

Document #3

ASSUMPTIONS AND PRINCIPLES CONCERNING CARE FOR PERSONS AFFECTED BY HUMAN IMMUNODEFICIENCY VIRUS DISEASE

Preamble

In its initial statement of Goals and Purposes, the International Work Group on Death, Dying, and Bereavement (IWG) declared itself to be an organization of international scope, committed to studying issues concerned with death, dying, and bereavement, transcending local need and national boundaries, and producing materials of social value. The statement charged its members with the responsibility of assuming relevant tasks, and challenged the organization to remain in the forefront of the field, making optimal use of its members talents. In keeping with these goals, the IWG has developed this position paper concerning the pandemic of Human Immunodeficiency Virus Disease.

Introduction

Infection with the Human Immunodeficiency Virus (HIV) constitutes a world-wide threat. The virus initiates a chronic disease, the end stage of which is termed Acquired Immunodeficiency Syndrome (AIDS). While a terminal illness may occur at any point in the disease, depletion of the immune system increases its likelihood after the onset of AIDS. The World Health Organization predicts that by the turn of the century 40 million persons will be infected. Even if a vaccine were to be made available, the problem of HIV infection would not be resolved. Given the number of persons who are currently infected -- estimated to be between 5 and 10 million -- health care systems will be challenged to the utmost.

The HIV pandemic has profound implications for both the individual and society. In the future if one is not infected by the virus, one will assuredly be affected by its consequences.

The International Work Group on Death, Dying, and Bereavement takes the following position with regard to the treatment and prevention of human immunodeficiency virus disease.

Basic Premises

1. The public health response to HIV disease has been affected by the political and social response to individuals infected with the virus.
2. Public health officials have attempted to balance the safeguarding of individual liberties with the protection of the health of the public.
3. Given the free flow of individuals within and between societies, and the variations of immune response to the virus, quarantine of individuals infected with HIV is both an ineffective and inappropriate response to the epidemic.
4. HIV-1 antibody testing should be voluntary and based on informed consent.
5. Anonymous testing must be a readily available option.
6. Pre- and post-test counselling is essential for an effective testing program.
7. The individual has the right to privacy and to confidentiality with respect to his or her medical condition.
8. Individuals who are seropositive have an obligation to inform the person or persons with whom blood or body fluids are likely to be exchanged.
9. Individuals have a right to know the seropositive status of persons with whom blood or bodily fluids are likely to be exchanged.
10. Individuals have a responsibility to protect themselves from HIV infection.

11. Contact tracing of partners potentially at risk for HIV infection should be implemented where feasible, particularly in low prevalence areas.
12. Individuals infected with HIV should have access to appropriate health care and should not be denied such care on the basis of race, creed, gender, sexual orientation, or economic status.
13. Treatment provided to HIV-infected individuals should be non-judgmental and non-discriminatory.
14. It is the responsibility of all those providing information to the public about the HIV pandemic to be certain that it is accurate, timely, and complete.
15. Educational presentations through the media aimed at preventing the spread of HIV infection should avoid stereotypic wording that fails to distinguish between 'high risk behaviors' and so-called 'high risk groups'.
16. Educational materials designed to inform citizens about risks of HIV infection should be sensitive to linguistic, cultural, religious, and educational variations in the populations being served.
17. Educational materials for health care workers pertaining to HIV disease should address the caregivers' attitudes, fears, values, beliefs, and knowledge about the disease.
18. Appropriate HIV education for health care workers should address the psychosocial and spiritual needs of the HIV-infected person and his or her family in addition to the treatment of the infection and its manifestations.
19. Health care workers have a responsibility to provide services and compassionate care to individuals infected with HIV, in keeping with the ethical codes that govern their professions.

20. Health care workers must use universal precautions and effective decontamination procedures in fulfilling their professional responsibilities.
21. Health care workers, using universal precautions, and effective decontamination procedures in fulfilling their professional responsibilities, have not been known to transmit HIV to their patients.
22. HIV-infected health care workers are expected to observe professional standards and safeguards in order to protect their patients from the risk HIV infection.
23. Hospice and palliative care programs have a responsibility to provide care to individuals who are terminally ill with AIDS.
24. Governments should take appropriate measures to assure the personal safety and civil rights of the HIV-infected person.
25. Governments at all levels should take a leadership role in addressing the HIV pandemic in non-judgmental and non-discriminatory terms, in committing the resources necessary to caring for those affected, and in developing education, prevention, and treatment programs.
26. Developed countries have a moral as well as a medical obligation to share their knowledge, expertise, and resources concerning HIV infection with developing countries.

Assumptions and Principles

Definitions

Assumption: a statement accepted as fact on the basis of commonly observed experience.

Principle: a collective judgment as to the proper response to the assumption.

PATIENT

Assumptions

Principles

24. Respect for the patient, regardless of the source of infection, is essential for good care.
 25. Care is most effective when the patient's life philosophy is respected.
 26. The care of those ill with HIV disease is a process that involves the needs of the patient, and his or her family, as well as those of the caregivers.
 27. It is important to avoid paternalistic interactions with patients. Individual rights to self-determination must be respected.
- Stigmas and taboos associated with HIV infection should be recognized and challenged both in and by the family, community, and society.
- The HIV-infected person's own framework of values, preferences, and life outlook must be taken into account in planning and providing care that is appropriate for and respectful of that individual.
- The interactions of those involved in the care of a patient must be assessed continually to achieve the best possible care of the patient. Optimal care cannot be accomplished, however, if the needs of the family, caregiver, or both, are neglected or negated.
- Patients' wishes for information about their condition should be respected. They should be given as much information about their condition as is desired, encouraged to participate fully in their health care, and supported in maintaining their self-determination.

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| 28. Dying patients often have personal and family issues to resolve. | Patients should have support and the opportunity to resolve personal and family conflicts. |
| 29. Patients with HIV disease often experience weakness, helplessness, loneliness, and isolation | The patient should be provided with a sense of protection and security by encouraging the continuing involvement of family and friends. Emotional, social, and spiritual, as well as physical needs must be addressed. |
| 30. The patient's needs will change over time. | Caregivers must be alert to changes in the patient, to the need for the inclusion of additional services, and for the provision of continuity of care. |
| 31. There are HIV-infected persons for whom newly available or experimental drugs or treatments may be appropriate. | New or experimental drugs or therapies that may provide symptomatic relief and enhance the quality of life of HIV-infected individuals should be incorporated into palliative care, in accordance with the ethical principles of justice, beneficence, and respect for persons. |
| 32. There are patients for whom aggressive, curative treatment becomes increasingly inappropriate. | Experimental and/or aggressive therapies should be discontinued when it results in a decrease of the quality of life, or at the patient's request. |

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| 33. Many of the physical and psychological symptoms secondary to HIV infection can be relieved. | The patient should be kept as symptom free, comfortable, and alert as possible. Discomfort in all aspects should be controlled to the extent possible. |
| 34. The varied problems and anxieties associated with a progressive illness can occur at any time of the day or night. | Twenty-four hour care must be available, seven days a week, for the patient and family, where and when it is needed. |

FAMILY

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| 35. In terminal illness the patient and family must be the unit of care. | Help should be available to all involved whether family of origin or family of choice, or friend, so as to sustain communication and involvement. |
| | Potential conflict between family of origin and family of choice needs to be acknowledged and addressed. |
| 36. The course of a terminal illness involves a series of clinical and personal decisions. | Communication among patient, family, and clinical team is essential to informed decision-making. |
| 37. Many people do not know how to manage infectious diseases in the home. | In order to provide care at home, families should receive education for infection control. |

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| <p>38. Many people do not know what the dying process involves.</p> <p>39. The patient and family need opportunities to be together privately.</p> <p>40. Complexity of procedures and time-consuming treatment can interfere with the life of the patient and family.</p> <p>41. Patients and families facing death frequently experience a search for the meaning of their lives, making the provision of spiritual support essential.</p> <p>42. Family members can be at risk physically and emotionally during the course of illness and during bereavement.</p> | <p>Family members should be given time and opportunity to discuss all aspects of dying, including their emotional needs, with the staff.</p> <p>The patient and family should have time alone, while the patient is living and after death occurs. A special area may need to be provided.</p> <p>Procedures must be arranged in order to provide adequate time for patient, family, and friends to be together.</p> <p>Emotional, religious, spiritual, and philosophical elements are integral to a comprehensive program of care.</p> <p>Appropriate care and support of family members must be made available.</p> |
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| <p>43. The problems of the patient-family facing HIV disease and terminal illness encompass a wide variety of issues: physical, psychological, social, spiritual, economic, and legal.</p> <p>44. Health care services customarily lack interdisciplinary and interorganizational coordination.</p> <p>45. A supportive physical environment contributes to the sense of well being of patients, of families, and of caregivers.</p> <p>46. Support for those providing care is essential in the long-term care of persons with HIV disease and their families.</p> <p>47. Home care is often desirable from a personal, social, and economic perspective.</p> | <p>Care requires the collaboration of individuals from many disciplines working as an integrated clinical team, meeting for frequent discussions with a commonness of purpose.</p> <p>The organizational structure must provide links with health care professionals and organizations in the community.</p> <p>The environment should provide adequate space and furnishings, and the reassuring presence of personal belongings, all of which contribute to putting people at ease.</p> <p>Formal and informal mechanisms for staff support need to be developed.</p> <p>Expertise in the home care of persons with HIV disease should be promulgated so as to meet the needs of patients and families.</p> |

48. Persons living with HIV disease and their families have developed much hard-won knowledge as a result of their illness experience. It is vital to acknowledge the contribution that persons with HIV disease and their families can make as educators to health professionals and to society.

49. Serial and/or multiple losses of family members or friends may generate different and more problematic reactions than those of a single loss. The consequences of serial and/or multiple losses must be more fully studied. In the meantime special attention must be provided to those who have experienced such losses.

CAREGIVERS

Assumptions

50. Health care workers may have attitudes, beliefs, and prejudices concerning people with HIV disease which impair their ability to provide care.

51. A body of knowledge in symptom control, patient, and family-centred care, and other aspects of the care of persons living with HIV disease is available.

52. Effective care of persons living with HIV disease presupposes emotional investment on the part of the caregivers.

Principles

All health care workers attending people with HIV disease must explore their knowledge, attitudes, and responses to the spectrum of HIV-related issues. Individual caregivers' biases must not be allowed to compromise care.

Institutions and organizations providing care to those with HIV disease must orient and educate new caregivers and keep everyone informed about developments as they occur.

Caregivers require time and encouragement to develop and maintain relationships with patients and their significant others.

53. Care of persons living with HIV disease can produce emotional exhaustion.

54. Caregivers may sustain punctures of their skin by contaminated needles and sharp instruments as well as other exposures which result in occupationally acquired HIV disease.

55. Some health care workers may be unprepared or uncomfortable discussing spiritual matters.

56. The clergy are usually seen as having primary responsibility for the spiritual care of the dying.

Effective support systems must be readily available.

Organizations and governments have a responsibility to compensate staff members for occupationally acquired HIV disease.

Caregivers should be offered opportunities to explore their values and attitudes about life and death.

Caregivers need to recognize their limitations and make appropriate referrals for pastoral care and counseling when the demands for spiritual care exceed their abilities or resources.

Caregivers should be aware that they each have the potential for addressing many of the spiritual needs of their patients and should be encouraged to offer spiritual care, as requested and within the limit of their capabilities, to dying patients and their families.

57. Ongoing involvement with dying, and bereaved persons may cause a severe drain of energy and uncover old and new spiritual issues for the caregiver.

Ongoing spiritual education, growth, and renewal should be a part of a staff support program, as well as a personal priority for each caregiver.

Developed by the Care for Persons affected by HIV Disease Work Group of the International Work Group on Death, Dying, and Bereavement.

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