

Chapter 24

***Financial and Legal Issues***

***Overview***

It is well known that people living with HIV/AIDS and their families experience emotional and physical difficulties. It is important to know that they also frequently face severe financial problems related to their inability to work, loss of benefits, and the costs associated with care and treatment. The resulting financial crisis can be so acute that it hinders patients' ability to deal with their health problems. The loss of a job and a drastic reduction in income clearly add to the burden of stress for the patient and family even as they try to cope with life-threatening illness.

Holistic palliative care professionals help patients and their families address the range of issues that confront them, including the legal and financial problems that HIV/AIDS brings upon them. Their role includes assisting patients to access any benefits due them and helping to link them to possible sources of financial assistance. Palliative care providers must therefore acquaint themselves with the legal and financial rights, benefits, and opportunities available to persons living with HIV/AIDS in their country.

While the governments of some countries have met the challenge of HIV/AIDS in many ways, those of other countries have been slower to rise to the challenge and meet the needs of infected and affected people. Where governments have been less responsive, families bear further emotional and financial burdens, and there is greater emphasis on the role of NGOs in providing care and support. This chapter offers examples of government-supported programs with particular emphasis on Uganda, whose development of financial support services and legal protections offers models for other countries to consider.

***Authors***

Fatia Kiyange

Zipporah Merdin Ali

Sarah Banenya

Lucy Finch

Eunice Garanganga

Carin Marcus

***At a Glance***

Financial and Legal Needs of People With HIV/AIDS

Roles of Palliative Care Professionals in Linking Families with Benefits

Accessing Programmes to Maintain Financial Independence

Life Insurance and Private HIV/AIDS Insurance

Wills and Other Legal Issues

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## Financial and Legal Needs of People With HIV/AIDS

Both the person coping with life-threatening illness and his or her family struggle with various issues that erode the family's financial resources. In Africa, the extended family system can be a potential source of financial support for the patient. Family members can mobilise funds for treatment and other costs. However, the traditional extended family system is also being overstretched and broken down by the extent of the needs and problems associated with HIV/AIDS in Africa. Very often relatives abandon work to care for their loved ones when they are sick, further eroding the financial resources of the family. In the era of antiretroviral therapy, patients may sell their property to purchase antiretrovirals (ARVs), leaving their families without shelter and other needs. HIV/AIDS also may provoke such psychological reactions as anger, depression, anxiety, and isolation, which eventually can break down communication within the family and make it difficult to mobilise financial resources.

Uganda and a few other African countries have begun to provide ARVs to some patients free of charge. In some cases, patients in research studies or working with public service are being given priority to access the limited supply of free drugs.

### *Patients Have Specific Needs Related to Addressing Their Financial Burdens:*

**Information:** Patient support groups, which can be provided by organisations running home-based care services, offer opportunities to inform people of the local resources available to them. Sometimes there are community-based agencies involved in providing financial assistance to vulnerable members of society. Most of the time, however, patients are ignorant of such services and need help in identifying and making use of them. Patients and families also need information on national policies — such as supportive workplace policies — that support quality of care.

**Assistance:** Even when patients are knowledgeable about their benefits, they may be too weak to begin the often bureaucratic and even corrupt process of accessing them. Helping patients to obtain their financial benefits can make a big difference at the end of life as it relieves them of stresses related to their financial/income status and can facilitate better planning and decision making.

**Emotional support:** Once patients are receiving entitlements such as terminal benefits and pensions, they may still need advice and advocacy to help address their practical needs, reduce their stress, and enable them to concentrate on their medical and emotional needs. The family's need for advice and information-giving does not end when the patient dies, but stretches over into the period of bereavement.

## Roles of Palliative Care Professionals in Linking Families with Benefits

### *Assisting Patients and Their Families to Obtain Benefits*

Palliative care providers are in a good position to discuss financial and legal issues with people living with HIV/AIDS. Such discussions give patients and families an opportunity to make rational decisions for their own and their ill loved one's protection, both during the period of illness and after the person's death. Palliative care professionals must be well informed about the unique laws and benefits in their own countries to be able to assist them.

**Guiding and advising:** Patients need to understand that they are entitled to these benefits and should not see them as charity, which they may consider demeaning. Patients often need help and encouragement to make the necessary claims and to ensure they receive the entitlements due them. They also may need assistance in rational decision making to help them avoid decisions that are detrimental to their families and children.

**Facilitating communication:** Professional carers play an important role in enhancing communication within the family. They can extend this role further to employers and the community at large by advocating for resources for people living with HIV/AIDS.

**Referrals to local resources:** Professionals can also be helpful in assisting patients and their families to make use of available resources in their communities. Maintaining a network of all local-, national-, and international-level caring organisations can help mobilise financial resources for HIV/AIDS patients and their families. Providing referrals to the relevant agencies in these networks can alleviate a family's financial constraints when they are struggling with so many other issues. It also helps to make use of existing structures for patient and family support.

### **Assisting to navigate bureaucratic systems:**

The social security benefits system is still weak in some African countries. Often it is inaccessible and sometimes non-existent. This is worsened by ignorance about the services where they are available. It is especially crucial in African countries with limited social security benefits for palliative care professionals to assist patients in navigating the system. This includes assisting in what may be the lengthy process of obtaining the birth certificates or other identity documents needed to access financial benefits.

To play an active role in helping patients and their families with financial or legal problems, palliative care professionals need to know about:

- Their country's social security and labor laws and procedures for claiming benefits
- Any special rules for claiming benefits for people with terminal illnesses
- Documentation needed to apply for various government benefits, including the locations and operating hours of relevant offices
- Their country's HIV/AIDS policies, including workplace policies.

#### **Box 24.1:**

#### **Actions Palliative Care Professionals Can Take**

- Hold discussions with patients' former employers
- Help patients to understand and sign relevant claim documents
- Sensitise relevant community leaders, employers, and others on the need and urgency for claims
- Offer patients practical assistance, such as transport and help in organising documents

## Programmes to Maintain Financial Independence

### *Income-Generating Projects in the Private Sector*

Programmes designed to help HIV/AIDS patients and their families should assist families with maintaining their financial independence. For example, experience in Uganda has shown the usefulness of credit schemes in boosting household incomes and, therefore, the ability of patients and families to meet their basic needs at home. Non-governmental and faith-based organisations also can provide opportunities for building skills and generating income. Patient support groups and training centres can teach a variety of skills to increase income. Examples include jewelry-making and beadwork, setting up community vegetable gardens, establishing a local craft market, and creating food parcels for industry. NGOs in many African countries help families by paying school fees and providing uniforms for school-age children.

### *Public/Private Partnerships*

The response to the legal and financial problems caused by HIV/AIDS should ideally be shared by civil society/voluntary organisations and governments. Uganda is a country with a well-developed public/private partnership. The government of Uganda has established programmes to assist with all aspects of HIV/AIDS, including its financial impact on patients and their families. The Uganda AIDS Commission, a government body under the President's office, works together with the civil/voluntary organisations to provide services to patients and their families—such as assisting with treatment, school fees for children orphaned by AIDS, food supplements, and other ways to bring relief to families experiencing AIDS-related financial problems.

Uganda's National Social Security Fund (NSSF), another example of public-private cooperation on benefits, is an arrangement set up by law to enable people in formal employment to save part of their earnings on a monthly basis. Every employer of more than five people is required to remit to NSSF a standard contribution of 15% — 10% from the employer, and 5% from the employee—calculated on the total wages paid during that month to an employee (see Box 24.2).

Zimbabwe has similar programmes in place, such as the AIDS levy passed by Parliament. Employees earning a certain level of income are required to contribute 3% of their salary that is used for prevention, care and support, mitigation, and research.

**Box 24.2:**

**Uganda's National Social Security Fund**

Uganda's NSSF is a compulsory savings scheme which covers all employees in the private sector, including non-governmental organisations and parastatal bodies that are not covered by the government pension scheme. Every worker is entitled to subscribe to the NSSF (NSSF Act, Cap 222), which administers and pays qualified contributing persons the following benefits:

- Old age benefit
- Invalidity benefit
- Survivors benefit
- Emigration grant
- Withdrawal benefit

The NSSF identifies people with HIV/AIDS as physically or mentally incapacitated and, therefore, potential beneficiaries of the invalidity benefit upon fulfilling such requirements as possessing certification from a medical doctor that they have HIV/AIDS, which the NSSF can verify.

The NSSF acknowledges the financial constraints caused by HIV-related hospital admissions, treatments, and transport to health facilities. Patients desperately need their savings to meet these needs and to plan ahead for their families. Despite the limitations of the law and NSSF policies, patients with HIV/AIDS are encouraged to file claims for their NSSF benefits with minimal difficulty.

NSSF makes available all the information necessary for filing a benefits claim to professional carers, patients, and families. A supportive letter from the organization providing health care services can facilitate the claim process. For patients who are too weak to reach the claims office, arrangements can be made for NSSF officials to visit the patient at home and obtain relevant information and legalities, such as the required thumbprint.

**Government-Run Health Care and Service Programmes**

Benefits for patients receiving palliative care may include social security benefits, pensions or gratuities, and disability grants, depending on the country and type of work they engaged in.

**Malawi:** In Malawi, every District is supposed to have a social welfare department, with a social worker as the welfare officer and an assistant. However, social workers are in short supply and the offices have no funds. While people who worked for companies may receive benefits from their employers, informal workers receive no social welfare benefits from the government. The social welfare department only plays an advocacy role, connecting people to humanitarian organisations. This means that the majority of people in Malawi have no social welfare benefits of any kind.

**South Africa:** The South African government offers several benefits to people with HIV/AIDS, including a disability grant paid to those certified by a clinic or hospital doctor as being unable to work and who have either low or non-existent household income. However, this grant may have to buy food for an entire household if it is the family's only income. The country also offers child support grants, a small monthly payment for children under the age of 11 years (to be extended in 2005 to those under 14 years) in a household with low income, and an old-age pension for women over age 60 and men over age 65 who have little other income. The old-age pension is often the sole source of income for an extended family, such as a grandmother caring for children and grandchildren living with AIDS.

**Zimbabwe:** The social welfare department has social workers that assist patients and families to get free medical certificates so that patients can be treated without payment at government hospitals and clinics. They use what is called a social dimension fund or social security fund. School fees for the children are paid for after an assessment has been made. However the system is overburdened by the huge number of infected and affected people.

***State Unemployment Insurance, Workers Compensation and Workplace HIV/AIDS Policies***

Workers compensation is payable by law to workers for injuries suffered and “scheduled” diseases incurred in the course of their employment. Scheduled diseases are those listed as occupational diseases contracted while the worker was employed. The existence of such benefits varies by country (some examples are described below).

Most people in Africa work in the informal sector, and would not qualify for workers compensation even in countries that have unemployment insurance programmes. When they have HIV/AIDS and are unable to carry on with their manual work, they normally have no form of social security benefits. People in this situation who are family breadwinners not only cannot afford treatment costs but also cannot meet the basic needs for their families. Palliative care professionals frequently confront the overwhelming financial problems of such patients. In Uganda, the NSSF has embarked on a campaign to encourage even those working in the informal sector to make arrangements to save for their social protection.

**Malawi:** In Malawi, government workers and civil service workers receive sick leave when they are ill, full pay when they are ill for the first six months, and then one-half pay for the next six months. However, sometimes workers continue to receive benefits for up to two years because no one checks once a name is in the computer. These workers also are entitled to final benefits, pensions, or a death gratuity which could be up to four times their annual salary and is payable to their beneficiaries—first their children, then their spouse, and a small percentage to their parents. The biggest share is given to the youngest child.

**South Africa:** South Africa offers state unemployment insurance. Workers apply for benefits when they lose their job. ‘Sickness benefits’ are paid out over a six-month period after a sick worker leaves work, providing all documentation is in order. Although all domestic workers and gardeners should now be covered by the fund, some small employers still are illegally not contributing to the unemployment fund so their workers cannot benefit. South Africa supplies free treatment for patients at community clinics. Although fees are charged at provincial hospitals, no patient can be turned away because of inability to pay.

**Uganda:** Uganda includes HIV/AIDS as an occupational disease under the Workers Compensation Act Cap. 225. A general campaign is in place on workplace HIV/AIDS policies intended to make a positive contribution to employees with HIV/AIDS in their workplaces. Such policies relate to financial contributions to treatment, particularly ARVs, granting of sick leave, period of continued salary payment, issues of psychosocial support, workplace stigmatisation, and facilitating access to other available services.

### **Life Insurance and Private HIV/AIDS Insurance**

Life insurance policies are generally designed to provide income support to the survivors of a deceased policyholder. In some jurisdictions these policies can also provide much-needed income support to a person living with HIV/AIDS. Life insurance policies that include an accelerated benefits provision allow a terminally ill person with HIV/AIDS to obtain a portion of the life insurance proceeds that would normally be reserved for the surviving beneficiaries. The remaining proceeds go to the surviving beneficiaries upon the ill person's death. Whether a private individual can arrange to take an HIV/AIDS insurance cover within these legal provisions is a matter to be negotiated with individual insurance companies.

Enquiries of insurance companies in Uganda indicate that there are no specific HIV/AIDS insurance policies at the moment, but there is increased awareness of the need for such policies. Following research by the National Insurance Corporation in Uganda, there is potential for utilising such policies if they are developed. Some companies are developing such insurance policies, although the existing general policies on life insurance are open to everybody including people with HIV/AIDS. One such policy is for child education insurance which many insurance companies are taking on.

## Wills and Other Legal Issues

Making a will is one way that people with HIV/AIDS can ensure that their finances are in order and their resources will benefit their surviving families. However, in Africa it is a social taboo to talk about the will because of the belief that doing so will cause immediate death. This is a challenge for palliative care teams which must confront the issue with their patients. Networking with legal organisations to intervene in such legal issues has proved helpful. More and more patients and their families are now requesting assistance in writing wills, which is indeed a great step forward. HCWs need to be sensitized and perhaps educated on how to best assist in such situations. It is important to remember that wills address not just issues of property, but other issues that are very important to the dying patient, such as place of burial and whom to leave orphaned children to.

**Kenya:** The picture in Kenya is perhaps typical of the picture throughout much of Africa. Wills are often not discussed due to traditional beliefs, and if they are written, may not be honored. More often widows and their children are left at the mercy of the deceased husbands' family members. However, slowly this is changing and the government of Kenya is now supporting widows in claiming their rights. FIDA (Federation of Women Lawyers) plays an important role in advocating for women's and children's rights.

**Malawi:** In Malawi very few people make a will because they fear it will hasten death. The men especially fear that their wives and families may bewitch them in order to inherit their property. As a result, property-grabbing from widows and children is rife. When wills are made, they are sometimes not honored. A campaign to sensitise the public on making wills is underway by the Ministry of Gender, Law, Society and Legal Aid. A bill is expected to be introduced in Parliament to outlaw property-grabbing. The Reserve Bank of Malawi has taken this further by requiring all its employees to make a will as a condition of service. The employees receive free legal advice and the wills are reviewed every year.

**Uganda:** In Uganda, a few programmes such as the Federation of Women Lawyers, the Legal Aid Project, and the Legal Aid Clinic are responding to the legal problems of HIV/AIDS patients without requiring clients to pay for services.

**Zimbabwe:** Zimbabwe features programmes, departments and offices similar to those described in other countries. In cities, palliative care training covers wills and other legal issues. Through networking, legal experts provide input, thereby creating awareness of what protections are available in terms of inheritance laws and other legal issues. Palliative care professionals give information, assist with straightforward issues such as simple wills, and link patients to appropriate experts. They also make referrals after discussions with patients or families.

