



IMPORTANT BUT NEGLECTED ETHICAL AND CULTURAL CONSIDERATIONS IN THE FIGHT AGAINST HIV/AIDS IN MALAWI

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Southern African countries have the highest HIV infection rates in the world. In most of the countries in the region, the rate among adults is at least 10%. The fight against HIV/AIDS has mostly been inadequate owing to the lack of proper consideration of ethical and cultural issues. In this article, the authors discuss the ethical and cultural dilemmas concerning HIV/AIDS, with Malawi as a case in point. It is argued that increasing financial resources alone, as exemplified by the Global Fund to Fight AIDS, Tuberculosis and Malaria initiative, without proper attention to ethical issues, morals and appropriate legal obligations, are unlikely to reduce the spread of HIV in southern Africa.

Background

The HIV/AIDS pandemic is currently one of the biggest global health and developmental challenges. Southern Africa has been greatly affected compared with other regions of the world. HIV infection rates are in excess of 10% among the 15–49-year-old age groups in most countries in the southern Africa region. In Botswana, which has a national population of about 1.6 million, about 36% of the 15–49-year-old age group are infected;¹ in Malawi it is about 11%, with Zambia, Zimbabwe and South Africa also registering at least 10–25% of the population infected by HIV. South Africa has at least 5 million HIV infected persons, thus being the country with the largest number of HIV infected persons. Unlike in India where HIV infection rates are highest in rural areas² pregnant women in urban areas in southern Africa have the highest registered infection rates. For instance, in the Greater Harare area (Zimbabwe) and urban Blantyre (Malawi) more than 30% of people are reported infected.^{3,4} The bulk of HIV transmission in Africa is either from heterosexual spread or from mother to child (in utero, intrapartum and through breastfeeding).

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The arrival, wide availability and accessibility of anti-retroviral drugs (ARVs) in the developed world has been associated with improved quality of life and greatly reduced mortality rates among HIV infected persons. In the developing nations of the world, ARVs remain mostly inaccessible to the majority of people who need them. Currently, however, increased attention given to the fight against HIV in developing countries such as Malawi, is causing a shift from messages on prevention and condom use alone and is now being directed towards the wider availability of ARVs, to some extent resulting in inevitable competition with other crucial areas of HIV prevention, care and support. This competition lies in the fact that, although the magnitude of the effect of ARVs cannot be underestimated, their optimal use can occur only in an environment where infrastructural capacities are continuously developing to rise to the challenge of increased accessibility. For instance, there is no argument about the fact that resources (trained personnel, financial and material) are limited globally but much more so in the developing countries. A choice, in many situations a difficult choice, must be made concerning whether to fund wider accessibility of antiretroviral therapy and condoms at the expense of increased HIV/AIDS awareness and condom use. Redeployment of human resources into HIV/AIDS intervention initiatives has the potential to create inequities in the general distribution of health care workers.

There is a growing realization, at least in the UK, that a significant proportion of HIV infection among its residents has been acquired from southern Africa.⁵ There is a need for nationals from outside the southern African region to appreciate the ethical, legal and cultural aspects of HIV. This article will attempt to discuss some of the ethical and cultural issues regarding HIV/AIDS in one of Africa's most affected countries, Malawi.

Ethical considerations

It is generally agreed that there are four major guiding principles in medical ethics: respect for autonomy, beneficence, nonmaleficence and justice.⁶ We suggest that appropriate consideration of all these principles is crucial to ensure an effective struggle against HIV. Matters regarding autonomy (self-governance or personal freedom, confidentiality and disclosure; and the best interests of patients) feature more highly in HIV/AIDS case management than in many clinical situations. Disclosure, meaning informing others who may have an interest in the patient about the patient's HIV sero-status becomes an ethical concept in terms of its definition as 'right' or 'wrong'. In South Africa, persons who have 'disclosed' have been killed in their own communities; some have been ostracized, and others have been sent out of their communities.⁷

Respect for autonomy versus the duty not to harm

Respect for confidentiality and privacy means respecting a person's autonomy. The benefits of confidentiality include that this encourages patients to seek care while promoting trust between patients and health practitioners, and prevents discrimination against patients based on HIV status or illness.⁸ Concern about breach of confidentiality may deter people from wanting to have a blood test. It is generally

understood that a breach of confidentiality may in fact thwart efforts to curb the epidemic because people may not come forward for testing and yet voluntary testing and counselling is generally perceived as an important step towards behavioural change whether or not an individual decides to use condoms or considers the use of ARVs or makes decisions about fertility issues.

Voluntary counselling and testing for HIV has been described as a cost-effective measure for preventing further spread of HIV.^{9,10} In order to protect confidentiality, some HIV test centres do not ask the patient's name or other identifiers. The introduction of anonymous HIV testing was associated with a 50% rise in testing rates in Oregon in the USA.¹¹

What is generally not appreciated well enough is that the duty to maintain confidentiality is not absolute. It is sometimes argued that, if health care providers were to divulge confidential information about a patient's HIV status to a third party (a person not directly involved in the care of the patient/client), such disclosure could in fact militate against further HIV testing. It is not a matter of conflict as to whether permission to disclose should be obtained from the patient. The problem is rather whether a health care worker has a duty to disclose to a third party when the patient is not, or appears not to be, willing to disclose his or her status.

Where there is the possibility of transmitting HIV to a third party (sexual partner for instance), one may justify the action of disclosure as an attempt to prevent harm to the third party. However, a health practitioner's first priority is that of his or her client, not the third party. Moreover, how can one justify harm reduction when the client or patient may already have infected or been infected by a sexual partner. What is happening here is a potential collision between the risk of undermining the principle of beneficence through withholding information about a person's HIV status to a sexual partner and the risk of violating the principle of autonomy by a health practitioner through the disclosure of HIV status. The importance of the two ethical values (respect for persons and nonmaleficence) should be balanced. Is it possible that one universal principle such as respect for autonomy or nonmaleficence is superior over another? It would seem not to be so. For instance, it is generally agreed that, as far as possible, health practitioners should endeavour to encourage clients or patients themselves to accept HIV disclosure to persons who may 'need to know', such as a sexual partner. On the other hand, the situation may change when dying patients would face rejection and abandonment if they were to disclose their HIV status. Disclosure in this case may have nothing to do with prevention of further HIV transmission and the third party (spouse) is unlikely to be protected from infection at this stage.

Malawi society is closely knit and the extended family is highly valued, with free sharing of information within the network; the respect for confidentiality is also observed to a high degree. Family members may feel they have a right to know about what is the relative's diagnosis and yet, in clinical situations, more western principles of autonomy may have been adopted. An HIV diagnosis may be difficult to keep confidential, especially from those relatives who feel they have a legitimate right to know. Relatives who are the patient's guardians in hospital or are paying for hospital costs may feel that such a right to know about the patient's HIV status is legitimately theirs.

Deciding on who has the right to know about the HIV status of an individual, other than the person concerned, is not an easy matter. Many people seem to agree that the

person's sexual partner(s) have a right to such information. However, disclosing such information may not be in the best interest of the person who has tested positive for HIV. Best interest here is being perceived in both a psychological and social sense. The best interest of the patient in this context is expressed in the individualistic approach, which is in contrast to the utilitarian concept of the greatest benefit for the greatest number. There is evidence suggesting that marital discord and family breakdown can occur in the event of an HIV positive test result. Is it then in the best interest of the person concerned to reveal this if it leads to collapse of the marriage?

The alternative to such a situation is where an individual fails to disclose his or her HIV status to a current or potential sexual partner. Assuming the partner is not yet infected and therefore has the potential to be infected in the future, a failure to disclose obviously puts the partner in harm's way. Even in situations where the partner is infected already, but may be unaware of his or her HIV status, if the HIV sero-positive partner discloses, the partner who has not had an HIV test is likely to gain from knowledge of such a test result, for instance, by considering having a test.

The sexual partner may need to take advice on family planning methods, should this be desired. When a person does not have the knowledge that a sexual partner is infected, that person cannot make informed choices about future pregnancies. Informed choices can be made only when there is information, understanding and free will.

When attending antenatal clinics in Blantyre, Malawi, many women report a desire not to inform their spouse in the event of an HIV positive test.¹² A study in Tanzania¹³ reported that HIV infected persons were more willing to disclose to a family member of the same gender as themselves but less willing to disclose to their sexual partner. The main reason given for nondisclosure is fear of marital breakdown and being accused of infecting the spouse.¹⁴ This obviously poses a moral dilemma. Should women be encouraged to inform their spouse about HIV sero-positivity even when there is the risk of marital collapse?

Women mostly attend antenatal clinics in the absence of their spouse, who is therefore not aware of HIV testing at the clinic unless the woman tells him. This practice of not disclosing to male spouses poses particular ethical and practical questions. The Malawi Demographic and Health Survey 2000 reported that 98% of children born prior to the survey had been breastfed at some point, with 97% having been breastfed within 24 hours of birth.¹⁵ The male spouse has a role in promoting breastfeeding either as a limiting agent or a facilitator of breastfeeding. Lack of knowledge about the HIV sero-positivity of his partner may prevent him from making an informed choice regarding whether or not to encourage and support breastfeeding, whether or not to opt for exclusive breastfeeding, and how to deal with situations that may facilitate HIV transmission to the infant.

Situations that pose the threat of HIV transmission through breastfeeding also raise ethical issues on the rights of the child. Although the availability of ARVs for the prevention of mother to child transmission of HIV is still poor, there are now increasing possibilities for access to this treatment in Malawi. Several mission hospitals, private hospitals and a number of government centres are offering nevirapine for the prevention of vertical HIV transmission. In most cases where financial cost is an issue, the male partner is central to the decision to acquire ARVs, as he is most likely to be the one with financial resources in the Malawi setting. As failure to know and disclose HIV status by the antenatal attendee also has implications for the

well-being of the fetus, should there then be a law to ensure that all people who are aware of their HIV status disclose to their sexual partners without fail? Should there also be a law protecting the well-being of those who have disclosed? In the present circumstances, it would seem that such an approach is worth exploring.

Personal versus family autonomy

There has been increasing interest in families in matters of patient autonomy.¹⁶ In the Malawian setting, even while there is a growing sense of an individualistic outlook, the majority of the people still have collectivist leanings, by which we mean to suggest that an individual's worth in society and meaning for existence is not just focused on individualistic needs or aspirations but rather on those of a society. For instance, in traditional Malawian society, raising a child is the responsibility of the community, just as he or she is responsible for her or his parents. In such a culture, it is therefore problematic to consider the individual patient as an autonomous being without due regard to the whole family or community. In Malawian culture, the family has a moral duty to care for its members. It is therefore not unusual for the family to contribute financially to the procurement of health care. Many hospital inpatients are also cared for by family members. It is unusual for a patient in Malawi to be hospitalized without a family member present.

In such a situation, a dilemma presents when the patient is unwilling to disclose a positive HIV status to family members who may contribute financially to the patient's care, decide with others whether and where to take the patient for care, and believe the hospital team is not doing all it can in the event that the general condition of the patient is deteriorating, but yet that person may not know what is wrong with the patient.

The ethical issues do not improve when the patient's family members ask the hospital care team about the patient's diagnosis. Unlike in the West where the appreciation of personal autonomy may be greater, in Malawi relatives generally feel they have the right to know what is wrong with a patient. After all, it is through knowing this that they can reasonably make decisions on behalf of, or together with, the patient. A health care worker who answers: 'I can tell you only if the patient agrees' or, 'The patient knows the diagnosis and he will tell you if he wants', obviously does not solve the whole problem. Moreover, any belief by the relatives that the health care team is hiding issues complicates matters further.

The definitions of what a family, or a sibling, or parents are also pose particular challenges. One's paternal uncle is often described as father, *bambo aang'ono* or *bambo aakulu* (the small father or the big father respectively, depending on the differences in age between one's own biological father and this other father). Cousins and other distant relatives can be described as sisters or brothers. To call a relative a cousin or nephew may seem that one is diluting the importance of the relationship, so then the cousin becomes a brother or sister, while a nephew or niece will be 'my son or daughter'. A health practitioner who is talking to the patient's sister or son or daughter should therefore always keep in mind that that person may not be a real or blood sister, son or daughter in the western European sense.

Insensitive disclosure?

Although many HIV positive persons fail to disclose their status for fear of stigma and discrimination, since 2003 there has also been a wave of mass media disclosures by HIV infected persons. HIV infected individuals continue to appear on television, are featured on radio and are written about in newspapers. Mostly, it has been argued that such openness will help the fight against stigma and discrimination. However, there are a number of ethical challenges posed by such practices.

The question must be asked whether these HIV infected persons are fully aware of the ramifications of their actions, since Malawian society seems to promote the collectivist as opposed to the individualist approach. If appearing on television would eventually lead to reduced stigma and discrimination for many, such a goal is obviously noble. However, other than benefiting many unknown persons, what impact do such disclosures have on the individual's immediate family, friends and sexual partners? Some people have disclosed their HIV positivity and at the same time pushed the blame onto their deceased sexual partners, whose relatives may take the view that they may be injured by such public disclosure by the widow or widower.

Premarital HIV testing

Premarital HIV testing has been suggested as one of the interventions to be pursued in order to curb the HIV pandemic in Malawi. Sadly, however, premarital HIV testing for couples and mandatory testing before marriage has not been accepted as yet by unmarried or married persons. Hesketh *et al.*¹⁷ have suggested voluntary counselling for HIV for all couples prior to marriage. Although this approach has not been accepted in Malawi, mandatory testing has been suggested. The problem arises in the fact that mandatory testing potentially conflicts with autonomy and the right to make informed choices. However, public interest can demand mandatory testing. The case is made even stronger if one considers the baby that may be born from a couple with HIV.

Premarital HIV testing can also be more effective if a couple decide on testing prior to being sexually active between themselves. The impact of testing would be markedly reduced for people who have been having penetrative unprotected sex as a couple for several years already. Perhaps there is a need to explore legal provisions to make such testing mandatory.

Legal provisions

It is of particular interest to note that having unprotected sex when a person has the knowledge that he or she is HIV infected but does not disclose such information to a partner is not a criminal offence in Malawi. An individual who is diagnosed as infected by HIV is under no legal obligation at all to inform her or his sexual partners. Currently, only in rape cases, can such practice be classified as 'aggravating' the crime. We believe that this is a weakness in the legal system of this country. Adequate and prompt reversal of such an anomaly is warranted. Although we agree in principle that it would not be right to disclose an individual's HIV status without obtaining his or

her permission, we ask ourselves whether it may not be good to disclose for the benefit of public health? It is a fact that perpetrators of rape abrogate their right to privacy, and therefore mandatory testing becomes reasonable.^{18,19}

Cultural limitations

The contribution of certain sexual behavioural customs in various African cultures to the spread of HIV is a matter for consideration in the design of interventions. Little headway has been made towards the elimination of these hazardous cultural practices. For instance, many sexual relationships are built on the premise of trust and monogamous behaviour and yet infidelity is widespread in many societies.²⁰

Malawian customs that have the potential to spread HIV/AIDS include *kuchotsa fumbi* and *kudzola mafuta*, literally removing the dust and putting on body oil, respectively (sexual intercourse after being initiated into adulthood). Both males and females are initiated into adulthood after attaining puberty, as a symbol of being adults. The initiates are told that if they do not follow this 'removing the dust' process, a curse may fall upon their parents and families. Many young people obviously believe this warning; others would just go ahead and conduct the exercise for the fun of it, having obtained an excuse to do so.

The other practice is the *fisi* (hyena) custom, which is when a man not being the spouse of a woman of an infertile couple has sexual intercourse with the woman in order to make her pregnant. In many cases, this would be done when it is strongly suspected that the cause is male spouse infertility. This sometimes becomes known in the following way. When a married woman cannot conceive and a reasonable period of time has passed, relatives inquire about the situation and volunteer to help, usually by offering herbal medicines. If this does not work, the man may be encouraged to have extramarital sexual affairs so that he can 'show' whether he is fertile or not. If there is no conception resulting from the extramarital affair(s), then a *fisi* may be hired. While in the West there has been debate on the ethics of sperm donation and surrogate parenthood, the practice of *fisi* poses even more ethical challenges because here the sperm is not provided from a test tube, but rather through a sexual encounter. Even more, the male sperm donor (the *fisi*) is known to the family, while in the majority of cases of sperm donation in the western world, the donor is not known to the recipient.

The other practice is that of *chimwana maye*: renting out a wife or exchanging wives with a friend when the friend comes to visit. Other practices are *kupita kufa*: the funeral cleansing, where the widow has sex with a man identified by the elders of the community. The practice of having sexual intercourse can take about a week as the woman is being cleansed by having sex with the hired man.

Chokolo, or wife inheritance, is the practice whereby a widow is given as a wife to a relative of her dead spouse. The reason for such a practice is said to be that the deceased's family would want to continue 'taking care of the widow'.

During the final day of initiation ceremonies for pubescent girls and boys, there are also associated sexual festivals where all restrictions are removed and free-for-all sex is the norm. The question of whether this is rape or not does not arise as people are not forced into sex; it is rather that all cultural and societal inhibitions to sex are removed during that period. A similar experience has also been described in Koovagam, India, during the Chittirai-Pournami festivals.²¹ During these festivities,

free-for-all sexual activity is part of the traditional celebrations. These festivals are conducted annually between mid-April and mid-June (the first month of the Tamil calendar) as homage to Aravan, a man who is featured in a Hindu story as a person who, when identified by his people, the Pandavas, had to be sacrificed in order to win a war. Aravan asked for sexual intercourse before he was sacrificed to the gods. In order to honour his request, Lord Krishna transformed into a beautiful woman and had sex with Aravan.

These beliefs and customs are so ingrained that various efforts to eradicate them have mostly failed. Some communities are trying to reduce harm by encouraging the use of condoms, whether for *kuchotsa fumbi* or *kudzola mafuta*, practices they have refused to eradicate. They do, however, encourage the use of condoms during sexual intercourse as part these cultural practices. How far this approach will curtail the spread of HIV/AIDS is yet to be evaluated. We are of the opinion that culture is intended to serve those who are bound by it and not the reverse. However, the use of condoms during potentially harmful cultural practices can be likened to 'harm reduction' in the treatment of drug addicts,^{22,23} which has been acceptable in the West for several years now.

A culture of silence and resistance to change is prevalent in Malawi. For instance, as in many African countries, HIV is reported to be spread predominantly heterosexually and same-sex relationship are considered to be insignificant in the spread of the virus in the general population. Such thinking may be unwarranted because evidence is pointing towards increasing homosexual practices.²⁴

Lack of condom use

The consistent and correct use of condoms has been described as an effective way of reducing the spread of HIV.^{25,26} Many people in Malawi understand this but the practice is not universally accepted. There are those people who argue that condom use (even in extramarital relationships) is against their religion. Others report the same impediments, namely that condom use means a lack of trust in a relationship and removes the 'sweetness', and that condoms cause cancer of the female genital organs. Other important groups also argue against condom use. They report potential latex condom failures, as condoms have 'holes' that can permit HIV to leak through. Public health officials dismiss many such persons outright. The sophisticated proponents arguing against condom use may even produce scientific data on their 'presumed' ineffectiveness.

We believe that it is unlikely that the availability of condoms would promote irresponsible sexual behaviour. Quite the contrary, condom use suggests that an individual has respect for self and others. For those that argue against condoms, it is better to consider which is superior: to have sex without condoms and face the risk of acquiring HIV or to use condoms and minimize the risk.

International co-ordination

The Global Fund to fight AIDS, Tuberculosis and Malaria²⁷ has brought new hope to African countries concerning access to ARVs generally and, more specifically, for the

prevention of mother to child transmission of HIV/AIDS. Many countries in need are yet to benefit from this project for a variety of reasons, including failure to agree on certain issues within a country.²⁶ Malawi has so far benefited from US\$136 million already provided. These international initiatives to combat HIV/AIDS should be complemented by appropriate cultural, ethical and legal progress. Allocating more financial resources alone is unlikely to achieve much reduction in the spread of HIV.

Conclusion

Ethical challenges relating to HIV/AIDS have been little discussed in Malawi and yet we believe these are crucial for any effective battle against HIV. Cultural impediments to curbing HIV have been identified but not much has been done to prevent their potential in the facilitation of HIV transmission. Malawi, just like many other southern African countries, needs to evaluate its priorities in the face of the HIV pandemic.

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