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School of Social Work

MSWE-001
HIV/AIDS: Stigma, Discrimination and Prevention

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School of Social Work
IGNOU, Delhi

Dr. G. Mahesh
School of Social Work
IGNOU, Delhi

Dr.. N. Ramya
School of Social Work
IGNOU, Delhi

COURSE PREPARATION TEAM

Unit Writers
Prof. Jyoti Kakkar
Prof. Gracious Thomas

Block Editor
Dr. Sonny Jose

Course Editor & Programme Coordinator
Prof. Gracious Thomas

COURSE PREPARATION TEAM (Revision)

Unit Writers
Prof. Jyoti Kakkar
Prof. Gracious Thomas

Course Editor
Dr. Archana Kaushik
Delhi University, Delhi

Programme Coordinator
Dr. Saumya

Print Production

Mr. Kulwant Singh
Assistant Registrar (P)
SOSW, IGNOU

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BLOCK INTRODUCATION

This block is the third block of the course on "HIV/AIDS: Stigma, Discrimination and Prevention" having five units.

The first unit is on: "Communication in HIV/AIDS Prevention". As the title suggests, the unit deals with the IEC strategies used for the control of the disease. It also talks about the challenges being faced in communication in context of HIV/AIDS, and the strategies used for some of the special population groups.

The second unit is on "Models of Behaviour Change" throws light on the importance of change in behaviour of an individual to prevent the spread of the disease. The unit talks about models of behaviour change and other considerations to behaviour change.

The third unit is on "Counselling for HIV/AIDS: Nature and Process." There is an elaborate discussion on the nature and purpose of HIV/AIDS counselling, its stages and the skills required of a HIV counsellor for addressing issues pertaining to HIV. It also talks about impact of values and attitudes of a counsellor on HIV counselling. You will also learn about the communication skills of a good counsellor and characteristics of a good client.

Unit four is on "Issues and Types of HIV/AIDS Related Counselling" that talks about the special issues that emerge in the case of HIV/AIDS. This unit mainly discusses about counselling in the context of Youth and children, Injection drug users, sex workers, etc.

Unit five is on "HIV/AIDS and Legislations". This unit deals with the legal aspects of HIV/AIDS. It throws light on some of the laws and legal policies for the prevention and spread of HIV/AIDS and rights of people living with HIV/AIDS.

On the whole, the five chapters presented in this block will enable you to have reasonable understanding about various aspects pertaining to meaningful interventions in the area of HIV/AIDS.

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UNIT 1 COMMUNICATION IN HIV/AIDS PREVENTION

* Jyoti Kakkar

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1.0 OBJECTIVES

The present unit discusses communication in the context of HIV and AIDS. As is well known, the pandemic of AIDS (Acquired Immuno-deficiency Syndrome) has been reported from almost all countries on the global map. The virus that causes AIDS, namely the HIV (Human Immuno-deficiency Virus) has been identified and studied extensively. It is a retrovirus and has different sub-types. Much headway has been made in the management of the syndrome. Vaccines are under trial and many debates are ongoing on their utilization. However a sure cure for AIDS is yet to come. Given this, prevention continues to be the best strategy for the mitigation of AIDS. Country reports from across the globe show that AIDS prevention has been the major focus in the intervention strategy. Policies and programmes have paid importance to IEC (Information, Education and Communication) strategies for the control of AIDS. In India too, there have been extensive efforts towards raising AIDS awareness. The principal focus of these strategies has been reaching out to the vulnerable populations through appropriate messages and simultaneously upscaling testing and support and care.

It hardly needs to be emphasised that communication techniques and strategies are important in the context of HIV prevention. In this regard, the present unit discusses the different types of communication, traditional and modern, particularly in the Indian context. Information, Education and Communication (IEC) and the role of media, barriers to communication, and the means of choosing a medium are also matters discussed in the unit.

* *Prof. Jyoti Kakkar, Jamia Milia Islamia, New Delhi*

1.1 INTRODUCTION

Communication is an integral part of every social exchange. Simply from interpersonal dialogue to global mass media (music, theatre or local radio) all of them have a specific role. Communication is a dynamic process that has shaped the development and growth of human civilization over centuries. Newer forms of communication keep on developing with advancement of technology. However, the traditional forms of communication keep on continuing in many traditional societies and can be well used to communicate and send messages to populations on even the most sensitive issues. This has been the case with communication for HIV/AIDS prevention in many countries.

HIV/AIDS is a health problem with multiple dimensions. As is well known AIDS affects people, usually in their most productive years. It takes its toll on every family when those who are the bread earners are incapacitated and the burden falls on either the children or the elderly. The HIV virus has definitely been reported to have taken it's toll on many communities and societies. With the 'burden of the disease' falling on many societies it has been recognized as a developmental problem.

Towards combating the pandemic of AIDS, many nations have taken a pro-active approach and evolved policies for AIDS prevention. Effective HIV/AIDS communication strategies are thus at the core of such policies and programmes.

1.2 DEFINITION

The word "Communication" comes from the Latin word "*communis*", meaning common. When we communicate, we are trying to establish 'commonness' with someone. That is we are trying to share information, an idea or attitude. The standard definition of communication reflects the everyday usage of the term 'to communicate'. It is defined as 'to impart', bestow, or convey, to make known, give by way of information. The New Webster's dictionary defines communication as " the act of communicating, transmission, the imparting or interchange of thoughts, opinions, or information by speech, writing or signs, which is communicated or imparted; a document or message imparting views of information"

There are numerous definitions of communications but the common strand running through them all is that "communication is a social process of interaction through messages". According to Dennis Mc Quail, communication is a "process which increases commonality". He describes human communication as "the sending from one person to another, meaningful messages."

An expanded definition considers communication as the processes of dialogue, exchange of information and resources, and the capacities that enable understanding, negotiation and decision making around an issue. Such an understanding of communication includes the technical focus on audiences and media channels for information in development communication programmes. It also brings into view the existing relationships and processes of dialogue in any setting, the resources and capabilities that different groups draw on for communication, and how these support individual and social change.

Communication in development has often been understood in a technical sense to refer to the variety of ways of providing information and 'messages' to people, and the different approaches and media 'channels' for this purpose. Participatory communication suggests a need to go beyond delivering 'messages' to particular groups of people to change their attitudes and behaviour, focusing instead on a two-

way process of dialogue and participation. A wide array of communication interventions have proven effective – from media and social marketing campaigns that raise awareness of HIV/AIDS, to peer education that supports HIV prevention efforts in particular high-risk groups. Communication interventions that promote engagement and dialogue – particularly among peers – have been key for changes in behaviour.

Any attempt to define communication has to take into consideration the idea of mutuality and commonness, an exchange, a shared environment, a social relationship among the participants, and the existence of a common need, urge, aim or goal.

1.3 INFORMATION, EDUCATION AND COMMUNICATION

The major approach of HIV/ AIDS prevention has been developing awareness, especially among the vulnerable populations. IEC (Information, Education and Communication) techniques have been used extensively and as a major strategy of prevention programmes in India. A look at the components of IEC is important.

(a) Information (Mass Media): The media of mass communication have a significant role to play in creating and sustaining public opinion and the political will to deal with the HIV/AIDS epidemic. The media can facilitate certain trends and phenomenon in the community or society that facilitate the spread of HIV/AIDS and inform the public about them. They help in educating the masses about the risk factors and about the importance of prevention. In doing so, they help create public awareness and mobilize public opinion against cultural practices that favour the spread of the epidemic.

Radio programmes and television programmes are widely accessible to populations, including those in the rural areas. However, radio telecast lacks interaction with the people. The television provides a certain amount of flexibility in developing interactive programmes, making it a more people friendly medium, however there are huge variations in the number of television receivers across the world.

A number of factors determine the usage of mass media in reaching out with the message of AIDS. Important groups are not reached out by the media prevention messages due to multiple factors. These can be political will and a possible repressive attitude of the authorities. Communities in remote areas and those that also communicate in minority languages are not reachable through use of media of mass communication. Also, in some cases the message may not be contextualized to the specific cultural context. In the context of AIDS, it is well understood that the content of the messages and an understanding of the behaviour it intends to change is important. For example, in some South African countries, media messages to rural, uneducated and poor populations have reinforced irrational fears, provoked rejection of sick people, resulting infact in a fatalistic attitude concerning prevention and self-protection. Reportedly, in South East Asia there are tribal populations that were so scared by images broadcast on the television that they refused to hear more about the disease (see UNESCO, 2001).

(b) Prevention Education: Education in the context of HIV prevention has mainly been targeting the youth. Specific information courses that are an integral part of the school curriculum were developed in many countries. It was aimed at reaching out to students and educators. All these efforts have highlighted the differences between the education levels, social/cultural background and local situations. Also it does not cover the out of school youngsters and illiterate populations.

(c) Communication (non-media): Communication here refers to the exchange of information between both professional information advisers and counsellors. In this context emphasis has been placed upon counseling. It is recommended that counseling should always accompany testing. This is to give them the right information and also to help them make future plans.

Advocacy is also needed in areas of safe attitudes and practices, including the use of condoms. In all these areas there is a serious deficiency in the design of communication strategies, that aim at building a political will and a supportive societal and cultural environment.

In India, IEC efforts operate at two levels. At the national level, National AIDS Control Organisation (NACO) is responsible for policy and strategy formulation, framing of guidelines for IEC activities and for implementing national level campaigns. On the other hand, at the state level, the State AIDS Control Societies (SACS) conduct communication need assessment studies and evolve their IEC strategies according to local priorities, within the overall national strategy and framework. Most of the field action takes place at this level. At both national and state level, political and media advocacy are being strengthened in order to create greater ownership of the programme which will result in impact awareness generation and behaviour change.

Check Your Progress I

Note: Use the space provided for your answer.

1) Briefly describe the role of IEC in HIV/AIDS Prevention?

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1.4 TRADITIONAL AND MODERN MEANS OF COMMUNICATION

Both traditional and modern means of communication have been used extensively in the HIV/AIDS prevention programmes. An understanding of the different types of media, their functions and the reasons behind choosing them is important.

The term traditional means of communication refers to methods used in a specific culture for communication of ideas and dissemination of information. It is important to understand the relationship between communication and culture. When we discuss the components of culture such as art, mythology, religious practices, family, social systems, we can well understand the role communication plays in the perpetuation of culture. A number of people who live together and are bound by a culture cannot function as a group if they do not have common means of communication.

Folk Media

Folk media means media of the people. The word folklore and folk media come from the German root word 'volks' (pronounced folks) which means 'people'. Folklore refers to the myths, legends, folk tales, riddles, costumes, dances, dramas, songs, etc prevalent in a particular community. Folk medicine refers to the various means of communication available to the rural and tribal people. It does not require any special training or money for its implementation. Inexpensive material available locally is what is needed. The folk media is totally operationalised by the people of the community and is characterized by a face to face contact. It can well be understood that because of such an origin and its ownership by the people it has a tremendous influence on the community. Even where the modern media of communication have reached, folk media have their own role to play.

India is a country with immense cultural wealth. There are as many as 6000 folk media and traditional art forms in India. They help in imparting the social values, preserving religious bonds, mobilizing people to take action around a common cause and preserve social bond and cohesiveness. Folk media are immediately recognisable vehicle for education; they are easily accepted by most Indian masses, it is therefore imperative for projects whose goals aim at behaviour change and sustainability in rural Indian settings to recognise and use the potential of folk media for the benefit of the rural folk as well as project implementers and funding agencies.

Some of the most widely used traditional forms of communications are

***Storytelling*:** It is probably the most universal among the various kinds of folk media. Many rural societies in India have a rich tradition of storytelling. The story teller uses histrionic gestures and rhythmic language to tell the story. The audience responds with laughter and body movements. The narration of the story sometimes goes late into the night. People normally gather in the village squares or courtyard. Themes of the stories can well bring forth the values that are held in a particular community or the traditions that are part of that culture.

***Tamasha*:** It is a lively form of folk theatre in Maharashtra. Its origin could be traced back to some 400 years old to the time of the Peshawas. A jester named Songadya acts as a master of ceremonies. He makes witty remarks. Tamasha uses both male and female artists. Tamasha has been traditionally used as a medium of entertainment and to communicate religious stories. Its contemporary use includes creating social and political change by generating public opinion. The government uses it today to popularise issues like family planning.

***Nautanki*:** It is a north Indian folk drama performed in an open theatre. This folk form gets its name from Rani Nautanki whose young lover disguised himself to get entry into her chamber. This form too has a narrator called *sutradhar*. Musical instrument like the kettle drum (*makkara*) and dholak are used. The dialogues are sung in popular folk melodies.

***Jatra*:** Jatra literally means 'journey'. It is a popular folk theatre of Bengal and Orissa. The name of this form is derived probably from the habit of the performers who wander from place to place to perform. Most of the stories are related to Krishna and Radha. Jatra helped to popularise the Bhakti cult among the masses. Later it was used to popularise the Shakti cult. During the freedom struggle Jatra was used for popularising the movement. The form consists of choral singing (juri), acting and rhetorical flourishes.

***Bhavai*:** It is a leading folk theatre form in Gujarat. A jester or clown called Ranglo enters into dialogue with the Naik or Sutradahar. The bantering, satire and gesture

of Ranglo provide laughter to the audience. He connects the past with the present and pokes fun at the political and social evils of the day. Bhavai uses a mixture of dialogue, mime, fantasy, acrobatics, magic tricks, dance and song. Various classical and popular music forms make this folk art a lively medium.

***Keertana*:** This folk art form is called *Harikatha* or *harikeertan*. It is a kind of concentrated drama, a monodrama in which a gifted actor portrays a series of characters and moods. It is believed to have spread from Maharashtra to Karnataka and Tamil Nadu about 150 years ago. Associated with the Bhakti movement, it was used by Kabir and Tukaram to preach religious faith and to bring about social and political reform. A different form of Keertana is used in Gujarat.

***Sumang Leela*:** It is a very popular folk drama in Manipur. In this folk form all the actors are women, dressed and disguised themselves into men and women. This folk form attracts lots of people and is usually held in the courtyard or public places around the colonies.

***Ballad forms*:** There are several distinct ballad forms in vogue in India to narrate stories. To name a few: Alha (Uttar Pradesh), Burra Katha (Andhra Pradesh), Jugani and Vaar (Punjab), Powada (Maharashtra), Villupattu (Tamilnadu).

***Folk Music*:** Folk music is another powerful traditional media in India. According to scholars, there are some 300 folk musical styles in India. The more popular among them are: Baul and Bhatiali (West Bengal), Doha and Garba (Gujarat), Chaiti and KAjari (Uttar Pradesh), Kolkali Pattu (Kerala, Bihu Assam, Mand and Panihari (Rajsathan), Rouf and Chakri (Kashmir), Susa and Dadaria (Madhya Pradesh), Mando and Dhalo (Goa), Boli (Eastern Punjab) And Layani (Maharashtra)

***Folk Sayings and Riddles*:** The rural folk of India appreciate these forms of communication regardless of their economic condition or educational status. These forms are rooted in the culture and tradition of the community that uses it. These media entertain as well as educate, and preserve social cohesion and harmony. They transmit religious and social values and cement a strong bond among the members of the community.

***Puppetry*:** Puppetry is essentially a folk art used since several centuries to relate myth and legend. The medium has undergone change and is being used in many present day situations to impart education, entertainment and even therapy. Puppetry is the art of animating figures representing human or animal motifs. Puppetry did not originate as a source of entertainment, but as a cult observance,. It has continued as an enduring art though it has undergone changes in preparation and presentation.

Modern Means of Communication

The modern means of communication have been made use of extensively in health interventions. Mass media are used to sensitise populations on the threats and the measures they can adopt to for disease prevention. Polio campaigns, the DOTS programme for tuberculosis, early detection of cancer are some campaigns that have made an impact on the masses. Let us take a look at these:

Radio: Radio is a cheap and useful communication tool. Almost every household in the Indian society, both urban and rural, owns one. Considering the affordability and accessibility, radio is the most popular medium in India. Radio has the capacity of being heard by a large, diverse audience. Folk media such as story-telling, drama,

poetry recitals, proverbs and music on the radio will appeal to rural audiences. Radio also offers opportunities for interactive participation by local residents. All India Radio, Vivid Bharati, Primary channel and FM Stations regularly air programmes that help carry the message to far flung areas through programmes like "Jeevan Hai Anmol" and "Lets Talk"

Print: Print Media plays a significant role in creating and increasing awareness on different issues of public concern, including HIV / AIDS among the people. Press campaigns featuring modes of transmission and prevention are a regular feature. Pamphlets, handouts, stickers, flash cards, wall hangings and posters are developed for greater reach.

Television: Television could be an effective means of communication for HIV/AIDS prevention. Television is both audio-visual, so it is a powerful means of communication. Initiatives have been taken up by Government of India, under Ministry of Health and Family Welfare through NACO, a nodal agency for HIV/AIDS in India through television programmes. Prasar Bharati and BBC have collaborated to make advertisements which are aired across the country. Television serials called "*haath mila*" and "*jasoos* vijay" have been aired on primetime television, providing information and generating awareness especially amongst the youth. NACO sponsored the Kalyani Health magazine in eight of its regional doordarshan kendras where sports and film celebrities endorse messages on HIV/ AIDS prevention.

Internet/ Websites/Fax/Telephone: Internet is a good option for people who do not have much time to commute from one place to another place to collect data and compare it. With the advancement in technology the world has become a smaller place where one person can access information about the other country sitting on the computer. This advancement in technology has made the work of researchers easier and less time consuming. Internet system plays a vital role in disseminating information, research findings and results. Fax and telephone can also be used where there is no internet facility and according to the urgency of the message. Toll free numbers also play a significant role when people want to communicate directly with officials and experts. In India, a toll free number 1097 is operational in more than 80 cities which people can make use of to seek clarifications and more information on HIV / AIDS.

1.5 CHOICE OF MEDIUM

While choosing the medium of communication one should keep in mind the following factors:

1. **Type of audience:** If the target audience we want to reach is educated, then the print form of communication may be used, but in case of uneducated audience, pictures, symbols or voice may be more suitable. Since levels of literacy tend to be lower in the rural than in the urban areas, radio serves as an excellent medium for reaching such audiences in many countries. Also, traditional forms of communication, such as folk songs, puppetry, street plays could be used considering the type of audience setting.

2. **Sensitivity of the issue:** Many aspects in relation to HIV and AIDS are not suitable for communication through media of mass communication. When risk behaviours, stigma and discrimination are being discussed it needs a highly personalized setting. These topics then become part of the curriculum for out-

reach activities and are best handled by people who have undergone training for the same.

3. **Complexity of the issue:** Many of the issues of the pre-test and post–test counselling are of a highly personal nature. They demand a very professional approach and a completely confidential setting. Given this, the Integrated Counselling and Testing Centers (ICTC) provide a suitable setting for such an interpersonal communication.

4. **Cost of the medium:** Cost of the different channels of communication vary by type and also by country. Whereas TV productions and airtime may cost a lot of time, radio is much less expensive and can reach specific audiences (e.g. youth in the rural areas). Thus, cost plays a determining role in the choice of media.

5. **Prevailing social norms:** As is well known, cultural differences determine the openness with which people discuss issues that are related to sexuality or HIV transmission. For example, in many countries there may not be enough support to communicate on public media messages related to condom promotion. Alternatives, such as traditional media in the form of *kirtans* may be more acceptable to people.

6. **Proposed outreach:** Some messages are meant for coverage to a large segment of the population whereas others are for only a small population. Needless to state, interpersonal modes of communication are needed when messages need to be tailored to individual needs.

Check your progress II

Note: Use the space provided for your answer.

1) Discuss the factors that determine the choice of a medium of communication in the context of HIV/AIDS.

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1.6 CHALLENGES OF COMMUNICATION IN CONTEXT OF HIV /AIDS

Since HIV was first reported in 1981, professionals from various fields have made considerable progress in understanding the pandemic better. Research is tirelessly going on to find a cure for AIDS and meanwhile to develop a vaccine towards its prevention. Commitment from Governments across the globe has created special bodies to look into the problem, develop policies and implement programmes towards the mitigation of the pandemic. No doubt, there has been some success. At present, with much advanced drug therapies, the AIDS afflicted can lead a better life than before. The high cost of the drugs is also being supported by many governments.

This being the situation prevention is the best option among all strategies to combat AIDS.

If one takes a look at prevention strategies, they by and large comprise of screening blood supplies, creating awareness of HIV / AIDS through the mass media, and promoting safer sexual practices. As is well known the HIV is a silent and invisible virus and it does not debilitate for a number of years. A large proportion of those who are infected with HIV do not even know that they are carrying it. So, communication strategies have an immense responsibility of educating people about the virus, its means of transmission and how to prevent infection.

To understand the immense challenge that communication strategies face in the event of HIV and AIDS, one needs to understand the behaviours it is addressing. They are largely sexual behaviours which are private and personal; behaviours that are habitual and repetitive (such as drug abuse); behaviours that satisfy physiological and psychological needs; behaviours whose discussion is taboo in most societies; behaviours that are moralized upon and stigmatized by society. If these behaviours are contextualized they are behaviours that are shaped by deep rooted cultural traditions, and in a number of cases they involve interaction between parties that are unequal (as we see between a CSW and her client). To bring about change in these is by no way an easy task. It requires a lot of understanding of the social context in which they occur and also an approach that would be targeted group specific.

Those who are involved in HIV prevention are well aware that success of any HIV prevention strategy can be ascertained only when there is a response efficacy. Targeted populations have no immediate benefit to observe upon changing their behaviour, and most changes that have to be made are not individual. Either they need the cooperation of another partner and / or they need the availability of services and products (for example, a supply of condoms).

Another task at hand for communication specialists is reaching out to population groups that are difficult to reach by the conventional media channels. Commercial sex workers, truck drivers, and migrant populations are some such groups who are in need of special interventions. In many such cases, peer educators have been able to make the desired impact (Singhal and Rogers, 2003).

Experiences of countries across the globe show that in a few countries early prevention interventions have effectively reduced HIV prevalence rates. Reportedly, Uganda was the first country to reduce its HIV prevalence rates (Green et al, 2003). This success is largely attributed to open and effective communication and to the political will to fight HIV/AIDS.

Whereas on one hand these successes have been learning experiences, on the other the failure of the programme in many countries has provided much learning. As already discussed sexual behaviour is something that is too personal and irrational. Even where alcohol and drug intake are concerned, people have their own reasons for taking to them and for giving them up. Individual may or may not perceive themselves to be at risk for HIV infection because of their drug or alcohol consumption, what to say of their sexual behaviour. Not only this even after success in reverting their risk behaviours they may revert or ‘ backslide ‘ to their risky behaviours (Kakkar, 2005). Experiences have shown that cultural norms play a key role, such that programmes have to address the risk behaviours and the cultural norms. Also, advocacy and social mobilization are integral components of

communication programmes. Hence, communication strategies need to be tailored to special population groups. To conclude, it is well understood that there is a need to combine mass media with interpersonal channels, together with both social and community mobilization (McKee, 2004).

Many authors now advocate a combination of mass media communication with activities that allow for face to face interaction, such as community based events and interpersonal communication/counseling. According to McKee (2004), strategic communication combines elements such as extensive use of data, careful planning, stakeholder participation, creativity, and high quality programming.

Researchers have highlighted the need for a systematic approach in communication strategies for HIV/AIDS prevention. Since time and cost are high in the programme development, it is imperative to have a scientific base to all intervention strategies and do away with adhoc approaches. In this regard, strategic communication would combine a series of elements, extensive use of data, careful planning, stakeholder participation, creativity, high quality programming, and linkage to other programme elements. When programmes are designed on the basis of data they would certainly have a better chance of being successful. Hence, specific expected outcomes must be set before each programme is designed. Whereas, the targets could be raising awareness and increasing condom use, now these need to be more specific. For example, in a particular community the objective could be to have 25 per cent of the youth to access HIV testing centers and get themselves tested in a period of two months. It goes without saying there has to be services of an Integrated Counselling and Testing Centers (ICTCs) available right there. Success of a communication strategy would thus be assessed on the basis of outcomes, i.e. how many youth accessed the services of an ICTC in the specified period.

Segmentation of the targeted audience has been shown to be of importance in communication for HIV prevention (Kakkar, 2005). Usually when messages are created for some vulnerable groups, they tend to bring forth an adverse response from the general population. They tend to disregard the messages as they link the risk not to certain behaviours but to certain groups. Interventions have to be designed so as to use the channels that reach the vulnerable groups, without drawing the attention of the general population, making the message audience specific and also highlighting the risk behaviours and not the risk groups.

Evidently, development of communication strategies for HIV and AIDS mitigation is no small task. It has to have a sound data base and also fall back on theoretical concepts. Also, research is needed at all stages of programme planning, designing and monitoring and evaluation. This would help in taking mid-way corrective actions and make the interventions more cost effective. Research generated knowledge on media usage and access is also of tremendous use. For example, it is important to have data on television viewer-ship and the best time slots to make space for AIDS prevention messages. Not only this, use of multiple channels is of great benefit. Here the radio, television and print media reinforce the messages for their maximum impact. Furthermore it is important that the services promoted by the media are actually available in that community for the audience to make use of.

Check Your Progress III

Note: Use the space provided for your answer.

1) Discuss the challenges faced while developing communication strategies for HIV/AIDS prevention.

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1.7 BEHAVIOUR CHANGE COMMUNICATION - AN APPROACH

Behaviour Change Communication (BCC) is an interactive process with communities (as integrated with an overall program) to develop tailored messages and approaches using a variety of communication channels to develop positive behaviours; promote and sustain individual; community and societal behaviour change; and maintain appropriate behaviours. In the context of the AIDS epidemic, BCC is an essential part of a comprehensive program that includes both services (medical, social, psychological and spiritual) and commodities (e.g., condoms, needles and syringes). It is important for individuals and communities to understand basic facts about HIV and AIDS, adopt key attitudes, learn a set of skills and be given access to appropriate products and services when they start to identify their risk behaviours and move towards making changes.

All behaviour change is not unidirectional. People can adopt safe sex practices and may well revert to their old patterns of risk behaviours. It is important therefore that they are supported in these efforts and helped in sustaining positive changes. They must also perceive their environment as supporting behaviour change. Also, they need easy accessibility to appropriate treatment for prevention, care and support. In most parts of the world, HIV is primarily a sexually transmitted infection (STI). Development of a supportive environment requires national and community-wide discussion of relationships, sex and sexuality, risk, risk settings, risk behaviours and cultural practices that may increase the likelihood of HIV transmission. A supportive environment is also one that deals, at the national and community levels, with stigma, fear and discrimination, as well as with policy and law. The AIDS epidemic forces societies to confront cultural ideals and practices that can contribute to HIV transmission. It needs people to go deep into the social fabric and be able to pick on the cultural practices and traditions that make up for increased vulnerability of some sub-populations to the HIV infection. BCC as a strategy then sets the tone for compassionate an\d responsible interventions.

BCC is an integral component of a comprehensive HIV/AIDS prevention, care and support program and has several roles to play. It has a number of different but interrelated roles. Effective BCC can first and foremost increase knowledge. BCC can ensure that people are given the basic facts about HIV and AIDS in a language or visual medium that they could be understood and related to. Next, it helps to stimulate community level dialogue. BCC can encourage community and national discussions on the basic facts of HIV/AIDS and the underlying factors that contribute

to the epidemic, such as risk behaviors and risk settings, environments and cultural practices related to sex and sexuality, and marginalized practices (such as drug use) that create these conditions. Further, it can also stimulate discussion of healthcare-seeking behaviors for prevention, care and support. BCC can lead to appropriate attitudinal changes about perceived personal risk of HIV infection, belief in the right to compassionate and non-judgmental provision of services, greater open-mindedness concerning gender roles and increasing the basic rights of those vulnerable to and affected by HIV and AIDS.

Communication about HIV prevention and AIDS mitigation should address stigma and discrimination and attempt to influence social responses to them. No doubt it has a number of objectives to fulfill. (a) BCC can spur individuals and communities to demand information on HIV/AIDS and appropriate services. (b) BCC can lead policymakers and opinion leaders toward effective approaches to the epidemic. (c) BCC can promote services for STIs, intravenous drug users (IDUs), orphans and vulnerable children (OVCs); voluntary counseling and testing (VCT) for mother-to-child transmission (MTCT); support groups for PLHA; clinical care for opportunistic infections; and social and economic support. (d) BCC programs can focus on teaching or reinforcing new skills and behaviors, such as condom use, negotiating safer sex and safe injecting practices. It can contribute to development of a sense of confidence in making and acting on decisions.

1.8 COMBATING STIGMA AND DISCRIMINATION

Stigma and discrimination are still an everyday experience for PLWHA (People Living with HIV and AIDS) and vulnerable populations, yet their complexity and diversity in practice, coupled with the failure to develop a greater understanding of their social roots, means they are often not addressed effectively. Stigma and discrimination are an example of where communication can be both part of the cause and the cure of social barriers. Stigma reflects existing social inequalities, since HIV is often associated with groups that are already marginalised in a way that compounds their marginalisation. Communicating that HIV/AIDS need not be a death sentence, and that households do not have to face them alone can be a vital source of hope. It can also make inroads into the stigma surrounding the epidemic. Reactions of denial and avoidance can often be a desperate coping mechanism for those faced with the prospect of caring for family or friends when their own households are near collapse. In this context, providing resources to strengthen community responses – including the possibility of treatment – can give people hope.

Addressing the barriers to universal access

Although few campaigns against stigma have been successful, breaking the silence around HIV/AIDS and moving discussions from the personal sphere to interpersonal and public arenas can help overcome it. Mass media have stimulated discussion through high-profile human interest stories featuring prominent individuals who put a human face to the epidemic.

The challenge for communication is how to move the issue of HIV and AIDS from a high taboo end towards a less taboo end. By having open discussions and being able to talk on the issue we can break the silence. This would be the first step in breaking the silence and reducing the stigma associated with AIDS.

One way in which a sexually taboo subject can be brought out in the open is by the

use of symbols. In the case of AIDS it has been the red ribbon. It is a symbol that is identified internationally with AIDS. The ribbon is distributed with pins, is placed on T-shirts, on caps, and posters and pamphlets. It is widely circulated by volunteers on the World AIDS Day that is observed on December 1st each year across the globe. In this way, without too many words, people can wear the ribbon and express their concern and support for those who are suffering from HIV and AIDS.

A range of communication approaches have helped reduce stigma by promoting discussion and awareness of the realities of living with HIV/AIDS. Initiatives include: discussion forums and publications to raise awareness on the situation of older people as carers in Zimbabwe; youth care-givers who have promoted awareness about transmission risks, family reconciliation and community discussions in Zambia; radio listening clubs to promote discussions of stigma in Malawi; and awareness raising and training with healthcare worker and faith groups in Ethiopia and Rwanda.

Another way to tackle stigma is through sustained dialogue within communities, using participatory approaches. Communication can help challenge stigma and discrimination at a range of levels, including advocacy, to ensure that policy and laws do not perpetuate discrimination enacting policies in institutional contexts like schools, workplaces and healthcare settings, promoting accurate information and frank dialogue with communities and households, as well as human interest stories in the media.

Innovative techniques, such as humour, have been used to help overcome the taboo over discussions on HIV and AIDS. These techniques are in particular of great success when discussions are held with adolescents and youth in a community setting. Many successful condom promotion drives have been handled by individuals who have made use of culturally appropriate humour to reach across with their message.

Sometimes barriers of communication can be broken when the audiences are captured in a place where they feel the much desired anonymity to have a discussion on an issue they are ‘shy’ to talk about. In conservative societies such as India, men are too hesitant to go to buy a condom from a chemist shop and even find it more difficult to have an open dialogue on sexuality with a health-care provider or a counselor. Definitely other ways are used to have such a dialogue.

Many organizations have made successful interventions by locating their programmes at the barber shops. Reportedly, in some localities of Tamil Nadu, men often have their beards and hair trimmed before visiting a commercial sex worker (Singhal and Rogers, 2003). The barbers now supply free condoms to their clients. The barbers are provided training and they take pride in their new role.

Many groups of People With AIDS have taken up the issues of discrimination. They have organized anti – discrimination campaigns using diverse communication techniques. These campaigns have been designed to reduce prejudice against groups such as the gays, injection drug users, and commercial sex workers. Campaigns have sometimes been led by political leaders and film personalities. The messages of these people of non – discrimination have reached out and made a significant impact. In India, a network of People Living with HIV/AIDS (INP+) was formed in 1997 by twelve persons in Chennai. They also have their divisions in other cities.

BCC and approaches towards stigma and discrimination: Stigma can manifest itself in a variety of ways, from ignoring the needs of a person or group to psychologically or physically harming those who are stigmatized. Stigma is often felt by PLHA, men who have sex with men (MSM), sex workers (SWs), IDUs, migrant populations

and others. The importance of addressing stigma in the context of BCC campaigns has programmatic implications that transcend questions of compassion and humane treatment. Failure to address stigma jeopardizes BCC programs in multiple ways: **Prevention** – BCC programs that fail to address stigma allow some people to ignore the messages of HIV prevention. Stigma can cause people to perceive individuals with or at risk for HIV as "*them*", reinforcing their feeling that HIV is not their illness. Failure to address stigma can also deter individuals from seeking out VCT and proper medical care, including MTCT prevention services. Stigma is also sometimes attached to carrying condoms. Stigma can work against prevention programs; for example, an outreach or peer education program for MSM, IDUs, or CSWs can be damaged by "round-ups" and detention of beneficiaries. **Quality of care** – Stigma can perpetuate harmful practices, such as discrimination against or poor treatment of PLHA, IDUs, MSM, or CSWs. **Policy** – Programs that fail to address stigma help perpetuate discriminatory laws and practices and, in some cases, result in failure to enforce laws against them. Such programs also miss an opportunity to influence policy direction. BCC programs that address stigma can work with and employ people from traditionally stigmatized groups, such as PLHA, SWs and MSM, as advocates for policy change. Such individuals can also serve as dedicated caregivers, social workers, peer educators and role models for change.

1.9 COMMUNICATION STRATEGIES FOR SPECIAL POPULATIONS

We have already discussed the significance of targeted interventions in the context of HIV/AIDS. Targeting is the process of customizing the design and delivery of a communication programme according to the characteristics of the intended audience. In this sense not only is the message to be conveyed but it has to be done in a manner which is culturally sensitive and appropriate. This can well be achieved when the targeted audience is involved in the programme in different ways that could be from the stage of research, designing to delivery or implementation. When such tailored messages are prepared and sent out to these special groups, they have an immense impact. For example, the Healthy Highways Project with truck drivers or the Sonagachi Project in Kolkata which will be discussed later.

If we take a look at commercial sex workers, they are undoubtedly a special group to whom messages have to be tailored. They have multiple sex partners, their clients. These clients can further pass on the virus to their spouse, who in turn can give birth to HIV infected children. Thus it is very important to develop specific interventions for the CSWs. The approach of having peer educators, that is, having persons from within the group to give the message to others, is an effective technique. The credibility of the researcher is high as he is perceived by the audience as 'one of us'. Most peer educators are themselves sex workers. When they begin education work, they are given training. They may continue with their sex work and being in the same work, have a relationship of trust with their audience. Also, their credibility is higher because they are from the same socio-economic background. They are trained to first establish a relationship, understand the problem, then reach out with the relevant messages and to do follow-ups if they want to change the individual's behaviour. This one to one approach works well with special groups.

One successful intervention that needs to be studied is the Sonagachi Project in Kolkata. The CSWs of this area are well organized. They have organized themselves and take up the cause of their members in relation to police harassment, education of their children, and small savings. Interventions were started in this area by training and mobilizing 180 CSWs and 100 other outreach workers. They led the programme

and motivated their peers to use condoms. As a result of this condom use escalated and this area has a very low HIV prevalence rate.

The Healthy Highways Project is another project in which the communication strategy needs to be highlighted. In this programme messages of safe sex had to be communicated to a very diverse group that is of truckers. The truck drivers and their assistants are usually on the move for as much as 25 days in a month. Being away from their spouse, they engage in sex with CSWs on the highway 'dhabhas' and also with other men. This project was started in 1997 with funding from DFID. The project reached out successfully to truckers in Andhra Pradesh, Karnataka and Tamil Nadu, bringing down STD prevalence and taking up condom use. Behind this was a lot of effort of preparing the communication material, mainly in the form of flip charts which were produced after a lot of formative research. Two characters were created, namely 'Ustaad' and his companion 'Vijay'. The communication material was generated in many different languages. Well trained outreached workers were then given this task of accessing the truckers at the waiting points on the highways.

Likewise, another success story of apt communication strategies in HIV prevention may be briefly mentioned here. Since ages, people from Ganjain district of Odisha (also from many other districts) migrate to Surat of Gujarat to work in cloth-mills. The migrants were vuluerable to HIV infection and they did not understand Gujarati. Orissa State AIDS Control Society and Gujarat State AIDS Control Society joined hands together and published material in Oriya for migrants staying in Gujarat. This proved beneficial experiment in prevention of HIV.

1.10 LET US SUM UP

In this unit you have learnt about the importance of communication in the context of HIV and AIDS. Both traditional and modern means of communication are important and can be made use of in transmission of messages. Since there is a need to tailor messages and reach out to the targeted audiences, communication strategies should be based on research. Communication strategies have to address the special issues of the vulnerable groups. Also, communication has a major role to play in combating stigma and discrimination.

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UNIT 2 MODELS OF BEHAVIOUR CHANGE

* *Jyoti Kakkar*

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2.0 OBJECTIVES

This Unit discusses the importance of understanding the dimensions of behaviour change in the context of HIV prevention. Various theories have been put forth to understand the context of AIDS. Concepts that are significant in the context of behaviour change, such as perceived susceptibility to harm, self-efficacy and also AIDS decision making are presented. It is well understood that being informed alone is not enough for people to initiate change in their risk-related behaviours. There are many other factors interplay to modify human behaviour. This unit will dwell into some of the most significant theories.

2.1 INTRODUCTION

As it is well known, a number of health problems have linkages with human behaviour. Many are easily linked to illness and disease. For example, consumption of tobacco is linked to many serious problems such as cancer. The behaviour – health link becomes clearer when examining the ten leading risk factors identified by the WHO for preventable death and disease the world over: maternal and child underweight; unsafe sex; high blood pressure; tobacco; alcohol; unsafe water; poor sanitation and hygiene; high cholesterol; indoor smoke from solid fuels; iron deficiency; high body mass index; or overweight. According to WHO, 40 percent deaths are due to these ten risk factors. It is well said that global life expectancy would go up by atleast 5 to 10 years if health promoting decisions would be taken by individuals, families, communities, and governments.

Risk factors translate into disease, disability and death. These then get classified into what is referred to as the 'burden of disease'. One can well understand that addressing risky behaviours rather than specific diseases is more cost effective. One risky behaviour can result in a host of diseases. Under-nutrition is itself a cause of as many as 60 percent of child deaths. In the same way unsafe sex can lead to a multitude of problems such as cervical cancer, unwanted pregnancies, sexually transmitted diseases and HIV. So we can well understand that behaviour has a significant role to play, both in the causation and management of illness.

* *Prof. Jyoti Kakkar, Jamia Milia Islamia, New Delhi*

The prime question that emerges is that can behaviour be influenced sufficiently to bring about this change and achieve health related goals? Behavioural science suggests that we can and offers evidence based theories of behaviour change.

2.2 UNDERSTANDING AND INFLUENCING HUMAN BEHAVIOUR

Human behaviour is multi-dimensional and complex. Though some generalizations can be made, individuals are unique in their perception of situations and more so in their response. Further individuals vary within groups and each group varies from others. However, considerable amount of research has been undertaken to understand and shed some light on the behaviour of individuals. The theories that have thus been propounded help in having a better insight into human behaviour and hence develop interventions that would guide behaviour in a positive direction.

Why is theory important? Theory is important because it goes beyond trying to explain actions or inactions of specific individuals to provide a unified basis for understanding, predicting to the extent possible, and influencing human behaviour in general. Earlier thinking on behaviour change primarily gave importance to sending messages using appropriate media. The messages were targeted to certain population groups considered vulnerable. For example, sending messages such as 'Use condoms, practice safe sex always' were common for AIDS awareness and safe sex. By and large this communication was unidirectional. Over the years the approach has changed. There is formative audience research on the relevant audience. Planning involves designing the intervention strategy, skill building, multi-chanelled education and advocacy using influential persons, community mobilization. It is now well understood that behaviour does not occur in isolation. The context has to be well understood for effectiveness of the intervention for HIV prevention. To illustrate this, if a young man has been motivated by media outreach programmes and perceives his behaviour as risky and determines to use condoms, he may not be able to put his determination into action. There are many things that may come in his way such as, peer influence, non-availability of condoms at affordable price or even non-availability of condoms at local health clinics. To conclude, behaviour change needs to place in a wider context, where organizations and systems have to play a supportive role.

HIV/AIDS has been extensively studied in the last three decades. Basic research, clinical research, epidemiological research across various countries of the world has contributed towards a better understanding of the virus. A large number of studies have been undertaken on AIDS awareness and prevention looking into the role of mass media and modalities of behaviour change among different population groups.

2.3 MODELS OF BEHAVIOUR CHANGE

In these models of behaviour change the individual is the most basic unit of behaviour change. Individuals can be reached out at any level – groups, organizations, communities and nations. Health professionals spend a large amount of their time in face to face interactions such as in giving instructions and in clients. In most cases of interventions for behaviour change, as also in the case of HIV/AIDS prevention, these efforts have been largely supported with generation of reading and visual materials such as pamphlets, booklets, videos and posters. These apart, mass media reaches out to the masses with the use of print and electronic media. These efforts are now supported by theories that highlight the need to have multi-dimensional

HIV/AIDS prevention and all this based on certain basic research and also on established theories.

In the past three decades AIDS has thrown up several challenges to professionals from diverse disciplines. A major concern for the professionals has been to provide treatment, care and support to the AIDS afflicted and to those who are close to them. The already prevalent health care systems have been burdened and strained. In doing so, the paucity of funds and of trained human resources has always been a major concern. Not only this, the factors that lead to the spread of HIV have entirely different dimensions; risky health related behaviours to name one. Human behaviour is contextual and unpredictable. Social and behavioural sciences have an urgent task to develop effective methods of conveying information that will effect attitudes and belief systems that influence risk behaviours. Towards this considerable research has been conducted. It focuses mainly upon self directed behaviour change that is a function of perception of risk, psychological assessment of costs and benefits, efficacy of change, etc. All these theories are useful when interventions are planned and designed, In light of the fact that in the case of HIV/AIDS, prevention is the best course of action, these theories must guide our interventions.

In AIDS prevention, we are primarily concerned with behaviours and not with populations. It is true that some segments of the population are more prone to be engaged in risk behaviours than others, but it is behaviour that puts a person at risk, and not their affiliation with any group. For this reason, prevention and care would depend upon their ability to influence specific behaviours.

Theory of Reasoned Action

This theory was propounded by Ajzen and Fishbein in the year 1980. The assumption of this theory is that humans are reasonable persons who, in deciding what action to take, systematically process and use whatever information they have. In this theory it has been stated that although substantive specifics are expected to differ from one behaviour to another, and from one population to another, the theory argues that most behaviours can be understood in terms of the same small set of theoretical constructs and psychological processes. The theory links behaviour to intentions, intentions to a combination of norms and attitudes, and attitudes and norms to behavioral and normative beliefs.

Research using the Theory of Reasoned Action (TRA) has explained and predicted a variety of human behaviors since 1967. Based on the premise that humans are rational and that the behaviors being explored are under volitional control, the theory provides a construct that links individual beliefs, attitudes, intentions, and behavior (Fishbein, Middlestadt and Hitchcock, 1994). The theory variables and their definitions, as described by Fishbein et al. (1994), are:

l. **Behaviour:** A specific behaviour is defined by a combination of four components: action, target, context, and time, e.g., implementing a sexual HIV risk reduction strategy (action) by using condoms with commercial sex workers (target) in brothels (context) every time (time).

2. **Intention:** The intent to perform a behavior is the best predictor that a desired behavior will actually occur. In order to measure it accurately and effectively, intent should be defined using the same components used to define behavior: action, target, context, and time. Both attitude and norms, described below, influence one's intention to perform a behavior.

3. **Attitude:** A person's positive or negative feelings toward performing the defined behavior.

When any behaviour is studied, its performance or non-performance depends upon the individual's intention to perform that behaviour. To change behaviour one must change the intentions of the person to perform and sustain that behaviour, and this change in intention has to be in the context of target, action, context and the time. In order to change the behaviour, attitudes and normative beliefs cannot be ignored.

Behavioural Beliefs: Behavioural beliefs are a combination of a person's beliefs regarding the outcomes of a defined behavior and the person's evaluation of potential outcomes. These beliefs will differ from population to population. For instance, married heterosexuals may consider introducing condoms into their relationship an admission of infidelity, while for homosexual males in high prevalence areas it may be viewed as a sign of trust and caring.

Norms: A person's perception of other people's opinions regarding the defined behavior.

Normative Beliefs: Normative beliefs are a combination of a person's beliefs regarding other people's views of a behaviour and the person's willingness to conform to those views. As with behavioural beliefs, normative beliefs regarding other people's opinions and the evaluation of those opinions will vary from population to population. The TRA provides a framework for linking each of the above variables together. Essentially, the behavioural and normative beliefs — referred to as cognitive structures — influence individual attitudes and subjective norms, respectively. In turn, attitudes and norms shape a person's intention to perform a behaviour. Finally, as the authors of the TRA argue, a person's intention remains the best indicator that the desired behavior will occur. Overall, the TRA model supports a linear process in which changes in an individual's behavioural and normative beliefs will ultimately affect the individual's actual behaviour. The attitude and norm variables, and their underlying cognitive structures, often exert different degrees of influence over a person's intention. For example, results from a study of northern Thai males revealed that men's perceptions of peer norms were the best predictor of condom use (VanLandingham, Suprasert, Grandjean and Sittitrai, 1995). To date, behaviours explored using the TRA include smoking, drinking, signing up for treatment programs, using contraceptives, dieting, wearing seatbelts or safety helmets, exercising regularly, voting, and breastfeeding.

Limitations: Some limitations of the TRA include the inability of the theory, due to its individualistic approach, to consider the role of environmental and structural issues and the linearity of the theory components (Kippax and Crawford, 1993). Individuals may first change their behavior and then their beliefs/attitudes about it. For example, studies on the impact of seatbelt laws in the United States revealed that people often changed their negative attitudes about the use of seatbelts as they grew accustomed to the new behaviour.

Stages of Change Theory

Mounting evidence suggests that behaviour change occurs in stages or steps and that movement through these stages is neither unitary or linear, but rather, cyclical, involving a pattern of adoption, maintenance, relapse, and readoption over time. The work of Prochaska and DiClemente (1986) and their colleagues have formally identified the dynamics and structure of staged behaviour change. In attempting to explain these patterns of behaviour, Prochaska and DiClemente developed a

transtheoretical model of behavioural change, which proposes that behaviour change occurs in five distinct stages through which people move in a cyclical or spiral pattern.

The first of these stages is termed **precontemplation**. In this stage, there is no intent on the part of the individual to change his or her behaviour in the foreseeable future. The second stage is called **contemplation**, where people are aware that a problem exists and are seriously considering taking some action to address the problem. However, at this stage, they have not made a commitment to undertake action. The third stage is described as **preparation**, and involves both intention to change and some behaviour change, usually minor, and often meeting with limited success. **Action** is the fourth stage where individuals actually modify their behaviour, experiences, or environment in order to overcome their problems or to meet their goals. The fifth and final stage, **maintenance**, is where people work to prevent relapse and make efforts so as to sustain these changes. The stabilization of behaviour change and the avoidance of relapse are characteristic of the maintenance stage. Prochaska and DiClemente further suggest that behavioural change occurs in a cyclical process that involves both progress and periodic relapse. That is, even with successful behaviour change, people likely will move back and forth between the five stages for some time, experiencing one or more periods of relapse to earlier stages, before moving once again through the stages of contemplation, preparation, action and eventually, maintenance. In successful behavioural change, while relapses to earlier stages inevitably occur, individuals never remain within the earlier stage to which they have regressed, but rather, spiral upwards, until eventually they reach a state where most of their time is spent in the maintenance stage. Further work undertaken and reported by Prochaska et el (1992) suggests that behaviour change can only take place in the context of an enabling or supportive environment. Prochaska's and DiClemente's model has received considerable support in the research literature.

An important aspect of both Prochaska's and DiClemente's approach is that each of the five stages of behaviour change is said to involve different cognitive processes and require different treatments or intervention strategies for the overall change process to be successful. Other researchers also propose that different stages in the change process require different intervention strategies, and generally recommend a multifaceted, community-based approach to intervention in which all stages are addressed so that individuals at all stages of "readiness for change" can potentially be influenced.

Social Cognitive-Behavioural Theories

Social Cognitive Theory explains human behaviour in terms of a triadic, dynamic and reciprocal model in which behaviour, personal factors, and environmental influences interact. It addresses both the psychological dynamics underlying behaviour and their methods for promoting behaviour change. It is a very complex theory and includes many key constructs. Self-efficacy is one of the key concepts.

Self-efficacy refers to one's confidence in the ability to take action and persist in action. It is seen by Bandura (1986) as perhaps the single most important factor in promoting changes in behaviour. Measures of self-efficacy and some of the other key concepts from Social Cognitive Theory have also been identified as key determinants of movement through the stages of change, (Oldenburg, 1999). Self-efficacy expectations have been found repeatedly to be important determinants of:

a. the choice of activities in which people engage

b. how much energy they will expend on such activities and

c. the degree of persistence they demonstrate in the face of failure and/or adversity.

In general, higher levels of self-efficacy for a given activity are associated with higher participation in that activity.

Learning and Behaviour Theories

Learning theorists have demonstrated that behaviour can be changed by providing appropriate rewards, incentives, and/or disincentives. In learning or behaviourist approaches, such rewards and incentives are typically incorporated into structured reinforcement schedules, and the process of behaviour changes is often termed behaviour modification.

While effective in bringing about behaviour change, such approaches require a high level of external control over both the physical and social environment, and the incentives (or disincentives) used to reinforce certain behaviours and discourage others. This kind of control is hard to maintain in real life settings, and thus, strict behaviourist approaches are subject to a number of limitations.

Social Learning Theory

Social learning theory is similar to learning and behaviour theories in that it focuses on specific, measurable aspects of behaviour. Learning theories, however, view behaviour as being shaped primarily by events within the environment, whereas social learning theory views the individual as an active participant in his or her behaviour, interpreting events and selecting courses of action based on past experience. The theory analyses psychosocial influences arising from the interaction of individual factors, the social environment, and experience. While the physical and social environment shapes behaviour, people are not passive in the process, since they in turn can act to change their environments.

According to Murphy (2005) the theory emphasizes behavioural capability: A person needs to know what to do and how to do it. There may be a need for training. She further states that self – efficacy is very important, that is a person's belief and confidence in one's ability to make the desired change. It is very important to bring about health related changes and recommends three ways of bringing about health related behaviours:

(a) Setting small, incremental goals – when one sets small goals and is able to achieve them, his or her self-efficacy increases. Changes targeted or desired then seem attainable.

(b) Behavioural contracting – agreeing to a formal process that specifies goals and rewards. It implies that individuals will receive feedback, guidance and praised for the progress made by them.

(c) Self-monitoring – feedback from self-monitoring or record keeping, such as keeping a journal, can reinforce determination to change and increase confidence in one's ability to achieve the desired action.

One important theory deriving from Social Learning Theory which has had a major impact on many current models of behaviour change is that of self-efficacy. As stated earlier, self-efficacy has to do with a person's beliefs in his or her abilities to successfully execute the actions necessary to meet specific situational demands. Such expectations have been found to be consistently related to behaviour for change or modification across a wide range of situations and population sub-groups.

Social Psychological Theories

Social Psychological theories are concerned with understanding how events and experiences external to a person (i.e. aspects of the social situation and physical environment) influence his or her behaviour. Emphasis is placed on aspects of the social context in which behaviour occurs, including social norms and expectations, cultural mores, social stereotypes, group dynamics, cohesion, attitudes and beliefs. A number of useful concepts have emerged from social psychological theories, including *attribution*, *locus of control*, and *cognitive dissonance*, to name a few.

Social Cognitive Approaches

Social cognitive approaches combine aspects of social psychological theories with components of both social learning theory and cognitive behavioural approaches. Social-cognitive approaches emphasize the person's subjective perceptions and interpretations of a given situation or set of events, and argue that these need to be taken into account if we are to understand adequately both behaviour and the processes of behaviour change.

A number of social psychological concepts have been found to be consistently related to behaviour change across a wide range of situations. For example, the social reality of the group (e.g. peer group, school group, family group etc.) will affect an individual's behaviour. All groups are characterized by certain group norms, beliefs and ways of behaving, and these can strongly affect the behaviour of the group members.

Expectations of significant or respected others can also have a strong influence on a person's behaviour. This phenomenon has been most consistently demonstrated in the early research on self-fulfilling prophecies, which showed that teachers' expectations of their students were consistently related to the students' subsequent performance, even when these expectations were based on falsified information. Thus, support and encouragement, or conversely, low expectations from significant or respected others, can affect and bring about (or not), changes in individual behaviour.

Health Belief Model

The Health Belief Model attempts to explain health-behaviour in terms of individual decision-making, and proposes that the likelihood of a person adopting a given health related behaviour is a function of that individual's perception of a threat to their personal health, and their belief that the recommended behaviour will reduce this threat. The model has been extensively used in studies of compliance in the context of health. In this model it is theorized that people are afraid of getting seriously ill and the health related behaviours (or health seeking behaviour) reflect the level of threat perceived and a person's expected fear reduction potential of taking action. Individuals calculate the net benefits of changing their behaviour. According to Kirscht and Joseph (1989) there are four components in this model: personal susceptibility to a negative heath condition; the perceived severity of the condition; the value of a behaviour; and barriers to action. The summation of all these create a situation where the individual's readiness to act comes forth. With circumstances being conducive, action is enacted and behaviour change may take place. Rosenstock (1974) suggested that a cue was necessary for action to occur. Some others added self-efficacy as an important element for change to occur.

Thus, a person would be more likely to adopt a given behaviour (e.g. walk or cycle regularly) if non-adoption of that behaviour (e.g. unclean air or confused traffic situations) is perceived as a health threat and adoption is seen as reducing that threat. To date, the Health Belief Model has not received consistent or strong support in explaining behaviour change. When the concept of self-efficacy is added to the model, however, prediction of behaviour increases.

AIDS Risk Reduction Model (ARRM)

The Aids Risk Reduction Model has been developed by Catania, Kegeles and Coates (1989). It is a conceptual framework for organizing the factors that may influence the people's abilities to change high risk sexual behaviours. It has built upon the earlier models such as the health belief model, self-efficacy theory, help-seeking behaviour. ARRM organizes the predictors of health behaviour in general and sexual behaviour in particular. As is well known behaviour change is not unidirectional. People may move back to their earlier behaviours. The process of behaviour change is broken into several stages: (a) recognizing and labeling one's behaviour as high risk for contracting HIV, (b) making a commitment to reduce high-risk sexual contacts and increase low risk activities, and (c) seeking and enacting strategies to obtain these goals. ARRM suggests that to avoid HIV infection people exhibiting high–risk activities must first perceive their sexual behaviours as those that place them at risk for HIV infection. They should be willing to make a strong commitment for changing their activities; this may require that they decide if the behaviours can be altered or whether the benefits of change outweigh the costs. Also, they should be willing to seek help by obtaining solutions. Help can be from informal social support or from professionals. Finally, enactment of solutions would require complex negotiations with sexual partners. These three processes are also termed as labelling, commitment and enactment. They are neither unidirectional nor irreversible. Further each state is influenced by a number of extraneous factors such as salience, perception of sexual enjoyment, condom attitudes, negotiation with spouse, peer influence, etc.

Check Your Progress I

Note: Use the space provided for your answer.

1) What is the importance of the theories of behaviour change in the context of HIV Prevention?

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2.4 PERCEIVED SELF-EFFICACY

It goes without saying that prevention from the AIDS virus requires people to take control over their own motivation and behaviour. All social efforts are by and large directed towards spreading awareness on HIV and its modes of transmission. People are educated and the assumption is that once they are aware they will take appropriate self-protective action. Heightened awareness and knowledge of health risks are important pre-conditions for self-directed change. However, information alone does not determine action.

According to Bandura (1989) people need to be given reasons to alter risky habits but also the means and resources to do so. Success requires the skills necessary and also strong belief in one's ability to exercise control. Perceived self-efficacy therefore is the belief held by people that they can have a control over their motivation and behaviour and also their social environment. Self – efficacy determines how much effort people will put in and how long will they withstand all adverse pressures in order to continue and sustain the changes made by them. A number of research studies have been conducted on the influence of self- efficacy on behaviour change. They go to show that every aspect of behaviour change – whether people consider changing their health habits, how hard they try, how much they change, and how well they maintain the changes they have attained. If they perceive themselves as not competent to undertake such changes, it often leads to a feeling of dejection and consequent stress and depression.

It then emerges that information alone is not enough. Some elements determine the translation of knowledge into effective action for harm reduction. These are social skills and a sense of personal power to exercise control over risk situations and these are incremental in nature. Each positive change builds on the perception of self efficacy. Further problems emerge when self protective behaviour comes into conflict with interpersonal relationships. The weaker is the self-efficacy, the more the chance of the person succumbing to outside pressure.

2.5 PERCEPTION OF PERSONAL SUSCEPTIBILITY TO HARM

As researchers have studied human behaviour and the response of people, they have often reported of situations where with precautions certain ailments could have been avoided. Yet people refrain from doing so. According to Weinstein (1989) if the benefits of the preventive measure are uncertain and the burden of change substantial, it is not surprising that few people would respond. This failure to acknowledge personal vulnerability has long been considered to be a barrier to the adoption of prevention measures. A substantial amount of evidence has been put forth to show that people tend to be unrealistically optimistic about their susceptibility to harm. They may not claim they are invulnerable but they do claim that their chances of suffering negative events are smaller than the chances of their peers.

To further explain risk reduction behaviour, Weinstein has explained that there are many motivations governing risk relevant behaviours. For example, use of condoms is an important way of reducing risk of HIV. But use of condoms, is also equated with reduction in sexual pleasure, and demonstrates lack of trust in the sex partner. Similarly, cigarette smoking is well known to result in harm to the body. However, the motivation to continue smoking is related to peer pressure and coping with a stressful situation.

Apart from these motivations, there are some determinants of threat perception. People usually learn about threatful situations from their acquaintances or from mass media. Risk is not an individual judgement but also a social and cultural construct. Many times people have objected to an AIDS care home being set up in their vicinity without actually being aware of the threat to their own health. It is just something they have learnt without actually knowing about it. Salience is another component that may raise the perception of threat. Salient refers to 'vivid images and frequent reminders'. Persons who have seen the suffering of an AIDS afflicted person and his family's struggle to cope may adopt all risk reduction behaviors in order to minimize his risk. It needs to be pointed out that salience influences many social processes so it may not impact hazard response in many cases. Most decisions about hazard response are influenced by the way in which problems are presented.

Perceptions of Personal Vulnerability: Until and unless people believe that they are at risk they will not take precautions. There is a wide variation between objective and subjective risk. When people see data on road accidents, not many of them feel that it would have any meaning for them. The problem is similar in the case of AIDS. 'It cannot happen to me' is the response that most people have when they come across messages in the context of HIV/AIDS. The error on personal susceptibility usually is directional. Mostly people have an optimistic bias; they think that their own vulnerability to harm is less than that of their peers. Why do people show this optimistic bias?

Some researchers report that this bias is because of an attempt by the individual to completely deny that this problem could be related to him. This defense mechanism helps him to avoid the anxiety he would feel upon admitting his vulnerability. A second reason that is given for this optimistic bias, is denying ones risk to enhance or preserve their self esteem. Self esteem is most at risk if the hazards in question are such as are preventable by one's own actions.

2.6 DECISION MAKING ON AIDS

What are decisions? Decisions are a set of choices among alternative courses of action (including inaction). In the context of HIV/AIDS a number of decisions have to be taken which are in no way easy.

1) One of the foremost decisions is related to whether to be tested or not. This outcome of this test would impact the physical and mental health and also the social and economic aspects. A person may respond to a positive result by beginning to take good care of his or her health, or may go into a state of complete self neglect, thinking that whatever he may do, in the end he cannot escape from AIDS. The mental health of the individual depends a lot on the ability of the individual to deal with the result. A person who has received counselling and is in a state where he can cope with the result is on one extreme. The other side is of a person who is unable to handle this situation and denies to be tested. The result would no doubt have an impact on the social relations. Whether the person is ready to share the result with the sex partner and close ones, the person is in a state to cope with the consequences, such as of stigma and discrimination. The economic impact are obviously on the increased health expenditure, the risk of loosing ones job and housing.

2) Another area of decision making in the context of AIDS is reading and developing an understanding of the pandemic. How keen is the person to learn about AIDS and have clarity? Is the information given in that reading material, a brochure may be,

organized or scattered? A quick look over can help the person resolve whether he would like to proceed or not.

3) An area of decision making that is highly contextual, involves a decision to be taken on whether to ask the partner to use a condom or not. Doubtless, it would affect the social relations and the physical health of both. The trust or lack of it between the partners would influence their mental health.

How can one help in the decision making process?

As social workers we have to be very well aware of the social and psychological dimensions of HIV/AIDS. Every aspect of HIV involves decision making that is critical to the client's life. It is important to know how much information can be shared at what stage and also the preparedness of the client to take decisions on his own. Attention needs to be given to the most pressing concerns. Having decided what to communicate, the next concern is how to communicate? Some methods are available in the literature and others need to be developed. Many clients may need help in organizing their decision making process.

Check Your Progress II

Note: Use the space provided for your answer.

1) What kind of decisions have to be made in the context of HIV/AIDS? How can persons be helped in this process?

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2.7 OTHER CONSIDERATIONS RELEVANT TO BEHAVIOUR CHANGE

Behavioural scientists have collaborated and identified eight key variables that account for most of the variance in any given behaviour. These eight key factors identified are potential determinants for intervention and behavioural change. They include an individual's behavioural intention; environmental constraints; skill or ability; attitude or anticipated outcomes of a given behaviour; norms; self standards; emotional reaction and self-efficacy.

The theorists concluded that, generally speaking, for a given behaviour to occur, at least one of these eight factors must be true:

1. The person should have a strong positive intention (or made a commitment) to perform the behaviour
2. There are no environmental constraints that make it impossible for the behaviour to occur
3. The person has the skills necessary to perform the behaviour

4. The person believes that the advantage (benefits, anticipate positive outcomes) outweight the disadvantages (costs, anticipated negative outcomes) of performing a behaviour
5. The person perceives more social (normative) pressure to perform the behaviour than not to perform
6. The person perceives that performance of behaviour is more consistent with his/her self image than inconsistent, or that its performance does not violate personal standards that activate negative self-sanctions
7. The person's emotional reaction to performing the behaviour is more positive than negative
8. The person perceives that he or she has the capabilities to perform the behaviour under a number of different circumstances. That is, they have the perceived self-efficacy to execute the behaviour in question.

The first three factors are viewed as factors "necessary and sufficient" for generating behaviour. That is for a given behaviour to occur, an individual must (a) have strong intentions to perform the behaviour, (b) have the necessary skills to do so and (c) not be restricted by environmental constraints. The remaining factors are viewed as factors that can actively influence the strength and direction of behavioural intention. That is, these dimensions generate a degree of influence on changes in behaviour. In fact, the theorists argued that an individual will not form strong intentions to perform behaviour unless they perceive the positive outcome of performing the behaviour as greater than the negative or that they have the ability necessary to carry out the behaviour.

2.8 LET US SUM UP

In this Unit, you have learnt about the importance of understanding the dimensions of behaviour change in the context of HIV Prevention. Some of the concepts that are significant in the context of behaviour change, such as perceived susceptibility to harm, self efficiency and AIDS decision making have also been discussed under the unit.

2.9 FURTHER READINGS AND REFRENCES

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UNIT 3 COUNSELLING FOR HIV/AIDS: NATURE AND PROCESS

* Jyoti Kakkar

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3.1 Introduction
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3.5 Stages of Counselling
3.6 Skills of a Counsellor
3.7 Impact of Values and Attitudes of a Counsellor
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3.10 Characteristics of a Good Client
3.11 Let Us Sum Up
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3.0 OBJECTIVES

In the present unit, the learner will look into the definition and process of counselling. The process of counselling will be discussed, and an attempt would be made to elaborate on the skills necessary for a counsellor. Further, the characteristics of a good counsellor and its importance would be highlighted. The various ethical issues involved during counselling too, have been highlighted. Finally, counsellor would be placed in the context of HIV/AIDS (pre-test and post-test counsellor).

3.1 INTRODUCTION

Counselling is a process of helping a person to learn how to solve certain interpersonal, emotional and decisional problems. It is a process through which guidance and support are provided to persons with problems. In counselling, people are helped to help themselves. Counselling can be done with individuals, with couples or with families.

Counselling seeks to resolve personal and interpersonal problems through a variety of approaches, in a manner that is consistent with the values and goals of society in general, and the client in particular. Counselling is based on a special relationship. This unique helping relationship allows the client an opportunity to learn, feel, think, experience and change in ways that are socially desirable. Most people enter the counselling relationship voluntarily. Although clients typically expect the counsellor to resolve their difficulties, the counselling relationship is actually collaborative; i.e., the counsellor and client collaboratively work towards the goals of counselling, with the counsellor acting chiefly as a facilitator of behaviour change.

* *Prof. Jyoti Kakkar, Jamia Milia Islamia, New Delhi*

Specifically stating, counselling has five important goals, namely

1) to reduce the emotional distress in the client.
2) to alter dysfunctional behaviors of the client.
3) to facilitate better adaptation of the client to his environment, and to develop his innate potential,
4) to assist the client to make wise, appropriate and realistic decisions, as well as
5) to provide information.

While much of the work in counselling may involve one to one interaction with the client, interaction with significant other persons in the client's life can also contribute towards the attainment of the goals of counselling. To facilitate the achievement of the goals of counselling, the counsellor uses his/her understanding of behavior, learning and interpersonal relationship to establish conditions favourable for the client to change.

The nature, course and techniques of counselling vary widely across client groupings, such as in the case of individual counselling, couple counselling, group counselling, etc. It also varies widely across categories of clients, such as children, adolescents, families, alcohol and drug addicts etc. Finally, the nature, course and techniques of counselling may vary widely across clients even if the client belongs to the same category because it is assumed that each client is a unique person, different from the rest.

In the process, the client is respected and treated as an individual with worth and dignity. The process of counselling is client centered and special attention is given to each individual's unique issues and circumstances. The counsellor makes an attempt to develop autonomy and self-responsibility in the clients, which is similar to the social work principles respecting the client's right to self-determination. It needs to be highlighted that counselling is not telling or directing the client, nor is it advice giving.

In the context of HIV and AIDS, counselling has specific objectives. It is a confidential process of communication between the client and a caregiver/counsellor, and is aimed at *enabling* the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process involves an assessment of risk to HIV infection and transmission, facilitation of preventive behaviour as well as the evaluation of coping mechanisms when the client is in situations of stress.

3.2 HIV/AIDS COUNSELLING: NATURE AND PURPOSE

HIV/AIDS Counselling

Counselling poses an essential part of HIV antibody testing. HIV/AIDS Cousnelling is universally performed in two distinct phases - before (pre-test) and after testing (post-test) - regardless of the client's HIV status.

Counselling prior to the test, known as Pre-test Counselling, will help the client understand the test results and its implications. The counsellor may also undertake a risk assessment by reviewing along with the client possible sources of infection (Jose & Jyothiram, 2008). It would also teach the client how to protect her/him from the virus, and gain the knowledge of how to prevent the spread of HIV. During pre-test counselling, the counsellor usually explains the following:

the test and how is performed;

AIDS, associated diseases and the ways HIV infection is spread;

ways to prevent the spread of HIV;

confidentiality or anonymity issues of the test results;

meaning of the possible test results - "positive" and "negative";

importance of post-test counselling;

information regarding who will be communicating test result;

The importance of informing one's sexual and drug-using partner(s), in the event of a positive test result.

After the above clarifications, She/he is required to give voluntary consent to carry on with the testing. The client is then referred to the nurse or the technician for HIV Antibody Testing. NACO policy rules out any mandatory testing in HIV. The client is issued a PID slip (person identification digit which contains a code number, age and sex) and appointment for post-test couselling, before s/he is sent to the lab for testing (Jose & Jyothiram, 2008).

A major component of HIV pre-test counselling is the risk assessment of the client in relation of HIV infection. It is important that the counselor assesses the actual level of risk the client faces as against the client's perception of risk. For this, the counselor needs to ask explicit questions, about an individual's practices including sexual practices, drug using practices, occupational practices and receipt of blood products, organs or semen donation. A detailed risk assessment can:

- Promote greater awareness and cancern about STI and HIV : Many client will have the opportunity to obtain new information about HIV transmission.
- Provide an opportunity to extend prevention counseling and education : Clients have different behaviours having varied risk of HIV transmission (for instance all sexual behaviours do not have same risk of HIV transmission). Providing clients with information on the level of risk associated with different risk behaviours can assist them in choosing to engage in lower risk activities.
- Help in determination of necessary health investigations: Clients at risk of HIV many also require investigations for STI, TB and other illnesses. Counsellor, during risk assessment, may identify these risks and refer the clients to appropriate centres/services.
- Implications for treatment : A detailed risk assessment can help the physician in determining a post diagnostic treatment strategies. Clients who are thought to have recent infection of HIV will require different medical management as compared to those who are diagnosed with late-stage disease.
- Prepare the clients in accepting positive or negative results of HIV test.

Following the testing, or on a later date when the result is available the client is subject to Post-test Counseling.

Post-test Counselling is undertaken irrespective of the test results, whether positive or negative. During the post-test counseling the client is informed about the result and counselled to cope with the immediate reactions to the test result. The counsellor will help the client to integrate and understand the meaning of the test result at all levels - rationally, emotionally, behaviorally, and medically (Jose & Jyothiram, 2008). It is explained that a negative test result does not mean that the client is immune to

HIV. The client is educated how high risk behaviours - including having unprotected sexual intercourse with an infected person, sharing needles or syringes with an infected person - may transmit HIV. Usually during post-test, the counsellor will discuss such behaviours and also the implications of the window period. If tested positive for HIV antibodies, the counsellor will first provide supportive counselling and later assist in referring the client to a doctor who specializes in treatment and monitoring of HIV. In the event of financial difficulty a counsellor can help the client locate necessary resources. A counsellor will also insist and assist in notifying the sexual/ drug partners, and still further refer the client to a support group for people with HIV as a means of coping with the disease.

Nature and Puprose of HIV/AIDS Counselling

As is well known, the virus that causes AIDS, namely HIV is selective in nature. It infects people through specific modes only: sexual transmission, injectible drug abuse, and perinatal transmission. This being so, professionals from various disciplines, whether they be medicos, economists, psychologists, social scientists, teachers, or even voluntary workers, need to assign prevention the foremost priority. This being so, counselling for prevention and behaviour change assumes utmost significance.

The second major area that is covered by HIV/AIDS counselling is the diagnosis and treatment of HIV. The diagnosis of AIDS has many dimensions including social, psychological, and spiritual. The process of supportive counselling aims to help the clients cope with this stress. Finally, the clients have to learn to live with the diagnosis of being HIV positive. They face multiple dilemmas such as sharing of their sero-positive status, their rights to employment, rights to marriage and in the case of infected women, the critical decision on whether to bear children or not. Each stage involves serious thinking and decision making. Counselling therefore has an important role to play.

HIV/AIDS counselling has two general objectives

1. to provide psychosocial support to those already affected; and
2. to prevent HIV infection by change in lifestyle/behavior.

In order to achieve these objectives, counselling seeks to enhance self-determination, boost self-confidence, and improve family and community relationships and quality of life. HIV/AIDS counselling therefore also means providing support to families and loved ones, so that they, in turn can help to encourage and care for people with HIV infection.

HIV/AIDS counselling is strongly recommended for

- persons identified as having AIDS or being infected with HIV, and their families;
- those being tested (pre- and post -testing) for HIV;
- those seeking help because of past or current risk behavior and planning their future; and
- those not seeking help yet involving in risk behaviour.

With these priorities in mind, the types of situations in which counselling is of value, and people seek care, might include

- persons with AIDS or other disease related to their HIV infection (opportunistic illnesses);
- persons experiencing difficulties with employment, housing, finances, family, etc. as a result of HIV infection;

- persons considering being tested for HIV;
- persons who have been tested for HIV (whether or not they are infected);
- family and friends of persons infected with HIV;
- health workers and other professionals in regular contact with persons infected with HIV;
- persons who choose not to be tested despite past or present risk behavior; and
- persons' who are unaware of the risk of HIV infection involved in specific behaviors they have, or are, engaged in.

Being diagnosed as having, recognizing the possibility of, or suspecting the existence of HIV infection or AIDS all have profound emotional, social, behavioural, and medical consequences. The personal and social adjustment required in the context of HIV infection often has implications in diverse contexts - family life, sexual and social relations, work and education, spiritual needs, legal status, and civil rights. Adjustment to HIV infection involves constant stress management and adaptation. It is dynamic, evolutionary, and lifelong process that makes new and changing demands on individuals, their families and the communities in which they live.

During the course of HIV infection, a broad range of physical needs and problems are likely to be experienced. These are not necessarily constant, and will progressively become more serious and difficult to handle. These call for increased and different resource, both for those who are HIV-infected as well as for the people looking after them.

Check Your Progress I

Note: Use the space provided for your answer.

1) Define Counselling. What is the significance of counselling in the context of HIV/AIDS?

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3.3 COMPONENTS OF THE COUNSELLING RELATIONSHIP

Empathy

Sympathy means having feelings of regret about another person's situation, but empathy is a feeling of emotional connection with the client and his problems, as if you have experienced them yourself. By reflecting on the client's experiences and trying to connect with what he must be feeling, the counsellor may be able to experience the client's pain.

After greeting the client on his arrival, the counsellor may want to communicate something appropriate to show that s/he empathises with the client, based on what the counsellor knows about him. The counsellor will then assess whether the client is guarded (unwilling to "open up"), hostile (resentful or angry towards the counsellor) or tearful (on the verge of tears), and respond appropriately. For instance, the counsellor could say to a guarded client, *"Coming to counselling is a very difficult decision, and I really feel that you are very courageous to be here."* To a hostile client, the counsellor could say, *"I can understand that you are upset to be here, and I appreciate your honest feelings about me and this situation. I hope that you will tell me all about your feelings. I think you will begin to trust me in time and understand that I am here to help, not to hurt you."* Later on, the counsellor could say, *"Anger usually comes after hurt. I can see that you've been hurt very much."* To the tearful client, the counsellor could say, *"I can see how much pain you are feeling. Please just let yourself cry and I will sit here with you."* (Winiarski, 2004)

Belief in the dignity of the client

This is more than just accepting or tolerating a person. It communicates to the client that s/he is worthy of love and entitled to be treated a unique individual and that her HIV status makes no difference to the counsellor.

Respect for the client's agenda

Never attempt to transform the client into the person you think s/he ought to be. Such an attitude communicates: (1)"I know what is best…", (2) "I'm more important than you…", and (3) "You don't meet my standard…" This approach is devoid of any respect for the client, and is not a good way to enter into a relationship.

A non-judgmental presence

As we go about our lives, our heads are filled with judgments. For instance, we tend to opinion that "my neighbour talks too much", or, "my wife isn't fair to me". As we start learning how to counsel, such judgments often enter our thoughts and tend to be communicated through our words. A counsellor should never let them enter into the relationship. As a counsellor gains experience, it gets easier not to be judgmental. When a counsellor finds himself or herself being judgmental, he/she should ask herself, "What is making me judge this client?" She/he may have a deeply personal reason that is not too obvious. For example, an angry reaction to a client may be because the client's behaviour or comments provoke a memory for the counsellor. The role of the counsellor is not to judge. Critical judgments never help.

Skilful listening

Becoming a good listener takes some practice. You need to focus entirely on your client's speech, expressions and mannerisms. Taking note of the subjects that your client does not want to talk about will also tell you something about the person. Skillful listening leads to skillful responses that probe and challenge. These are important in helping a client to explore her feelings, understand problems and emotions, and come to terms with her situation.

Safety

The counsellor is responsible for the emotional as well as the physical safety of the client. This involves acting ethically and taking steps that involve the following:

Ensuring confidentiality

Since there is so much of stigma and discrimination surrounding HIV and AIDS, you may not tell anyone else about your client's without a written consent from the latter. There are exceptions to this rule. For instance, you may have to discuss your client with your supervisor, or you may have to report the client to the authorities if she threatens to harm someone else.

Never making promises that cannot be kept

It is human nature to say things like, "Every thing will be all right." We may do this automatically in an attempt to assure and make the client feel better. It is important to avoid such assurances because it ignores the reality of the client's situation and is probably not true. Quite often the things we say as counsellors are really to make us feel better as counsellors, rather than to reassure the client.

3.4 WHO IS A CLIENT?

A client is someone who agrees to counselling. The client brings along his/her problems, fears, suspicions and other emotions to the counselling sessions. The counsellor communicates only one request, one of openness, so that the client will try out the counselling process. The client need not be enthusiastic, and usually is not. There are scores of messages of acceptance and care that counsellors can communicate that can open up closed hearts. Sometimes the client is not just one person; there may be two or more people in a relationship, or even an entire family. In such cases, a skillful counsellor has a very clear idea of who the client is, and what his responsibilities are to each person.

Obvious needs

Most of us who work in the area of HIV / AIDS understand the critical needs of people living with HIV (PLHAs). Often, HIV and AIDS are not the most pressing issues, and not even close to what needs immediate attention. Often, a client's more critical problems include:

little or no money;

hunger, with no access to food;

illnesses - people with HIV/AIDS eventually contract "opportunistic infections" that occur when the body's immune system is unable to fight off organisms that cause sickness. Also, people with HIV also have other illnesses, such as high blood pressure and malaria;

difficulty in accessing health care - care if ever available, may be kilometres away and the client may not have transportation;

emotional distress - because of the lack of mental health care, many people have psychological difficulties that are not recognisable and hence may not be treated;

overwhelming family responsibilities - most of the cases are single women or widows with children. They have to sacrifice their own health and welfare for that of their children. Others may have taken in the children of their deceased relatives, or care for relatives who show up at their doors. There may still worse, be child-headed households in which children shoulder adult responsibilities;

Shame, **D**iscrimination, **S**tigmatisation;

destitution, homelessness or inadequate shelter.

3.5 STAGES OF COUNSELLING

The term 'process' refers to a sequence of events. There is a process involved in counselling while dealing with various situations. The process in counselling comprises of the following stages:

Stage One - Establishing Rapport - gaining the client's trust

Stage Two - Defining and understanding of needs, boundaries and roles

Stage Three - Ongoing supportive counselling

Stage Four - Closure or ending the counselling relationship

STAGE 1 - Establishing Rapport

This stage is characterized by the initial interview. It comprises of the first contact with the client and creating an ambiance for the client to trust aimed at disclosure. It includes completion of the intake process, which recruits the client into the formalities of counselling. The initial interview is much important for the following reasons:

1. It helps the counsellor get to know the client better, and plan appropriate intervention. These plans include taking up the client for counselling or referring the client to another, appropriate, treatment service;
2. It helps the client to get to know the counsellor better, and obtain reassurance and even crisis support, as necessary;
3. It allows the counsellor the opportunity to explain the nature and goals of counselling, and make the practical arrangements for counselling;
4. It is a stage at which the client the counsellor assures confidentiality to the client and discusses the limits of confidentiality;
5. All efforts are directed towards complete ventilation of feelings and statement of the problem in clear, unambiguous terms;
6. The counsellor answers all the questions of the client so as to clarify client's expectations of the counselling process;
7. By the end of this stage the counsellor describes the kind of help the counsellor can offer and also their commitment to work with the client;

Clients who come into therapy are seldom clear and concise in their communication. More frequently, their thoughts are muddled, and heavily laden with emotional content. Clients do not say, "I am anxious", or "I am depressed". Instead, they frequently commence with an account of what happened, where and when.

Such details are necessary, but it is all the more important for the counsellor to first understand what is bothering the client. This understanding provides the framework for an understanding of what the client subsequently describes. Therefore, the counsellor should gently but firmly encourage the client to clearly state the problem in a few words; to provide a bird's eye view, so to speak. Or, the counselor may even paraphrase whatever is being transpiring between them.

Once the counsellor has obtained a clear understanding of what the problem is, he needs to learn about its background. He needs as much information as is possible to make a systematic evaluation of the problem, its causes and its effects. The assessment so conducted provides the counsellor with a working model of the client's problem

situation. This working model is necessary because it guides the counsellor's thinking. This model, of course, needs to be continually updated with information obtained from subsequent sessions. It is important to ascertain the magnitude and extent of the client's problem situation, isolate his dysfunctional behavior, and to establish whether the client is amenable for counselling or whether further primary psychiatric intervention is necessary. In this context, it may be necessary to postpone completion of the intake process until a psychiatric evaluation rules out the existence of serious disturbances which require primary medical therapy.

STAGE 2 - Defining and Understanding of Needs, Boundaries and Roles

Problems seldom exist in a vacuum. They are generated by certain circumstances, and they, in turn, generate other problems. Thus, a client's problems cannot be satisfactorily addressed unless all the related issues are identified and tackled.

Family dynamics frequently contribute to circularity of problems. Therefore, while assessing circularity the counsellor must remember to evaluate each family member's role in symptom formation and symptom maintenance in order to identify the person's need for therapy. In this stage all efforts of the counsellor are directed at taking a detailed history with specific details. The counsellor clarifies client's needs, prioritizes them and then set the client's goals. While listening to the client, the counsellor makes a complete study of the client's beliefs, knowledge and concerns. Finally, he explains the roles and boundaries of the counselling relationship to the client.

During this stage a lot of importance has to be placed upon the clarification of expectations. As already stated, the counsellor needs to find out what the clients expects from counselling. Some client's believe that once they tell the counsellor their problems; it is the counsellor's responsibility (and not their own) to find the solution. Some clients believe that the counsellor will magically remedy problems that have existed for years. More specifically in the context of HIV/AIDS, the counsellor should take care to guard against unreasonable expectations, such as expectations of dramatic cures, total cures, one sided compromises, etc.

Also in setting of goals for the counselling process, the counsellor has to be very realistic. General goals of counselling are to reduce emotional distress, to reduce dysfunctional behavior (here, high risk behaviour), to promote adaptation, to help realise their potential, and to assist in decision-making. After obtaining a general understanding of the client's problems and expectations, specific goals of therapy need to be set. The counsellor needs to guide the client in the setting of specific goals because the client is quite likely to be uncertain of what may be expected from counselling.

Such goals are best explicitly stated as specific emotional and behavioral changes that are acceptable and desirable to the client and to society. Thus, an ethical element exists. It is important to break down the details of the goals into subcomponents which, by virtue of such identification, are more easily tackled. Such sub-components helps translating the goals to be specific, measurable, achievable, realistic, and more specifically timebound (SMART) in order to be translated into definite action (Jose, 2008). There is no bar to the number of goals as long as the goals are specific, clearly defined, reasonable and attainable.

There are many reasons why goals should be so specifically set. Setting specific goals gives a direction to therapy. Setting specific goals allows focusing of attention upon the relevant issues, and discourages irrelevant digressions. Setting specific goals also allows an objective evaluation of the progress of therapy. Counselling

seldom concludes with perfect results; such an assumption leads both counsellor and clients to consider therapy a failure. By listing specific goals, both counsellor and clients can identify the goals that have been attained, derive satisfaction from them; alternately it may also occasion an introspection as for the reasons of failure in achieving goals if any, and work out strategies to achieve them.

Establishing a Contract

In formal psychotherapy, the therapist and client establish a contract with each other. While a formal contract is unnecessary during counselling, an informal understanding between client and counsellor is essential and should be established. They should be clear between themselves that the client will strive to his best with the support of the counsellor to work towards the achievement of his goals.

Discussing the Practical Details of Counselling, and Making the Practical Arrangements

The last step during the initial interview is to discuss practical details about counselling, and to make the practical arrangements for counselling. The counsellor needs to explain to the client what counselling does and does not. The client particularly requires understanding that counselling provides the guidance; working towards adaptation is the responsibility of the client. The counsellor also needs to explain to the client the need for motivation to change, the need for honesty during therapy, the importance of leaving nothing hidden, etc. Practical arrangements including details such as the frequency, duration and timing of therapy sessions, financial aspects etc. for counselling should be considered.

Duration of the Initial Interview

With experience, the initial interview can usually be concluded over a single session of about one hour duration. Sometimes, the initial interview may spill over into a second session; a variety of reasons such as the non-availability of a key family member, an absence of clarity of problem situation, deep emotional trauma or even resistance from the client could be responsible for the same.

STAGE 3 - Ongoing Supportive Counselling

Assessment as an Ongoing Process: For a few sessions after the initial interview, the counsellor will need to continue to assess the client's psychological framework and his problem situation. The procedure will focus on collecting more detailed clarifications. During the assessment phase, the counsellor modifies and updates his working model of the client's psychological build and the problem situation. During assessment, the counsellor continues to provide support, guidance and other elements of counselling as the situation demands. Information in the assessment phase obtained primarily from the client, may also be cross checked with the significant others in the client's life, should the counsellor deem it necessary, and should the client consent. The information obtained should include not just present but also the past. Depending upon the circumstances, the counsellor may request for information about the client's early childhood, emotional development, education, track record at work, etc.

Information is primarily obtained through verbal channels. But the counsellor can often glean much from the way the client dresses, speaks or communicates non-verbally.

This face of ongoing supportive counselling occupies the bulk of the period of counselling. It is the phase during which the counsellor analyzes the client's feelings and behavior, provides a feedback to the client, provides support and guidance, and eventually effects behavior change. The following need to be considered towards effecting behavioural change:

1. the emotional factors that need to be corrected to resolve the dysfunctional behaviour;
2. to manifest faulty ways of thinking that need to be corrected for a resolution to the dysfunctional behaviour;
3. the social and environmental factors that have to be addressed to resolve the dysfunctional behaviour.

The counsellor throughout this phase encourages continued expression of thoughts and feelings, exploration and identification of options available to the client and their evaluation, identification of existing coping skills, development of further coping skills, and enabling behaviour change. This has to be completely guided and monitored. The approach has to be totally flexible and adaptive to the needs of the client at every stage. Wherever required, referrals should be made.

STAGE 4 - Closure

This stage marks the closure of the counseling process. Counselling should never be abruptly terminated; rather, it should follow a series of formal stages, letting the client branch out into life gradually, so to speak.

Evaluation of Readiness for Termination

Counselling is always conducted with predetermined goals, set in consultation with the client, and modified as required during the course of therapy. The counsellor also approaches each case with a specific plan in mind. Accordingly, as the therapy progresses and the goals of therapy are progressively attained, the counsellor must evaluate readiness to terminate. He needs to answer the following questions:

- Is the plan of therapy running its course?
- Has the client grasped the principles of the therapy?
- Are the goals of therapy in the process of being attained?
- Will the client's morale stand up to termination?, and finally,
- Is the client able to maintain functional equilibrium?

The last question is particularly important because clients enter therapy with hope, and often show greater adaptation during active therapy than their degree of internal adjustment actually warrants. Therefore, if therapy is prematurely terminated under the assumption that the client has attained functional equilibrium, disequilibrium and decomposition may occur soon after the modified effect of the therapy is withdrawn. If the answer to all the above questions is 'yes', then the counsellor concludes that the therapy is approaching the termination phase.

Sometimes, therapy termination may depend not upon intra-therapy factors (such as are addressed by the above questions) but upon external influences, such as time constraints or unforeseen contingencies. Wherever possible, the counsellor would be well advised to keep in mind and plan for termination accordingly. However, even if the termination of therapy is unplanned, the steps of termination are best

religiously adhered to the extent permitted by the circumstances. The counsellor has to ensure the existence of a support system and supports being accessed by the client as per his needs.

Therapy may also terminate because the client feels that he does not wish to continue; or because of a failure to make progress towards the set goals. Provided that the termination is not abrupt as when clients drop out of therapy, the counsellor must endeavour to adhere to the steps of termination again as may be applicable under the circumstances.

Provision of Advance Notice of Termination

Many counsellors fail to realize that while they are following a specific plan during therapy, the client is merely following the counsellor's lead. The client does not know what further assignments the counsellor wishes to undertake, or what further techniques in therapy the counsellor wishes to employ. Therefore, unless the counsellor provides sufficient advance notice of termination, the fact of termination is likely to catch the client unprepared.

Adequate advance notice of termination is necessary so that the client can psychologically orient himself towards independence in functioning (i.e., unsupervised by the counsellor). This psychological orientation refers to not only an unconscious preparation for independence but also a conscious preparation as evidenced by seeking appropriate clarifications regarding handling of post-termination contingencies.

Discussion of Readiness to Terminate Therapy

The counsellor should always be aware that while he may consider therapy to be approaching completion, the client may yet have many internal problems to resolve. Therefore, the client's appraisal of the situation is essential before termination is formally announced.

The discussion of readiness to terminate therapy should cover the client's understanding of what has transpired during therapy, his doubts and misconceptions, and his confidence to handle future situations on his own. The counsellor should usually bow to the client's judgment if he wishes to prolong therapy. However, the counsellor must guard against dependency (on the counsellor, and the counselling process) underlying the wish to prolong therapy.

Review of the Course of Therapy

Assuming that the therapy has succeeded in establishing a functional equilibrium, it is necessary that the client understands the dynamics of the re-equilibration. Such an understanding provides the client with the tools necessary to maintain the functional equilibrium after termination. The counsellor therefore draws to the client's attention the problems with which he had initially presented; the goals that were set up for therapy; techniques that were employed in therapy to attain these goals; assignments that were given; interpretations and insights that resulted; progresses and setbacks in therapy; and, other issues important to the course of the therapy.

The client thus obtains a 'bird's eye view' of his therapy, or a somewhat objective perspective, much as though he was looking at himself from the outside. It hardly needs to be stressed that the counsellor should elicit the above from the client using appropriately worded questions rather than summarize the course of therapy himself.

Emphasis of the Client's Role in Effective Change

Clients particularly in India, tend to glorify the counsellor in having made them functional again. Although this may be gratifying to the ego of the counselor, it is more important for the client to understand the initiative that he himself has taken in bringing about the change. Hence, the client need to be complimented for having taken the positive effort in effecting the change, change in itself of any nature being difficult. Such a compliment should positively reinforce the client's functional (as opposed to dysfunctional) behavior, and give him the confidence to handle a crisis in future. The counsellor should of course explain his role as that of a facilitator and guide to the client on his road to functional health, and assure assistance when needed in future.

Warning Against 'Flight into Health'

'Flight into health' refers to the phenomenon of dramatic recovery occasioned ostensibly by therapy but in fact by nonspecific factors such as hope; temporary benefits stimulated by the novelty of therapy; beliefs that a resolution of superficial issues has solved the entire problem; euphoria over minor or transient gains; etc. Such a reaction is quite common in therapy. There is a definite possibility that although the goals of therapy may have been attained, such may not be long-lasting; the client may relapse shortly after he has been returned to the original environment with all its former stressors.

Warning the client against this 'flight into health' keeps him aware of the realities of the situation and guards against unwarranted euphoria; it most importantly serves to protect against disappointment, should difficulties in adjustment resurface after therapy has been concluded. Such difficulties are far more common than realized.

Giving Instructions for the Maintenance of Adaptive Functioning

Given the possible risk for setbacks - temporary or otherwise - after termination, the client should receive adequate counselling about how to handle potential troublesome situations. Such counselling should cover all levels of prevention - primary prevention, to preclude the development of crises; secondary prevention, to identify destabilization early and to defuse the crisis with the minimum of disturbance; and tertiary prevention, to minimize the damage done, if any, and to affect the necessary steps for correction.

Types of situations and how they are to be dealt with are ideally discussed in detail with specific reference to examples from the course of the therapy. As earlier, it is preferable that the counsellor elicits the examples and the solutions from the clients rather than didactically advise. Elicitation from the lips of the clients is always best, because it tests and confirms the clients' understanding of the therapy. This is especially relevant because clients tend to remember and accept best what they have themselves spoken of, and because the clients are more likely to select the most important client-relevant contexts in the discussions.

Discussion of Follow- up Sessions

It is never advisable to conclude therapy abruptly. However well motivated the clients, however sincere the counsellor, and however seemingly successful the therapy, many clients run into problems after termination. This can be attributed to issue that arised, or simply to issues that were for some reason or other unresolved during the actual therapy. It is therefore necessary for the clients to

continue to maintain contact with the counsellor for continuation of assistance in the maintenance of the functional equilibrium. The frequency of such follow-up sessions is decided based, upon individual circumstances, and can increase or decrease depending upon the need.

Stressing of 'Open Doors'

'Open doors' refer to the continued, uncritical accessibility of the counsellor to the clients. The clients should clearly understand that they need not feel guilt in case of relapse of dysfunction - guilt that they have 'failed the counsellor'. Instead, they should consider that the counsellor is always available to them, and that he will uncritically resume therapy as and when needed. This gives the clients the confidence that even if they relapse, all is not lost.

When above is completed to the satisfaction of both client's and counsellor, the therapy is terminated formally.

Check Your Progress II

Note: Use the space provided for your answer.

1) Briefly describe the stages of the counseling process.

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3.6 SKILLS OF A COUNSELLOR

The counsellors are required to work with their clients across a 'bridge' of relationship. In this helping process they certainly have to possess specific practice skills in effectively reaching out to their clients. These skills are essential for effective communication and the development of a supportive client-counsellor relationship. These skills include:

a) Listening and empathy

The most important component in good listening skills is the ability of the counselor to convey **empathy**. Demonstrating empathy helps the counsellor to establish a relationship of 'helping' the client and a rapport is thereby formed that makes the client trust the counsellor to reveal his innermost feelings. To convey empathy, specific listening skills are very effective: A good eye contact that is culturally appropriate is important in showing the client concern and attentiveness to his/her problem. Body movements such as nodding of the head convey that the counselor is listening. Cues and prompts further encourage him to continue with his narration. Few and only minimally appropriate interruptions is what is best in such a situation where the client is opening up.

Counsellors however need to continuously clarify and summarize for their clients. Also, paraphrasing and reflecting are very helpful techniques. In paraphrasing

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the counselor restates in his or her own words, the essence of what the client has said. This helps in reassuring the client that he is being heard and helps to focus on his / her problem. In the same manner, the Counsellor may reflect upon the emotions of the client, helping them to explore their reactions to these events in their life.

b) **Questioning**

Questioning is no doubt a very important aspect of the counselling process. It helps to have indepth information of the client's situation and it helps to assess the clinical condition of the client. It is important to keep the following things in mind in the process of counselling: ask only one question at a time; ask questions that serve a purpose; be brief and clear; ask questions that encourage clients to talk about their feelings and behaviours.

c) **Silence**

Effective communication is the essence of the communication process. Needless to state, silence is also an important tool in the hands of the counsellor. Firstly, it gives the client time to think about what to say and how to say it. It gives the client an opportunity to experience and cope with diverse emotions that emerge when he is talking about his problems. It leaves the client with the option to set the pace of the session and he does not feel that he is being rushed through the counselling process. It also offers the option of discontinuing the sharing if it becomes excruciatingly painful or disturbing for the client.

d) **Non-verbal behaviour**

Mehrabian asserts that more the half of the communications that we do are non-verbal in nature. Thus, all aspects of **non-verbal communication** become significant in the counselling process. Counsellors need to be aware of what their clients are communicating through their non-verbal behaviour and what they themselves as counsellors are communicating to the clients through their non-verbal behaviour. Their postures, gestures, facial expressions, eye contacts, all have a meaning. All paralinguistic indicators such as pitch and tone of the voice, sighs and grunts have to be taken note of by counselors.

3.7 IMPACT OF VALUES AND ATTITUDES OF A COUNSELLOR

We all develop our values in the social and cultural context in which we grow and mature. The attitudes, values and beliefs we uphold, influence our day to day behaviour. The manner in which we perceive the others' behaviour, as well as how we interpret and explain, are guided by our value systems. It is well accepted fact that values differ within and between countries, regions and groups. Thus, it is important that those involved in the counselling process are well aware of their attitudes, values and beliefs. Also, they should know how to handle their responses when they have clients with different values and attitudes. This can only happen when they learn to accept their clients even when their opinions differ.

Counseling never attempts to make people conform to certain sets of acceptable behaviours. Counsellors need to deal with their strong negative emotional reactions to clients and certain situations, and must be frank enough to question themselves in various situations. When difficulties emerge in the counsellor-client relationship they should resolve them through supervision, peer consultation, consultation with experts, and if necessary, even by means of referral.

3.8 CHARACTERISTICS OF A GOOD COUNSELLOR

Everybody can offer to counsel, but not everybody has the skills to be a good counsellor. Ideally, a good counsellor must:

1) be fluent in the language of his client in order to guess what is unsaid, and to correctly interpret nuances in communication.
2) understand the culture to which the client belongs; devoid of such an understanding, the counsellor may misinterpret various behaviors that the client manifests.
3) have charisma and personality, and should inspire confidence and respect in his client.
4) have much experience of life; without such an experience, it is difficult to put the client's problems and behavior in correct perspective, or to provide appropriate guidance.
5) be reasonably mature and intelligent to understand the client's problems, formulate an appropriate plan of management, and carry it through; without maturity and intelligence is one who may show poor judgment when counselling clients.
6) have a healthy set of values; during therapy, the counsellor's values inevitably percolate down to the client.
7) have knowledge of psychology; that is, he should understand the intricacies and the workings of the human mind.
8) be knowledgeable about the range of psychological disorders that individuals experience, and the characteristics thereof.
9) be knowledgeable about the client's problem field; for e.g., unless a counsellor knows much about children, he will find it hard to competently counsel a parent who is having difficulties with his offspring. It will help if counsellor is also experienced, in addition to being knowledgeable in the client's problem field; for e.g., a counsellor who is a parent will be able better understand and counsel a client with parenting problems.
10) be free of emotional problems. A counsellor who is unhappy and may not be able to give his client undivided attention. Furthermore, his judgment may be clouded by his personal problems. A good counsellor must be particularly free of problems in his client's area of difficulties.
11) be well trained with sufficient theoretical and practical exposure to counselling.
12) have good communication skills; he must know what to say, when to say, how to say it, and when it should be said; alternately, he must also know what is not to be said.
13) be genuinely motivated to help person in distress. He should not counsel merely out of a feeling of duty.

While counsellors can be of any age or sex, most clients tend to prefer their counsellors to be older than they are. Some clients may find it easier to confide in a counsellor of a particular gender or even sometimes there is preference for same-gender counsellors.

Check Your Progress III

Note: Use the space provided for your answer.

1) Describe the qualities you would expect in a good counsellor?

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3.9 COMMINICATION SKILLS OF A GOOD COUNSELLOR

As has already been highlighted, communication is integral to the counselling process. Counselling being an interpersonal process, good communication skills are essential if a counsellor is to be effective. Let us look into the specific communication skills, important for effective counseling.

1. A good counsellor is conscious of his body language and the impact that it has on the client. He makes culturally appropriate eye contact with the client, nods to convey his interest to the client, and avoids signs of boredom (yawning) or restlessness (fidgeting).
2. A good counsellor listens far more than he talks. He practices reflective listening; that is, paraphrasing every now and then to reflect the gist of what the client just said. He does not interrupt unless absolutely necessary.
3. A good counsellor is polite, courteous and tactful. He is aware of the client's sensitivities and does not make his client feel guilty for past mistakes. He practices good timing in conveying his insights to the client.
4. A good counsellor is clear and unambiguous in his communication. He sticks to the point, taking one problem (and only one) at a time. His statements are relevant and meaningful.
5. A good counsellor encourages, he talks positively. He makes supportive and appreciative statements to his client, and gives praise wherever due.

Some frequent statements that a counsellor may make are:

In enquiring : "Tell me about/ tell me more…."

In summarizing : "So, basically, what you mean is …."

In understanding : "Is this what you are trying to say?"

In handling silences : "Take your time, there is no hurry, …… (and much later after a reasonable pause) … what are you thinking of?"

3.10 CHARACTERISTICS OF A GOOD CLIENT

Counselling can benefit everybody, irrespective of age, sex, culture, creed and other characteristics. Intelligence is also not a prejudicial issue, provided that the client is sufficiently intelligent to understand what is happening during counselling. In most cases clients approach the counsellor of one's own choice or through referrals. However, in most cases of alcohol and drug addiction, a client is motivated and sometimes forced to seek counselling.

There are certain client characteristics, however, which can increase the extent to which a client may benefit from counselling. These characteristics describe a 'good' client, and they are:

1. A good client is self-motivated for therapy, and is not brought unwillingly by a friend or family member.
2. A good client is flexible, and is willing to accept that his point of view may be incorrect. He is willing to consider alternate opinions that may facilitate better and effective adjustment.
3. A good client is cooperative; he participates fully in the exercises suggested by the counsellor.

Client characteristics which suggest a favourable outcome are fewer past problems, better previous adjustment in social and other walks of life, healthy family life and healthy social life, and good medical health, ability to relax and enjoy leisure pursuits, emotional maturity and good judgment.

3.11 LET US SUM UP

To conclude, the importance of counselling in the area of HIV/AIDS can no longer be undermined. Unlike other diseases, HIV/AIDS requires special care and attention to the client groups. Although the concept of counselling in medical services is well known, the practice of this strategy in developing countries is almost absent. In India, efforts are being made to provide counselling services at least in some of the medical institutions. The Integrated Counselling and Testing Services have become the nodal points for HIV/AIDS counseling. Counselling can help the HIV infected to live a life of dignity and also help to prevent further spread of the infection. In fact anyone who feels that he/she has been involved in risk behavior which can cause HIV infection needs counselling. Similarly those who have been already infected require counselling services which will enable them to plan their future course of action to live a meaningful and productive life.

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UNIT 4 ISSUES AND TYPES OF HIV/AIDS RELATED COUNSELLING

* *Jyoti Kakkar*

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4.0 OBJECTIVES

In Unit-3 we discussed the Nature and Process of Counselling. The importance of Counselling in the context of HIV and AIDS cannot be undermined. We will now look into the special issues that emerge in the case of HIV and AIDS and the needs that have to be addressed in the case of special population groups, be it the drug users or commercial sex workers. These are of great importance for counselling to be effective.

4.1 INTRODUCTION

Counsellors may be employed to do special tasks, such as counselling people who want HIV tests at Voluntary Counselling and Testing Centres (VCTCs), helping people take their HIV medicine correctly, conducting HIV prevention programmes, or meeting the special counselling needs of children and adolescents. This unit looks at issues that need to be addressed by the counsellors who take on these important functions. It highlights the importance of specific interventions as per the need of the clients.

4.2 COUNSELLING ISSUES

Voluntary counselling and testing

HIV testing plays an important role in the fight against HIV and AIDS. Special voluntary counselling and testing (VCT) centres have been set up in many countries, including ours, and hospitals and clinics also have services for voluntary counselling

* *Prof. Jyoti Kakkar, Jamia Milia Islamia, New Delhi*

and testing. Many governments, non-governmental organisations and donor organisations urge people to be tested for HIV in their efforts to control the pandemic of AIDS. People who support voluntary testing say that being tested helps people focus on HIV issues, whether they are found to be infected or not. In areas that have HIV medicine available, they can seek medical care after finding out that they are infected. The care may include medicine that can lengthen their life if it is taken properly, called antiretroviral medicine. In countries without anti-retrovirals, a person who has been told he or she is infected can still take steps to live a healthier life. People who are tested are taught about ways to prevent HIV infection of themselves, if they are not infected, and of other people.

Counselling at VCT centres requires special training. Counsellors learn to use a standard list of questions and responses when working with people who want to be tested or who want to hear their test results. The need for professionally trained counselors is high and there are not many available who are well experienced to take up this challenging task. Many who are placed in this job are given training quickly. There is little time for them to practice counselling skills. Some VCT programmes focus on the biomedical and prevention aspects of HIV, giving little or no attention to emotional, social and spiritual issues. The neglected issues could include harmful emotional responses to news of infection, mental illness, alcohol abuse and the potential for family troubles. VCT centres could serve clients better with additional attention to the emotional needs of clients.

Anonymous or confidential: Testing is usually anonymous or confidential. One should be aware of the difference between the two. Anonymous testing means a test result is not attached to a person's name. At a test site, a person does not give his or her name. The person is given a code name or number to use when he or she returns for the result. Confidential testing is different. It means that the test result is put into a file, such as a medical record, with the patient's name. This is usually what happens at a medical clinic or hospital, so doctors and nurses can better treat their patients. In this case, "confidential" means that only those who need to see the test result may read the clinic's files. In some small communities, just being tested leads to stigma and discrimination. Some people are concerned that neighbours who work at VCT centres will gossip, or that people who work at clinics or hospitals will read the files and learn of a person's HIV infection. As a result, people sometimes travel for hours to be tested where no one knows them. VCT centres are now being located in buildings where many people do business, or in campus of universities so no one can say that someone entering the building is going to the VCT centre.

The HIV test: Tests at VCT centres and clinics determine if someone has an "antibody" to HIV, which is a product of the body's response to the presence of HIV. You may hear that someone is "antibody positive" - this means that the person is HIV infected. When some one is in medical care, the person may be given a "viral load" test that directly measures the amount of virus in the person's body. The actual HIV test given at VCT centres and clinics will differ depending on the methods available. With one test, a clinic staff member takes blood from the person being tested. The blood sample is sent to a laboratory for testing. The client returns for the test results a week or two later. Many people, made anxious by the testing and the possibility of infection, do not return for their results. Newer tests are available in which the results are available within minutes. Because the new tests provide faster results and don't require a lot of blood, people are more likely to be tested and less likely to be anxious.

The VCT counsellor's official tasks fall into two general categories:

1. **Pre-test counselling**, which includes educating the client about the test and its outcome, as well as screening the person for suitability for testing depending on the propensity towards high risk behaviours
2. **Post-test counselling**, which includes notifying the client of the test result. If the person is infected (tested positive), the result is explained, supportive counseling is provided and instructions given for medical assistance. Both infected and non-infected people are counselled regarding prevention of infection.

VCT Counselling procedures: VCT counselling procedures, also called protocols, differ from country to country and even from clinic to clinic (or counselling centre). Protocols are the counselling and testing procedures set up by a clinic. Sometimes these procedures are deliberately ignored - for example, when no counselling is provided before or after an HIV test. Not providing counselling may be illegal and certainly is unethical. Counselling procedures usually emphasise a client's biomedical or physical issues. Clinics and VCT centres require employees to work through the required checklists of questions and procedures. However, counsellors still need to find time for compassion. If time and the supervisors allow, the counsellor does more, asking questions and expressing concerns about the client's emotional, social and spiritual aspects.

Some checklists may not lead to a good assessment of the client's emotional situation. It may be helpful to assess several issues:

Anxiety

It is normal to be anxious when being tested for HIV and especially while you wait for the results. While it is normal to be anxious or nervous, if you should have a VCT client, who is so anxious that the individual is having trouble functioning, you should be curious about why this is the case. It is possible that the client has a biomedical problem, such as lack of oxygen (hypoventilation), an overdose of a medicine, a serious psychiatric condition or even strong denial, or a strong conviction that a positive test result means quick death. An excessively anxious person may be too distracted to understand the counsellor's teaching. If a severely anxious client is tested, the wait between the test and the results may be too much to tolerate, resulting sometimes in a serious crisis.

Depression

If a person who comes for testing seems depressed, a counsellor may want to ask questions about the symptoms of depression. Depression may cause the client to react very negatively to news of infection, leading to despair, suicidal thinking or even suicide. In such cases, HIV testing should be postponed until the symptoms of depression disappear.

Severe mental disorders

People with serious mental disorders should not be tested for HIV without psychiatric support. Symptoms of severe mental disorders include:

problems recognising what is real and what is not; speech that doesn't make sense;

delusions and even unshakeable beliefs (which are not culturally acceptable) about cures, aliens, strangers and other aspects of life;

alcohol abuse and intoxication.

The abuse of alcohol and other substances is common enough and enquiries should be made about their use when someone comes for a test or for test results. An intoxicated client seems slowed down and a bit disoriented. Signs of intoxication include slurred or halting speech, slowed thinking and actions, and walking unsteady.

symptoms should raise several concerns about having an HIV test or receiving results: Why is an intoxicated person at the clinic? The client should be completely sober so that she can make an informed decision to be tested. It is unlikely that an intoxicated client can fully understand the counsellor's instructions. Did the client think intoxication was necessary to tolerate the anxiety? Is the client's condition masking depression or a serious mental disorder? Is the client treating this serious event as trivial? Is the client addicted? Intoxicated individuals should be instructed to return when they are sober and are able to understand and work with the counsellor. The counsellor may give the person information about where to seek assistance, if any is available, for the alcohol or substance abuse problem.

Facing the anxiety-causing HIV test: Being tested for HIV often makes the person extremely anxious. Even people who have little or no chance of being infected get upset at the thought of being tested or waiting for the result. Imagine the anxiety of people who think they may have been infected! Added to this is the unfortunate situation that just being tested, makes people vulnerable to stigma and discrimination in some communities.

The client's social situation: A person may come alone to be tested and s/he may seem to be alone. But this individual is part of a larger system: a family. A counsellor may want to know how a test result showing infection will change the client's relationship with her family. Will the family learn about the result and will the family members need support and guidance if the result is positive? The counsellor is encouraged to look at the big picture and help with all the consequences. Some questions, perhaps not on an official checklist, which the counselor may raise include:

Is the client currently in a sexual relationship?; Is the partner's HIV status known?; Is safer sex being practised?; Does she plan to tell her partner or other family members about the test result? If not, why?; If the test is positive, and the partner learns about it, what are the predictable results? Will family members be supportive or rejecting? Is there a risk of violence? All these aspects need to be discussed and the counselor may need to help the client at every stage of problem solving.

Check Your Progress I

Note: Use the space provided for your answer.

1) What are the issues that are addressed by counsellors in pre-test and post-test counselling?

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4.3 TREATMENT AND DRUG ADHERENCE

As countries begin to offer anti-retroviral medicines to people with HIV and AIDS, some counsellors will assist clients to take the medicines as prescribed. Some counsellors may join hospital staff and receive special training to counsel clients about their medicines. Increasingly, counsellors act as members of care teams that include the client's doctor, nursing personnel, family and others. Doctors often prescribe combinations of different types of medicines to fight the virus in different ways. These combinations are the Highly Active Anti-Retroviral Therapies referred to as HAART (say "heart"). There are several important reasons why clients must take their medicines in the way they are prescribed. This is the client's best chance of improving quality of life and extending life.

Counsellors can assist their clients with HIV related medicines in the following ways:

Counsellors must learn the names of the medicines, the dosage to be taken, how often, if they should be taken with or without food, and the possible side-effects. Similarly, guides are available in some countries that provide ARVs and counsellors should read them. Sometimes colour photographs of different pills are available from pharmaceutical companies, chemists, or HIV/AIDS advocacy groups. Non-governmental organisations (NGOs) should request the local distributor of ARVs to make a presentation to the counselling staff, showing the colours and shapes of the pills and capsules, describing typical dosages and explaining possible side-effects that the medicines cause. A counsellor could introduce himself to a local hospital, chemist or clinic and ask if he can learn about the medications and contact them with questions. Having a relationship with a local chemist or doctor is important because prescribing guidelines may change, new medicines may become available (or old medicines be discontinued), or other news may emerge.

The counsellor who deals with medication issues should think of himself as part of a team that includes the doctor, family members and other people. He has to be in constant consultation with other team members. The relationships built on behalf of the client should be face-to-face, rather than at a distance. For example, the counsellor could accompany his client to the clinic and introduce the client to the doctor. The counsellor could then explain that he is assisting with the medicines, share the unique concerns of the client and request the doctor phone him if concerns emerge. On the same basis, he could phone the doctor to enquire about the progress.

Medicines for HIV/AIDS can be confusing, especially for people who have difficulty remembering or reading instructions. Assisting the client with this is an opportunity to be creative. He can draw pictures and organize pill boxes for the client. However, a counsellor cannot always be with his client, but family members or special friends are usually around. Using similar methods, the counsellor can train the family members to remind the client to take the correct pill at the right time.

4.4 YOUTH AND CHILDREN

Children affected by HIV and AIDS also have a wide range of situations that can come to a counsellor's attention. Some young children may be HIV-infected and, if medicines become available to them, they will live with the infection as they grow older. Others may not be infected, but they may lose their parents or other family members and suffer great emotional pain.

Data show that young people aged 15 to 24 years old account for more than 50 percent of all HIV infections worldwide (excluding perinatal cases) and more than 6000 young people are newly infected with HIV each day throughout the world (see UNAIDS, 2000). Not many of them are even aware of their positive status. Sexual activity for the young begins before the age of 15 years in many countries. However, VCT services are not designed to address the specific needs of youth.

A major issue in rendering VCT services to youth is of parental or guardian consent before a medical procedure can be conducted on those who are below the age of consent. This may include HIV testing. It is important that relevant legislation be understood when these services are rendered.

Children who are HIV infected have mainly acquired the virus through mother to child transmission. It is understood that children born to HIV positive mothers would test HIV positive till they are 18 months old with the standard testing procedure. Parents face a lot of stress and anxiety till they ascertain the actual test results. Counsellors have a lot of role to play at this stage. Other considerations that need to be kept in mind in counselling such parents and children are the age, maturity and health of the child. Sometimes, a child who is not informed about the status may have many suspicions of what is going on at home; circumstances of the child and his / her level of exposure.

Counselling children and teenagers is very different from working with adults. Talking techniques that are suitable for adults are not helpful to children. Very few children have the words to describe their feelings, the patience to sit and talk seriously with an adult, or the belief that an adult will understand them. Counsellors take older children and teenagers to such places as sports venues. The belief is that the counsellor-client relationship will build as they play together and, gradually, the teenager will begin to talk about feelings. The counsellor can then begin to go deeper into the issues that need to be addressed so as to help the client. These methods are time consuming and work with one child at a time. Counsellors are taught a variety of techniques to help children improve behaviours and get over their fears and other problems.

Organising services: The counsellor may have to take additional responsibilities when working with young clients. These may include: teaching parents or caregivers to care for the children better, advising on matters of discipline, ensuring that the child gets proper health care, including arranging transportation to school and play.

Where children have lost one or both parents due to AIDS the problems are even more complicated. After the deaths of parents, other family members, including their grandparents, may take up the care for children. Media has often highlighted the trouble the old grandparents have gone through in making education or treatment available to these children. A few of these children may end up on the streets fending for them selves. New orphanages are being founded in countries where previously families always cared for children. Issues that come in the context of a counselor with regard to orphans include: the failure of welfare systems to provide for children in child-headed households, prostitution and theft for survival continuation in school; emotional problems such as depression, trauma and the likelihood of these problems to carry forth into their adulthood. Only recently have governments begun to recognise the existence of orphans.

Interaction with children: Counsellors have to keep a number of things in mind when dealing with children. Firstly, they have to make use of concepts and language that are age appropriate. They must ascertain the level of knowledge of the young

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persons about HIV and AIDS. Give children time and chance to move at their pace, leaving a lot of space for their questions.

4.5 INJECTING DRUG USERS

Injection drug users (IDUs) inject drugs into their veins and this is usually done in groups. Needles are often shared in this activity. Sexual relationship too may be prevalent between the group members. The chances of infection through the injecting route are much higher than sexual route of transmission. Countries such as China, India, Indonesia, Malaysia, Myanmar, Nepal, Thailand and Vietnam are showing considerable rates of HIV prevalence among the IDUs.

It is important to have an understanding of the legal and ethical factors that are applicable in a particular country. For example, the illegal nature of drug use can drive many drug users away and they may refrain from accessing services. Similarly stigma and marginalisation can lead to further isolation of the drug users.

In the context of drug users the voluntary testing and counselling services have the following aims: To bring about behavioural changes among the drug users that would make them adopt safe practices both in their injecting habits and sexual behaviour. Further, in particular risk-reduction counselling aims at using techniques of interpersonal communication to help the IDUs to clarify their feelings and thoughts about their problems. Also, sometimes group counselling is resorted to for the education of the drug users. Counsellors may have to be involved in a lot of problem solving for the drug users. Issues that may be addressed can be many, ranging from identifying obstacles in adopting harm reduction practices, motivating the clients, structured therapy, assessment of post traumatic disorder and suicide risk assessment. Follow ups are of utmost importance in maintaining a sustained pattern of behaviour change.

4.6 SEX WORKERS

Sex workers is a term that refers to a broad section of people who may be engaged part-time or full-time in sex work. They may be men, women or transgender. They may be engaged in such sexual activity by choice or under compulsion. Sex workers are especially vulnerable to HIV infection due to their large number of sexual partners and often high prevalence of sexually transmitted infections. Also, many studies have reported of the difficulty faced by sex workers to negotiate safe sex with their clients and infact they may accept more payment from the clients who are reluctant to use a condom. Another dimension that has to be faced is the simultaneity of drug use and sex work. Thus prevention has to be dual - harm reduction for injection drug use, as well as the reduction of HIV transmission through sexual contact - in the same population group. STI management is also a priority issue.

Given the above, the sex workers have specific needs that have to be addressed by VCT. The diversity among these groups is so large that no single model is available. In many cases, peer based education programmes have been found to be useful. The services need to be tailored to different situations.

Assuring anonymity for sex workers is important to encourage them to access services and wherever possible these should be made available to them at the nearest location. The challenge is to reach out the services to the indirect sex workers, who are hard to reach. Many married men and women, especially those who are migrants belong to this category. The services broadly can then be categorized into three: Information

and behaviour change services; condoms and other barrier methods; sexual health services. To reach out effectively with these services the use of informal contacts and key informants has been found useful.

In the context of prevention counselling, a range of strategies and activities can be used to convey information and behaviour change messages. The objective is to provide the sex workers with knowledge about HIV transmission and ways to reduce the risk of HIV transmission. The attempt is to clarify misconceptions and clarify misunderstandings of traditional practices and beliefs.

Next, through the process of counselling, the counselors can educate and empower the sex workers to negotiate and adhere to consistent condom use. They need to be sensitized to the neccesity of having safe sex even in the relationships that they consider are long term and safe. In addition to interpersonal counselling peer based interventions have been found to be effective.

If one goes beyond prevention counselling with the sex workers, there are those who are already infected. Counsellors can help them to decide about disclosing their HIV status, the strategies they can use to disclose, ongoing support in this effort, referral to care and support programmes, and looking for means of alternative livelihood.

4.7 MEN WHO HAVE SEX WITH MEN (MSM)

The term has been developed to refer to all sexual acts between men and includes the 'gays' and 'homosexuals'. The term includes men who exclusively have sex with other men; men who have sex with other men but mostly have sex with women; men who have sex with both men and women and with no marked preferences, men who have sex with other men for money or else because they have no option, such as is the situation with men in prisons. Some MSMs may be highly visible where others may never reveal their identity.

The implications of understanding the behaviour and psychology of this group in the context of HIV is important. In some parts of the world MSMs have been largely affected by AIDS. Their numbers in terms of HIV prevalence are higher than among the general population.

Developing interventions for MSMs is not easy because of variations in the definition and perceptions of gender, sexual roles, and homophobia. Many MSMs continue to have sex relations with both men and women so as to decrease their chances of being identified.

There are many barriers to VCT for MSMs. Main among this is the lack of dependable data on them. There is much difficulty in reaching out to them. Few counsellors are aware of the psychological issues affecting the MSMs. In some cases their own moral and religious objections and also some element of homophobia may deter them form working with MSMs.

In reaching out to the MSMs the counsellors have to first of all accept them totally with all their variety of sexual behaviours and complexity of relationships. They have to take their client through the process of developing a strategy of disclosing their status to their male and female partners. They need to promote condom use for both anal and vaginal sex, and promote alternatives to penetrative sex. Educational materials have to be developed so as to reach out to the MSMs with all information regarding HIV risk and enable them to assess their risk to HIV infection.

The endeavour in these interventions is to keep the whole process confidential. The programme needs to be steered by professionals who do not make value judgements about behaviours. The services have to be accessible to the MSMs and to do so it has to be kept in mind that they should be appropriate in location and also available late evenings or over weekends.

4.8 PREVENTION OF MOTHER TO CHILD TRANSMISSION

At the end of 2003, it was estimated that 2.5 million children under 15 years were living with HIV/AIDS and 700,000 children were newly infected in 2003. A large number of those who are infected have got the HIV from their mother at the time of labour and delivery or after birth, through breastfeeding. Anti-retroviral therapy can reduce the HIV virus concentration in maternal fluids, tissues, and breast milk, which can help in reducing the risk of infant exposure to high maternal HIV virus during intrauterine, intrapartum and post delivery.

The efforts directed at PMTCT are at four levels

(a) Primary prevention of HIV infection among women of child bearing age;

(b) Prevention of unintended pregnancy among HIV infected women;

(c) Prevention of perinatal HIV transmission among HIV infected women;

(d) Provide care and support to HIV infected women and their families.

The issue of an HIV test administered on pregnant women also has implications for the Counsellors

For many who are anxious of their HIV status, it would be a relief to know that they are not infected. For those who are HIV infected it would mean initiating action so as to make efforts to reduce the chances of the baby getting infected through the use of antiretrovirals during pregnancy and labour. Such individuals need to be educated on healthy living, and to protect themselves from further infection. In many cases the results of the test lead to a lot of stress and anxiety. The client may not be able to cope with the report of the test, face the dilemma of sharing their status and also live with many anxieties. Also, it may result in many relationship problems and stigma and discrimination. In addition, there may be problems of continuing with job and looking for alternative sources of income. Thus, it is evident that continuous counselling and support are imperative in all these areas.

There are many psychological consequences for women who are tested HIV positive (see WHO, 2004)

For many women the HIV status comes to them after their spouse, partner or a child have tested positive, adding to an already prevalent trauma. When either of the sex partners test HIV positive it is oftentimes a disclosure that either s/he has another sexual partner and may result in domestic violence, conflict and even separation. There may be women who conceal their HIV status because they fear abandonment and consequently isolation. The women face dilemma on many fronts and would definitely need help in taking decisions. Some may even show extreme emotional reactions, such as anger towards the person who may have infected her. Her reaction to her changed health status and uncertainty about the future of her family may bring forth many emotions. She may show a lot of grief and sorrow and also a lot of anxiety in coping with these multiple issues. A number of clients may express a

feeling of guilt at having made their children HIV infected. Also there are reports of a greater incidence of post-natal depression in the HIV positive women.

Couple Counselling: The whole issue of testing and counselling women who are HIV positive, and faced with the issues of childbirth needs to incorporate the partner. Counsellors need to be aware on techniques of couple counselling and encourage their clients to be accompanied with their partners. Counsellors efforts have to be made towards both the partners in building a relationship of trust. Both the partners have to be given sufficient space, and counsellors have to pay full attention to their verbal and non - verbal communication. Given the fact that couples may be married or not, counsellors should show their readiness to work which ever be the case setting aside their values, prejudices and beliefs.

Counselling to other Vulunerable groups

This apart, migrants and prisoners from those vulnerable groups who are prone to HIV infection due to their socio-cultural environment. As mobile population and migrants are away from their family for a long period of time, their need for affiliation drives them to other partners, which may lead to unsafe sexual practices. Also, job pressure and insecurities lead to, tensions. Substance abuse and alcohol consumption, viewed as means of relaxation, lead to loss of social and sexual inhibitions. This, in turn, promotes unsafe sexual behaviour. Low level of awareness and lack of knowledge about the support system add to the vulnerability of migrants to HIV infection. Prisoners and detainees are highly vulnerable to HIV infection as sharing of infecting equipments are quite common in prisons, inmates are sexually assaulted and high rate of homosexuality is prevalent, especially due to the lack of any other source of entertainment or because of emotional upsurge. Poor access to knowledge about safety and condoms, needles syringes accentuate prisoner's susceptibility to HIV infection.

4.9 LOSS AND GRIEF

Loss and death in the context of HIV and AIDS are a reality. The world has experienced loss and death to slavery, war, genocide, high infant mortality and fatal illnesses, including malaria and tuberculosis. Now HIV and AIDS have joined the killers, although too many communities have still not publicly acknowledged the death toll and the emotional trauma of so much dying and death. In some countries such as Africa there has been a widespread impact and the people there need to push the pain deep down inside themselves in order to soldier on and survive. For a counsellor, comforting people who are dying and the survivors poses tremendous challenges. HIV and AIDS counsellors must be able to talk openly with clients about dying, death and grief. The goals and plans that they decided on together must fall by the wayside when the client's health takes a turn for the worse. Then it is time for one person to sit with another. But we are all just humans and this is not easy to do. A person's own history of loss has a great impact on the way that person deals with more loss. For example, if a young woman hasn't finished mourning the loss of her own child, it would be difficult for her to face so many mothers and fathers grieving the losses.

In many ways AIDS is like all other ailments. A sense of loss, and the grief that comes with HIV infection, doesn't begin with death. Probably as soon as the client finds out that he is infected with HIV, he immediately goes into grief. For any person who comes to know that he is HIV infected, the reality of life immediately is

stark. Everything changes and suddenly there is so much insecurity and fear of the future.

In most countries to reveal ones illness, or even to be suspected of having HIV, a woman risks losing her family, losing her job and her home, and being tormented by cruelty caused by ignorance and fear. The fear of discrimination makes many people move away from the place where they were residing. In one such reported case of a migrant worker employed as a 'rickshaw' puller being diagnosed with HIV, there was total resistance by them to the wife being tested and before the counsellor could work towards convincing them, the couple ran away from their home in a slum. On further enquiry, it was revealed that they left their '*jhuggi'* and ran away to their village along with their children, hoping for anonymity there.

The reactions to the reports of HIV test can be from complete denial to acceptance. Most often, counselors will find their clients in any of these states before they finally come to a stage of acceptance, which may not be complete. A person may be in a stage of complete denial. He or she may ask for a re-test or even a confirmatory test to be repeated. The counselor has to provide all the necessary information and support. Simultaneously the person may feel anger, rage, and the envy towards healthy people. When the person comes to a stage of realization he learns that he has to face up to the great loss as the time draws nearer. This depression is for himself and for those who are close to him. As much as there is diversity among people, there is a diversity in their reactions. Counsellors have to be prepared that some people face death head-on and don't go through the other stages. Others may show a combination of the different responses.

Check Your Progress II

Note: Use the space provided for your answer.

1) What is the nature of loss and grief in the context of HIV/ AIDS that is usually dealt with by counselors?

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4.10 COUNSELLING STRESS AND COPING

The counsellor uses his self to reach out to a client, to establish trust, to understand the client, to feel the client's feelings, and to respond with compassion and competence. The counsellor learns about HIV/AIDS and teaches others. In most cases the counsellors deal with other people in the client's world and addresses issues as diverse as ignorance, and hostility (stigma and discrimination).

Counsellors work with their entire self in the process of counselling. They use their body of knowledge, their own professional skills and principles in working with their clients. Counsellors, qualified with specialized body of knowledge and skills to work with the AIDS afflicted, are not many. A number of them are known to take on too

many clients and work for too many hours. It is often seen that people who take up the job of counsellors are mostly caregivers whose focus is on other people and not on themselves. All their attention and work is to make other people feel better. Some of them have always been like this.

It goes without saying that counselling is not an easy process. No areas of health care and counselling are emotionally easy. But HIV and AIDS, at the intersection of so many problems, are especially difficult. In the context of AIDS as you have seen in this Unit, the clients' situations are complicated and often can't be fixed, but only changed a little. Counsellors witness the suffering, orphaning and deaths of spouse and children. They are with their clients on a long and difficult biomedical, emotional, social and spiritual journey. There are fresh challenges each day and with each new client. Counsellors have to be alert to everything that is said or not said. The task of counselling in this specialized setting makes specific demands on the counselors.

'Burnout' is a term that was first used by a psychologist named Herbert Freudenberger. It is now such a popular concept that many books have been written on the topic. Burnt-out counsellors are always exhausted and under stress. They don't relax easily. The selfless, overworked counsellor pays a high emotional price: possible burnout and loss of effectiveness in about two years if they do not take good care of themselves. The counselor then needs to recover from the emotional trauma. It is a shame to lose such good people so soon.

Counsellors need to ensure that they take care of their own physical and mental health if they have to be able to work with clients for many years. This requires counsellors to focus and work on meeting their own emotional needs. It also means that organisations and institutions, however tight their finances may be more sensitive to the needs of their employees and volunteers.

With most clients who suffer from AIDS, often there isn't much that a counsellor can do to make a visible and significant difference. The counsellor then feels incompetent and frustrated. At such times they should focus on the fact that they are recognising and appreciating their clients individuality and dignity. This acceptance in the counselling relationship is very important and meaningful for the clients. It is their experience, and may be the only one, that being HIV positive does not mean that they would be rejected by all.

People who spend so much time meeting the needs of others, addressing issues of those who are aggrieved, may either lose touch with their own feelings, or even if they know their needs, they still neglect themselves. When people are not in touch with their own feelings, there is a danger that these feelings may emerge in different forms. For example, a counsellor working for a community organisation may start missing appointments with her clients. She offers what sound like good excuses for her absences and she believes that these explanations are true. Initially the counsellor does not understand that her absences are actually expressing her feeling of being overwhelmed. The absences serve the purpose of giving her relief. The frequency of her absences keeps on increasing. If a counsellor knows what she needs emotionally, what could be the reason for not asking other people to help meet those needs? It may not be culturally acceptable to ask for help. Being herself in the role of a care giver and helping clients, the person may consider this kind of help-seeking as weakness and even professional incompetence to cope with stress.

Counsellors should always remember that counselling is a process to empower the client to take control of his or her own decisions and actions. Counsellors should be aware of their desire to make clients into something they are not, to rescue them or to change them. Their ambition and initiatives to resolve problems oftentimes need not translate in reality. As is obvious multiple factors operate and the client's progress may depend on the varying capacities of the client. It should not be forgotten that counselling is for the welfare of the client. If a counsellor acts on her/his rescue fantasies, and promises more than what is achievable, s/he will hurt her client.

The counsellor who thinks she will transform a client's life is in an illusion. She is creating a situation that is an emotional disaster for the client. The counsellor, to meet her own need to experience success and power, may push a client to make changes that show the counsellor's power. This misuse of authority in the counselling relationship may communicate to the client that s/he isn't good enough. When the client cannot satisfy the counsellor, the client feels like a failure. Consequently, the situation becomes more stressful for both the counsellor and the client. It is thus important that counsellors refrain from transmitting their feelings to the clients.

Most counsellors, especially those in their early years are keen to see quick results. Improvements and positive changes in the clients make some counsellors feel competent and good about themselves. A more skilful approach is to help the client with small changes. Each small change should be taken note of and reinforced for sustenance. The success of the client should be of foremost importance rather than the counsellor's success. Each sense of achievement transferred to the client lays the foundation for his or her empowerment. To conclude, no success achieved through the counselling process is too small to be ignored.

Counsellors have a burdensome task. In this process they should keep in mind that they are not overburdened. Competent and responsible counsellors often find themselves with more clients than they can handle. Their anxiety to do their best with each client as well as to achieve perfection finds them short of time and exhausted by the end of the week. No doubt, they cannot continue to operate under pressure for long and it takes a toll on them. Counsellors, given the nature of the task at hand, should 'say no' when the workload is beyond their capacity. Counsellors must consciously learn to resolve this situation as soon possible. The entire burden of the work to be done has to be shared in the organization. He or she is not solely responsible for all the tasks. Hence, it is better to do well as much as one can.

As in helping professions it is important that counsellors working with clients on HIV and AIDS should not be expected to do a skilful job without supervision. Too many emotional issues keep arising that can push the counsellor over the edge forcing them into making mistakes. Supervision or debriefing should be seen as an opportunity to discuss emotional reactions related to clients, as well as to plan strategies, as well as to perfect and learn new techniques (Jose & Mani, 2000). Debriefing which is undertaken with the peers or even with the supervisor provides a forum where counsellors ventilate and share the feelings they sometimes have towards their clients, and which they find difficult to resolve and deal with. When such hindrances come, supervision plays a critical role. It is advisable that such supervision is offered not by employers but by a neutral professional person.

Organisations should evolve strategies to de-stress their staff because working with AIDS afflicted and their family members takes its toll on the caregivers. There are many ways in which this can be done. Pleasant surroundings, colourful pictures, and

facilities such as good cooling in summer are important. Counsellors should maintain an active lifestyle, eat and sleep well. Yoga and meditation can be taken up on a regular basis.

Check Your Progress III

Note: Use the space provided for your answer.

1) What can counsellors do to make counselling work more effective and less stressful?

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4.11 LET US SUM UP

In this Unit we discussed various issues and types of HIV/AIDS related counselling. Counselling is an essential component of any intervention in the area of HIV/AIDS. The deliberations described in this unit dealt with various tasks being carried out by an HIV/AIDS counsellor. From the explanations given in this unit, we understand that a counsellor not only undertakes counselling in a particular setting, but also assume responsibilities for various aspects associated with the client which may include follow up of time schedule, taking appropriate medicine at appropriate time etc. All these issues have been dealt with while discussing on voluntary counselling and testing, treatment and drug adherence, counselling with youth and children, injecting drug users, sex workers, MSMs etc. On the whole, this unit provides most of the important issues and types of counselling. However, one must undertake specific training programme to be a good counsellor in HIV/AIDS related area.

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UNIT 5 HIV/AIDS AND LEGISLATIONS

* Gracious Thomas

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5.9 Further Readings and References

5.0 OBJECTIVES

After studying this unit, the learner should be able to:

- understand different trends in law-making related to people living with HIV/AIDS (PLHAs)
- explain the provisions of Fundamental Rights in the Indian Constitution related to PLHAs
- list out the laws useful to prevent the spread of HIV/AIDS, and to enforce the rights of PLHAs
- visualise a legal policy on HIV/AIDS that will help in framing more effective laws

5.1 INTRODUCTION

In this unit, we shall examine some of the legal aspects concerning HIV/AIDS at the various levels – national as well as international. Due consideration will be given to legislations covering HIV/AIDS in the context of the Indian Constitution.

This HIV/AIDS epidemic highlights the tensions and conflicts between health and human rights, as well as the State's powers and its duties. It has also revealed weakness in our legal system and health infrastructure in India. Not much reflection, debate nor research has been undertaken in order to understand and articulate the rights of victims of HIV/AIDS, who are themselves citizens with dignity. Neither has the Government perhaps given much thought to understand its Constitutional duties towards Indian citizens affected by this epidemic nor taken much effort to tackle this problem through framing appropriate laws and schemes. The inadequacy of training of doctors, nurses, and other health workers on HIV/AIDS and human rights has sharpened the experience of discrimination among victims of AIDS. The existing laws and legal policies have revealed deep rooted biases and inherent contradictions which makes it difficult for all those vulnerable to infection, to access medical services. Protection of rights sanctioned by law is a key element in successfully dealing with HIV/AIDS.

* *Prof. Gracious Thomas, IGNOU, New Delhi*

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Trends in HIV related law making

Laws are framed by governments and are enacted in order to respond to the specific needs and demands of its citizens in view of protecting and promoting their rights and for their development. Laws specify the rights and duties of citizens and also impose penalty in the event of their violations.

Until 1985, no country in the world had adopted any comprehensive laws for the protection of the PLHAs. During the period, 1985-90, a large number of countries adopted legislations related to AIDS. The main objective of these laws during the initial period was to prevent and control AIDS, and the resultant law-making were related to:

1) classification of HIV/AIDS;
2) compulsory notification – (obligatory reporting to the authorities);
3) protection of the identity of the infected persons (confidentiality);
4) compulsory HIV Testing on specific population categories, e.g., aliens entering the country, "high risk groups"- commercial sex workers, drug addicts, professional blood donors, homosexuals;
5) access to information and education about HIV/AIDS;
6) prevention of discrimination against infected persons and emphasis on their human rights;
7) providing compensation and welfare schemes to health workers infected by HIV-positive while working among the infected persons;
8) ensuring cleaning supply of blood.

In law-making related to PLHAs, several countries has taken divergent approaches to the issue of HIV/AIDS. Some have taken penal (coercive) approach, some have followed pragmatic (facilitative), while few others adopted the rehabilitative (compensatory) approach. Different perceptions of HIV/AIDS such as it being a disease, a catastrophe, a divine curse, etc. have also influenced the enactment of laws.

In order to remedy the discrimination faced by the PLHAs, many countries have enacted laws to guarantee equality and provide protection against discrimination. International Guidelines on HIV/AIDS and human rights recommends that "States should enact or strengthen anti-discrimination and such other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities against discrimination in both the public and private sectors." The goal of these laws is to achieve equality for PLHAs.

5.2 INDIAN LAWS RELATED TO PLHAs AND CONSTITUTIONAL PROVISIONS

At present there is no comprehensive law in India to respond to the rights and needs of PLHAs. India is yet to take steps to fulfill its obligations under the expand UNGASS Declaration on commitment on HIV/AIDS. It has to enact a nationally applicable rights-based statute, which can provide a holistic coverage, consistency, clarity and predictability so as to enable the courts to effectively pass judgements in cases related to HIV/AIDS. By seeking justice through courts, it can empower people to fight against the violations of rights and to establish a just social order and a humane society where sick and the poor can experience the promises guaranteed by the Constitution of India.

Constitutional Provisions Related to PLHAs

The provisions relevant to the HIV/AIDS situation in India are found in Part III and IV dealing with Fundamental Rights and Directive Principles of State policy respectively. Some of the Fundamental Rights guaranteed by the Indian Constitution will be of help to understand the rights of the HIV/AIDS patients.

Since Articles 14 to 18 guarantee every citizen equality before law and equal protection of the laws, any law that isolates HIV/AIDS patients denying them treatment on any ground can be challenged before the High Courts or the Supreme Court. In the same manner, if any government hospital or dispensary refuses to admit or treat HIV/AIDS patients, of course without adequate reason, the same may be challenged as violations of the Fundamental Rights.

The PLHAs are stigmatized because of the association of HIV infection with illicit or immoral sex behaviour. Such stigma is fuelled by the lack of understanding of HIV, prejudice, unavailability of adequate treatment, irresponsible media reporting, etc. Thus, stigma results in discrimination in treatment, employment, education and social relationship due to fear of HIV infection. This sort of discrimination is one of the most significant human rights abuses faced by HIV/AIDS affected persons. It includes segregation in schools and hospitals, forced medical testings and denial of the right to marry. In principle, discrimination is antithetical to equality. Article 14 of the Constitution of India guarantees equality before the law, and equal protection of the laws to all persons without any discrimination. So the state cannot arbitrarily discriminate among citizens including PLHAs. If any classification of PLHAs is made it must be rational otherwise it would be unfair and unjust and violative of their fundamental rights. This freedom from arbitrary discrimination is enforceable against the state and its agencies. But at present this Article does not offer any protection against private parties. According to the report of the National Commission to Review the Working of the Constitution the definition of 'State' under Article 12 of the Constitution can be amended to include any private person or entities engaged in functions which are of a public nature.

Article 15 of the Constitution of India elaborates on the principle of equality enunciated in Article 14 by prohibiting discrimination on the grounds of religion, race, caste, sex or place of birth. Similarly, Article 16 provides for equality of opportunity in public employment. But these constitutional provisions do not address the legal problems faced by PLHAs, especially against discrimination in employment and treatment.

Article 19 guarantees certain fundamental freedoms. There are other freedoms too that are enforceable though not listed under Article 19. They are right to travel, right to privacy, right to receive higher or professional education, right to human dignity, right to speedy trial, right to information, etc. Under this provision, we can approach the courts seeking correct information and scientific data regarding the health care and other facilities available to the HIV/AIDS patients. Right to information on medical care is one of the freedoms that can be used to help the HIV/AIDS patients.

Under Article 21, which guarantees life and personal liberty, medical care is considered as a fundamental right. In a Supreme Court case it was laid down that there is 'an obligation upon the state to preserve the life of every person by offering immediate medical care to every patient.' Any act that endangers life, thus, can be challenged in the courts. Refusal by doctors or nurses to treat HIV/AIDS patients, will constitute a violation of the fundamental right of the patient. There is an urgent need to spread information regarding HIV/AIDS universally as the dreaded plague is likely to strike anyone, any time. Under this Article we can force the state to give

information regarding the efforts to prevent HIV/AIDS that is assuming proportions of national calamity.

Since the right to health in India is a fundamental right, every barrier to equal access to health care must be dealt with by the State. Legal duty of care-guidelines must be given by the Government to health-care workers to prohibit discrimination of any kind against HIV-positive patients and to provide them with equal care. The government must make it mandatory for all health care practitioners to use universal precautions irrespective of the patients' sero-status. This policy can eliminate the need for mandatory testing before admission to a hospital.

Generally speaking, only the aggrieved can approach the courts. However, with the filing of the Public Interest Litigation (PIL) under Article 32 any public-spirited person or social activist or voluntary organizations can approach the Constitutional courts to redress grievances of individuals or class of people who are disadvantaged on account of their poverty, lack of education or other handicaps. In a PIL (Rakesh vs State of Bihar), the Supreme Court appointed a committee of experts to study the issue of the mismanagement of a mental hospital in Bihar. The Bhopal Gas Tragedy, and the Narmada Dam Case, are examples of this right utilized by public-spirited persons. Action may be resorted under this Article, whenever the rights of HIV/AIDS patients as citizens are violated.

5.3 LAWS USEFUL TO PREVENT THE SPREAD OF HIV/AIDS

Municipal Laws

Municipal laws in many cities require that every medical practitioner, who treats or becomes aware of the existence of any dangerous disease, should give information of the same to the Executive Health Officer. (e.g.: Section 421 of the Mumbai Municipal Corporation Act)

Epidemic Corporation Act

In the event of threat of an outbreak of any dangerous epidemic, and when the ordinary provisions of law are insufficient to tackle the disease, Section 2 of the Epidemic Corporation Act gives power to Health Officers of the state government to take such adequate measures including prescribing temporary regulations to be observed by the public or any class of persons to prevent the outbreak and/or spread of any such epidemic disease.

The Carriage of Passengers Suffering from Infectious or Contagious Diseases Rules,1990

According to Rule (1) a railway administration should not carry persons suffering from AIDS. A person suffering from AIDS should not enter or remain in any carriage on a railway or travel in a train without permission of the Station Master or other servant in charge of the place where such person enter upon the railways.

A railway servant giving such permission to any person suffering from the disease, and agreeing to pay the usual amount of fares for receiving a berth, shall arrange for his separation from other persons travelling in the same coach.

Drug and Cosmetic Rules, 1993

According to Rule H of Part XIIB [1993, GSR 28(E)] every licensee of a Blood Bank should get samples of every blood unit tested for freedom from HIV antibodies,

either from such laboratories specified for the purpose by the Central Government or in his own laboratory. The test result shall be recorded on the label of the container also.

The Delhi Artificial Insemination Human Act, 1995

Under Section 10(1) the semen bank before accepting the semen for artificial insemination shall test the donor for presence of HIV - 1 and 2 antibodies by using a highly sensitive ELISA Kit, and only if found negative, shall the donor be allowed to donate. The following sections too give tooth and claw to the act:

Sec. 11. stipulates that the donated semen shall be stored either by cryo preservation of liquid nitrogen freezing or any other safe method for a period of minimum three months in order to exclude window period of HIV 1 and 2 infection in the donor. Sec. 12 requires a second ELISA Test to be performed on the donor at the end of three months. According to Sec. 13, a qualified medical practitioner, Government hospital or any other private hospital or the semen bank performing artificial insemination, shall require the following: testing the recipient for “HIV 1 and 2” and sexually transmitted diseases before performing artificial insemination (Clause (b)); seeking a written consent of the recipient for using the semen on the basis of a single ELISA Test being negative, where facilities for cyro-preservation and liquid nitrogen for semen are not available (Clause (g))

Section 269 of Indian Penal Code

Under Section 269 Indian Penal Code, performance of a negligent act likely to spread infection of a disease dangerous to life is an offence punishable with imprisonment for a term up to six months or with fine. In order to punish a person under this Section it must be proved that he acted unlawfully or negligently. Any HIV infected person, if after testing positive, indulges in sex without taking the precaution or using contraceptives, will be liable to be punished under Section 269 IPC.

Section 270 IPC

A Blood Bank, which negligently supplies blood containing HIV virus, can be punished under Section 269.

Section 304-A IPC

A doctor or a medical personnel can be prosecuted under Section 304-A of the IPC, if a patient dies on account of his negligence.

If a person dies as a result of HIV infectious blood negligently supplied by a blood bank, the person responsible for the supply can be punished with at least a two year term of imprisonment or with fine.

5.4 LAWS USEFUL TO ENFORCE THE RIGHTS OF PLHAs

Criminal Procedure Code – Sections 133 to 143.

Criminal Procedure Code (Cr.P.C) lays down the procedure in a criminal case. The part relevant for HIV/AIDS comes under sections 133 to 143 of Chapter XB titled Public Nuisances. Any unlawful obstructions or nuisance at any public place or at

any way or channel, which is or may be used by the public are to be dealt by the magistrates. The conduct of any trade or occupation or keeping goods, dangerous to the health or physical comfort of the community, is also barred. Obstructions in hospital or blood banks compounds, corridors, stairways or wards, etc. are public nuisances that comes under this chapter.

Criminal Procedure Code – Section 357

Another useful provision deals with provision for compensation to victims. Section 357 of the Cr.P.C provides for compensation to victims of crimes and allows compensation to be ordered after the conviction of the offender. Thus, public nuisance, annoyance and obstruction or inconvenience to life can be overcome, if the legal provisions are properly resorted to. If these laws are used, then blood banks operating without proper license, recycling of used syringes, needles and blades, hospitals flouting safety and sterilization norms, etc. can be held accountable and penalised. Hair-cutting saloons and beauty parlors have limited chances for HIV/AIDS spreading and can be effectively controlled if the provisions on public nuisance are used.

Law of Torts

Tort is a civil wrong independent of contract. Liability in Tort arises from breach of a duty primarily fixed by law, which is generally towards others. For example, although there is no separate contract between members of a municipality requiring that all the municipal areas to be kept clean by the municipality. The municipality, which taxes people, is duty bound to provide civic amenities. So also is the case of a hospital and a patient, implying that there will be no negligence on the part of the hospital. The hospital is bound to show due diligence in treating the patient.

In Laxman B.Joshi vs. T.B Godbole (AIR 1969, SC 128), the Supreme Court held that a doctor, who holds himself as skilled and knowledgeable when consulted for the purpose, owes his patient certain duties of care – the duty of deciding whether to undertake the case, a duty in deciding what treatment to give, and for the administration of the treatment. A breach of any of such duties will constitute an act of negligence by the doctor and the hospital.

If any person dispensing medical service violates any of the provisions of law related HIV/AIDS patients, he can be sued for compensation under the Law of Torts, in addition to the remedies provided in the respective laws. The Law of Torts can also be used to discipline unethical or greedy practitioners of medicine. The government hospitals that do not care for the patients or those private hospitals or doctors offering free, but faulty medicare will also come under the Law of Torts.

Consumer Protection Act, 1986

Today, we have a well-developed medical jurisprudence. Damages can be sought for unethical, deficient or negligent medicare. Medical negligence can be brought before the courts for damages under the Consumer Protection Act, 1986. This Act can also be used to fight AIDS. If contaminated blood is supplied, the amount paid can be got refunded along with the compensation. In the same manner, tattooing, faulty blood testing, side effects from medicines, misleading medical or para-medical publications or teachings, etc. are all actionable under law.

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5.5 A LEGAL POLICY ON HIV/AIDS

The fear generated by the HIV epidemic has not helped the cause of HIV/AIDS patients. Sex workers, gay men (MSMs) and drug users (IDUs), who were among the first 'to be infected by HIV, are already targets of punitive legal provisions. Some suggestions made by Julie Hamblin in a UNDP paper, 'People Living with HIV: The Law, Ethics and Discrimination' are apt in summing up this Unit.

Protective and Supportive Legal Framework

The law can, and must be used, to establish a protective and supportive framework for people affected by the epidemic and not a punitive one. The element of collaboration and mutual support that emphasizes the common interest between the infected and the uninfected, and between the government and individuals, is essential.

Creating a supportive legal environment can involve both negative and positive legal interventions. The negative interventions arise from the need of an absence of law in some contexts. The laws which we do not need are the laws that discriminate against the people with HIV and alienate them from their communities, making it less likely for people to share on common interests, to reduce the effects of the epidemic. Similarly, there are also positive legal interventions that can actively promote the supportive environment. The latter interventions include:

- human rights and related legislations that give legal rights such as the right to privacy, the right to protection against unlawful search and seizure, as well as rights to protection against unlawful detention.
- anti-discrimination laws providing redressal in the event of discrimination, denial of housing, and even access to health care, etc., for people living with HIV/AIDS (PLHAs) and their family or friends.
- protection of the confidentiality of a person who is HIV positive.
- right to object to forced extraction of consent, before HIV testing is undertaken.
- encourage appropriate workplace practices, eg: infection control procedures and HIV education for employees.

Such approach towards the constitution of a legal policy on HIV must intend to use law not as a weapon, but as a protective instrument that respects the worth of all individuals and reinforces co-operative efforts to deal with the effects of the epidemic. Of late, it has been proposed to introduce a draft HIV/AIDS Bill in the Parliament. A draft copy has been prepared in consultation with all the stake holders and is in the process of being finalized.

Check Your Progress I

Note: Use the space provided for your answer.

1. Which Articles of the Constitution of India can be used by PLHAs to protect their fundamental rights to equality, non-discrimination, basic freedoms and right to health?

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5.6 RIGHTS OF PEOPLE LIVING WITH HIV/AIDS (PLHAs)

Several nations have legislated on HIV/AIDS. In the absence of legislation, the judiciary in many countries have issued judgments on several issues related to HIV/AIDS. These judgements reflect legal approaches to HIV/AIDS.

Responses to Discrimination in Employment

In the context of employment, PLHAs have often been denied jobs and discriminated against. Some private companies even dare to terminate the services of HIV positive employees.

In a specific case filed by a HIV-positive school teacher against transferring her from a teaching post to an administrative post, a U.S. Court held that the mere theoretical risk of transmission of HIV was not a sufficient ground for change of job as she was still capable of teaching. Further, the court observed that denial of employment would do irreparable harm to the petitioner. The above judgement was based on the contention that AIDS is a progressive disease of the immune system, and that there are several stages in the course of an untreated HIV infection. During the symptomatic phase, the HIV infected individuals were capable of maintaining productive lives and could remain gainfully and productively employed, especially if properly treated.

In the context of employment, the courts in Canada and the U.S. observed that if there is no significant risk of transmission, removal of an employee from his/her employment would constitute a violation of the right to equality, and the right against discrimination. However, a HIV-positive employee cannot invoke protection against discrimination if there is a significant risk of transmission to co-workers. The courts further held that if risks of comparable magnitude are acceptable in a work environment, then risks posed by a person who is HIV-positive cannot be considered significant.

The South African Constitutional Court in the case *Hoffman v. South African Airways* (CCT 17/00; 28th September 2000), held that the Constitutional right not to be unfairly discriminated against could not be determined by ill-informed public perception of persons with HIV. The denial of employment to a PLHA impairs the individual's dignity, and constitutes unfair discrimination, violating the right to equality guaranteed by Section 9 of the South African Constitution.

The Australian as well as Namibian courts have found that dismissing or excluding an officer or recruit on the basis of his HIV status constitutes unfair discrimination.

Judicial Responses in India

In the landmark case MX v. ZY [AIR 1997; Bombay 406], the Bombay High Court held that it is arbitrary, unjust and unlawful to dismiss a worker, who is still qualified and fit to perform the requirements of the job, and who does not pose a risk to others on the job. The courts have also acknowledged that mandatory pre-employment testing is not acceptable. Any rule mandating medical fitness as a prerequisite to employment must have the objective of assessing the person's capacity to fulfill the job requirements and the extent to which the individual poses a health hazard. Therefore, it is unlawful to terminate an employee on the basis of HIV status unless s/he is not medically fit to do the job, or there is a significant risk to the safety

of other workers. India is also one of the few places, where compassionate employment is granted to survivors of the deceased HIV-positive employees of the State, upholding the right to earn a livelihood under Article 21 of the Constitution.

Response to Discrimination in Education

In *Eliana Marlinez v. School Board of Hillsborough Country-Florida* [861 F. 2d 1502] a U.S. Court held that if there is a remote theoretical risk of transmission of HIV, and the student is otherwise qualified to be educated in a classroom, s/he could not be excluded from regular classes. It has also been held in the U.S. that unless there is a significant risk of transmission, it is unlawful to prevent an HIV-positive student from attending a school's regular education classes and participating in extra-curricular activities.

In another case in the U.S., it was held that it is a form of employment discrimination to bar, HIV-positive students or staff members of an educational institution from accessing public documents. [*Racine Unified School Dist. Vs. Labour and Indus Review Commission*, 476 N.W. 2d 707].

Judicial Responses to Maintain Confidentiality of Health Status of PLHAS

Initial responses to HIV/AIDS in many parts of the world propounded public disclosure and isolation, and resulted in stigma and discrimination, which in turn would be deleterious in controlling the spread of infection. In an epidemic that witnessed unprecedented stigma and ostracism, the disclosure of an individual's HIV-positive status exacerbated prejudices and had a devastating effect on their lives. Thus, people began avoiding accessing public health facilities, which violated the confidence reposed in it and stigmatized them further. This ultimately forced HIV-positive persons to hide their status thereby driving the epidemic underground and rendering any attempts to control it ineffectual.Quite similarly in the education sector, disclosure of HIV-positive status has also led to gross discrimination, whereby children have been expelled from school and denied their fundamental right to education.

As a consequence, policies began to recognize the importance of the non-disclosure of health status as a part of a sound public health strategy and an essential human rights response to control HIV/AIDS. Confidentiality is also recognized in international instruments as a central component both of the human rights framework, as well as in the response to HIV/AIDS. Confidentiality has been recognized as a legal principle in various forms. It has been established as a common law principle through several judgements, and also in various circumstances outside the framework of HIV/AIDS. In understanding confidentiality as a legal right and a corresponding duty, courts have found that there should be a relationship between two persons, the confidante and the person who confides and the relationship should be one whose nature is dependent on factors of mutual trust or knowledge or skill or with the objective of imparting services. Common law has also witnessed the evolution of further principles with respect to confidentiality. In the health care context, for instance, courts have found that a doctor is bound by duty not to disclose information obtained in his/her professional capacity, without the consent of the patient unless compelled by law to do so. Courts have also held that where a physician determines that the patient poses a serious danger to a foreseeable victim, then the physician owes a duty to warn and protect the third party.

Courts have also found that the right to confidentiality is vital in cases of HIV/AIDS. This has been done by balancing the public interest to maintain confidentiality against

the public interest to disclose. Courts have held that HIV-positive status falls within a legally recognized zone of privacy and that involuntary/non-consensual disclosure of HIV test results could undermine the public health interest as it discourages persons from getting themselves tested for HIV. Where a newspaper disclosed that doctors in a hospital were HIV-positive and threatened to disclose their names, the hospital obtained an injunction against the same from the court. The court found that the public interest in preserving the confidentiality of doctors with HIV outweighed the public interest in the freedom of press to publish such information, and that the latter public interest would not be impeded due to non-disclosure of the names. Courts have also held that there is an obvious public interest in preserving the confidentiality of those who are HIV-positive, particularly health care workers who report that they are HIV-positive. If health care workers are to be encouraged to notify their status, then it is essential that all care be taken to protect the confidentiality of such reports.

In a landmark case in South Africa (Jansen van Vuuren and another NNO *v* Kruger 1993 (4) SA 842 (A)), where a physician shared the patient's HIV-positive status with the patient's dentist over golf without the consent of the patient, the court found that the physician's duty to maintain confidentiality was axiomatic. The court observed the disclosure as unreasonable and awarded damages worth 5000 Rands (Jose & Jyothiram, 2007). Where a health-care worker revealed a patient's HIV-positive status and identity without the patient's permission, but with approval of her superiors, she and her employer were found liable. Where a health care institution failed to maintain the HIV-positive status of a surgeon in their employment, it was held to be a breach of his right to confidentiality. Some courts have even gone to the extent of holding that a municipality, which did not train its employees in the need for confidentiality of HIV/AIDS-related information, would be liable for improper release of that information.

Examining the body of jurisprudence on this issue, it is evident that legislatures and courts have gone to lengths to protect the confidentiality and have often found that the same must be protected on grounds of privacy and public interest. However, confidentiality is not a principle without exceptions, and statutes and judgements have enunciated these as well, yet always conscious of the fine balance required to be maintained between general protection and exceptional disclosure.

The law also envisages situations, where it may be necessary to disclose the HIV-positive status of an individual irrespective of the consent being obtained. Such exceptional situations are list:

a) Cases where notification to public authorities is required by law;

b) Cases where disclosure is necessary in the public interest;

c) Cases where disclosure is necessary for the administration of justice;

d) Cases where disclosure is necessary for treatment of the patient;

e) Cases where disclosure is necessary to protect another person (from harm).

Response to Maintenance of Confidentiality in India

There is no specific law to maintain confidentiality of the health status of PLHAs in India. According to the judicial interpretation of the Supreme Court, Article 21 of the Constitution of India guarantees every citizen including PLHAs the right to live with human dignity and to safeguard his/her privacy. The concept of confidentiality is related and derives from the fundamental right of privacy-that every person has the

right to a sphere of activity and personal information that is exclusive to her/him and that s/he has the right to disclose or not to disclose such information the individual considers in her/his best interest.

In India however, the judicial developments in the sphere of confidentiality related to the health status of PLHAs are very limited. In one case [Mr X v. Hospital Z, (1998) 8 SCC 296] the Supreme Court suspended the right of HIV-positive persons to marry. Although the judgement recognized the right to privacy and the duty of physicians to maintain confidentiality, it held inter alia, that the Code of Medical Ethics formulated by the Medical Council of India creates an exception to confidentiality when public interest was at stake, and where there is an immediate or future health risk to others. The court found that the disclosure of the appellant's HIV-positive status to a prospective spouse was not violative of the principle of confidentiality since the spouse was saved by such disclosure. The Court, however, failed to lay down any conditions and protocols by which such disclosure was to be made. It also added that an HIV-positive person who marries and transmits the infection to the spouse, would be criminally liable under Sections 269 and 270 of the Indian Penal Code, which criminalise those who perform a negligent or malignant act likely to spread a disease dangerous to life. In 2002, however, the Supreme Court set aside its own observations vis-à-vis the right for marriage, privacy/ confidentiality and criminal liability, but also stated that in the facts of the particular case, the appellant's right was not affected due to revelation of his HIV-positive status to relatives of the prospective spouse.

Although jurisprudence roots confidentiality in the principle of privacy, this has not been the interpretation of courts within the constitutional framework, nor has it been reflected in statutory law, thus making it purely a common law principle. The few regulations that do deal with the issues of confidentiality in India, do so with an abject insensitivity and lack a thorough analysis.

Principles and Suggestions to Enact Laws to Maintain Confidentiality

India immediately needs a specific legislation to protect the right of privacy and confidentiality. It must incorporate in the law certain provisions based on the following principles and suggestions:

- every person has the right to privacy, i.e., the right to determine for themselves as to when, how and to what extent information about them is communicated to others.
- every person has the right to confidentiality of personal information including the HIV status, sexual and drug use practices, gender expression, sexual orientation, livelihood, etc.
- the right to confidentiality should be ensured in various settings including diagnostic testing centers, counselling services, health-care institutions, the workplace, during research, educational institutions, the judicial system, the insurance sector, during adoption and in children's care homes, in the media and any other settings that may access and record information on HIV and/or vulnerable status.
- Data protection mechanisms should be provided in all settings to ensure the maintenance of confidential information.
- Disclosure of HIV-positive status may be permissible in very specific circumstances.

when the person concerned gives information and written consent for disclosure of her/his status.

when such disclosure is in the best interests and welfare of the patient's treatment.

when HIV-positive status is required to be revealed to a court for the administration of justice.

when disclosure is necessary to protect another person, who is in imminent risk of being infected.

when disclosure of HIV-positive status outweighs the public interest to maintain confidentiality.

when disclosure is required by statute.

disclosure of HIV-positive status in the aforementioned circumstances is only permissible after following a specific and detailed protocol as prescribed.

an HIV-positive individual who knows of her/his status has a duty to inform the same to her/his sexual partner, needle-sharing partner, blood bank, adoption agency (in case s/he wishes to adopt); an adoption agency has the duty to inform a child's HIV-positive status to prospective parents.

5.7 LEGAL STRATEGY REQUIRED FOR HIV/AIDS LAW

We need an AIDS law to stop the spread of the disease and in curbing all sorts of discriminative practices. We need a comprehensive legislation taking the form of an HIV/AIDS Prevention and Rehabilitation of Victims Act. Various points in strategy for enacting AIDS laws in India, are suggested below:

It must:

1. harmonize state laws with the National Policy on HIV/AIDS;
2. regulate public health standards for sex workers;
3. provide for privacy, and redressal against discrimination at their work place;
4. ban compulsory testing for HIV of specific groups;
5. promote ethical values related to sex;
6. frame laws on HIV/AIDS, based on up to date scientific knowledge of the disease, its cause and effects;
7. supplement and complement the medico-social strategy to fight the disease;
8. replace punitive approach with preventive and rehabilitative approach;
9. frame laws in conformity with the human rights jurisprudence;
10. protect communities from life threatening infections such as HIV/AIDS;
11. recognise the basic needs of the AIDS patients and protect them from unjust and inhuman discrimination;
12. encourage people to undergo voluntarily testing for HIV;
13. advocate for awareness through education for prevention;
14. protect confidentiality and privacy of the HIV/AIDS positive;
15. create a well equipped communication system and a centralized information service on HIV/AIDS;

16. allow tax relief to persons and organizations who support and serve those infected with HIV/AIDS;
17. establish a central agency to co-ordinate the efforts of those working to prevent HIV/AIDS.
18. identify priority areas for HIV related legislations, and formulate suitable policies.

Some of the legal provisions that must be included in the HIV/AIDS related laws are listed below:

1. means to check the spread of AIDS;
2. emphasise the rights and dignity of the AIDS patients;
3. encourage voluntary testing among the people;
4. setting up AIDS surveillance clinics;
5. prohibiting isolation of AIDS victims;
6. maintaining confidentiality about the identity of the HIV/AIDS afflicted;
7. preventing any sort of discrimination by the State on the ground of an individual's HIV status in matters of employment, education, travel, etc;
8. regulating the services to the patients by medical personnel;
9. insuring medical personnel working among HIV positive persons or AIDS persons;
10. penalising breach of confidentiality regarding the identity of the HIV-positive/ AIDS persons;
11. mandatory screening of HIV in manufacture of blood related products;
12. Providing facilities for confidential testing, security and rehabilitation of the victim;
13. Compulsory testing of blood donated;
14. incurring severe penalties to intravenous drug users for sharing needles and other drug equipments with other users;
15. initiating disciplinary action against health-care workers and other medical personnel refusing to provide adequate care to patients suffering from HIV/ AIDS;
16. declaring AIDS patients or HIV positive patients as disabled, entitling them special protection;
17. ensuring education of the masses on AIDS by the state;
18. punishing HIV-positive/AIDS patients for sexual contact with another or donating blood, organs or transfer of body fluids such as semen, blood, vaginal secretion, tissues after knowing fully well about their AIDS/ HIV-positive status;
19. regarding special care to special children born out of HIV-positive mothers;
20. persuading persons engaged in commercial sex work to undergo test for HIV voluntarily.

5.8 LET US SUM UP

In this Unit, the reader has been exposed to judicial responses to various issues related to HIV/AIDS, especially in matters related to the discrimination of HIV/ AIDS affected persons in employment, and the requirement to maintain confidentiality of health status of PLHAs. We also had a review of the laws useful to prevent the

spread of HIV, useful laws to enforce rights of PLHAs, rights of people living with HIV/AIDS, and various aspects pertaining to a legal policy on HIV/AIDS. This Unit also explains the legal strategy required for an AIDS Law.

5.9 FURTHER READINGS AND REFERENCES

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