

Fact Sheet 6 HIV/AIDS: fear, stigma and isolation

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• Introduction:

HIV/AIDS is a condition that continues to generate fear, misunderstanding, misinformation, and discrimination, and there are few nurses and caregivers in the world who have not been affected in some way by the disease. In addition, nurses and caregivers are also living with HIV. As one nurse commented, "We continue to hear stories of people with AIDS being shunned and isolated, forced out of their jobs or homes, refused medical and nursing treatment, stripped of their human and civic rights. And all for a disease that doesn't even spread through casual contact. That people already suffering should be subjected to such indignity is intolerable and even more so when it occurs in health care institutions by health care professionals who should know better." (Report of the ICN Conference on HIV/AIDS, 1994 p.17).



A nurse takes blood from a monk in the blood bank at Rangoon General Hospital. Blood samples are tested for HIV and discarded if contaminated. (Credit: WHO)

• Emotional, cultural, sexual, religious, and legal issues facing nurses and caregivers

Emotional issues

Fear of contacting HIV and becoming sick and dying from the disease.

Nurses and midwives witness not only their patients, but also their friends and loved ones dying from AIDS.

Nurses and midwives witness the fear, stigma, isolation, marginalization and discrimination that many people living with HIV (PLHA) experience. Witnessing such attitudes leads some nurses/midwives to treat PLHAs in similar ways.

Nurses/midwives are also infected with HIV. They often withhold this information from their colleagues for fear of discrimination, isolation and neglect.

Many nurses and caregivers find it difficult to talk about sexuality, death, drug use, prejudices, morals and religious beliefs.

Where rates of HIV/AIDS infection are high, there are significant numbers of nurses and caregivers who are themselves infected. As they care for PLHA, they witness firsthand how they too will become sick and die.

• Cultural, sexual, religious, and legal issues

Cultural, sexual, religious, and legal influences often make discussion about sexual practices, preferences, sexual desires, the number and type of sexual partners, and the use of birth control difficult. In addition, there is often a "cloak of silence" related to sexual practices and to illicit drug use. Such subjects are often taboo and associated with embarrassment, shame, guilt and rejection. Nurses and other caregivers may also experience these same feelings of embarrassment, shame, and guilt as they practice certain risk behaviours in their own personal lives. The additional fear of HIV/AIDS as a fatal illness compounds the problem of discussing these difficult subjects. In some societies, the use of condoms as a method of birth control (as well as control of HIV transmission) is not sanctioned by the religious leaders. Finally, the cultural norms of silence regarding sexual practices, preferences and desires can be problematic. These sexual practices might include men having sex with men, sexual abuse, child abuse, and heterosexual intercourse.

In conclusion, experiences of fear, stigma, isolation, discrimination and marginalization related to HIV/AIDS come from:

misinformation about HIV transmission (Fact Sheet 1)

fear of contracting HIV

fear of caring for PLHA when the nurse/midwife fears that she/he too may have the illness

religious teachings and influences related to sexuality and birth control

the cultural norms of silence regarding sexual practices, preferences and desires

legal issues related to the misuse of legal and illegal substances, particularly intravenous drug use

•Compromised care

Negative attitudes, beliefs and values, or misinformation about HIV, significantly limit a caregiver's ability to provide effective, respectful and dignified care for PLHA and their families. Some documented negative behaviours of health care workers include:

condemning the PLHA (referring to or considering the PLHA as a "bad person" or "careless person")

isolating or avoiding the PLHA because of embarrassment or not knowing how to handle the situation

refusing to treat or care for the PLHA or his/her family

reluctance to disclose one's own HIV-positive status to other health care workers for fear of discrimination, isolation, and condemnation

the inability to discuss sexual practices, preferences and desires because of embarrassment, shame or guilt etc.

ignoring or avoiding discussion and counselling about risky behaviours and HIV prevention and care.

inability or unwillingness to approach the PLHA and family in a nonjudgmental, caring and supportive manner.

Nurses' and midwives' moral and ethical responsibilities

In 1996, the International Council of Nurses (ICN) produced a document on Reducing the Impact of HIV/AIDS on Nursing and Midwifery Personnel. As part of this document, ICN stressed that nurses and midwives have a moral and ethical responsibility to care for all people, including those with HIV/AIDS. The ICN Code for Nurses affirms that "the nurse's primary responsibility is to those people who require nursing care."

The ethical issues in HIV/AIDS prevention and care include,

the ethical duty of nursing/midwifery personnel to provide care, and

the responsibility of HIV-positive nursing/midwifery personnel to protect their patients.

In situations where HIV/AIDS and human sexuality cannot be discussed openly, nurses and midwives often feel embarrassed and uncomfortable about discussing sexual issues or may totally ignore topics during health education sessions. This behaviour perpetuates the conspiracy of silence.

Because of the serious consequences of HIV/AIDS, nurses and caregivers should be prepared to break with tradition and to accept and provide counselling and education about these topics. Nurses and midwives must be perceived as competent professionals, capable of discussing issues openly and confidently, and of acting fairly and compassionately. If nurses could become the role models for such open and compassionate behaviour, others would soon follow their example.

An important first step in attending to the care needs of PLHA would be to advocate for compassionate, dignified and competent care for our own HIV-infected colleagues.

• Strategies to improve care

Looking inward

First, nurses and caregivers must examine their own beliefs, values, assumptions and attitudes toward HIV/AIDS. Recent documentation suggests that health care workers are some of the worst offenders in discriminating against, and refusing to care for, PLHA. Such behaviours are unacceptable. However, change will only come about through examining long-standing negative thoughts, feelings and behaviours. This can be done individually or with peer group support. The questions posed at the end of this Fact Sheet provide a starting point for this personal and group exploration.

Education

The irrational and often exaggerated fears associated with HIV/AIDS (even by nurses and midwives) can be directly addressed through educational programmes based on sound medical, social and psychological knowledge. To be successful, such programmes must be sustained and supported over a period of time (see Fact Sheet 9). Knowledge about HIV/AIDS is constantly expanding, and nurses and caregivers must be continually updated through continuing education programmes and Fact Sheets such as these. They can then take on the important role of educating others. That is, they can advocate, not only for Universal Precautions (Fact Sheet 11), but also for universal tolerance and knowledge about AIDS.

Prevention

Prevention strategies will continue to be compromised if fear, ignorance, intolerance and discrimination against HIV infected persons persist. Nurses and midwives have a responsibility to help normalise HIV so that the modes of transmission and prevention can be addressed without the emotional and attitudinal overlay that limits open dialogue about AIDS.

Care

Effective and dignified care can only be given where respect and compassion for others is the norm. Looking inward to examine and challenge long-held beliefs, values, assumptions and attitudes will go a long way to providing compassionate and respectful care. Such care can then be demonstrated to others. When health care is provided with both knowledge and compassion, it makes the difference between misery and isolation, and the provision of comfort, in a setting of dignity and respect.

Questions for reflection and discussion

What fears or misunderstandings do you have?

How might these fears or misunderstandings affect your practice?

Where do you think these fears/misunderstandings come from?

How might you overcome these fears/misunderstandings in order to provide care, support, counselling, education, and advice in the prevention and care of HIV?

How might you be influence others in their care of PLHAs and their families?

How do you see your role in providing and promoting safe, moral and ethical care to PLHAs and their care givers/families/communities?

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