

15. Physician's dilemma in the management of HIV/AIDS in Africa

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Introduction

The Universal Declaration of Human Rights, which encompasses basic rights —civil, political, economic, social and cultural— for all peoples of the world, and which was adopted by the United Nations in 1948 is a basic international pronouncement of the inalienable and inviolable rights of all human beings.

Many international and regional treaties have been formulated and adopted using the framework of the Universal Declaration as the reference point. Some of these treaties include:

- The American Convention on Human Rights —adopted by the Organisation of American States in 1969;
- The European Convention for the Protection of Human Rights and Fundamental Freedom which was adopted by the Consultative Assembly of the Council of Europe in 1950;
- The African Charter on Human and Peoples Rights adopted by the Organisation of African Unity (OAU) in 1986;
- The Human Rights Covenant that underpins the rights of people living with HIV/AIDS and which inform public health policy on HIV/AIDS derives principally from the United Nations Declaration of Human Rights.

The advent of HIV/AIDS raises a wide range of social, public health, cultural, and ethical issues, which need to be addressed and weighed carefully in order to effectively prevent and control AIDS infection.

While the principle of human rights have gained international recognition and acceptance, the logic behind ethical principles, especially as it applies to HIV/AIDS, still eludes health care professionals in Africa, especially as these principles do not lay down precise legal obligations.

Most of the declarations and opinion papers on Ethics, Humanity, Right, Law and HIV, including the July 1994 Dakar declaration have dwelt in broad terms on the guidelines and tenets of Ethics and HIV research, HIV in the workplace, discrimination, empowerment, confidentiality and privacy, commitment and responsibility. However, declarations have failed to address pertinent and worrisome questions which many health care providers encounter in their day to day involvement in the care and management of people living with AIDS. The debate

that had been generated on confidentiality shows that a considerable amount of thoughts need to be put into the issues.

To encourage the protection of the rights of people living with HIV/AIDS in Africa, and to promote ethical principles in the management and care of people living with HIV/AIDS in Africa, several organisations have been formed and networking activities are already in place among these various organisations in Africa. Laudable roles have been played by some African based NGOs and other International Agencies in promoting and protecting the human rights of people living with HIV/AIDS in Africa, and also in ensuring that African people living with AIDS live in dignity and in a free environment.

For example, the African Network on Ethics, Law, and HIV, which was established in 1991, has assisted in the formation of National arms in 13 African countries and has vigorously pursued the issue of rights, dignity, equity, and justice for people living with HIV/AIDS in Africa. This African Network, in collaboration with the UNDP's (United Nations Development Programme) 'HIV and Development programme' (Dakar and New York), reaffirmed in July 1994 the fundamental value of respect for human rights, life and human dignity, by producing guiding principles on ethical and human rights aspect of HIV/AIDS — now generally referred to as 'Dakar Declaration 1994'. The Nigerian Network on Ethics, Law, and HIV/AIDS was formally launched in October 1997, with active participation of the African Network, the UNDP HIV Regional office, and the Overseas Development Agency.

Similarly, the 'Sociétés d'Afrique et Sida' Network, which was established in 1993, has established a unique information-sharing facility through its publications and encouraged debate on social and human dimensions of the AIDS epidemic in Africa.

The AFRICASO Network (African branch of ICASO, International Council of AIDS Service Organisations), which was established in 1991, has developed links between ethical and legal networks in Africa and has actively supported the Network of African people living with HIV/AIDS.

The African AIDS Research Network, a Nigerian branch was formed in 1989, was the first African based network to develop strategies on the observance of ethics in HIV research and management. It held the first workshop on 'Ethics and HIV and Human Rights' in Lagos, Nigeria in 1991, producing a set of guiding principles on research and HIV in Africa.

With the efforts of these various organisations, positive strides have been made in some African countries on the issue of Ethics and AIDS. For example, the South African Government has abolished all screening for HIV/AIDS as a prerequisite for employment in any avenue of government services. The decision was reported as binding on all the public services, including defence personnel, the police, nurses and teachers.

Unfortunately, many countries in Africa still lag behind in the progress towards an equitable and just treatment of people living with

HIV/AIDS. For example, in Zimbabwe the Harare Association of women with HIV/AIDS reported that about 90 percent of widowed or divorced women living with HIV/AIDS have reported discrimination in health care, education and employment. In Nigeria, a Nigerian navy captain ordered that all people with HIV/AIDS in his state be arrested and confined to a centre, to curb the spread of the virus.

There are still many areas of concern on some pertinent ethical issues that need to be urgently addressed in order to make HIV preventive measures viable in African countries.

Case presentation

Clinical observations of physicians' involvement in the daily management and care of people living with HIV/AIDS in Nigeria, as well as in some parts of Africa, provoked the following questions:

1. How have African physicians coped and responded to the AIDS epidemics in Africa?
2. How have they acted or reacted when faced with conflicting interests e.g., public health interest, personal interest, community interest, patient's interest and the third party's interest?
3. How have African physicians and health professional bodies reacted against threatening oppressive laws, against the rights and dignity of people living with HIV/AIDS?
4. How had the physicians responded when confronted with the economic hopelessness of their patients living with AIDS, and yet the need to care for them?
5. What are the collective roles of other professionals e.g., social scientists in the protection and promotion of human rights of people living with HIV/AIDS?

Case history

This case history was presented at the International Conference on 'Social sciences and AIDS in Africa', in Sali Portudal (Soyinka 1996). A 27 year old female patient, with an history of frequent miscarriages was secretly tested for HIV, and was found to be HIV sero-positive. The husband of the patient was employed in a University Teaching Hospital, where the test was carried out. The policy makers in the Teaching Hospital knew about the test result. A few months after the test was carried out, the spouse of the lady took ill, with some renal problem needing renal dialysis. However as it is generally done in this hospital (as in other hospitals in Nigeria as well), all patients needing renal dialysis are screened for HIV (without consent and without counselling). The reason for this action is that the hospital possesses only one renal dialysis machine, which will not be used for HIV positive patients. Consequently the man who is a surgeon was clandestinely screened for HIV and he too was positive. He was not

put on renal dialysis machine, and he was not informed why. The surgeon asked questions to which various flimsy excuses were given.

The surgeon eventually improved in health after he was given peritoneal dialysis and he wanted to resume his duty—a move that was stoutly resisted by fellow doctors and other care professionals who were privy to his sero-status.

A private delegation was sent to the policy makers in the hospital to advise against his being reinstated as a surgeon, as it was feared that he could infect other health care workers during operation. He was considered a source of occupational hazard. The dilemma in terms of decision making began to arise for the policy makers. Should he be withdrawn from the routine theatre duties? If so, on what basis? If he is not removed the hospital faces an industrial action which would eventually blow all the previous mis-management of the case into the open.

The wife of the surgeon eventually got pregnant again and delivered a baby girl. The baby, after about 6 months started to develop signs and symptoms of acute paediatric AIDS—failure to thrive, and other acute signs of immune deficiencies—in terms of protracted opportunistic infections. The consultant paediatrician, who had knowledge of the parents' sero-positivity requested for HIV test to be done on the baby, without the parents' knowledge or consent. This was however advised against after consultation with the Network on Ethics, Law, HIV/AIDS in Nigeria.

Post-script

After the first version of this paper had been delivered in 1996, it was reported that the child in question died at the age of 11 months, while the mother also died in a faith healer's set-up. She was reported to be delirious and withdrawn before she died. She was worried over her lack of knowledge about the cause of her child's death and her frequent history of miscarriages. The surgeon it was learnt, is still oblivious of the true picture of events that befell him and his family, however, he is reported to have a very strong feeling that he had been deceived and his rights might have been grossly violated.

Comments

In the discussed scenario, the case of the surgeon and his family had been mismanaged and mishandled. There had been gross violation of human rights and ethical principles at various levels. The attitude of health care professionals towards a fellow professional had been very unprofessional. A fact that opens the eyes to what really happens to millions of people who happen to be less privileged than the surgeon. The institution in question failed to handle the situation correctly and also failed to make amends to the already bad situation. It feared eventual litigation—which presupposes that the actors knew their right and can be assured of obtaining justice.

The case also shows how unprepared physicians are to take crucial decisions outside the realms of pure medicine, how it had been difficult to apply personal moral judgement on such issues where there are conflicting ethical interests such as consent, confidentiality, the right of patient, the common right and in this case the 'assumed' right of other health care givers —not to get infected.

On the principle of non-discrimination, the Dakar declaration states: "Every person directly affected by the epidemic should remain an integral part of his or her community with the right of equal access to work ... justice and equality".

Discussions

In analyzing why such a violation of basic tenets of human rights and ethics could occur in an institution of higher learning, in Nigeria and why there had been a culture of silence surrounding the events, one needs to examine the position of the physician within the context of a developing country.

In African setting, the physician is considered to have the ultimate responsibility and final decision on what happens to his patients. In such a setting, personal attitude, moral outlook and character become very crucial and important to the total outcome of the practice of ethics. The social, cultural, religious and economic environment will also bear on the outcome of the crucial decisions that may be taken, especially when the issue under discussion is HIV/AIDS and care.

Unfortunately, the physicians in such a setting, as we pointed out earlier, are unprepared to take crucial decisions outside the realms of pure medicine. Further, in a different environment where there are checks and balances and where ethical principles have been fine-tuned and where there are shared responsibilities in care and decision making matters, the situation might have been differently handled.

The demands placed on African physicians to take absolute control, definitely outstretch the type of training that the doctors were exposed to. It goes perhaps beyond their professional competence.

Physicians tend to act as professional groups, where individualised personal ethics is often viewed as an aberrant behaviour within the group. Personal ethics is influenced greatly by personal perception and character, the environment, judgemental aptitude and perception of values. Through professional pressure, physicians are not often allowed to exercise these qualities.

In the course of our interactions with physicians, patients and other groups of people, a very complex relationship of 'fear' and 'attitude' between the clients and the physicians in respect of HIV/AIDS was noticed. The fear of the patient that his HIV sero-positive status will become aware of his immediate relatives, colleagues and community, and the fear of the physician, desperate for strength and guidance to be able to inform a patient of his seropositive-status. Both situations pose serious dilemma for physicians. The other dilemma of physicians also lies in personal ethics, fears and helplessness in respect of the

environment in which they have to operate. Intertwined in all these are the doctors' personal attitude to people with AIDS, inability to confront a case that they perceive as hopeless (viewing it mainly from the medical point of view).

More important, based on empirical evidence, we can confirm the three types of dilemma confronting physicians in Africa:

1. *The patient's fear of disclosure of a HIV sero-positive status*

In a survey carried out in Nigeria, Soyinka *et al.* reported in 1996, that 58 percent of female respondents and 17 percent of male respondents respectively reported that they would inform their spouses if they had HIV infection. In the same survey, 76 percent of male respondents (almost the same percentage of those who would refuse to tell their wives if they had HIV infection) said that they would wish to know or be told if their wives had HIV infections. In other words, a majority of the respondents would want to know if their spouses had HIV infection, but they will not allow their spouses to be told if they had the infection.

The result of this survey, illustrates the type of problems that African physicians face when critical decisions have to be made on confidentiality, or shared confidentiality, patients' right and the third parties' right. The physician in most of the case faces a dilemma on how to decide and take the responsibility for his action.

2. *The physician's inability to cope with issues of character, cultural, social or psychological impediments.*

A face to face interview with purposely selected physicians was conducted in hospitals, to investigate their reaction to an HIV positive person or people with AIDS. Majority of doctors admitted that they have not being too friendly toward them. They have primary interest in protecting themselves against being infected and the interest of the patient is secondary in this matter. Eight out of ten doctors who participated in this interview said that they have the right not to attend to an AIDS patient.

Asked to rate how comfortable they would feel, to inform a patient about his/her sero-status, 90 percent said that they would feel highly uncomfortable, and 80 percent even said that they would not want to perform the duty.

Many admitted that they are impeded by cultural or psychological factors which makes it difficult to inform the patient that he/she is positive. A large majority of the physicians felt that breaking such news does not belong to the doctor's function, but to that of the nurse. It was said that nurses are trained to break bad news. One wonder if this is really so.

When asked to expatiate further on the cultural and psychological impediments, many said that usually, an 'outsider' is not supposed to break such bad news and that they would rather tell a senior member of the family who in cultural terms should consult other members and then, it would be decided on how and who would break the news.

Eighty percent of those interviewed again expressed the fear that they would not be able to cope with the patient's reaction if they were to break the news to him or her.

3. *The social environment of the physician*

Another dimension of the dilemma faced by the physicians in the developing countries of Africa is the hopelessness and helplessness of the situations and the environment in which they operate. The environment of abject poverty, scarcity or total absence of basic needs, deprivation and glaring inequality of resources distribution and justice, in which the doctors and the majority of their patients live. Even though, the physicians may fare a little bit better than those they are supposed to care for, but only just a bit. They may be able to take two meals a day instead of half or send their children to a low-grade school instead of into the street.

Most physicians in Africa usually work in a culture of 'NA' which means 'not available' —no water, no drug, no electricity, no oxygen. And so they acquire the culture of not being available both in body and soul and end up not caring.

Ethical conviction becomes lacking in impoverished physicians who are greatly influenced by their environment, what they see, what they obtain and what they learn to perceive of their patients. Their character is thus influenced by the larger ethical norms of their society. In most cases, the leaders —i.e., the governments themselves lack personal ethical norms with which to govern and guide the governed.

Few professional bodies (i.e., medical) in Africa are known to have taken a stand against ethical violations against the people with AIDS, which are either committed by their colleagues or by their government.

A good example of the acquiescence and total acceptance by African physicians of questionable practices dictated to them by donor agencies is the controversial topic of the sentinel surveillance which is usually carried out for epidemiological surveillance using commercial sex workers (CSW), pregnant women and other medically unwell groups that must visit the hospital for help.

After participating actively in sentinel surveillance —using CSW, pregnant women, patients as subjects of research, one started thinking about the morals of this exercise. I started raising strong reservations against it, having concluded that it was not right. During an ethical workshop organised by the African AIDS Research Network in Lagos in 1986, this issue came up for discussion.

A World Health Organisation officer came to this workshop and strongly defended the need of such surveillance from the epidemiological point of view. One's epidemiological sense of judgement was called to question by most people that were present at this meeting, including social scientists.

Again, during the African Conference on AIDS and STDs in Yaounde, the same issue was raised, but was deftly silenced by the WHO team and many colleagues. Why can we not openly discuss the ethical principles involved in the sentinel surveillance?

Conclusion

It is difficult to conclude except in the abstract because there are yet many questions to be discussed and concluded.

1. The interest of the person with AIDS and the confidence he or she has in the physician must not be breached —and the physician who has acquired the intimate knowledge of the patient because of his profession must not fail his patient.

2. The person with AIDS has legitimate fear —the fear of discrimination, social denial, segregation, loss of job, etc., if the disease or sero-status were to be divulged, even to closest family.

3. The fear of the patient is further justified because of the informed relatives reception and finality of actions or inactions if they knew that he or she is a person living with AIDS.

4. The physicians dilemma is also real. They have not been prepared to handle how to give a total care and to care with sufficient empathy, or how to face people's emotions when it is about dying, e.g., in people living with AIDS, or in other diseases that create unfounded panic within the community.

5. The physicians problems are further compounded by their lack of understanding of their environment, and what they perceive as a dead-end.

6. Even though, well knowledgeable on how HIV can be transmitted, not transmitted, and prevented, many physicians still have baseless fear of contracting the infection from their patients.

The attitude of the physicians in this respect will negatively influence the behavior of other care givers, nurses, laboratory technologists, etc.

7. The culture of poverty, illiteracy and deprivation undoubtedly easily leads people to adopting humiliating measures and reactions to people with AIDS.

8. The African culture of care that has so much helped in keeping the family together is disappearing very fast —and thus making the concept of community care for people with AIDS difficult.

9. All the above mentioned facts, coupled with the unusual responsibilities placed on African physicians to take decisions over life and death, make the physicians burden to be extra large. So large for them to carry alone.

This brings one finally to the issue of relationship between the social scientist and the biomedical researcher and the physician.

By design or by default, there is a glaring absence of our social scientists in our hospitals or in the communities. They may be in the communities carrying out research, but they are not there to complement care. It is difficult to see the outcome of social science based theories, hypothesis or research, translated into practice in the hospitals and the communities. The much talked about collaboration

and joint effort has not been translated into effective action. In fact, the gap seems to be increasingly widening.

The patient, in this particular case, the patient with AIDS comes in between. He looks at the physician most of the time because he is the person that tradition has taught him, is the man that can help him. Little does the patient know that the doctor himself need help.

Outstanding dates

- 1948 — Universal Declaration of Human Rights.
- 1950 — Council of Europe. Consultative Assembly.
- 1969 — American Convention on Human Rights.
- 1981 — OAU African Charter on Human and Peoples Rights.
- 1991 — African AIDS Research Network International Workshop on 'Ethics Human Rights and AIDS', Lagos Nigeria.
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- 1994 — African Network on 'Ethics, Law and HIV', Dakar Declaration 1st July 1994.

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Femi SOYINKA, *Physician's dilemma in the management of HIV/AIDS in Africa*

Summary — Illustrating with a case history, the paper discusses ethical issues faced by physicians in the poor resource setting in Africa. Physicians are confronted with personal, moral, professional and societal problems when faced with the responsibility and tasks of making decisions on human rights and professional ethics in the management of patients with AIDS in Africa. Professional competence of health care providers are called to question when moral and ethical decisions have to be taken on issues such as informed consent, confidentiality, public health/community interest and individual interest. Most African physicians are ill-equipped by training and lack of appropriate facilities to handle social, psychosocial, cultural and economic issues related with HIV infection. Fear of nosocomial infection is real in physicians and lack of preventive measures in the work place result in negative attitude in caring for people with HIV/AIDS. Open discussion on controversial ethical issues such as sentinel surveillance, breast feeding of HIV infected women, vaccine trials, is necessary. The role of social research to improve and enhance good practice in the care of patients and preventive measures needs reappraisal.

Keywords: ethical dilemma • AIDS patients care • applied social research.

Femi SOYINKA, *Le dilemme du médecin dans la gestion du VIH/sida en Afrique*

Résumé — A partir d'une histoire de cas, ce texte discute des problèmes éthiques auxquels les médecins sont confrontés dans un environnement à faibles ressources en Afrique. Les médecins font face à des problèmes personnels, moraux, professionnels et sociaux quand ils ont à assumer leur responsabilité et ont le devoir de prendre des décisions relatives aux droits des personnes, à l'éthique professionnelle dans la prise en charge des patients atteints de sida en Afrique. La compétence professionnelle des travailleurs de la santé est remise en question quand des décisions morales et éthiques sont à prendre sur des questions comme le consentement informé, la confidentialité, l'annonce, l'intérêt de la santé publique ou de la communauté et l'intérêt personnel. Beaucoup de médecins africains sont mal équipés, et manquent des ressources appropriées pour traiter de questions sociales, psychosociales, culturelles et économiques liées à l'infection à VIH. La peur d'une infection nosocomiale est réelle chez les médecins, et du manque de mesures préventives sur le lieu du travail résulte une attitude négative envers les personnes vivant avec le VIH/sida. Il est donc nécessaire d'ouvrir un débat de fond sur les questions éthiques controversées comme la surveillance sentinelle, l'allaitement maternel des femmes infectées par le VIH, les essais vaccinaux. Il y a donc un grand besoin d'une réévaluation du rôle de la recherche en sciences sociales pour améliorer et renforcer les pratiques de la prise en charge des patients aussi bien que les mesures préventives.

Mots-clés : dilemme éthique • prise en charge des malades • recherche sociale appliquée.