

Aids in Uganda: Initial Social work Responses

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ABSTRACT

AIDS, which was first diagnosed in Uganda in 1983, has since reached epidemic proportions, with approximately 1,5 million persons estimated to be infected by 1991. Although the government of Uganda with several collaborating organisations has commenced a comprehensive programme of preventive education and services, patterns of sexual behaviour, unless changed, threaten to facilitate the further spread of HIV. Social work professionals have adopted a broad range of activities in varying organisations in beginning efforts involved in combating the spread of HIV/AIDS. Further involvement may be related to the extent that the social aspects of the disease are given heightened attention by the policy-makers in Uganda.

Introduction

No professional group in the human services in Uganda can ignore the question, "What response does AIDS require of us?" For, the disease has become a household name in this small landlocked East African country. This discussion will focus on the epidemiological dimension of the AIDS scourge. Some attention will be given to those behaviour patterns that appear to put Ugandans at risk of infection, for these differ from factors identified in industrialised countries. Of principle concern, however, is to suggest what social workers are attempting to do about the AIDS scourge. Some obstacles and opportunities are suggested as viable strategies to maximise the professional contribution.

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The Epidemic

From one to one and half million

At some point in time Uganda must have had just one single case of AIDS. But spreads. Grasping this fact, and understanding the social as well as the biological factors that cause the process, is vital if nations are to stop this deadly disease before it spreads too far. Uganda did not.

From 1981, when the first Ugandans started suffering from a disease never before seen, to 1982 when the local medical specialists were called to Rakai District to examine the phenomenon, to 1983 when the first cases of AIDS were diagnosed, the Human Immunodeficiency Virus (HIV) had spread into all parts of the country.

By December 1988, at the first review of the AIDS Control Programme (ACP), 6 772 confirmed cases were reported. Uganda's Ministry of Health estimated that as of October 1989 between 800 000 and one million persons, out of a total population of 16,5 million, were carrying the virus. In 1991 the figure was 1,5 million. AIDS has now been reported in all 38 districts of the country.

Ninety percent of all Ugandans live in rural areas. AIDS was entrenched first in the villages among the populations least served by health or social services before it spread to the urban centres. It only later became what some choose to call an "urban disease". The disease started appearing among smugglers and wealthy traders and fishermen in Rakai District. The local people believed that the patients were bewitched because of their prosperity of unfair practices against Tanzanian traders who lived in Bukoba on the opposite side of Lake Victoria. Soon, people began to notice that the wives were also falling sick, and by 1985 it was clear that this disease was heterosexually transmitted. This is made clear by the impact of AIDS on health care facilities. Thirty percent of the beds in the major hospitals in Kampala, the capital, are filled with male and female AIDS patients. Thirty percent of women attending antenatal clinics are also infected with the disease.

Moreover, 20% of all Kampala residents are believed carriers of the virus. The travel of people between the urban centres and villages is high, and thus the expectation is the increasing numbers of persons in rural areas will contract the disease. From the current 6% seroprevalence for the nation as a whole, the percentage is likely to rise.

Of the totals reported by the ACP Surveillance Unit, 89% were adults, mostly aged between 15 and 40 years, with 51% and 49% male to female cases, respectively. Children aged 11 years and below make up 10% of the cases. Of this latter total, almost all are paediatric cases through perinatal transmission whereby the disease is passed from mother to child. Less than one percent of the cases is

found among children whose ages range between six and 15 years. The "burden of orphans" has already begun to be felt in the hardest hit district, Rakai. 24 000 orphans who have lost one or both parents because of the disease have been enumerated. This, however, is held to be a conservative figure.

The figures above underscore the point that AIDS is rampant in Uganda. Particular to the fact of the age distribution, AIDS kills the young and most socio-economically productive sectors — the 15 - 40 year-olds in whom much has been invested in terms of education. Their loss is expected to adversely affect agricultural production and other facets of the development of the nation. In striking the rich and the poor, too, AIDS has hit all levels of society.

The spread of AIDS and its control

Epidemiologist Struchiner (1990) describes AIDS as "a disease of poverty." In conditions of poverty, he asserts, the AIDS virus flourishes. Another view is that the high rates of AIDS that currently plague African countries are intimately linked to their history of underdevelopment.

As a consequence of distorted, export-oriented economies shaped by centuries of colonial rule, these nations confront problems of an increasingly marginalised peasant labour force, the social disorganisation of rural society, a growing migrant labour force and the emergence of squalid slums surrounding major cities with contingent high rates of unemployment and prostitution. Lacking adequate resources to counter the diseases which fester under such conditions, these countries suffer enormously from malnutrition, malaria, measles, tuberculosis and sexually transmitted diseases.

An examination of the AIDS menace in Africa should take very seriously the context in which the problem is being experienced. An analysis of the Ugandan situation through the 1980's from the contextual perspective will reveal that a combination of factors appears to have conditioned the present strength of the attack of the disease on the society. The nation was in a state of civil war for about 20 years, from the 1970's. There is prevailing widespread urban as well as rural mass poverty. The elementary necessities of life, such as clean drinking water, sanitation, sufficient amounts of food, clothing and adequate shelter are not guaranteed to the majority of Ugandans. Most villages lack any social welfare services at all. Schools are closing for lack of funds by parents to pay school fees for their children or salaries to retain teachers. Over the years of political upheaval, the health system, until recently neglected, suffered near collapse. AIDS, thus, appeared at a time when Uganda was ill-prepared to fight it.

Yet, it has attempted to put a national operation into place through its AIDS

Control Programme which, in broad outline, addresses the problem through health education, training of medical personnel and leaders of public opinion, through national surveillance activities, blood screening and testing. Programmes of counselling and patient care have been promoted largely through non-governmental organisations. The government works through the central Ministry of Health with its efforts being supported by local non-governmental organisations (NGOs), and the World Health Organisation, UNICEF, USAID, UNDP, Save the Children and other international organisations. In collaboration with these the government has pursued the goals of prevention and involvement.

Of the latter aim, Uganda's policy has been one of "openness". The media as well as international researchers have been permitted to monitor the spread of the disease within Uganda's borders. Its strategy has been inclusive: from 1988 a decision was taken to decentralise AIDS prevention activities. District medical personnel have the responsibility to work with local leaders through "Resistance Councils", with non-governmental organisations including missionary hospitals through education and services.

Any progress that has been made to arrest the spread of HIV/AIDS through this extensive involvement of all relevant parties must be measured against the earlier described constraints within the Ugandan setting, of poverty and backwardness, due to a history of underdevelopment. The second aim, that of prevention, has been conditioned to a large extent by the traditions and cultural norms that underlie the behaviours which clinic findings have confirmed are at the base of HIV transmission.

Unlike the industrialised countries of North America and Europe and South America, Africa's AIDS epidemic has not been spread by homosexual practices or through intravenous drug abuse. Neither of these are known in the Ugandan cultures, except in the confined situations of some institutions such as prisons. Even the ineffectiveness of Uganda's health care system may have been a blessing in disguise, as the country's blood bank system was also adversely affected when AIDS began to strike. The result is that only one percent of the Ugandan carriers were infected through transfusions of contaminated blood, and fewer still were infected through needle injections.

AIDS and the Social Worker: An Overview

Within the short period accelerated efforts by the government and other organisations to check the advance of the virus in Uganda, ie 1986-1991, the social work profession has been proactive. Its engagement with the problems of AIDS has spanned a wide range of activities; there are challenges still; the opportunities for

greater participation exist. What the Ugandan social workers are doing may suggest ways of preventive work to professionals in countries which have yet, if ever, to experience the massive rates of infection that Uganda now witnesses.

Areas of Involvement

A purposive sampling was taken in April 1990 of all social workers known to be employed full time in AIDS related organisations in Kampala and in Entebbe — the headquarters of the Ministry of Health — and who were available at the time of the survey. Twelve of the 16 listed persons who are currently involved in AIDS activities in these two settings were interviewed. A few others are expected to be full-time practitioners elsewhere in the country: some other professionals have duties that bring them into contact with persons with AIDS from time to time.

Of this latter category are the social workers who are employed by the Ministry of Rehabilitation which concerns itself with broad social welfare problems. This ministry addresses itself to the macro consequences of HIV/AIDS, such as the needs of widows and orphans, more than with the individual persons with AIDS. The role of social workers in the Ministry of Health, too, focuses indirectly on the problem through activities of health education, mobilisation, research and programme management.

The largest influx of professionals has been into non-governmental indigenous and international humanitarian organisations. These include the AIDS Information Centre (AIC) and The AIDS Support Organisation (TASO), the two agencies that provide testing and counselling and counselling and relief, respectively. The church related hospitals at Nsambya and Rubaga, Kampala, employ practitioners on a full-time basis. The Red Cross, World Vision, the Experiment in International Living, Save the Children Fund, UNICEF, USAID serve as agencies for much social work activities. The ACP of the Ministry of Health and the Medical Research Council (UK) provide opportunities for indirect social work practice.

The Expanding Roles

Supportive counselling is the most visible of the several functions being undertaken by an increasing number of graduates. This role, more than any other at present, calls for direct professional intervention with AIDS sufferers and their families. Its expansion is facilitated by the decentralisation of ACP activities and the establishment of additional AIDS counselling services in the districts through TASO and AIC. In connection with counselling is the role that professionals are playing in building or strengthening social networks between persons with AIDS

and their families to the communities to secure the assistance that they require, be it health care, funds, transport or emotional support. Networking is also used extensively by the social workers for liaising with other professionals in advocacy, identifying resources and in making referrals. Building a community-based support system is an area assigned increasingly to the professionals.

Social workers engaged by the Uganda Red Cross, the ACP, and the churches have, for example, assumed major responsibilities in health education activities. These have included designing and executing KAP studies, developing appropriate materials and conducting community education. Others at ACP, where community mobilisation is a dominant concern, also fulfill the functions of mass/health/AIDS educators. They target audiences such as Resistance Councils of local leaders, religious leaders, teachers, employers, the security forces of the military, the police and the prisons, school children, women's groups, agricultural and other extension staff at the district to village level, as well as in towns. This is labelled as primary dissemination. In addition, social workers in the non-governmental agencies and in the government are heavily involved in the training of trainers through seminars and workshops which too, are, held at the district level.

Research into the social, cultural and behavioural aspects of AIDS has provided an important entry point for social work into the policy-making and programme development areas. This activity has been spearheaded by the Department of Social Work and Social Administration, significantly. In 1988-1990, 16 graduates obtained field research experience; eight are now employed as full-time AIDS researchers. Through this same activity, the Department has gained a seat on the gazetted, or statutory, National Committee for the Prevention of AIDS, and on the executive committee of the AIDS Information Centre, the Network of AIDS Researchers in East Africa, and several other bodies.

The pretest already referred to and national WHO/ACP/Makerere University Social and Behavioral Survey on AIDS have been completed, with data being currently analysed. These sources potentially provide vital baseline data for further social planning and intervention.

The continuing challenges

The yet limited numbers of social workers who have addressed the AIDS challenge is in part a consequence of the way that AIDS control and prevention was introduced into Uganda as probably, in other parts of Africa. The disease was viewed initially as a medical problem. The near-monopoly of AIDS by the medical profession continues to the present time.

Therefore, a major barrier to increased participation by social workers tends to be their exclusion rather than their reluctance to get involved. Hospitals and non-governmental organisations persist in hiring non-qualified persons to undertake social work - related functions, particularly, counselling. There is an apparent lack of awareness on the part of local social service agency leadership, of the complexity of handling AIDS-related stress problems. The difficulties of community mobilisation for combating an epidemic and building support systems are not fully appreciated. The dangers of hurriedly setting into place old solutions to new social problems, such as is happening in the mushrooming of orphanages, have not been fully appraised. In addition, global institutional building to deal with AIDS at the national level has progressed only slowly. There are therefore few agencies that concern themselves with the problem, holistically, and consequently which provide opportunities to social workers for employment.

To address the difficulty of penetration, attention is being given to inclusion of AIDS education into the training syllabus for social workers at the undergraduate level at Makerere University. An already developmental and broad-based approach rather than a clinical orientation in social work education prepares the professional for a practice stance in the great variety of agencies and fields already described. More needs to be done, however, to indicate to others the multi-disciplinary approach that is necessitated by this multi-dimensional problem in the African context. There is a need for formal courses in health as a social issue, however, rather than the informal approach that is now being taken.

What about the fear that professionals have of contracting AIDS? The practitioners reported that while at the onset of the epidemic most of them were afraid of working directly with persons with AIDS, such fear gradually gave way to empathy, sympathy and a desire to help remove from the society the high level of blaming, discrimination and stigma that nevertheless still prevails among some people who think of themselves as being free of AIDS.

Conclusion

The Human Immunodeficiency Virus (HIV) is currently widespread in rural as well as urban parts of Uganda. With an estimated 1,5 million persons potentially carrying the virus, most of whom are unaware of being HIV infected, hundreds more will become infected in the years ahead. AIDS deaths, now in mounting proportions, leave in their wake social problems of the surviving children, spouse, families and whole communities. Uganda's health care system is being further strained. Sexual behavioral patterns that are deeply embedded in the traditions of

society will need to be better understood and effective means found to sensitively influence change. Given these several facets of the problem, what have social workers learned that may guide their probable intensified effort to prove relevant in the face of the AIDS epidemic?

The broad-based activity of most practitioners suggests that the attention of the profession will not be focused solely on the primary sufferer, the person with AIDS. The needs of the family, the survivors, including whole communities that are being adversely affected by the disease will also need to be considered through direct and indirect intervention. Social workers may initially increase their strength, numerically, in taking up positions as counsellors. The societal context will continue to beckon them to a more critical engagement, with the totality of needs the AIDS epidemic generates.

The advocacy, education, training, research, and administrative roles that have emerged as dominant activities of social workers in Uganda will likely be further promoted. To ensure maximal impact the professional will require further development. The responsibilities plus the involvement of some social workers in policy-making have not been matched yet by an indepth and systematic review of the AIDS content in social work education to understand what is needed for the opportunities that will emerge in future practice in AIDS control and prevention. Much of AIDS education is done piecemeal. This suggests the need for specific courses in schools of social work within Africa to prepare professionals for employment in the health sciences.

The social work profession in Uganda, however, has taken an aggressive posture commensurate to its interpretation of AIDS as a deadly threat to the nation. Although the threat is new, the professional achievements are already commendable. But there is the urgent need for greater clarity of goals and specific strategies set by professionals, if the initiatives highlighted above are to be sustained and surpassed as Uganda confronts the AIDS epidemic.

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