

# **AIDS, the Individual, Family and Community: Psychosocial Issues +**

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## **ABSTRACT**

This article examines the impact of the HIV/AIDS pandemic on individuals, families and communities within Africa. The author notes that AIDS presents a challenge to the helping professions to provide a meaningful response to some of the serious psychosocial issues involved. These issues include depersonalisation of those affected by the virus; a tendency towards over-identification and "burn-out" on the part of the helper; fears of contagion, dying and death and a sense of helplessness and anger. Social isolation, stigmatisation and rejection may lead to further undesirable negative consequences for those with HIV/AIDS.

Extending from the psychological and social implications of the disease, the article then examines some of the socioeconomic effects, including the loss of the most active and skilled category of the workforce. The article examines relevant ethical issues and considers how special education and community programmes can help in reducing the spread of the disease.

## **Introduction**

AIDS is a syndrome with frightening social and cultural meaning. It has long-term comprehensive effects on personal relationships, social institutions and cultural processes. Its effects extend to shape the way individual and collective lives are organised. Social norms and values have also affected perception of AIDS and the efforts to control or treat the disease. AIDS is also in the process of reshaping many aspects of society, its institutions, norms and values, interpersonal relations and cultural processes (Nelkin; Willis & Parris, 1991).

Lifestyles are at the heart of the debate on AIDS concerning transmission and prevention, and this poses a major challenge to societies. The emphasis is on surveillance and containment of the virus. It is argued that the only effective way of prevention is a drastic restructuring of attitudes toward intimate social relations. The period of free sex and over indulgence must end and be replaced by a careful and responsible living (Vass, 1992).

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Responsible living, in terms of the relationship between the AIDS-infected person and the family and community, is desirable. However there are always difficult situations and problems which arise once a person is diagnosed as HIV positive, or when AIDS is manifested. The focus of this paper, therefore, is a discussion of the psychosocial effects of AIDS on social life. The psychosocial effects are discussed within the context of the life of an individual who is HIV positive or has AIDS, and the possible reactions and responses that are induced in the individual, the family and community.

Using standard psychosocial explanations, the impact of AIDS on social life is identified and discussed. The contention is that the epidemic and its impact must be understood in the context of the serious socioeconomic problems being experienced, for example in Africa, and the consequences for productive structures and general well-being at the individual, family and community levels.

## Scope

WHO (1990a) views AIDS as the most pressing health problem in the world today because of its capacity to spread very rapidly and its impact on young to middle-aged adults. In most countries of sub-Saharan Africa it is reported to be the leading cause of death among women aged 20-40, and that generally it mainly affects the significant age group 15-35 years, as in Uganda, Zaire and Zambia (WHO, 1990b; Jackson, 1991; Kazembe, 1993).

The epidemic is spreading particularly fast in sub-Saharan Africa through heterosexual means and transmission to babies to the extent that a quarter of all AIDS cases relate to babies. Also it is estimated that 20-30% of all sexually active adults in some urban areas are infected. This rapid heterosexual spread is influenced by factors such as multiple sex partners, and the extent of other underlying factors including urbanisation, migrant labour, poverty, population displacement, rapid cultural changes, inadequate social services (especially in health, education and welfare); and the inferior status of women (Jackson, 1991).

Even though AIDS has raised a major medical concern, it is basically more than a medical problem. It has psychological, social, ethical, legal, economic, material and political implications. It also has serious and long-term implications for socioeconomic development and the general quality of life in society. It has the potential to change mortality and fertility patterns and the nature of population growth in many countries (Jackson, 1991). It also has implications for training, employment and production patterns. On the whole, it has implications for social structures and social life; family units; male-female relationships; numbers of orphans; and the dynamics of parenting when the middle generation dies. There is no area of national socioeconomic life that is spared by AIDS in the long run.

Major problems of care, involving medical, spiritual, psychosocial, material and practical needs become acutely apparent, especially when patients must be cared for at home. For example, with many African families, loss of income from work by the main breadwinner may reduce the available level of nutrition within the context of increasing medical costs and levels of stress. In addition, friends and family members may draw away at a time when people need practical help with a lot of activities such as household chores and emotional support. Although the extended family may be pressed to take on additional responsibilities, however they may be so pressured and overwhelmed that they may be unable or unwilling to take care, for example, of orphaned children who will then need other sources of care. In the face of the AIDS epidemic, the family (extended or otherwise) has been over-stretched.

Children and youths who may end up as care-givers for dying parents and also for younger siblings may suffer by dropping out of school, and because of inappropriate adult responsibility without adequate emotional and social support. Children caring for other children, and the very old caring for orphans have become a major characteristic of some African societies despite the popular argument that there are always appropriate members of the extended family to do such jobs.

## **Psychosocial Issues**

AIDS presents both medical and social challenges. There are difficulties related to sorting out and understanding personal, group, community and professional responses to issues raised by a condition that is stigmatised but not understood by the majority of people. Several psychosocial issues impact on persons with AIDS, their families and their social groups. Even though the psychosocial context will differ from society to society, the process and the interpretations may have many common elements. Thus the notion adopted here is that even though the following explanations may be typical of western perspectives, African and Third World societies in general may learn useful lessons from these when dealing with the AIDS pandemic in the context of the family and community. Relevant psychosocial issues are the following:

1. *Fear of the unknown and the tendency to depersonalise the infected.* Detachment on the part of care workers, family and friends may replace empathy and objectivity. Such behaviours and attitudes increase both emotional and social distance at a time when they are most needed.
2. *Over-identification.* However in most African societies instead of fear and detachment, the tendency may often be towards over-identification. Although identification is a necessary element of the therapeutic relationship, over-identification occurs when an objective stance is lost and leads to the investment of an unrealistic amount of time and energy in the sick person, often fusing

personal needs and professional responsibilities. In most Third World contexts, cultural, social and moral obligations often reinforce this. Support for those caring for persons with AIDS becomes important in maintaining an appropriate balance in relationships in the face of sociocultural obligations; in preventing burn-out; and in preventing a situation where the care-takers neglect their own well-being.

3. *Fear of contagion.* This is based on the notion that AIDS can somehow be transmitted through the air or by contact. This has become a common misconception. Professionals as well as ordinary people still remain fearful despite the recommendations for precautionary measures such as wearing of gloves if in contact with body fluids, etc. On the other hand, especially in the African context, lack of adequate knowledge may lead to erosion in the fear of contagion. Thus, many people fail to take the necessary precautions when dealing with bodily fluids. Sometimes the ignorant belief that it "cannot happen to me" makes people living with those infected by HIV/AIDS take reckless risks.
4. *Fear of dying and of death.* This is separate from both fear of the unknown and of contagion but at the same time linked to them. Being around a dying person brings up unresolved feelings regarding ones own mortality and existence. This conflict is often made worse by the death of a young person or the knowledge that a young person is about to die.

At the extreme end, and again in many African societies, a time of dying and of death is also a period to show affection and solidarity. Thus the tendency to engage in risky behaviour may increase both during the period of sickness and after the sick person has died. An example of risky behaviour is the sexual cleansing of the widow/widower who must have sex with someone in the family in order to be relieved of the spirit of the deceased; or the widow may be inherited by a member of the man's family (Banda, 1993).

5. *Denial of helplessness and hopelessness.* People with AIDS activate a sense of helplessness and hopelessness in those around them, but this is often difficult to acknowledge. However, in the long run, care-givers, for example, may accept personal failure, knowing, for instance in the case of full-blown AIDS, that the life cannot be saved.
6. *Anger.* This may develop because of the feeling of helplessness of the sick person, the helpers and all around them. This may be the result of guilt which may again lead to blaming the victim. Anger may be an unconscious attempt

to punish, resulting in irrational, explosive and unpredictable behaviour. Anger may also be a form of self-preservation, to protect one from experiencing the pain of loss and death. Anger towards the person with AIDS can either provoke the helper to decrease the number of contacts, or direct their own anger at the person. This may result in a blocking-out of empathy and becoming emotionally unavailable.

A critical requirement of working with persons with AIDS is that one be available, reliable, empathise and respond emotionally, particularly during times of regression. Instead of being aware of feelings and admitting to the negative ones, professionals, community and family members may deny them and may find reason not to relate to those who activate them. On the other hand, even though feelings may not be denied, they may not be discussed since ones' social obligations require carrying out tasks dutifully irrespective of personal costs.

AIDS may be experienced negatively, to a greater extent, in the context of extreme poverty, even with helpful social networks and psychological support. Poverty further overstretches weak coping capacities and pushes vulnerable individuals and families into disorganisation and crisis. Thus, a diagnosis of HIV infection leads to chaos: and disrupts and upsets the operational balance and structure of families. There may be initial shock, anger, and chaos following the diagnosis. Continuous fear, disbelief, anxiety, pain, stress and emotional ups and downs are also experienced.

If a child is diagnosed with HIV, the effects continue throughout life. Many reports from Africa indicate that those diagnosed with HIV/AIDS go through many of the psychosocial problems experienced in the West such as denial, anger, fear of death and hopelessness (Septimus, 1990; Chipanta, 1993).

## **Social Isolation**

Most families and many individuals in Africa are unwilling to share the diagnosis with friends and relatives due to a sense of guilt and shame associated with AIDS. It is not so much the sense of guilt associated with unfaithfulness and promiscuity. It is rather the fear of community disapproval of the sickness which may lead to stigmatisation, isolation and termination of association with the infected and the entire family. The loss of social supports may lead to isolation which may in turn induce depression and difficulties in dealing with family issues and tasks. There are several examples from Ghana, Zambia, and Zimbabwe where families have thrown out members for being HIV positive. Others have lost jobs and in an extreme case a young woman who came out in the open about her illness was attacked on the streets in Ghana by a mob. Septimus (1990) indicates that socio-economic problems in families further contribute to depression.

AIDS introduces a new and overwhelming set of conditions. Without income, employment and medical support there are very few, if any, resources, to break the vicious cycle that drains psychological and physical resources and extends vulnerability. Sociocultural factors and societal responses to AIDS seem to aggravate the distressing reactions of guilt, self blame and lowered self esteem which may usually result from unresolved conflicts about hidden sexual behaviour and be reinforced by societies which blame peoples' infidelity for the disease. Thus, infected persons and their relatives, friends, etc experience a feeling of contamination in relationship to sexuality and physical-affectional closeness. This is compounded by the sexual transmissibility of the disease (Macks, 1987).

Actual or feared rejection by family, friends, spouses, social support systems and employers also contributes to high levels of stress. Underlying this feeling of distress is the desire to find an internal sense of hope and empowerment to help one focus on living rather than dying. Thus the infected need assistance in adapting psychologically to the physiological and psychosocial changes that they go through which lead to their loss of status. Some are forced to abandon their source of income. Others have a feeling of failure accompanied by their disappointment that their future plans and ideals will never materialise. Drastic alteration of life style due to fatigue, debilitation and loss of mobility and bodily functions may result in isolation, boredom and in some cases result in increased drug and alcohol use (Macks, 1987).

The challenge, according to Macks (1987), is to recognise the interrelationship of the physiological, psychological and sociocultural aspects of AIDS for each patient and attend to them simultaneously. A comprehensive bio-psychosocial assessment is necessary (eg, data related to personality factors, coping skills, strengths and weaknesses, history of psychiatric problems, social functioning, etc). Also attention to cultural, religious and spiritual values is critical.

AIDS affects the entire family and its effects have created the need to constantly reassess the dynamics of the family, safeguarding the civil liberties of family members and ensuring minimal community services for the family. Families and their members have identified the potential for isolation as one of their most difficult social and psychological problems. This is in addition to each family member confronting the possibility of social isolation from the family unit, the neighbours, and the larger community. There is also the emotional pain of dealing with an overwhelming situation (Newmark & Taylor, 1987).

## **Socioeconomic Issues**

The serious repercussions of HIV/AIDS on African social development is demonstrated by its possible demographic impact. It is estimated that about one in 40 men

and women are already infected, and that in some areas of the continent it is as high one in four. The epidemic is also notably serious among young adults and pre-school children. Half of all infections are also among women in their reproductive years. Thus, there are major consequences for reproduction and population structure (Kalilani, 1993).

It is argued that with the current nature of the epidemic the number of reproducing women may decline to the extent that births will become inadequate to replace losses due to deaths. Also as women become aware of the hazards to pregnancy and the new-born infant due to HIV infection, they will opt not to reproduce. Even though these will slow down population growth, the reduction will basically involve young people and workers, the most active part of the population. The basic problem, in this regard, is that the decrease in population will be selective – among the young and sexually active age groups and will more than offset health and social improvements in life achieved so far (Kalilani, 1993).

Another social impact of AIDS is indirect costs in terms of production losses based on assumptions related to the age, sex, education and incomes of those who die of AIDS and whose economic contributions are lost forever despite the high levels of resources invested in them. For every educated and employed person in Africa, there are thousands who never had the opportunity. Thus, the hope for any future benefits from them is also lost. Such losses include present as well as future income and the benefits that would have accrued to the family, relatives, and society as a whole. There is also the threat of increased absenteeism from work because of constant ill-health, caring for sick relatives and attending funerals.

In addition to these actual and potential indirect losses, AIDS also creates the need to care for those infected and at the same time find adequate and effective ways to replace their contributions to the household and the community. In any case Africa presents a situation where the better-educated with higher socioeconomic status are the ones most infected by AIDS. Thus there is the issue of replacing this category of people in a region with severe shortages of skill. The increasingly limited number of skilled personnel will also exacerbate the pressures on the socioeconomic infrastructure and services, and further reduce productivity.

Some employers will try to minimise the impact of AIDS by discriminating against infected employees. They may try to screen out those with HIV from employment, travelling or further training, leading to more isolation and impoverishment of those with HIV. Such behaviour is unjustified and counter-productive. Such practices are not only inhumane but may incur long-term costs by impeding preventive efforts.

Africa, and the Third World in general, is faced with critical shortages of skilled manpower at all levels coupled with expensive training costs. Thus, loss of skilled labour to AIDS is very costly in terms of wasted training and replacement costs.

There is also, in some instances, close dependence of entire nuclear families on the place of employment. For example, in mines and agriculture people live in compounds or housing schemes attached to the place of employment. Loss of the employee means loss of housing as well as income and often schooling for children. The social cost of AIDS is therefore very substantial and far-reaching. The primary concern of AIDS and employment relate to recruitment; rising costs of insurance, health care and pensions; time-loss; reduced productivity; and lowered morale (Jackson & Pitts, 1991).

Increasing experience of seeing one's network of friends and relatives decimated in a manner that used to be associated with old age, and the knowledge that from now into the future we are dealing with an incurable disease, produce a horrific picture of the future. Despite this, there is still the vital need to act positively: while diagnosing HIV and prescribing the means of alleviation and control are manifestly medical matters, setting limits to acceptable (sexual) behaviour, commending changes in lifestyle and helping people come to terms with the disease will involve social workers and others in the helping professions.

Problems and paradoxes facing those who confront the reality of the imminent death of themselves, loved ones and relatives will increase for some time despite all efforts and investment of resources, and irrespective of the level of community involvement and care (Coxon, 1990). It must be noted also that in institutional terms some industries such as insurance will be affected more negatively than others. Others, such as rubber production for condoms, disposable syringe manufacturing and the pharmaceutical industry, stand to benefit a great deal (Jackson & Pitts, 1991).

## **Some Ethical Issues**

At the personal level, an individual has to confront a range of new and inevitable painful ethical decisions or choices. These will differ depending on the condition of the individual, for example, whether he/she has AIDS, our relationships whether he/she has tested positive or whether he/she is free of infection. Those in settled monogamy may think they are secure and have nothing to fear. However where sexual relationships are concerned, no one can be absolutely sure of another person's fidelity. In the advent of AIDS, secret unfaithfulness carries a lethal potentiality (Almond, 1990).

The young are bound to experiment with sex. In the face of AIDS how are they to do it safely? Some unsafe experiments are bound to happen. Thus, sex education would have to include detailed and specific technical instruction in barrier protection that seems neither desirable nor necessary for contraceptive purposes alone. In this regard, the concept of the condom as a normal accompaniment of sexual intercourse must be positively promoted. This is in the belief that some protection is better than no protection at all (Almond, 1990).



It is also necessary to avoid promoting random sexual activity in the promotion of condom use. Experimentation for its own sake now has no moral defence if it ever had one (Almond, 1990). The ethical imperative for the young is to place emphasis on relationship. There is need to increase awareness of the unacceptable risks involved in random or anonymous sex. For those who are affected, the ethical imperative is honesty and compassion. Honesty dictates that one needs to know, and this should not be affected by considerations of social and economic consequences. Compassion, which is consideration for others, dictates that the knowledge is needed so that others are not deliberately put at risk.

AIDS is most prevalent among young adults and hence most sufferers, in relative terms, have young parents, who under normal circumstances would be looking forward to a period free of parenting, or a time when they could depend on support from their children. In this situation, AIDS presents a case of generation reversal. Instead of being free and cared for themselves, parents have to go back to a type of parenting with no hope that the child will become an independent person due to AIDS infection (Bamford; Gaitley & Miller, 1988).

## **AIDS and Social Support**

With AIDS, the social system itself is under strain. Hence the experience has been such that sufferers, to a great extent, are confronted with indifference and persecution by society. The process through which the virus spreads is seen as a threat to the dominant values of society and also as a moral threat. At the same time, a biological threat is attached to the moral one due to the transfer of the virus from the so-called "guilty" to "innocent" people. This has resulted in a moral panic which has forced societies and individuals to resort to discrimination and the creation of social and physical distance between themselves and sufferers (Bamford; Gaitley & Miller, 1988). However as people come to understand HIV/AIDS, the panic has reduced and the infected are becoming more and more accepted by both society and individuals.

The social nature of humans underlies the critical importance of social support in facilitating adjustment to stressful life events, and in decreasing vulnerability to stress-related disorders. Social support helps in adapting to the stressor and decreasing the emotional effects on the individual. It comes in many forms and includes physical aid (material goods and services); psychological aid (verbal exchange); emotional support (empathy, esteem and concern); appraisal support (feedback); informational support (education); mutual obligation and reciprocity; and social integration and nurturance. Social support is therefore a coping assistance which is necessary in the context of the levels of stress associated with HIV/

AIDS and the need to help sufferers re-gain their self esteem (Schwartz, 1987; Lynch, 1992). It is with respect to social supports that indigenous societies are supposed to have advantage over western industrialised societies.

Both AIDS Related Complex (ARC) and AIDS have an extensive impact on the social as well as the economic status of those affected. ARC patients sometimes feel they are in a "gray zone", on their way to AIDS but uncertain as to when or how. Also psychological distress sometimes leads to vague somatic symptoms which do not respond to medical treatment, thereby increasing the patients' fear and anxiety. The challenge is towards enhancing emotional supportive interventions to address those symptoms. Social support must therefore be a primary concern of all HIV-infected individuals and groups (Lynch, 1992). It is supposed to be the network which has the capacity to sustain socio-psychological support and hence provide the justification for the necessary care for those affected.

Lynch (1992) suggests that women as a group may be affected more than men. Women are known to use social supports more than men. In particular, women may respond more positively to support which is more intimate and of a self-disclosing nature than the task-oriented support men are often associated with. Women's social supports, therefore are more adaptive in reducing stress.

In addition, the role women play in families as the source of nurturance, and with responsibility to care for the family also places an added burden which is difficult to discard even when the woman becomes ill. This may mean that women are more burdened with demands and tasks from their social networks. Thus even though social networks can be supportive, when combined with gender roles they may also become additional sources of stress. Some issues are also unique to women. Some of these may relate to future and present pregnancies and questions about partner's sexual behaviour and orientation. These may lead to further questioning of one's femininity and sexual adequacy (Lynch, 1992; Buckingham & Rehm, 1987). In addition to this, the subjection of women's sexuality to the demands and dictates of men, and the overall secondary status of women, make them more vulnerable, even in the face of adequate social supports.

## **Community (Social) Education**

Individuals and communities require open minds about AIDS which will allow for responsible safer sex education and practices. Community education is necessary to enable the fearful to understand and confront the source of the fear including the pain of the disease, of being rejected by a partner, family, friends, and relatives; the fear of being disabled and disfigured physically; the fear of losing control of one's mind and life; the fear of the common knowledge that one is dying of a sexually transmitted disease; and fear of social, domestic and occupational disruptions (Kirkpatrick, 1988).

In addition, families, groups and communities also need to come to terms with, and address the anxieties, shock and sense of helplessness when a member is infected with HIV. They often develop depression and obsessional worries because of fear of being infected; uncertainty about what to do next; the conflict that is associated with avoiding infection, and at the same time the need to express physical love and affection; and uncertainty about how to help. On the whole people need to become psychologically comfortable with those who are infected, sick, and dying as well as those in the process of being bereaved (Kirkpatrick, 1988).

Psychosocial needs studies have shown that persons with AIDS respond as others have responded to life-threatening illness – with anxiety, distress and depression and that they go through the same stages of anticipatory grief, denial, anger, bargaining, depression and acceptance (Schwartz, 1987; Kubler-Ross, 1969). Thus, they require assistance in dealing with this feeling of distress and mood fluctuations, compounded by an overwhelming sense of helplessness and hopelessness (Macks, 1987).

AIDS therefore calls for special education and community programmes. Most infected people have no symptoms and yet can transmit the virus to others. The challenge is to persuade them not to spread an infection they may not even know they have. People must also be sincerely convinced that someone who appears perfectly healthy can transmit a deadly virus. It is also evident that some of those involved in high risk behaviours, eg male and female prostitutes and people with several sexual partners, are difficult to reach with conventional methods of communication. Social norms and other barriers may separate them from community organisations and institutions and hence make them difficult to reach. Also some people engaged in high-risk behaviour may not see themselves at risk. Again considerations for the present may overwhelmingly outweigh thought for the future. For example, poverty may force one to undertake sexual favours for money, or for fear of rejection and loss of partner. Educational messages must therefore focus on behaviours instead of groups (Panos Dossier, 1988).

In addition, AIDS is associated with practices often regarded as immoral or illegal, eg prostitution, infidelity and homosexuality. This results in the refusal of some policy-makers to support educational and service-delivery programmes. At the same time some groups consider discussion of risk factors or preventive measures unacceptable. It is therefore important to find educational language, concepts and images that are inoffensive and acceptable beyond the targeted groups. A related issue is the development of imaginative community care services; and promoting supportive attitudes in the community in general, and in organisations and agencies to address AIDS-related needs.

## Conclusion

A major challenge of AIDS has to do with the understanding of the syndrome and the psychosocial factors associated with it, both at the individual and societal levels. This is necessary in order to deal with the difficulties that arise with the onset of AIDS. When an individual is infected, the socioeconomic and psychological dynamics in which that individual operates also change, and in many instances, very dramatically.

Community educational activities require committed attention and answers to issues concerning how to deal with the psychosocial problems that confront individuals infected with AIDS and their families; and how to minimise, or control the impact on societal institutions, processes and productive activities. Understanding and dealing with the psychological reactions and processes that an infected individual goes through, perhaps, is a fundamental requirement for effective care, especially at home.

A comprehensive set of services and care creatively designed and delivered in both institutional and community settings, can only come with an understanding of the psychosocial impact of AIDS on individuals, families and communities, and their associated direct and indirect costs at both the micro and macro levels of society.

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