-in HIV and AIDS patients. WAMATA offers out-patient care through hospital services, hospital-based counselling, visits to hospital clinics, and out-patient visits.
WAMATA's most difficult task has been getting men involved in its programme. Most men come once or twice to get information but then do not return. Men also do not want to tell their partners if they are HIV positive nor are they willing to use condoms with their wife or partners.

The participants in the workshop suggested that home care may be a better solution than institutional care because when patients remain in hospitals, the women often have to leave their families in order to care for the patient at the hospital. It was suggested that governments could help people who have family members remaining in the hospital by providing family members at home with food, water, and firewood.

Participants discussed the role of the individual country governments and National AIDS Programmes in working with the community and in supporting the work of nongovernmental organisations. They felt that an important ingredient of successful community-based programming would be to have top level support to ensure the programme's sustainability and increase the community’s feeling of responsibility and commitment to its activities. The role of the National AIDS Programme is changing and, as a result, causing some discussion about how NGOs and the National AIDS Programme should interact. Given the increasing demand for services, NGOs are quickly expanding their activities, often to such an extent that they have difficulty managing the multiple facets of their programmes.

3. The reorganisation of traditional institutions within the community to meet the needs for AIDS prevention and care.

In some communities, traditional healers have taken on the dual responsibility of providing medical care for HIV and AIDS and teaching traditional roles and values that support safe sex practices for AIDS prevention. For example, in countries where polygamy is the norm, traditional healers encourage men to be faithful to their wife or wives. However, Dr. James Jijide, representing the Zimbabwe National Traditional Healers Association (ZINATHA), noted that in many countries traditional values are fading due to the process of modernisation and the economic crisis. Many couples are forced to live apart as one partner migrates to find work, a situation that often encourages multiple sexual partners.

Also, encouraging adherence to traditional values can sometimes have a negative effect, in that such beliefs often tend to reduce women's social and economic opportunities and to reinforce men's authority in the community to make decisions. Women, especially those with low education and economic status, are traditionally recognised as powerful or prestigious only in certain situations, such as initiations and other ceremonies, or through high fertility. Most of the time, they are given less respect and value. Yet four out of five traditional medical practitioners (TMPs) in Zimbabwe are women!

The ZINATHA HIV/AIDS programme has undertaken a variety of activities to meet community needs for prevention and care of HIV infection. Because practitioners and patients work together in the healing process, ZINATHA's actions have been dynamic and participatory. ZINATHA holds seminars and workshops for TMPs and TMP-midwives on the clinical care of persons with HIV/AIDS. They also work with key community leaders and volunteers on traditional home-based care activities for clients and their families and they conduct extensive information, education, and communication (IEC) activities using a variety of media formats.

Because of the respect TMPs command within the community and their understanding of cultural values, they may be able to influence sexual behaviour through counselling about safer sexual practices. ZINATHA also promotes the traditional functions of aunts and uncles that support cultural norms for parenting and...
traditional family structure. TMPs are urging their communities to respect the extended family, because it serves the emotional, material, and social needs of those individuals directly and indirectly affected by AIDS.

In many sub-Saharan African countries, sex and sexuality are topics rarely talked about openly, yet in the context of AIDS prevention, they must be discussed. Because social norms impose restrictions on discussions of sex, few people are experienced in dealing with these sensitive matters. Which community members are most appropriate to talk about sexuality? Who can they talk to? When? In what context?

KIWAKKUKI, the “Kilimanjaro Women's Association Fighting Against AIDS,” is a community-based initiative using traditional means of communication to teach AIDS prevention. Dr. Hores Isaack-Msacky, a pediatrician at the Muhimbili Medical Centre in Dar es Salaam, explained that KIWAKKUKI’s programme was started in response to the increasing effects of HIV/AIDS on women, in particular, and the community at large in Kilimanjaro, Tanzania. Since women felt they were the most vulnerable and affected group, they started this programme to mobilise other women to prevent HIV infection and provide care.

KIWAKKUKI offers counselling in a traditional African manner—older members of the family act as advisors to younger relatives, providing them with information on an array of topics ranging from family planning to sexual behaviour and values. Because it is considered improper for a mother to talk to her daughter about intimate matters, particularly anything to do with sex, KIWAKKUKI members take the initiative to educate young people, especially girls, in sex and sexuality, including HIV/AIDS prevention and condom use. KIWAKKUKI staff believe that as “older women” within the community, they are in a position to have a significant impact on the younger generation's sexual behaviour.

The conference participants felt that working sexuality education into traditional networks may be an appropriate mechanism to encourage behaviour change in countries that rely heavily on the value of cultural norms. In addition, health professionals (including TMPs, nurse-midwives, and traditional birth attendants) need to teach sexuality and safe sex practices, because their work offers a natural entry point into sexuality and family planning education.

4. The impact of the changing socio-economic environment of AIDS on women and children.

Given the declining economies of many African countries, women now turn more frequently to commercial sex work to support themselves and their families. Programmes such as the Voluntary Women Rehabilitation Institute (VOWRI) in Nairobi, Kenya have tried to organise income generation activities for women as an alternative to commercial sex work. As described by Ms. Jane Muriithi, an educator and public relations officer from the Know AIDS Society of Kenya, VOWRI’s programme focuses on promoting STD/HIV prevention and behaviour change by empowering women to negotiate for safer sex practices and by assisting women to start small businesses so that they have an economic alternative to the commercial sex industry. Counselling services are provided for individuals, couples, and community groups.

Participants pointed out that, as is the case with many other income-generating programmes, the VOWRI programme lacks an effective marketing strategy and little effort has been made to set up a market or to provide women with loans. Without these necessities, women's businesses will not be sustainable and, ultimately, will not provide the women with a reliable alternative source of income. Additionally, participants suggested that women will not leave commercial sex work simply for marketing opportunities; they want literacy programmes, more social and economic power, and increased self-esteem. They are more interested in long-term sustainable work, not to mention an income...
comparable to what they are earning as commercial sex workers.

Ms. Patricia Kamanga, a lecturer at the Department of Post Basic Nursing at the University of Zambia, described the efforts being undertaken in the community of Matero, outside Zambia's capital, Lusaka, where a branch of the social service organisation, CINDI (Children in Distress), has been formed. The community calls its programme "Kwasha Mukwenu," which in the local language means "help your friend."

CINDI and Kwasha Mukwenu provide:
1) care and counselling to individual patients and family members who are HIV positive or living with AIDS, both in primary health care units and at home; 2) community counselling through regular classes on HIV/AIDS prevention and care; and 3) a "caretaker family" arrangement that cares for orphans of parents who have died of AIDS.

Each member of Kwasha Mukwenu adopts two to three families called "caretaker families" of which s/he is the "caretaker parent." Each caretaker parent also identifies new cases of persons with sexually transmitted diseases or infected with HIV and children in difficult circumstances, especially those orphaned as a result of their parents dying of AIDS. The programme ensures that orphans attend school and that they have food, medical care, clothes, shelter, and emotional support. Ms. Kamanga stressed the need for the government to recognize that many of these orphaned children will soon become heads of households and to make social services and resources available to them to help them cope with these new responsibilities.

WHAT HAVE WE LEARNED FROM THESE LOCAL INITIATIVES?

The diversity and creativity demonstrated by the eight community-based AIDS prevention and care initiatives in these five countries suggest that many communities are taking responsibility for the prevention of HIV transmission, as well as providing care and support for AIDS-affected individuals, their families, and the community. In such resource-poor environments, their mission is large and ranges from counselling and education to providing home-and hospital-based care for patients, family members, and orphans. As much as their activities vary, all eight programmes share some common missions and strengths, as well as shortcomings.

One shared strong point is their ability to involve local people in the programme's development and management and to include their voices in the decision-making and the conduct of activities. Such participation is believed to be important in maintaining long-term community support and contribution of resources. Another common thread is that women have played a fundamental role in the development of many community-based programmes. Because women feel they are the segment of the population most severely affected by the AIDS epidemic, they have taken on much of the responsibility to counteract it and to garner material and psychological support needed from the community-at-large. Given women's commitment to protecting themselves and their families, their involvement will bode well for the programmes' continued and increased sustainability.

Some of the initiatives have been successful in working with their National AIDS Programme as well as with other NGOs involved in prevention efforts. Such cooperation strengthens their services, avoids duplication of services, and uses resources more efficiently. Also, working with the National AIDS Programme has brought them credibility and support from the government.

All eight programmes use volunteers and health providers from the community, providing the respective communities with another type of care and treatment in addition to that received.
from medical professionals in health facilities. With an increased range and choice of services, more people are able to find acceptable and accessible types of treatment.

Some of the common weaknesses shared by the programmes include the difficulty of involving men in counseling and education, and convincing them to adopt safe sex practices. Most of the programmes found that men do not want to use condoms, even when HIV positive, and are reluctant to limit their number of partners or to remain monogamous. As the discussion at the meeting demonstrated, in Africa, there is minimal communication about sex either within the family or between men and women. Further, women are not given much opportunity to make decisions about sex and family matters.

Most of the initiatives described here stem from grassroots efforts to address HIV transmission and, therefore, have been structured in an ad hoc way. Due to limited resources and the urgency of the situation, most have not been able to devise means to assess the effectiveness of their services. This lack of evaluation does not allow them to identify weak programme areas nor find low-cost ways to improve them.

Financial sustainability is another big concern for these programmes. Many of them exist on the limited financial support available from the community, the National AIDS Programme and, occasionally, donor agencies. The insecurity of the funding situation hampers their ability to continuously provide necessary services or to institute programme improvements.

RECOMMENDATIONS TO STRENGTHEN AIDS PREVENTION INITIATIVES

The eight representatives of the community-based programmes offered the following suggestions for strengthening local initiatives, such as those described above.

- Augment IEC efforts and produce materials in local languages
- Involve men in provision of services and IEC efforts
- Strengthen community involvement and outreach
- Increase collaboration between institutions
- Train staff in programme management and administration
- Obtain political and financial support from the government
- Undertake operations research to understand the most effective aspects of programmes and identify areas for improvement
- Build on already existing resources in the community such as traditional healers, women, and the voluntary spirit of community members

Given the highly visible level of commitment to developing and maintaining these programmes and the severity of the AIDS epidemic in the region, it is clear that local initiatives such as these will continue to play a valuable role in the community. National and international efforts should be directed at helping them become viable, integral parts of the community with a clear mission, a manageable set of activities, and tangible resources.
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For more information about the Community-Based AIDS Prevention and Care in Africa: Building on Local Initiatives project or to request copies of the case studies, please contact:

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Publications can also be requested from:
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