UNIT 8 MORAL AND ETHICAL ISSUES ON HIV

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8.1 INTRODUCTION

In two and a half decades HIV/AIDS has evolved from a medical curiosity to a worldwide human tragedy and an international emergency. It has proved to be a developmental disaster and has created a security crisis with social impacts more devastating than any war. Its impact is wide-reaching, and even in those parts of the world where the epidemic has been relatively slow to evolve, there are worrying signs of its gathering strength. It has spread beyond the so-called high-risk groups, to vulnerable populations such as the poor, the marginalized, young women and children. It both thrives on and fuels inequalities.

HIV/AIDS is a disease that is closely linked with human behaviour and any discussion on the matter needs to be firmly grounded in respect for human dignity. The danger is we could look at solutions to the pandemic that only address public health concerns without considering the individual person or that we could place maximum emphasis on individual freedom without concern for the social implications of our actions.

Ethics concerns the morals of human conduct. It applies categories such as 'right' or 'wrong' to human actions. In this section we will first attempt to highlight some of the major issues that apply to HIV/AIDS and then look at how one can proceed ethically to act under the constraints of the situation.

In the face of the pandemic we can examine two major groups of people. In the first case we view the vast majority of people who are not yet affected by HIV. We need to study ways in which they can be prevented from infection. The second category of people we look at are those who are already infected. Our task will be to see how we can treat them in a humane manner with compassion and care.

8.2 OBJECTIVES

In this unit we will examine some of the ethical and moral issues that flow from the HIV pandemic in the world. Bearing in mind that HIV affects human persons, any attempt to prevent its spread or to treat those affected must be rooted in deep and profound respect for the individual and society. We will look at ethical issues related to prevention of HIV/AIDS presenting a holistic vision and paying special
attention to sexual transmission (which the ABC strategy is directed to) and injecting
drug use. Our world also has a large population of people living with HIV/AIDS
(PLWHAs). We will, therefore, examine some of the ways in which we can reach
out to them with compassion in ways that are ethically appropriate. This would
mean respecting their rights, avoiding stigma and discrimination, encouraging
voluntary counselling and testing (VCT), maintaining confidentiality, etc. When
we remember that PLWHA are human persons then our approach and interaction
with them will become morally adept. Thus, after reading this unit, you will be
able to:

- identify ethical issues related to HIV and AIDS;
- describe ways to reach out to PLWHAS; and
- appreciate the importance of compassionate behaviour towards PLWHAS.

### 8.3 MORAL AND ETHICAL ISSUES RELATED TO HIV PREVENTION

**Holistic vision**

Before we enter into a specific ethical evaluation of the diverse sectors in HIV
prevention, we need to re-affirm that prevention is more than a technique or a
strategy that can be reduced to a given number of programs. In an interesting
analysis CAFOD has used the ‘problem tree’ paradigm to identify the factors
involved in the HIV pandemic.²

![Figure 8.1: The Problem Tree](image)

The trunk of the tree represents the problem which is the pandemic, the **impact**
on persons, communities and society in general - is illustrated in the leaves and
branches. The roots of the problem can be divided between the superficial roots -
the ‘risk factors’ like the body fluids which transmit the virus - and the deeper
roots - the ‘vulnerability’ factors like social and gender inequality, war, international trade structures, political, religious and cultural factors - which are at the basis of the devastating impact of the pandemic. Thus, to really make prevention a reality, strategies need to address all the three layers of the pandemic. They need to mitigate the impact, reduce the risk and decrease personal and social vulnerability.

Figure 8.2: HIV Prevention Framework (From Ann Smith, Jo Maher et al., HIV prevention from the perspective of a faith-based development agency, 2).

To have truly effective prevention we need to have both, a clear vision of the human person as the source of our preventive ethical approach; and, also a holistic approach in addressing any preventive strategies. No AIDS prevention will be possible if the medical, psychological, sociological, moral, religious and cultural facets are not integrated and harmonized. To effect any change in the HIV situation calls for the uniting of forces in a collaborative, multi-sectoral approach in which diverse actors working in line with their unique strengths interact in a concerted manner complementing each other in the battle against the pandemic. Sadly there are no ‘quick fix’ solutions.

Also it becomes mandatory that prevention strategies be developed within the geographic context for which they are designed, by local people who are expert, experienced and attuned to their reality, and supported and validated by the wider international community. They must combine and reconcile good scientific and development practice with established ethical norms.

As we proceed to discuss the more specific ethical concerns in HIV prevention we must never lose sight of the larger picture. This vision will ensure an authentic respect for the person and will effectively curtail the pandemic.

Epidemiological data

We are aware that HIV can be transmitted through sexual contact (vaginal sex, anal sex, and, oral sex); parenteral - blood contact (injections/needles, cutting tools such as scalpels, razors, blades, transfusions and transplant of an infected organ, contact with broken skin); and, perinatal - mother-to-child transmission (MTCT) (during pregnancy, delivery or breastfeeding). Diverse modes of transmission predominate in different areas. In 2004, NACO released a study of cumulative AIDS cases in India. It found that 85.69% of HIV infections were transmitted sexually. Perinatal transmission accounted for 2.72% of infections, IDUs 2.24%, and unsafe blood and blood products, 2.57%. NACO was unable to ascertain the mode of transmission in 6.78% of cases.3

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Ethical Issues in preventing the sexual transmission of HIV/AIDS

This is the most common way in which HIV is transmitted in many developing countries. It is also an area that is marked by much moral and ethical diversity.

One of the commonly mooted proposals in the world of HIV prevention is the ‘ABC’ approach. “ABC” is an acronym for ‘Abstinence/delay of sexual debut, Being faithful/partner reduction, and Condom use’. Uganda is often cited as the ‘success story’ of the ‘ABC’ approach.

The three major components of the “ABC approach” are abstinence, be faithful and condoms. The target of this approach is threefold: 4

1. In the first place it promotes increased sexual abstinence. This implies (a) fewer people who have ever had sex, measured as an increase in the age at initiation of sexual activity among young people and a decrease in the proportions of women and men who have ever had sexual intercourse; and, (b) fewer sexually experienced people who continue to have sexual intercourse, measured as an increase in the proportions of youth and adults who have ever had intercourse but who are not sexually active.

2. An increase in the proportion of people in monogamous relationships (also referred to as ‘zero grazing’), measured as (a) a reduction in the proportions of unmarried, sexually active men and women who had multiple sexual partners; and, (b) a reduction in extramarital sexual relationships among married men and women.

3. An increase in condom use among sexually active men and women.

This approach seeks to promote the integration of diverse facets of the prevention spectrum. It brings together areas such as abstinence and delay of sexual debut, and fidelity within marriage, along with promoting the use of condoms in cases where the first two options are not available. While the ‘A’ and ‘B’ components are considered risk avoidance strategies, the ‘C’ component is considered a risk reduction strategy.

Within a holistic framework the ‘ABC approach’ has a place in the risk reduction layer but needs to embrace a more nuanced vision. None of the components can be presented as the only option, or be promoted to the detriment of the other, while the strengths and limitations of each component are honestly presented. The basis for applying the ‘ABC approach’ should always be “good epidemiology” and genuine concern for human values, “not dogmatic political or religious agendas”. “A, B and C as risk reduction strategies are set alongside initiatives to mitigate impact and reduce vulnerability, all as intertwined components of national or regional HIV prevention strategies.”

Let us now discuss briefly the role of abstinence, fidelity and condoms in prevention of the sexual transmission of HIV. This is the most common way in which HIV is transmitted in many developing countries. It is also an area that is marked by much moral and ethical diversity.

Abstinence

Abstinence is commonly understood as the deliberate decision to avoid something. People choose to abstain from many different things in their lives such as from sweets, meat, chocolates, tobacco products, alcohol and/or other drugs, and/or sexual activities. They do so for a variety of reasons such as health, personal religious beliefs, commitment to a cause or person, fear and disinterest.

Sexuality in general and adolescent sexuality in particular is viewed generally through the lens of religious, moral and personal values; and, they are influenced
by principles of freedom, the right of self-expression and an individual’s right to choose what to do with his or her body. Thus, the topic of sexuality is philosophically, morally, religiously, politically and personally charged. The bottom line is that while all people want to live their sexuality (their own or that of their children) in a happy, healthy and safe manner, there are divergent beliefs on how to do so. In matters of sexuality, since no one advocates life-long abstinence for all, the issue in the case of teens and adolescents is to delay what is clearly a healthy and normal part of life until they are mature, in a long-term relationship like marriage.

In general the term ‘sexual abstinence’ is used to indicate:

- delaying the age of first sexual encounter. Evidence suggests that the abstinence aspect of ‘A-B-C campaigns has been most successful among young people, for whom delaying the age of sexual debut was an important risk reduction strategy;
- not having sex until the person is in a more stable relationship;
- not having sex until marriage;
- as a mutually agreed and free choice (one of a number of possible options) by and between HIV discordant couples; and
- as a preferred option for a specified period in a person’s life.

Sexual abstinence is described diversely by different people. For one person, it may mean no physical contact with potential partners - no kissing, no holding hands. For another, it may mean abstaining from one particular behaviour, such as avoiding vaginal intercourse. In the context of risk avoidance strategies it would mean having no sexual intercourse: vaginal, oral, and/or anal; as well as refraining from other activities that precede the coital act.

Abstinence programs encourage unmarried individuals to abstain from sexual activity as the best and only certain way to protect themselves from exposure to HIV and other sexually transmitted infections. Abstinence until marriage programs are particularly important for young people, as an “estimated 11.8 million young people aged 15 to 24 are living with HIV/AIDS. Each day, nearly 6,000 young people between the ages of 15 and 24 become infected with HIV.” Not surprisingly sexual activity among teens varies in different regions of the world. In many of the countries hardest hit by HIV/AIDS, sexual activity begins early and prior to marriage with a significant minority of youth experiencing first sex before age 15. With young people everywhere reaching puberty earlier and marrying later, they are sexually mature for a longer period prior to marriage. Some programs have successfully delayed sexual debut and others have effectively promoted “secondary abstinence” - returning to abstinence among sexually experienced youth. These programs have promoted abstaining from sexual activity as the most effective and only certain way to avoid HIV infection; the development of skills for practicing abstinence; the importance of abstinence in eliminating the risk of HIV transmission among unmarried individuals; the decision of unmarried individuals to delay sexual debut until marriage; and, the adoption of social and community norms that support delaying sex until marriage and that denounce cross-generational sex; transactional sex; and rape, incest, and other forced sexual activity.

Most religious traditions have consistently promoted ‘abstinence before marriage’ as an element of ethically acceptable behaviour.

Within the Indian tradition, brahmacharya has been unanimously considered a means of obtaining God-experience. It has the etymological meaning of living in Brahman,
the Supreme Being, or in accordance with Holy Scripture. The English rendition of the word could be ‘chastity, virginity, celibacy, purity or self-restraint’. The brahmacharya ashrama is the first stage of life, wherein the young person spends his time in learning the sacred traditions and preparing for the very next stage which is marriage (grihasta ashrama). The brahmacharya had to “abstain from wine, meat, perfumes, garlands, sweetmeats and women... avoid lust, anger and greed...gossip, slander and untruth... He should neither look at, nor touch women. Let him sleep alone in continence.” Using this symbol of brahmacharya as an ideal that the young should strive for would be of great importance in promoting abstinence. Again linking this tradition to important figures in contemporary Hinduism such as Ramakrishna and Gandhi - men revered for their religious and social contribution to present-day India, could help make their vision and ideals a challenge for young Hindus to strive for.

In general, society needs to help parents and those who educate the young to address ways of motivating youth to premarital abstinence over time and across relationships, even in the face of potential social and partner pressures to do otherwise. This will be the healthy and happy way for adolescents to truly enjoy authentic human living in preparation for total marital self-giving.

Be faithful

The ‘be faithful’ component of the ‘ABC strategy - the second prong of the tripartite approach is similarly rife with varied and diverse interpretations. In the strict sense it indicates entering and remaining in a monogamous relationship. It has special significance in the married state of life, when young people choose their life partner and enter into a mutually enhancing marital relationship. A more nuanced interpretation of ‘be faithful’ might mean:

- a single, mutually faithful partner, whether in marriage or in a long-term committed relationship;
- serially monogamous relationships (provided a degree of stability exists within these relationships. What this means for individuals will vary, depending on current practices and alternative possibilities);
- a strategy of reducing the number of partners; and
- a strategy of reducing the instances of casual sex.

It is important to note that the ‘B’ component of the ‘ABC strategy has been generally overlooked and underrated with most of the polemic centering on the ‘A’ and ‘C. In fact it has been called the “neglected middle child of the ABC approach”. “Yet evidence suggests that fidelity, including to a strategy of reducing the number of partners, and of reducing instances of casual sex, has been the most effective component in countries where the ABC has been used.” Its apparent strength comes from giving it the above indicated wider interpretation based on epidemiological principles rather than on commonly accepted moral principles.

It seems trite to claim that much of the global pandemic of HIV is the result of multiple sexual partnerships. With greater frequency of casual sex and concurrent partners the risks of STIs and HIV increase dramatically. Because the viral load and infectiousness is dramatically higher during the early stage of the HIV infection transmission risks are even higher with frequent partner change among the newly infected, and the presence of other STIs further heightens the spread of HIV.

Partner reduction seems to have paid rich dividends in decreasing HIV incidence in Uganda and Thailand. In Uganda, the proposal of ‘zero grazing’ with reduction of casual sexual partners had a large role to play. Both men and women reported...
many fewer casual partners. In Thailand, along with the “100% condom” approach, there was a notable decrease among men seeking casual sexual encounters with CSWs.

It is also becoming apparent that the epidemiological changes in these and some other countries are the result not only of individual behavioural change but also stem from the evolving of group norms with the causes varying from fear of infection to repeated targeting by media campaigns and support by faith based organizations (FBOs). The end result has been that avoidance of risky sex is becoming a community norm.

These overall patterns seem to strongly imply the important role of fidelity and partner reduction. However, little attention is paid to these factors despite their epidemiological importance and rather wide acceptability. Formative research still needs to study ways in which fidelity can be feasibly targeted for diverse groups, along with ‘A’ and ‘C’.

In what way can the ‘B’ be promoted in HIV prevention? Given the complexity of sexual relationships and the diversity over different parts of the globe, we could suggest that ‘B’ implies the elimination of casual sexual partnerships; the development of skills for sustaining marital fidelity; the importance of mutual faithfulness with an uninfected partner among individuals in long-term sexual partnerships; VCT with their partner for those couples that do not know their HIV status; the endorsement of social and community norms supportive of marital fidelity, by respecting local cultural customs and norms; and, the adoption of social and community norms that denounce cross-generational sex; transactional sex; and rape, incest, and other forced sexual activity.

While the above-mentioned strategies are wide ranging we must never forget that mutual fidelity within marriage is the key to ‘B’ strategies; and, the most effective way to prevent transmission of HIV.

Condoms

Condom and other prophylactic measures need to be seen for what they are - risk reduction approaches (as opposed to risk avoidance approaches that ‘A’ and ‘B’ propose). Epidemiological data confirms that condoms, when used consistently and correctly reduce but does not completely eliminate the risk of HIV infection. This is crucially relevant if any prevention approach is to be both just as well as honest. No cultural or ideological factors would ever justify false information on risk reduction strategies or should prevent the transmission of accurate scientific data. The evidence thus far available, suggests that condom social marketing (CSM) has been successful when targeted at identifiable high-risk behaviour groups [e.g. commercial sex workers (CSWs) and injection drug users (IDUs)] with few other risk reduction possibilities. When the target has been the general population CSM has been less effective.

To understand how ‘C works in HIV prevention strategies, it will be useful to describe that condom use programs promote:

- the understanding that abstaining from sexual activity is the most effective and only certain way to avoid HIV infection;
- the importance of risk reduction and a consistent risk-reduction strategy when risk elimination is not practiced;
- the importance of correctly and consistently using condoms during every sexual encounter with partners known to be HIV-positive (discordant couples), or partners whose status is unknown;
• the critical role of VCT as a risk-reduction strategy;
• the development of skills for obtaining and correctly and consistently using condoms, including skills for vulnerable persons; and the knowledge that condoms do not protect against all STIs.

To date, arguably the most successful condom promotion program is that of Thailand. Realizing that it had a serious HIV/AIDS problem and that the most common mode of transmission was due to commercial sex especially by young men entering military service, the country initiated the "100% Condom Programme", whereby condoms were mandatory for all CSWs in all sex acts in brothels in the country. The key target - reducing HIV prevalence and incidence on a national scale - was realized, with a substantial decline being noticed. Even in the Ugandan experience, it would be wrong to conclude that condoms played no part in the success story, just as it would be wrong to claim that condom promotion was the sole reason for Thailand's success. In Uganda CSM was targeted principally at the commercial sex industry, and reported condom sales and condom use increased significantly.

Another example of a successful program in HIV prevention by means of condom promotion took place in Sonagachi, one of the oldest and largest red-light districts in Calcutta. The target was to get CSWs to use condoms consistently and correctly and it was carried out specifically through peer education programs. In 1992, the year the project began, consistent condom use with clients was 3%. By 1998, this figure had reached 90% of CSWs within the project. In 1998, HIV prevalence among CSWs was just 5%.

It seems apparent from these success stories that the first step in prevention programs that focus on CSM was the correct assessment of the main factors driving the epidemic and a precise understanding of local socio-cultural characteristics. "High-risk groups must remain a key target in nascent, concentrated, or generalized epidemics". It is in this context that condom promotion needs to be part of a package of comprehensive primary HIV prevention through behaviour change, specifically targeted at high-risk behaviour groups. It serves as the first step on the road to fidelity or secondary abstinence.

One of the key questions to be asked is: "How reliable is the use of condoms in preventing HIV transmission?" In understanding the reliability of condoms for HIV prevention we need to make a distinction between their efficacy and effectiveness. The term efficacy means that an intervention has a measurable benefit when used under perfect conditions in a very controlled setting (in vitro). Effectiveness, on the other hand, indicates that an intervention has a measurable benefit when used by a group of people in the real world (in vivo), under normal circumstances (which are rarely ideal).

One of the most detailed and rigorous studies done on the effectiveness of the condom - popularly known as the NIH report - is that conducted by four U.S. government agencies (USAID, the Food and Drug Administration, CDC, and the National Institutes of Health).11

The efficacy of the condom can be compromised by breakage, slippage and degradation of the latex. Similarly it is important that condoms are used correctly and consistently. The efficiency relies on many human factors such as personal and individual issues (lack of trust, inability to negotiate their use, negative perceptions about condoms); government and social issues (availability, acceptability, CSMs).

The NIH report concluded that the "methodological strength of the studies on condoms to reduce the risk of HIV/AIDS transmission far exceeds that for other
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STDs.” Consistent and correct condom use decreased the risk of HIV/AIDS transmission by approximately 85%. These data provide strong evidence for the effectiveness of condoms for reducing sexually transmitted HIV.” A review of scientific evidence - in the post-NIH report period - for the effectiveness of condoms in preventing STIs, reached the same conclusion on the effectiveness of condoms viz. that while condoms are not 100% effective, they provide significant protection and can substantially reduce the spread of STIs within populations.12

Two important issues need to be mentioned in this regard:

1) That condom promotion does not lead to increased sexual activity is borne out now by definitive studies. In Sierra Leone, a study found that a condom distribution programme for students did not increase the number of sexually active youth but did reduce unwanted pregnancies among those who were sexually active. Similarly, the evaluation of an HIV program among Latino youth that included the promotion and distribution of condoms did not increase sexual activity among the adolescents studied. Recent data from Switzerland, too, suggest that a public education campaign promoting condom use can be effective without increasing the proportion of adolescents who are sexually active.13-14 While the condom remains a key resource in the battle, it cannot be regarded as the whole answer.

2) CSM strategies need to be carefully targeted for maximum effectiveness. As we have mentioned the success of most of the condom promotion campaigns have been a consequence of their being targeted at specific risk-behaviour groups. This could also have an indirect protective impact on other segments of the population (e.g., spouses of clients of CSWs). The best solution is to create awareness and acceptance of condom use in the general population while directing the interventions into condom promotion at high-risk behaviour groups.

It has been our effort thus far to present the pros and cons of condom usage. In all fairness it must be said that the correct and consistent use of the condom is effective in securing some protection in risky sexual encounters. But, there are many other factors that come into play in real life situations, that it would be grossly unfair to individuals and society, if one were to promote the condom as the most perfect solution. At every stage in our fight against the pandemic, we need to use evidence-based data to ensure that the strategies used are effective, whether they are directed to individuals, high-risk behaviour groups or to the general population. The larger ethical issues cannot be forgotten.

Condoms without responsible people are not as safe as some would like to think. They serve as “technological fix-it” device when the real issues are about human relationships and attitudes. They cannot be the ultimate answer and the last word, since they are not a fool-proof means to avoid HIV. Many difficulties remain in their acceptance, in access to them, in their usage, and in their efficacy. This is especially true where poverty and gender inequality make their use problematic. Condoms are necessary but inadequate because they do not resolve the basic problem. Since women do not control them and are often the victims of violence, they will be only partially effective.

However, under far from normal conditions when the very sex act which is meant to promote life is a potential source of death, extraordinary steps are called for to preserve life and health. The ‘ABC approach with the nuances of promoting primarily abstinence and fidelity, while leaving condoms as the last resort (harm reduction, ‘the lesser evil’), seems to be in some way (be a viable solution in these difficult and challenging times. For these three to be practiced by increasing proportion of the population requires the pervasive spread of an environment of
social responsibility where the government demonstrates a sense of responsibility towards all citizens, the community towards its members, the medical system towards patients and individuals in inter-personal relationships including sexual relationships.

**Conclusion**

"Many approaches to the prevention of HIV infection exist." Sadly some of the solutions are inadequate because patterns of transmission vary widely between countries and even within countries. With good epidemiological studies, strategies can be evolved to reduce incidence and prevalence first among high-risk groups and then among the general population. What needs to be targeted immediately are the risk behaviours of the populations under consideration. At the same time long term changes in behavioural norms are desirable and can be made possible with the involvement of NGOs.

Good HIV prevention strategy needs to be **effective** - contributing to a well-established decrease in HIV incidence and prevalence along with decrease in STD incidence; **relevant** - it must follow from a good understanding of the context and culture; **efficient** - with all the existing public health and authority structures working together; and, **sustainable** - with norms being changed with regard to visits to CSWs and extra-marital sexual relationships (leading also to diminished frequency).

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**Check Your Progress**

**Notes:**

a) Use the space provided for your answer/

b) Check your answers with those provided at the end of this unit.

1. What is the ‘ABC strategy for the prevention of HIV/AIDS?

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2. What is abstinence?

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3. How effective and efficacious are condoms for prevention of HIV transmission?

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Ethical issues in preventing blood contact - IDUs

One of the ways in which HIV is transmitted is via blood contact and one of the high risk behaviours that need to be addressed is sharing needles among IDUs. To prevent the spread of the virus one of the recommended solutions is needle exchange programs (NEPs). The most common way in which injection drug users (IDUs) transmit HIV is by sharing contaminated injection equipment.

Initially epidemiologists believed that IDUs and their immediate sex partners would be a closed group not contributing to a generalized epidemic. Globally about 5-10% of all HIV infections are attributable to IDU. Bearing in mind that the efficiency of HIV transmission per injection is almost six times higher than for heterosexual acts, one begins to understand the risks that IDUs are likely to take and the high probability they have of contracting HIV.

Risk avoidance strategies for IDUs are focused on detoxification and drug abstinence programs to help drug addicts to kick the habit. Contrary to popular beliefs about IDUs there is a growing body of evidence to suggest that with proper strategies they will change their behaviour to reduce personal and transmission risk for HIV/AIDS. The research findings suggest that formal collaboration between NEPs and drug treatment programs could increase the proportion of IDUs in treatment. We must, however, keep in mind that some IDUs are unwilling or unable to stop. NEPs are a harm reduction response to this situation. Other risk reduction strategies consist in encouraging IDUs to practice safer sex by using condoms, and guiding them to use VCT.

The first NEP was developed in Amsterdam in 1984, with limited resources and frequent political resistance. It is only in the past ten years, that they have evolved into more formalized programs and these have been rigorously evaluated. As of December 2000, there were at least 46 regions, countries and territories that reported having at least one NEP. The one thing that all NEPs do is to provide IDUs with clean needles and syringes and other material required for the safe injection of drugs in exchange for used equipment. An IDU could leave a little of his/her blood in the needle itself, and/or in the barrel of the syringe. Another person using the same injection equipment, could, therefore, be infected when exposed to the contaminated blood in the syringe/needle. Similarly someone coming into accidental contact with a used needle is also at risk; NEPs try to increase the chances that a needle will only be used once, and that it will be brought back for exchange and safe disposal.

Along with the NEP another strategy that is often used is counselling the IDU to behavioural change. This latter goal is facilitated by repeated individual contact which can help the program coordinators to interact, counsel and help IDUs to risk avoidance behaviours. The human contact and protection from disease that these programs suggest communicates a powerful message to addicts that their lives and well-being are valued by the community, even though they may be unable just yet to be able to break the cycle of addictive behaviour."

The focus of NEPs is on reducing the risk of serious health consequences to the person and to the community.

Research does show that NEPs reduce HIV risk among IDUs, yet the practice remains controversial, with fears that NEPs could increase drug use due to ease with which injecting equipment is made available. Studies show that NEPs are associated with many positive health outcomes such as reduction in the incidence of HIV, HBV and HCV, decreased needle sharing, decrease in syringe reuse and increased rates of entry into drug treatment programs. One concern is that NEPs
could increase drug use. In general studies do not show increased use of drugs following the introduction of a NEP. Another concern is whether NEPs increase the number of contaminated syringes found on the street. If the NEP is designed to be a one-for-one exchange, it will not.

With good results being shown in primary drug prevention, the main target should be to help drug addicts to avoid all forms of drug dependence with well-planned de-addiction programs. Part of the strategy is to encourage IDUs to go for VCT and to identify their serostatus. “Comprehensive strategies that include drug treatment, long-term recovery programmes, and prevention are urgently required”. But harm minimization is also important. It is in this area that NEPs have a role to play. They cannot be considered the best solution to risk avoidance for IDUs, but when integrated with other programs of HIV awareness and treatment they can be considered a step in the right direction.

Check Your progress

Notes: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

4. How effective are NEPs in preventing the transmission of HIV?

8.4 MORAL AND ETHICAL ISSUES RELATED TO CARING FOR PLWHA

Basic rights of PLWHA and ways in which these rights can be violated

It is important to note that PLWHA have certain basic rights that should be protected. They have a right to basic health care and treatment just as any other sick person has. Doctors and health care workers (HCW) have a moral duty to treat all patients, including PLWHA. Medicine is always focused on how to safeguard and improve health and hence anyone who enters the field commits themselves to this principal task. Doctors accept this as part of their professional ethics which obliges them to treat all patients they are competent to help. Similarly, this is part of the commitment that an HCW undertakes. We also need to bear in mind that the risk of occupational exposure to HIV/AIDS is much lower (0.1-0.3%) than for other infectious diseases such as hepatitis B (6-30%) or hepatitis C (1.8%).

Therefore, it is unethical for any health care provider to refuse to provide care for a person just because he or she is a PLWHA. Similarly, it is unethical to take care of a person conditional on that person going for voluntary counselling and testing (VCT).

This obligation is subject to some extenuating circumstances. For example if the risks of treatment are excessive, there are very questionable benefits and health care facilities are limited, the HCW is not competent to treat the person concerned.
It is, therefore, necessary that all HCWs be educated:

1. To treat.

2. About the risks of transmission in health care settings and means to prevent transmission by taking due precautions.

3. About the ethical and legal duty to provide care.

4. About psychological and emotional needs of PLWHA.

All health and human services for persons who are seropositive or who have AIDS should be delivered in a sensitive and nondiscriminatory manner. At the same time, we also recognize the right of HCWs to adequate protection against HIV. The health and human services described should be available to all who suffer from the disease including those without the resources to pay.

Continued research and care needs to be part of the core strategy of caring for PLWHA. It is essential that drugs to control the infection be developed. Government agencies should draw up clear guidelines on the use and effectiveness of new and emerging drugs. Similarly social justice requires that public and private agencies seek creative ways to meet the health and human service needs of those who are seropositive. It is imperative that a continuum of care be developed that allows for the integration of all necessary services within a given community.

Stigma and discrimination

In many parts of the world AIDS is perceived as a disease of “others” - of people living on the margins of society, whose lifestyles are considered “perverted” and “sinful.” Discrimination, stigmatization, and denial (DSD) are the expected outcomes of such values, affecting life in families, communities, workplaces, schools, and health care settings.

Stigma is defined as an undesirable or discrediting attribute that a person or group possesses that results in the reduction of that person’s or group’s status in the eyes of society. Stigma can result from a physical characteristic or from negative attitudes towards the behaviour of a group such as homosexuals or CSWs. Discrimination, which can be expressed as both negative attitudes or particular behaviours, is described as a distinction that is made about a person that results in their being treated unfairly on the basis of their belonging, or being perceived to belong to a particular group. This same negative perception can lead to denial of the very existence of persons or groups or negation of their just rights.

Because of HIV/AIDS-related DSD, many policies and programmes that are urgently needed remain undeveloped. PLWHA continue to be burdened by poor care and inadequate services, while those with the power to help do little to make the situation better.

DSD is present in the institutional context such as education and schools (some seropositive children are denied admission into school or are segregated), employment and the workforce (employment is refused to PLWHA), health care facilities (persons who belong to high-risk behaviour groups are denied treatment and care), religious institutions (PLWHA are prevented from attending some rituals). Similarly DSD is noted in community contexts where tabooing or silence about HIV/AIDS leads to widespread unfounded fears and social isolation of PLWHA. Within the family context, DSD takes the form of abandonment of PLWHA who are members of the family or segregation of nuclear families in which a member is a PLWHA.
Some outcomes of HIV/AIDS-related DSD for PLWHA are:

— fear of AIDS stigma (of being identified with "deviant," "morally sinful" behaviour, mainly sexual promiscuity and visiting sex workers);

— fear of loss of reputation in the family and society, and of damaging the family's social reputation;

— fear that HIV serostatus will be revealed and of being identified as sexually deviant;

— fear of social discrimination and isolation, of being avoided or shunned by others;

— fear of various illnesses and debilitating ill-health, of painful conditions, of not receiving medical attention, and of being denied admission to hospital;

— fear of being deserted, of loss of significant relationships, and of loss of trust and confidence;

— fear of losing one's job or source of income;

— fear of passing the infection to others, whether spouse, children, or other family members; and

— fear of death and of dying early, of dying uncared for, and of being denied last rites.

As a result many will not reveal their status, will not go for VCT and thus remain oblivious to their HIV status passing on the infection to others. Once we understand that DSD produces, legitimizes and enhances social inequality, we realize its immorality and the need we have to create structures to overcome it.

There are many ways in which DSD can be reduced. One of the key means is to educate and empower PLWHA helping them to challenge (legally and socially) this DSD- Another way of reducing DSD is to remove the secrecy that surrounds HIV and openly confront its presence in our families and societies. With the taboos removed much of the DSD will be diminished. Special attention needs to be paid to emarginated groups who are perceived as indulging in high-risk behaviours. When their right to privacy is upheld they will be encouraged to seek VCT and treatment. Laws can be enacted that will reduce DSD and effective complaint mechanisms need to be put in place in the health-care sector for people seeking to protect their rights as patients. Similar policy guidelines need to be developed in the employment sector and the educational sector. Given that one of the principal factors that determines DSD is low levels of HIV/AIDS knowledge, there is a crying need for awareness programmes that will give scientifically accurate information and enable the formation of appropriate attitudes and behaviours towards PLWHA and belonging to groups which indulge in high-risk behaviours.

A growing body of legislation considers the PLWHA a handicapped or disabled person, with right to the defense of other rights that enable the individual with disabilities to achieve the fullest measure of personal development of which he or she is capable. The inalienable dignity of all human persons and the need especially to protect those "who are vulnerable and most helpless" can never be overlooked.

Discrimination against those suffering from HIV or AIDS is a deprivation of their civil liberties.
Check Your Progress

Notes: a) Use the space provided for your answer.
   b) Check your answer with those provided at the end of this unit.

5. Describe some of the ways in which DSD can be reduced?

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VCT and other constructive ways of dealing with PLWHA

Before we discuss the ethical issues concerned with VCT, it is essential to note three principles that govern all testing proposals. In the first place the purpose of testing must be ethically acceptable. Its goal must be treatment of the affected, protecting public health or preventing transmission of disease. Secondly, the use of the test results must contribute to the well-being of the individual and the society. Finally, the benefit to public health must warrant the extent of intrusion into personal liberties. Thus if the benefit to public health is minimal or uncertain, the gross invasion of personal rights is not justified.

In all testing it is essential to note the need for free and informed consent. Since every individual enjoys autonomy, he or she has the right to decide after being informed about the potential benefits and harms that may come from testing. Consent does not apply to testing of donors of blood, organs or other bodily products. Here the intention is to provide safe blood or organ donation. So the donor needs to be informed that an HIV-related test is to be performed and the results must be shared with the donor, maintaining confidentiality. Consent does not apply to testing that is performed as part of an anonymous HIV screening programme for epidemiological or research purposes.

"Voluntary HIV counselling and testing (VCT) is the process by which an individual undergoes counselling enabling him or her to make an informed choice about being tested for HIV. This decision must be entirely the choice of the individual and he or she must be assured that the process will be confidential."¹⁹ VCT is not only a key component for prevention and care of HIV-infected individuals but also the gateway to prevention and care. This includes helping the infected person begin to accept the fact of their infection and plan for the future; promoting and facilitating prevention of further transmission; providing access to early medical care and management of infections; making reproductive health care available, including sexually transmitted infection screening and treatment and access to family planning; providing maternity services to reduce mother-to-child transmission; encouraging support from family and the community; and, providing both social and spiritual support. Thus, VCT can be used as a form of prevention rather than strictly for diagnostic purposes.

VCT incorporates both pre-test counselling and post-test counselling. In pre-test counselling clients are helped to understand and perceive their own risk (and the risks that their behaviour may pose to others) and reduce that risk. Counselling should supply information about the disease, the ethical aspects involved, immediate emotional support, and information about resources for continuing emotional and spiritual support. Once the test results are in, there is crucial need for post-test counselling, too. In this phase those who are positive are given all the emotional support that they need and treatment regimens can be established. Sharing a seropositive result with one's sexual partner is also a very important part of
prevention. When the test result is negative the client needs to be guided (if applicable) to change risk behaviours.

VCT is an important entry point to other HIV/AIDS services, which can benefit clients with positive or negative results. When it is well implemented, VCT services offer the possibility of benefitting the community by "normalizing" the existence of HIV/AIDS, thereby reducing stigma and promoting awareness.  

VCT is an essential component of prevention of MTCT programs because such programs cannot be implemented if women do not know their HIV status. Programs, however, should not focus only on identifying seropositive women, but they should also focus on risk reduction and helping women who test negative to remain that way.

Broadly based routine voluntary testing and educational programs are needed as a matter of public policy. These voluntary programs should always guarantee anonymity and should be preceded and followed by necessary counselling for individuals diagnosed as seropositive or seronegative.

To date there is no justification for universal mandatory HIV testing, given the possibility of false positives or false negatives, the high financial costs entailed, and the potential for DSD, invasion of privacy, and the creation of a false sense of security. In the absence of a known cure and since behavioural modification cannot be imposed, compulsory screening is unethical, ineffective, unnecessarily intrusive, discriminatory and counter-productive. HIV testing without informed consent and confidentiality is to be considered a grave violation of human rights.

There are special problems associated with HIV testing for immigrants and refugees. False positive test results may exclude some from migrating, and some may be deported before the tests are confirmed. A more flexible and humane government policy seems necessary.

Confidentiality and professional secrecy

Another issue that needs to be addressed in the context of an ethical discussion is that of confidentiality and privacy. When VCT is done it is important for the person being tested to know that the results of the test will be kept private. If there is no guarantee of privacy, many of those who indulge in high-risk behaviours will go underground fearing the stigma, discrimination and ostracism. At the same time there may be reasons why the positive results of an HIV test needs to be revealed to prevent harm from coming to an innocent third party (very often the married sexual partner of the seropositive person). It must also be borne in mind that if confidentiality is easily breached then many may lose total trust in the medical counselling profession.

We need to bear in mind that the responsibility to make the revelation of their HIV status lies wholly with the seropositive person. The right to autonomy and to give informed consent means that the presumption should always favour confidentiality. However, there may be circumstances that warrant disclosure. Initially all efforts must consistently be made so that the seropositive person reveals his/her status to their sexual partners and others they are in danger of infecting. If they do not do so after repeated reminders partner notification could be considered. In deciding for disclosure or confidentiality in a particular case, the following points are relevant.

1. The two main factors in favour of disclosure are (a) the need to prevent the infection of others and (b) the need to provide medical care to the PLWHA. If disclosure in a particular case will reduce the danger of infection to others or increase the ability to treat the individual effectively, it may be the right course of action if no other effective action is possible.
Continued research and care needs to be part of the core strategy of caring for PLWHA. It is essential that drugs to control the infection be developed. Government agencies should draw up clear guidelines on the use and effectiveness of new and emerging drugs. Similarly, social justice requires that public and private agencies seek creative ways to meet the health and human service needs of those who are seropositive. It is imperative that a continuum of care be developed that allows for the integration of all necessary services within a given community.

Check Your Progress

Notes: a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

6. How does one decide whether under certain circumstances partner notification may be justified?

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8.5 LET US SUM UP

This unit has examined in detail some of the ethical issues involved in HIV/AIDS. In the area of prevention - it has discussed the ABC approach as an effective means to stop the spread of the pandemic and the possibility of NEPs to minimize the harm that comes to IDUs from drug addiction. On the topic of caring for those who are already afflicted by the scourge of HIV/AIDS, we noted that it is imperative that we respect the rights of PLWHA and that we ensure that they have access to treatment. Any form of DSD is contrary to the dignity that every human person enjoys, and must be reduced and eliminated. We also discussed issues such as VCT and confidentiality. In all our ethical proposals we must never forget to view the larger picture and attack the spread of this virus at its roots. Respect for the dignity of the human person within a holistic paradigm will help us arrive at solutions that honour this inherent dignity that each person enjoys.

8.6 UNIT-END EXERCISES

1. As a teacher, how would you help a HIV positive student in your class to adjust in the society?

2. Remember any instance of discrimination against a child in your school due to any reason. Analyse that situation and the responses of the various sections to it.
8.7 SUGGESTED READINGS


HIV Transmission and Testing


8.8 ANSWERS TO CHECK YOUR PROGRESS

1. “ABC” is an acronym for ‘Abstinence/delay of sexual debut, being faithful/partner reduction, and Condom use’. Uganda is often touted as the success story’ of the ‘ABC approach.

The three major components of the “ABC approach” are abstinence, be faithful and condoms. The target of this approach is threefold. In the first place it promotes increased sexual abstinence. It also works to increase the proportion of people in monogamous relationships (also referred to as ‘zero grazing’); and, an increase in condom use among sexually active men and women. While the “A’ and ‘B’ component are considered risk avoidance strategies, the ‘C component is considered a risk reduction strategy.

2. Abstinence is commonly understood as the deliberate decision to avoid something. People choose to abstain from many different things in their lives such as from sweets, meat, chocolates, tobacco products, alcohol and/or other drugs, and/or sexual activities. They do so for a variety of reasons such as health, personal religious beliefs, commitment to a cause or person, fear and disinterest. In matters of sexuality, since no one advocates life-long abstinence for all, the issue in the case of teens and adolescents is to delay what is clearly a healthy and normal part of life until they are mature, in a long-term relationship like marriage.

3. In understanding the reliability of condoms for HIV prevention we need to make a distinction between their efficacy and effectiveness. The term efficacy means that an intervention has a measurable benefit when used under perfect conditions in a very controlled setting (in vitro). Effectiveness, on the other hand, indicates that an intervention has a measurable benefit when used by a group of people in the real world (in vivo), under normal circumstances (which are rarely ideal).

4. One of the ways in which HIV is transmitted is via blood contact and one of the high risk behaviours that need to be addressed is sharing needles among IDUs.

To prevent the spread of the virus one of the recommended solutions is needle exchange programs (NEPs).
5. One of the key means is to educate and empower PLWHA helping them to challenge (legally and socially) DSD. Another way of reducing DSD is to remove the secrecy that surrounds HIV and openly confront its presence in our families and societies. With the taboos removed much of the DSD will be diminished. Special attention needs to be paid to emarginated groups who are perceived as indulging in high-risk behaviours. When their right to privacy is upheld they will be encouraged to seek VCT and treatment. Laws can be enacted that will reduce DSD and effective complaint mechanisms need to be put in place in the health-care sector for people seeking to protect their rights as patients. Similar policy guidelines need to be developed in the employment sector and the educational sector. Given that one of the principal factors that determines DSD is low levels of HIV/AIDS knowledge, there is a crying need for awareness program that will give scientifically accurate information and enable the formation of appropriate attitudes and behaviours towards PLWHA and belonging to groups which indulge in high-risk behaviours.

A growing body of legislation considers the PLWHA a handicapped or disabled person, with right to the defense of other rights that enable the individual with disabilities to achieve the fullest measure of personal development of which he or she is capable. The inalienable dignity of all human persons and the need especially to protect those “who are vulnerable and most helpless” can never be overlooked. Discrimination against those suffering from HIV or AIDS is a deprivation of their civil liberties.

6. We need to bear in mind that the responsibility to make the revelation of their HIV status lies wholly with the seropositive person. The right to autonomy and to give informed consent means that the presumption should always favor confidentiality. However, there may be circumstances that warrant disclosure and partner notification. The two main factors in favor of disclosure are (a) the need to prevent the infection of others and (b) the need to provide medical care to the PLWHA. If disclosure in a particular case will reduce the danger of infection to others or increase the ability to treat the individual effectively, it may be the right course of action if no other effective action is possible. But in general (a) disclosure should be confined to those who have the right to know, (b) try to ensure that the recipients of the information will use it for proper purposes, and (c) maintain the obligation to patient confidentiality.