

Chapter 22

Ethical and Human Rights Issues

Overview

In recognising the importance of human rights within the health field, the Patients' Rights Charter states that every patient has the right to:

- A healthy and safe environment
- Participate in decision making
- Access to health care
- Knowledge of one's health insurance/medical aid scheme
- Choice of health services
- Be treated by a normal health care provider
- Confidentiality and privacy
- Informed consent
- Refuse treatment
- Be referred for a second opinion
- Continuity of care
- Complain about health services

The South African Department of Health wrote the Charter to apply to people in all health care situations and define the ethical responsibilities of health care workers in providing care (Department of Health, South African Government, 1996).

South Africa's National Association of People With AIDS (NAPWA) developed the AIDS and HIV Charter (Box 22.1). Although this document as well as the Patients' Rights Charter express an ideal to strive for, the difference between the ideal and reality needs to be addressed. The discussion on gender, sexuality, and HIV/AIDS expresses some of the human rights difficulties that have arisen as a result of gender inequality.

This chapter presents some of the important human rights and ethical issues that arise in palliative care and pays particular attention to how these issues bear on the treatment of patients living with HIV/AIDS. It provides a systematic approach to the ethics of palliative medicine — one that grounds the ethical principles appropriate for this field in the theoretical ideals of palliative medicine.

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Human Rights Applied to HIV/AIDS

Protecting the human rights of people living with HIV/AIDS has been a necessary part of AIDS policy since the beginning of the epidemic because of the issues of discrimination and stigma. The NAPWA AIDS and HIV Charter reflect the broad range of concerns that people who are infected and affected by HIV must be concerned about.

Box 22.1:

AIDS and HIV Charter of the National Association of People With AIDS of South Africa

In the Light of

- The existing discriminations against persons with AIDS or HIV and their partners, families and care givers,
- The danger that the growth of the epidemic in South Africa will lead to an increase in unfair and irrational treatment of those affected by AIDS and HIV,
- The desirability of greater awareness and knowledge of AIDS and HIV among all South Africans, and
- The need for concerted efforts by all South Africans to stop the spread of HIV,

This charter sets out those basic rights which all citizens enjoy or should enjoy and which should not be denied to persons affected by HIV or AIDS, as well as certain duties.

1. Liberty, Autonomy, Security of the Persons and Freedom of Movement

1. Persons with HIV or AIDS have the same rights of liberty and autonomy, security of the person and the freedom of movement as the rest of the population.
2. No restriction should be placed on the free movement of persons within and between states on the ground of HIV or AIDS.
3. Segregation, isolation or quarantine of persons in prisons, schools, hospitals or elsewhere [is not acceptable] merely on the ground of HIV or AIDS
4. Persons with HIV/AIDS are entitled to autonomy in decisions regarding marriage and childbearing although counselling about the consequences of their decisions should be provided.

2. Confidentiality and Privacy

1. Persons with HIV/AIDS have the right to confidentiality and privacy concerning their health and HIV status.
2. Information regarding a person's HIV status must not be disclosed without that person's consent, and, after death, except when required by law, without the consent of his or her family or partner, except in cases of clear threat to and disregard of an identifiable individual's life interest.

3. Testing

1. HIV antibody testing must occur only with free and informed consent, except in the case of unlinked, anonymous epidemiological screening programmes.
2. Anonymous and confidential HIV antibody testing with pre- and post-test counselling should be available to all.
3. Persons who test HIV-positive should have access to continuing support and health services.

4. Education on AIDS and HIV

1. All persons have the right to proper education and full information on HIV or AIDS, as well as the right to full access to and information about prevention methods.
2. Public education with the specific objective of eliminating discrimination against persons with HIV/AIDS should be provided.

Box 22.1: (continued)

5. Employment

1. HIV should not be the basis for pre-employment testing or a ground for refusing to employ any person.
2. HIV or AIDS do not, by themselves, justify termination of employment or demotion, transfer or discrimination in employment.
3. The mere fact that an employee is HIV-positive or has AIDS does not have to be disclosed to the employer.
4. There is no warrant for requiring existing employees to undergo testing for HIV.
5. Information and education on HIV and AIDS, as well as access to counselling and referral, should be provided in the workplace after appropriate consultation with representative employee groups.

6. Health and Support Services

1. Persons with HIV or AIDS have the right to housing, food, social security, medical assistance and welfare equal to all of our society.
2. Reasonable accommodation in public services and facilities should be provided for those affected by HIV or AIDS.
3. The source of a person's information should not be a ground for discrimination in the provision of health services' facilities or medication.
4. HIV or AIDS should not provide the basis for discrimination by medical aid funds and services.

7. Media

1. Persons with HIV or AIDS have the right to fair treatment by the media and to observance of their rights to privacy and confidentiality.
2. The public have the right to informed and balanced coverage of, and the presentation of information and education on HIV and AIDS.

8. Insurance

1. Persons with HIV or AIDS, and those suspected to be at risk of having HIV or AIDS, should be protected from arbitrary discrimination in insurance.

9. Gender and Sexual Partners

1. All persons have the right to insist that they or their sexual partners take appropriate precautionary measures to prevent transmission of HIV.
2. The specially vulnerable position of women in this regard should be recognised and addressed, as should the specially vulnerable positions of youth and children.

10. Prisoners

1. Prisoners with HIV should enjoy standards of treatment equal to those of other prisoners.
2. Prisoners with AIDS should have access to special care which is equivalent to that enjoyed by other prisoners with serious illness.
3. Prisoners should have the same access to education, information and preventive measures as the general population.

11. Equal Protection of the Law and Access to Public Benefits

1. Persons with HIV or AIDS should have equal access to public benefits and opportunities and HIV testing should not be required as a precondition for eligibility to such advantages.
2. Public measures should be adopted to protect people with HIV or AIDS from discrimination in employment, housing, education, child care and custody and provision of medical, social and welfare services.

12. Duties of Persons With HIV or AIDS

1. Persons with HIV or AIDS have the duty to respect the rights, health and physical integrity of others, and to take appropriate steps to ensure this where necessary.

Source: NAPWA.

Gender, Sexuality, and HIV/AIDS

As noted by Dr Geeta Rao Gupta, of the International Centre for Research on Women (Gupta, 2000), sexuality is distinct from gender yet intimately linked to it. An unequal power balance in gender relations favours men, translating into an unequal power balance in heterosexual interactions, in which male pleasure supersedes female pleasure and men have greater control than women over when, where, and how sex takes place. Dr. Gupta adds, 'Imbalance in power between women and men in gender relations curtails women's sexual autonomy and expands male sexual freedom, thereby increasing women's and men's risk and vulnerability to HIV'.

Women's Vulnerability

- A culture of silence surrounds sex dictating that 'good' women are expected to be ignorant about sex and passive in sexual interactions. Thus women may be uninformed about risk reduction or disempowered with regard to negotiating safer sex.
- Traditional norms of virginity for unmarried girls increase young women's risk of infection by restricting their ability to ask for information about sex out of fear that they will be thought to be sexually active.
- Virginity also puts young girls at risk of rape and sexual coercion in high-prevalence countries because of the erroneous belief that sex with a virgin can cleanse a man of infection and because of the erotic imagery that surrounds the innocence and passivity associated with virginity.
- Accessing treatment services for sexually transmitted diseases can be highly stigmatising for adolescent and adult women.
- The desire for motherhood prevents the uses of barrier methods to reduce the risk of HIV infection because these methods also prevent conception.
- Economic dependency increases women's vulnerability to HIV. Women are more likely to exchange sex for money or favours and less likely to negotiate safe sex or leave an abusive or risky relationship.
- Violence against women contributes both directly and indirectly to women's vulnerability to HIV.

Men's Vulnerability

- Men are expected to be more knowledgeable and experienced about sex. This prevents men from seeking information or admitting their lack of knowledge about sex or protection, and results in their experimenting with sex in unsafe ways, and at a young age, to prove their manhood.
- Believing that variety in sexual partners is essential to men's nature reduces the effectiveness of prevention messages that call for fidelity in partnerships or a reduction in the number of sexual partners.
- Cultural norms that emphasize men's sexual domination over women implicitly accept violence against women and encourage homophobia. The stigma associated with homosexuality results in secrecy and denial of risk of infection.
- The expectation that men are or should be invulnerable contrasts with the expectation that men should protect themselves from potential infection and encourages the denial of risk.

Power Imbalance and HIV/AIDS

The following examples illustrate how sexual power imbalances impact on HIV/AIDS:

- A Tanzanian study found that men decide to seek voluntary counseling and testing (VCT) independent of others, while women feel compelled to discuss testing with their partners before accessing the service, thereby creating a potential barrier to accessing VCT services.
- In many societies women are socially ostracized, marginalised, and even killed as a consequence of exposing their HIV status.
- Men are more likely to abandon an HIV-positive partner. On the other hand, it is expected that women will initially get angry with an HIV-positive partner, but ultimately accept him.

Overcoming Inequality

Sexual inequality can be overcome through interventions such as:

- Recognizing, understanding, and publicly discussing the ways in which the power imbalance in gender and sexuality fuels the HIV/AIDS epidemic.
- Ensuring that imbalances are not allowed to reinforce damaging gender and sexual stereotypes.
- Promoting gender-neutral programmes. This includes using prevention education messages not targeted to one sex, such as 'be faithful' or 'stick to one partner,' and providing care services that make no distinction between the needs of women and men. (These programmes need to recognise that women may need greater social support than men, or that women might prefer to be seen by female counselors, and providers.)
- Promoting gender-sensitive programmes that recognise and respond to the individuals based on their gender and sexuality (e.g., providing women with female condoms or microbicides).
- Transforming gender roles and creating more gender-equitable relationships. Projects such as Men as Partners (MAP, Planned Parenthood Association of South Africa) work with men and women to redefine gender norms and encourage healthy sexuality.
- Working with couples as the unit of intervention, rather than with individual women or men.
- Empowering women by improving their access to information, skills, services and technologies, and by encouraging participation in decision making and creating a group identity.

Theoretical Ideals For Ethical Decision Making

Like other fields of medicine, palliative medicine is informed by theoretical ideals (Gillon, 1994; Ellershawe, 2000) that guide clinical decisions. This section discusses two of these ideals: honouring the patient's dignity and promoting patient well-being. Honouring patient dignity is sometimes identified with the need to respect the patient's autonomy. There are a number of complicating factors when considering the promotion of patient autonomy within the context of medical care in Africa, especially in the field of HIV care.

It is important for health care workers (HCWs) to base their practice on sound ethical principles. The approach to medical ethics developed by Beauchamp and Childress provides a good foundation for medical care. It is based on the four *prima facie* principles of autonomy, beneficence, non-maleficence, and justice. *Prima facie* means the principle is binding unless it conflicts with another moral principle, in which case we must choose between them (Gillon, 1994).

Application of these principles varies in different parts of the world and different cultures. In the USA, for example, autonomy is an overriding consideration, whereas in the UK and South Africa, the principle of distributive justice is more pressing.

Autonomy

Autonomy literally means 'self-rule'. Respect for autonomy promotes the individual's right to make his or her own decisions. This places responsibility on the HCW to ensure that the patient is fully informed. Information sharing is based on good communication and assessment of the patient's understanding, and includes assessment of how much the patient wants to know.

In the African context, patient autonomy may contradict traditional cultural norms in that the needs of the family and community are to be considered ahead of those of the individual; for many people the senior male family member makes decisions for individuals. Medical practice

in Africa also has followed a paternalistic medical model. This means that the move to a partnership between HCW and patient that allows for mutual decision making is a challenge for both people.

Respect for autonomy includes addressing such concepts as informed consent, confidentiality, and truth telling. Autonomy promotes the development of a trusting relationship between HCW and patient. It also means that the patient becomes an active member of the management team, which restores a sense of control in the face of an illness that has deprived him or her of that control.

According to the South Africa Medical Association (SAMA), the South African Constitution awards every person the right to access health care, non-discrimination, privacy and confidentiality and an environment that is not harmful to his or her health or well-being (SAMA, 2002). These rights accrue to patients, HCWs, and the public alike. SAMA's ethical guidelines on HIV point out that respect for human dignity should guide any HCW's actions, as it also underpins good patient care.

Testing for HIV

An HIV test that is done without the person's consent is in itself an interference with a person's right to freedom, security (bodily integrity), and privacy (see Box 22.2). A person can only be tested at his or her own request, although HCWs may advise patients to undergo HIV testing for the purposes of good patient care. HIV testing also may be requested in the case of needle stick injury or rape. If a HCW in South Africa suffers a needle stick injury and the patient is not willing or capable to grant consent, it is possible to test an existing blood sample. Rape suspects also can be tested for HIV without their consent in South Africa. It is vital for HCWs to know the laws in their own country regarding HIV testing.

Box 22.2:

Sources for Pre- and Post-Test Counselling Guidelines

In order for HIV testing to be conducted ethically, with informed consent, proper pre- and post-test counselling must accompany HIV testing. All HCWs should be oriented to the importance of HIV counselling and those who perform HIV testing should be trained in pre- and post-test counselling. Guidelines are available from numerous sources, including:

- Each country's National HIV/AIDS Programme in the Ministry of Health. The MOH can identify any exceptions in which testing may occur legally without a person's consent.
- Wilson D, Naidoo S, Bekker LG, Cotton M, Maaartens G. 2002. *Handbook of HIV Medicine, South Africa: Oxford/Southern Africa.*

Informed Consent

Informed consent means that the patient is given sufficient information to make an informed decision and that he or she actually understands the information and the implications of acting on it. In the multicultural setting, language and cultural barriers may prevent patients from asking questions or expressing their concerns. In this case, an interpreter should be available to assist, and all interpreters should receive appropriate training including respect for confidentiality.

Consent for HIV testing must be voluntary and consent should be written. There may be situations where the patient is not able or capable to give informed consent. In South Africa, a child 14 years or older may independently consent to medical treatment including HIV testing. If the patient is not competent or is not of legal age of consent, his or her legal guardian, spouse, parent, adult child of legal age of consent, or the hospital superintendent must consent on his or her behalf for any required medical procedure.

Post-Test Counselling

The duty to provide post-test counselling falls on the HCW who requested the test. Counselling services and support groups are important resources after post-test counselling. Patients should know that they have rights and responsibilities in relation to their HIV status. They have the right to confidentiality and the responsibility not to infect others. Patient confidentiality enhances trust in the relationship between patients and HCWs and helps assure appropriate health care.

There are health care initiatives that promote voluntary disclosure by people living with HIV. For example, in the roll-out of antiretroviral therapy (ART) in South Africa, patients are required to disclose to one family member and one community member to ensure treatment support prior to starting on antiretrovirals (ARVs). Where ARVs are available, disclosure is to the person's benefit. Where ARVs are not available, the disadvantages of disclosure, such as stigma and discrimination, may still outweigh the benefits for the person living with HIV.

The SAMA guidelines state that a patient's HIV status may only be disclosed if the patient consents to disclosure. It should be explained to patients that not disclosing their HIV status to those responsible for their direct care may compromise their treatment. Health care facilities and HCWs are responsible to ensure that personnel procedures support appropriate conduct that maintains confidentiality.

Informing sex partners is an extremely complicated issue. Part of pre- and post-test counselling is informing patients of the need to disclose their HIV status to their partners. The HCW's first line of action should be to persuade the patient to self-disclose or to consent to disclosure. The patient should be encouraged to be responsible in his or her sexual activity to prevent infection of the sex partner. Pre- and post test counselling and referral to a counselling service should be offered to the partner.

If the patient is unwilling to disclose, the HCW may offer to speak with both partners regarding health promotion in general and to disclose if the discussion warrants it. In South Africa, if the patient is still unwilling, the HCW may disclose the patient's status if the following conditions are met:

- The sex partner should be a known and identified person.
- The sex partner is at risk of being infected.
- The patient is informed beforehand that the HCW intends to breach confidentiality.

If a patient firmly believes that disclosure to a partner will put his or her life at risk, the HCW first duty is to protect the life of the patient and act in his or her best interests. (See Chapter 21: Human Sexuality for a discussion of these issues.)

Beneficence and Non-Maleficence

Beneficence (to benefit the patient) and non-maleficence (to do no harm) are closely related. In medical treatment, any intervention also carries a risk of harm, such as medication side effects or surgical risks. The risks are even more marked when managing a patient with life-threatening illness, where the risks such as side effects of chemotherapy or ART must be weighed against the offer of cure or control of the disease. HCWs are well aware of the concept of risk versus benefit and each decision in caring for patients considers these factors.

HCWs should reflect on patient care decisions with the question in mind, 'Will this treatment benefit the patient?' and only proceed with the treatment if the answer is affirmative. This may require considering risks versus benefits and deciding whether the benefit outweighs the risk. ART offers the ability to change HIV infection from a terminal illness into a chronic manageable disease. There has been much discussion of the toxicity of ARVs as a risk that should not be imposed upon our patients. But with adequate treatment support and monitoring of the patient's condition, there is no doubt that the benefits of

ARVs outweigh the risks. This is true even for patients with low CD4 count who are at risk of experiencing a stormy immune reconstitution reaction.

One factor contributing to beneficence is rigorous and effective professional education (Gillon, 1994). HCWs who keep up to date with current knowledge in their field are able to weigh risks versus benefits of interventions. This is especially important in the fields of HIV and palliative care as both disciplines developed since many current HCWs received their original training.

Justice

Justice is the principle by which competing claims may be decided in fairness. It can further be considered according to distributive justice (fair distribution of resources), rights-based justice (e.g., all people have the right to equal health care), and legal justice (according to the country's laws). Often there are a number of competing claims, such as patients in a private health care setting having access to health care that is not afforded to patients in the public health care setting.

In African countries, restricted health budgets and lack of basic public health services such as safe drinking water and sanitation result in more attention to distributive justice and less to rights-based justice. However, rights-based justice has been the compelling principle underlying the introduction in Botswana and South Africa of prevention of mother-to-child transmission (PMTCT) programmes and the roll-out of ART. It is to be hoped that access to ART will become possible in other African countries as the economics of providing these drugs become more favourable, and as the cost of not providing ART — in the loss of economically active citizens and the cost of providing care to orphans — is recognised as being far higher than the cost of providing ART with good monitoring and treatment support programmes. Over and above the economics of providing or not providing ARVs is the moral cost to our countries.

Futile Treatment

Advances in medical technology have resulted in patients' lives being extended by interventions now available to us. However, the availability of advanced technologies and interventions does not mean that interventions are appropriate to all patients (Ellershawe, 2000). The HCW should inform the patient and family regarding the effects of treatment, its benefits and burdens, and the likely improvement in the person's quality of life, and should then support the patient's decision. If the patient chooses not to have further treatment, the withholding or withdrawal of treatment is a sound medical decision based on ethical principles. There comes a time when comfort treatment is more important than life-sustaining treatment.

'A doctor has neither the duty nor the right to prescribe a lingering death'.

Prof Robert Twycross

The Doctrine of Double Effect

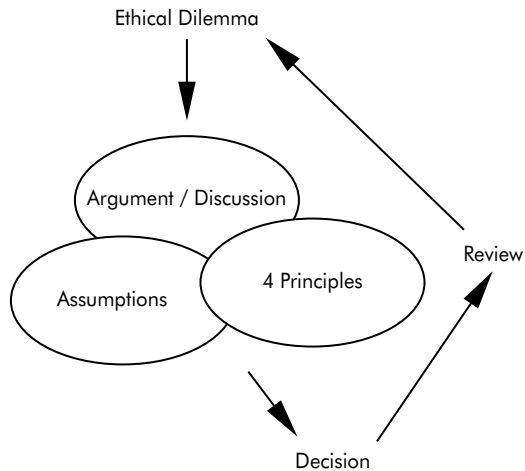
The doctrine of double effect asserts that a bad effect, such as the patient's death, may be permissible, if it is not intended and occurs as a side effect of a beneficial action (Thorns, 1998). It is important that the primary aim is to relieve distressing symptoms and that the death of the patient (should that occur) is unintentional. Whenever doctors try to help a patient, they inevitably risk harming them, but the principle of beneficence should always outweigh maleficence. Fear of double effect should not be a reason for withholding treatment that would bring relief (National Council for Hospice and Specialist Palliative Care Services, 1997). In essence, the intended effect must be a good one, the bad effect may be foreseen but not intended, the bad effect must not be the means of bringing about the good effect, and the good effect must outweigh the bad effect.

The practitioner should be aware of the effective palliative care techniques that can relieve distressing symptoms without shortening life. Considered decision making, including consultation with palliative care practitioners and discussion with patient and family, will assist in forming a management plan that will benefit the patient and protect against risk of abuse of the doctrine of double effect.

Ethical Decision Making

In considering ethical decisions one also has to decide who makes the decision — is it the HCW in charge, the patient, the health care team? Who comprises the team? In practice, we consider the facts and assumptions in palliative care, including cultural issues and ethical principles, debate the issue, come to a working decision, and reassess the decision if appropriate (see Figure 22.1).

Figure 22.1:
The Process of Ethical Decision Making



Advance Directives

Patients may choose to sign an advance directive or living will which may include the following:

‘If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as the testament to my wishes. If there is no reasonable prospect of my recovery from physical illness or impairment, expected to cause me severe stress or to render me incapable of rational existence, I request that I be allowed to die and not to be kept alive by artificial means and that I receive whatever quantity of drugs that may be required to keep me from pain or distress even if the moment of death is hastened’.

SAVES Living Will
(SAVES, 1997)

Whereas this document may not be legally binding, it does give the HCW and palliative care team guidance as to the patient’s wishes. The drawback with the advance directive or living will is that the patient may change his or her mind but be unable to communicate it (Ellershawe, 2000). In South Africa, there is also an anomalous law that does not regard as valid the directives of incompetent persons even though they were expressed while the persons were competent.

Euthanasia

Euthanasia Versus Physician-Assisted Suicide

The word euthanasia comes from the Greek word for 'a good death, a gentle, easy death' (Doyle, 1998). This differs from current definitions of euthanasia, which include the direct, intentional killing of a person at his or her request as part of the medical care being offered (Association for Palliative Medicine of Great Britain and Ireland. May 1993. Submission from the ethics group to the House of Lords). and the deliberate intervention with the express intention of ending life to relieve intractable suffering at the patient's request (Slome, 1997). Physician-assisted suicide differs from euthanasia in that a physician complies with the request for a prescription of a lethal dose of medication from a competent patient and it is then the responsibility of the patient to take the medication.

The possibility of legalising euthanasia has been a topic of debate in many countries and HCWs, especially palliative care practitioners, need to maintain their knowledge surrounding a debate that would undoubtedly affect their clinical practice.

Responding to Requests for Euthanasia

A request for euthanasia is a difficult and challenging aspect of care and the experienced practitioner will realise that there is no easy answer. Certainly the request is a cry for help that demonstrates the person's sense of hopelessness and despair. It should also be recognised as a perceived gap in care.

An appropriate response by the HCW includes an acknowledgement of the patient's anxieties, concerns, and fears; a discussion of unrealistic and realistic fears; and an explanation of what interventions are available. Most importantly, the HCW must recommit to care of the patient and family throughout the illness until the very end.

Currently there is a trend away from the ethic of prolonging life at all costs towards the ethic of emphasising the quality of life and the quality of dying over duration of life. Saving lives will always remain a primary goal of clinical practice, and the passion to prolong life is responsible for the exceptional advances in medicine over the past century (Tobin, 1968). But when it does not take into account the fact that at some point life cannot and should not be prolonged, it creates rather than alleviates suffering. In medicine, we need to accept that dying is a natural part of living.

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