The Association of Nurses in AIDS Care (ANAC) is a nonprofit professional nursing organization committed to fostering the individual and collective professional development of nurses involved in the delivery of health care to persons infected or affected by the human immunodeficiency virus (HIV) and to promoting the health, welfare, and rights of all HIV-infected persons.

The members of ANAC strive to achieve the mission by:

- Creating an effective network among nurses in HIV/AIDS care
- Studying, researching, and exchanging information, experiences, and ideas leading to improved care for persons with HIV/AIDS infection
- Providing leadership to the nursing community in matters related to HIV/AIDS infection
- Advocating for HIV-infected persons
- Promoting social awareness concerning issues related to HIV/AIDS

Inherent in these goals is an abiding commitment to the prevention of further HIV infection.
Since its founding, ANAC has shown a singular commitment to improving the lives of those affected by HIV/AIDS. Nowhere is this commitment more fully articulated than in ANAC’s Core Curriculum for HIV/AIDS Nursing. Drawing from the expertise of frontline clinicians and scholars, the first two editions of the Core Curriculum provided nurses with the evidence-based knowledge to provide quality care to the diverse groups that comprise the HIV/AIDS population. In this third edition, we have endeavored to uphold the standard of excellence set by the editors of the first two editions. The clinical management of HIV/AIDS is constantly evolving, thus the third edition of the Core Curriculum has evolved to keep pace. Toward that end, the reader will notice that some topics contained in the first two editions are gone, replaced by new topics that the editors believe represent the current salient clinical issues in HIV/AIDS nursing. Additionally, we have added case studies with test questions to assist nurses to apply the Core Curriculum’s content to the management of patients in a variety of settings.

For the past 13 years, ANAC’s Core Curriculum for HIV/AIDS Nursing has been an indispensable resource for nurses who care for persons with HIV/AIDS. The editors and I believe that the third edition continues this tradition of excellence. I welcome your comments.

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(4) Eligibility requirements for entitlement programs
(5) Other needs, such as visual screening, stress management, and self-care and wellness strategies

5. Limitations of case management
   a. Access and quality of care issues
      i) Barriers to care may include difficulty in finding an educated provider; issues related to funding sources (e.g., third-party source/insurance, Medicare/Medicaid, managed care or public funding) or the healthcare delivery system; and social stigmatization.

6. Development of standards and protocols for case managers
   a. Education level and experience are key to quality of care for patients.
   b. Case managers should identify both strengths and weaknesses of the systems within their service area.
   c. Development and ongoing evaluation of all external referral sources across a wide network of services and providers should be conducted.

REFERENCES


11.2 ETHICAL AND LEGAL CONCERNS

1. Since the early days of the HIV/AIDS epidemic, ethical and legal issues have raised questions and concerns in relation to HIV/AIDS care; these issues have been due, in part, to the characteristics of HIV disease, the nature of the epidemic, and the nature of the populations infected with and affected by HIV.
2. Four principles are commonly used by healthcare professionals in dealing with ethical and legal issues in HIV care (Beauchamp & Childress, 2009):
a. Nonmaleficence: avoiding harm or injury to others
b. Beneficence: promoting the good or welfare of others
c. Respect for autonomy: respecting the liberty, privacy, and self-determination of others
d. Justice: treating others fairly

3. Other relevant principles include fidelity (keeping promises, contracts) and veracity (telling the truth).

4. Nurses caring for HIV-positive people and others affected by HIV must be aware of these ethical principles when evaluating their actions and the actions of others. Decision making is also guided by state and federal laws; thus, ethical and legal issues are closely related and often interrelated.

5. Other common approaches to ethical decision making in health care have been described (Lo, 2005) and include the following:
   a. Consequentialist approach: Actions are judged by the rightness or wrongness of their consequences (also described as utilitarian approach).
   b. Deontological approach: Actions in and of themselves may be wrong, regardless of the outcome (e.g., lying, breaching confidentiality).
   c. Case-based approach (casuistry): This involves comparing a current case to exemplar or paradigmatic ethical cases.
   d. Care-based ethics: Originally described by feminist ethicists and espoused by nurses, this ethical approach seeks to look beyond abstract, ethical principles and takes into account relationships and attempts to avoid interpersonal conflict.

6. Specific ethical issues in HIV care
   a. Individual choice: autonomy and self-determination
      i) Individual choice is based on the ethical principle of respect for autonomy; autonomy deals with one’s right to self-determination (Beauchamp & Childress, 2001; Lo, 2005).
      ii) Autonomy incorporates the concepts of confidentiality, informed consent, the right to accept and to refuse medical treatment, privacy, and disclosure.
      iii) Autonomous individuals are free to choose and to self-govern.
      iv) Within the context of health care, informed consent assists a person to voluntarily choose a course of action.
      v) Other elements of informed consent require that the person understands the information, mutually participates in the decision making and does not merely sign the form, and accepts the plan for care freely and without coercion.
      vi) Autonomy requires a person to be competent to have decision-making capacity.
      vii) Healthcare providers are obligated to protect persons with diminished capacity, as well as those who have never had the capacity for decision making.
   b. Inequitable access to care
      i) Disparity has been noted in the United States in relation to access to health care, research participation, and experimental therapies.
      ii) Many HIV-infected patients rely on Medicaid; others have no healthcare insurance, which has a major impact on their ability to get necessary care and therapies.
      iii) Managed care may also complicate the ability of patients who need complex or expensive treatment to get adequate care.
iv) All states participate in AIDS Drug Assistance Programs (ADAPs), which provide healthcare services, including medications, to patients; nurses are in an excellent position to advocate for access to these entitlements (see http://www.atdn.org/access/states/index.html for individual state resources).

v) Nurses should also advocate for their patients’ access to clinical trials (see http://www.aidsinfo.nih.gov/ClinicalTrials and http://www.cpcra.org).

vi) People of color and women in the United States have been documented as not having equal access to HIV therapy and clinical drug trials (Cargill, 2006; Cargill, Stone, & Robinson, 2004; Krawczyk, Funkhouse, Kilby, & Vermund, 2006).

vii) Ninety-five percent of people with HIV/AIDS live in developing countries; HIV/AIDS is the leading cause of death in sub-Saharan Africa and the fourth cause of death worldwide; only 23% of people in the world who need HIV antiretroviral treatment currently receive it (UNAIDS, 2006).

viii) HIV has placed an additional financial burden on economically deficient healthcare systems in underdeveloped countries. It has taken 25 years to mount a significant global response to the HIV epidemic (UNAIDS, 2006).

ix) Antiretroviral therapy is extremely expensive, and global issues remain significant regarding cost and access to HIV therapy.

c. Privacy, confidentiality, and disclosure

i) Protecting the privacy of patients and safeguarding information that should remain confidential is central to maintaining autonomy and nonmaleficence.

ii) The following questions are designed to help healthcare providers consider the best ways to strike an appropriate balance among beneficence, nonmaleficence, justice, and autonomy (Green, Derlega, Yep, & Petronio, 2003):

1. What approaches to teaching risk reduction or avoidance behavior respect the patient’s autonomy and privacy?

2. Does anyone besides the person being tested have a right or need to know the results?

3. How does one reconcile the duty to warn with the duty to maintain privacy and confidentiality?

4. Should results be disclosed only with the consent of the person being tested?

5. What criteria are used for overriding confidentiality? (Not all ethical models will support all criteria.)

6. What safeguards protect the confidentiality of patient information?

7. How does a healthcare worker maintain privacy within the context of third-party notification policies? Mandatory testing? Mandatory names reporting laws? Partner notification requirements?

8. What ethical models/principles can be used to establish that partners have a right to information about a person’s HIV status if the infected person doesn’t want them to know?

9. What ethical models/principles would make it difficult to establish such rights?

10. How is partner notification accomplished?

11. How does duty to warn compare with privilege to warn? (Consequences of warning others may include violence.)
(12) How does disclosure violate the principle of justice in these situations?
(13) How can the healthcare worker assist patients in making disclosure decisions?

d. Discrimination and worker protection
i) The incidence of HIV/AIDS is disproportional among minority and disenfranchised groups.
ii) HIV/AIDS still carries a stigma not attached to many other serious diseases.
iii) To protect against or minimize discrimination, nurses must be aware of persons and groups that remain most vulnerable to obvious forms of discrimination.
iv) Nurses must consider the following about groups of HIV-infected patients:
   (1) Which groups are most likely to suffer a significant loss of autonomy in the healthcare system?
   (2) Which remain the most vulnerable to discrimination and thus the injustices involving privacy and confidentiality?
   (3) Which are most likely to face significant discrimination in the workplace?

e. Estate, will, and advance care planning
i) Planning for the future entails attending to one’s future healthcare needs, to a time when autonomous decision making is no longer possible, as well as to the care of one’s dependent minor children, and disposition of one’s tangible assets.
ii) Estate and will planning are appropriately carried out with the assistance of an attorney. Planning should happen early in the illness trajectory and be delayed until the patient is near to death.
iii) Future care of dependent children needs advance consideration, standby guardianship and custody arrangements for minors require legal proceedings, and some patients may need volunteer legal services if unable to afford legal costs. Again, planning should ideally begin early because hospitalization may occur urgently, with no time for making these legal arrangements.
v) Advance directives may include assigning a surrogate decision maker for healthcare decisions, called a healthcare proxy or durable power of attorney for health care, as well as providing directions for types of care desired (treatment directives), called a living will or do not resuscitate (DNR) order (Fins, 2006; Ulrich, 1999).
vi) Some states require that a person provide specific advance instructions (also referred to as “clear and convincing evidence”) about withholding or withdrawing artificial food and hydration; a proxy decision maker in these states may not make decisions about these medical treatments.
vii) Living wills are not recognized in all states but may suffice to provide the “clear and convincing evidence” needed in a court proceeding.
.ix) A DNR order is another form of treatment directive, one that authorizes withholding cardiopulmonary resuscitation (CPR) in the event of cardiopulmonary arrest.
.x) In many terminally ill AIDS patients, a DNR order is completely appropriate, and a focus on comfort care and palliation of symptoms is often desired by patients and families at the end of life.
x) HIV patients may be wary of signing advance directives because of a mistrust of the medical system (Jones, Messmer, Charron, & Parns, 2002).

xi) Other researchers have described situations in which patients may specifically not want someone to act as their surrogate decision maker. These antiproxies were often legal next of kin (Martin, Thiel, & Singer, 1999).

f. Ethical issues and the public health

i) The goal of prevention and public health campaigns includes HIV-positive and HIV-negative persons and focuses on keeping the whole community healthy. When considering public health interventions, one must ask the following:

(1) What approaches to teaching risk reduction or avoidance behavior respects autonomy and privacy?

(2) What ethical reasoning is used to support the provision of clean needles to drug users or condoms to teenagers?

(3) What ethical reasoning is used to oppose such programs?

(4) What are the issues that face risk reduction programs for children?

(5) What risk reduction approaches are supported by research?

ii) Nurses and other healthcare professionals may encounter HIV-infected individuals who continue with unsafe behaviors:

(1) How should healthcare professionals respond to those who practice unsafe behaviors that put others in jeopardy?

(2) How can respecting autonomy and culture be used to justify a minimalist approach to intervention?

(3) How can the utilitarian framework (“the rightness of an action based on consequences”) be used to justify a more interventionist approach?

(4) Is there a role for compulsory testing for those who engage in unsafe behaviors? When might compulsory testing be protective of public health? What are the negative implications of this? In what instances is it more political than scientific?

iii) Testing of childbearing women and newborn infants

iv) Reasoned ethical positions can produce contradictory answers to questions.

v) What information and which ethical model/principles support your positions on the following questions? What information and which ethical model/principles would support contrary positions?

(1) What advice should an HIV-infected woman receive about pregnancy?

(2) With data that demonstrate the effectiveness of prenatal AZT in reducing the rate of transmission of HIV from mother to fetus, should all pregnant women be HIV-antibody tested?

(3) Should HIV testing be mandatory or voluntary?

(4) If the HIV antibody test is positive, is there an obligation to provide the patient with access to AZT?

(5) Is there an obligation for a mother to take AZT?

g. Ethical issues related to clinical trials

i) Disparity has been noted in access to research participation and experimental therapies.
ii) People with HIV infection are often willing to take the risks of unproven therapies, including participation in underground buyers' clubs, expanded access programs, and clinical trials.

iii) The exclusion of certain groups from research has been seen as discrimination rather than protection; access to clinical trials is generally seen as a benefit.

iv) AIDS activists have challenged attitudes and some regulations regarding research participation and access to experimental therapies as too restrictive and discriminatory.

v) Nurses are in an excellent position to advocate for access to care and to clinical trials for their patients.

vi) In addition, trial design, rigid exclusion criteria, the use of placebos, double blinding, and clinical endpoints have been challenged by AIDS activists, researchers, alternative practitioners, and some pharmaceutical companies.

vii) Scientific conflicts of interest, scientific integrity, competition in HIV research, and the role of economics in research have become important areas of concern.

viii) The demand for quicker results, more effective clinical trials, and scientific integrity have led to stricter oversight by safety monitoring boards.

ix) Community representatives have become more involved in decisions about research through community advisory boards.

x) The right for people with terminal diagnoses to access investigational drugs has not been sustained by the courts (Abigail Alliance, 2008; Moller, 2006).

h. Obligation to provide care

i) According to the American Nurses Association's (ANA's) first provision of the Code of Ethics for Nurses, "The nurse, in all professional relationships, practices with compassion and respect for the inherent dignity, worth and uniqueness of every individual, unrestricted by consideration of social or economic status, personal attributes, or the nature of health problems" (2001, p. 7).

ii) An ethic of care emphasizes caring for others and their significant relationships and recognizing the special obligations toward and a willingness to act on behalf of people with whom one has a relationship (Gordon, Benner, & Noddings, 1996).

i. Protecting healthcare workers

i) If standards of practice include universal precautions, are healthcare workers protected by knowledge of a patient's HIV status?

ii) What changes in purchasing practices would better protect healthcare workers from occupational exposure to infections?

iii) What infectious agents are most responsible for occupational morbidity and mortality among healthcare workers?

j. Euthanasia, assisted suicide, and suicide

i) Euthanasia refers to the deliberate administration of medication to end a life (Quill, 2001).

ii) Suicide refers to the deliberate taking of one's own life.

iii) Euthanasia (except in the situation of capital punishment) and suicide are illegal acts in the United States, except assisted suicide in Oregon.

iv) Assisted suicide concerns providing patients with the means to end their life should they choose to do so (King & Jordan-Welch, 2003).
Assisted suicide has been a passionately debated topic in recent years and is currently legal in the United States only in Oregon and Washington State; the right to die is not guaranteed by the U.S. Constitution (Vacco v. Quill, 1997) but may be authorized by individual states.

The ANA condones neither active euthanasia (1994a) nor assisted suicide (1994b).

ANAC’s “Scope and Standards of Practice” definitively endorses palliative care “throughout the course of the [HIV] disease state” (2007b, p. 22) but does not have an explicit position on assisted suicide.

Voluntarily ceasing intake of hydration and nutrition has been described as an alternative to assisted suicide (Harvath et al., 2004; Schwarz, 2004).

Both ANA and ANAC wholeheartedly encourage pursuit of palliative care practices, which include aggressive attention to pain management, psychosocial, and spiritual care (ANAC, 2006, 2007a, 2007b; see also Ferrell & Coyle, 2001).

Expert, compassionate care at the end of life is now recognized as a critical component of the wellness–illness continuum (Lynn, Schuster, & Kacelnik, 2000).

Although palliative care is increasingly recognized as a standard of care throughout the trajectory of the illness for patients with many chronic diseases, people with HIV/AIDS are still significantly undertreated with regard to pain and symptom management (ANAC, 2007b; Harding et al., 2005).

ANAC’s position statement on palliative care endorses the following tenets (2006, para. 1):

1. Palliative care should be part of the comprehensive care of all patients with HIV/AIDS.

2. Palliative care should be integrated into the standard of care for patients with HIV/AIDS and their families from the first diagnosis of HIV until death.

3. Every provider should be able to provide or refer patients for palliative care, while simultaneously providing therapeutic treatment.

4. Palliative care should be integrated into education about HIV/AIDS for all providers.

5. Insurance plans, including Medicaid and Medicare, should eliminate any barriers to obtaining palliative care.

6. Research in this area is lacking and should be supported and encouraged.

REFERENCES


11.3 Preventing Transmission of HIV in Patient Care Settings

1. Infection control
   a. Infection control is necessary to help ensure a safe environment for patients and healthcare workers (HCWs).