Counselling is Caring That Goes beyond Curing for HIV Positives

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Abstract: HIV/AIDS has had a devastating impact at individual, household and community levels. AIDS has challenged several aspects of contemporary social life and conventional approaches to health care. The social and medical responses to diseases have probably not been challenged so intensely for a long time. One social response to HIV/AIDS that has received much attention is the counselling of people affected by the disease. This paper reviews pertinent issues that must be considered when counselling people who are affected. These are discussed from the point of view of goals of counselling derived from two different counselling situations: counselling for the prevention of transmission that addresses both infected and non-infected people and counselling for the provision of psychological support for those who are affected. Counselling in HIV/AIDS care is unique but there are similarities and differences between counselling in HIV/AIDS care and counselling for general health promotion. Some of the problems associated with HIV/AIDS counselling in Delhi are presented and some ways of dealing with them are suggested also be provides the remarkable approaches of counselling to enhance the life style patters of HIV Positives. This qualitative research investigates the role of HIV Integrated counselling and testing centre (ICTC) and treatment in enabling HIV-positive to cope with this disease. They described experiencing gendervariant stigma and depression on confirming their HIV status and commended the role of counselling in supporting them to adopt positive living.

Keywords: HIV/AIDS counselling, Integrated counselling and testing centre (ICTC).

1. INTRODUCTION

Counselling is caring that goes beyond curing for HIV positives:

To counsel means 'to advise, to recommend, to advocate, to exhort, to suggest, to urge' (*Oxford Dictionary*1996:131). However, counselling as a concept, as observed by Miller and Bor (1991) has many interpretations. Whatever its goals, counselling is directed towards Assisting people to take decisions, to effect a change, to prevent problems or crises or to

Manage them when they arise. Hopson (1981) thus, from a problem-solving perspective, saw Counselling as helping people to explore problems and clarify conflicting issues, and to Discover alternative ways of dealing with the problems by taking appropriate decisions and Action. Counselling has been defined as a process of helping/enabling a person/people solve certain interpersonal, emotional and decision-making problems.

Counselling involves:

Supporting individuals to take charge of their own life by:

- > Providing information
- > Facilitating emotional adjustments
- Enhancing mental health

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And enabling them to:

- Understand and accept the problem
- > Develop resources to take adaptable and realistic decisions
- Alter their own behaviour to produce relatively enduring, desirable consequences

Counselling is...

- > Specific to the needs, issues and circumstances of each individual client
- An interactive, mutually respectable collaborative process
- Goal directed
- Oriented towards developing autonomy, self-responsibility and confidence in clients
- Sensitive to the sociocultural context
- > Eliciting information, reviewing options and developing action plans
- ➤ Inculcating coping skills
- > Facilitating interpersonal interactions
- > Bringing about attitudinal change

Stages of counselling:

- 1. Rapport building
- 2. Assessment and analysis of the problem
- 3. Provision of on-going supportive counselling
- 4. Planning and initiation of steps
- 5. Implementation of the plan
- 6. Termination and follow up

2. COUNSELLING FOR HEALTH PROMOTION

Interpretations of the term 'health promotion' may vary, but in general, the function of health Promotion is to help people take responsibility for their health and adopt a lifestyle Conducive to good health, to promote behaviour which leads to quick recovery from illness, And to enable them to cope with dying. Counselling for general health promotion, the avoidance of diseases is both individualistic and group-oriented and usually considered an essential component of public health. The emphasis is on adopting what are considered good 'health habits'. Issues considered include good personal and environmental hygiene, good nutrition and safe drinking water, adequate exercise, relaxation and rest, and avoiding high levels of stress and health-risk behaviours such as smoking and excess alcohol consumption. These issues can be discussed openly and without fear of isolation or stigmatization.

Counselling to help a client attain quick recovery during an acute illness, however, usually incorporates more focused information about meeting needs specific to the particular illness. This is often rewarding for the counsellor as the time during which the client is intensely dependent is shorter than that required to manage a chronic illness. When the disease is not life-threatening, stigmatizing and expensive to manage, although it may be chronic, there are fewer demands and less stress on the clients, their significant others and the counsellor.

Counselling for general health promotion is consistent with efforts to promote ideals of the infinite self through actions that are not too probing to the self. It is generally amenable to open discussion and to the adoption of actions which others in the society consider will equally promote their own health. Emphasis is on helping clients adopt actions that are consistent not only with enhancing the quality of life but also with increasing life expectancy. With counselling for socially accepted, non-stigmatizing illnesses, the emphasis for the client, the family and the health care workers must be on the whole person.

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Counselling for general health promotion emphasizes those things controlled by the clients and their social group, with assistance from the state, which enhance self-preservation and thus reduce morbidity and postpone mortality. Counselling for HIV and AIDS, however, is more complicated since HIV-positive people face difficulties arising from the nature of the disease, the way it progressively affects and consumes the biological self, and the difficulties that arise from the social perception of the illness and the people affected by it. As well, it causes strains in social relationships. Probably the biggest problem in meeting the needs of people with AIDS is that they must accept impending death while the health care model makes consistent and rigorous efforts to increase life expectancy. This is why AIDS counselling is different from other forms of counselling in general health and disease management. What then is AIDS counselling?

3. HIV/AIDS COUNSELLING

WHO (World Health Organization) defines HIV/AIDS counselling as a confidential dialogue between a client and counsellor aimed at enabling the client to cope with stress and take personal decisions relating to problems arising from HIV/AIDS (WHO 1995). The counselling process includes the evaluation of personal risk of HIV transmission, facilitation of preventive behaviour and evaluation of coping mechanisms when the client is confronted with a positive result.

AIMS and Importance of HIV/AIDS counselling:

HIV/AIDS is a life-threating, life-long illness. Diagnosis of HIV/AIDS has many implications-Psychological, social and physical. Counselling in HIV/AIDS care is an interaction of information Exchange, skill acquisition and emotional support between the counsellors, the person infected with HIV and others significant to the client who include family members, friends, Health practitioners, employers and people who give spiritual support. The interaction is Directed at meeting the physical, psychological and socio-economic needs of the client to enable him or her to attain optimal physical, mental and social health and functioning: to provide continuous support and to prevent HIV transmission to others. Preventive counselling and behaviour change can prevent transmission of HIV and improve the quality of life.

Aims of HIV/AIDS counselling:

- 1. Facilitating decision to undergo HIV test
- 2. Providing psychological, social and emotional support for
- People who have contracted the virus and
- Others affected by the virus
- 3. Preventing transmission of HIV by
- Providing information about risk behaviours(such as unsafe sex or needle sharing)
- Motivating people to take good care of their health
- Assisting them to develop personal skills necessary for behaviour change and
- Adopting and negotiating safe sexual practices
- 4. Ensuring effective use of treatment programmes by
- Establishing treatment goals
- Ensuring regular follow up.

4. NEED OF SPECIALIZED COUNSELLING

AIDS counselling is different from other forms of care. The disease is not only a health problem with diverse consequences for an individual, but equally a problem for the family and society; it is also associated with intense and progressive human suffering which arouses diverse emotional reactions. Such reactions include fear, denial, loss, grief, anxiety, anger, rejection, isolation, annoyance, blame apportioning, pity, self-condemnation, depression and suicidal thoughts (Moynihan 1991; WHO 1995b). It is not only the clients who go through the grieving process but every person in their social network. Managing the disease involves personal issues and often requires talking about things that are

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dreaded and aspects of life ordinarily considered very private. The uncertainty about several aspects of life was noted by Miller and Bor (1991). These are concerns about whether AIDS will develop and whether family and friends will reject the person infected. There will be doubts about their willingness to give support and about the availability and usefulness of treatment and the course of the Illness. Other concerns are related to myths and lack of complete knowledge about the disease. The clients may be very fearful of the social attitudes that question their self-worth and may bring scorn on the family. HIV also brings anxiety about possible family conflicts and problems concerning work and finance as the disease progresses. There may also be problems with friends, problems about meeting basic life needs, problems derived from sexuality and sexual relationships, changes in body image and anxiety about dying and death. AIDS counselling is different because the disease is accompanied by concerns that are not associated with other diseases, however severe; it is still a highly controversial disease with many facets; personal, social, political, legal and religious. Human rights, public health and many more aspects are involved in coping with it. Miller and Bor (1991) summarized the uniqueness of the particular counselling needs of people with HIV/AIDS. They noted that the disease has no cure, it is infectious and the most at risk are the young in the prime of their productive, active sexual and reproductive lives. The disease is almost always fatal, there are periods of acute illness and the end-stage is one of chronic illness which results in bodily changes, including changes in appearance. The terminal nature of AIDS challenges the illusion of immortality of the young. Associated with this are the practical, psychological and economic adjustments that have to be made by everyone affected. Again, there is the fear of so many uncertainties. HIV/AIDS is associated with incomplete knowledge and often with conflicting information. Significantly, definitive co-ordination of care is needed because of the many persons who are involved. Service provision as effective patient management can prevent many problems and enhance the quality of the patient's life. Looking at the process of AIDS counselling, WHO affirms that it is a confidential, personalized process, until the client decides otherwise. The process involves reacting to the client's needs through conversation, without being didactic. It must be empowering and should help the client take decisions that will affect not only his or her life but those of the significant persons, especially the members of the family. Counselling in HIV/AIDS is not only to protect and help clients, it is also meant to protect the other members of the family and community as clients are shown their role in preventing infection and in contributing to the general control of the disease. The factors that make HIV infection and AIDS unique make necessary specialized counselling which according to Miller and Bor (1991) should provide personalized information and give social and psychological support focused on strengthening the client's sense of responsibility. The client needs this help to accept and benefit from new information which can enable the adoption of changes in lifestyle. Counselling should help the patient to define the problems that accompany the disease, and enable the persons concerned to make realistic decisions on how to reduce the impact of the disease on the patient and significant others. It should help people to acquire knowledge, skills and attitudes as well as the confidence to make the necessary lifestyle changes that facilitate preventive and therapeutic behaviour. This becomes particularly useful in resolving anxiety about relationships, intimacy and sexuality. Counselling should also help clients to accept the uncertainty of their future and objectively analyse such feared issues as illness and treatment, pain and separation from loved ones by death. Clients can also be helped to understand beliefs, religion and views about self as well as legal, ethical and human rights issues, as these are important to the clients and their significant others

An understanding of this need for specialized counselling gives the counsellor a good base from which to adopt the most appropriate theoretical approach which will most help those who are infected and those close to them. The appreciation of HIV/AIDS as a chronic disease that has social implications and makes demands on everyone related to the person affected raises the question of who should be counselled.

5. PEOPLE WHO SHOULD BE COUNSELLED

Everyone needs counselling, although from different perspectives, as everyone has a role to play in care and in controlling the spread of HIV. Importantly, every sexually active person exposed to risks of contracting HIV needs individual counselling, focused on the behaviour that puts the person at risk. Counselling should be for men and women irrespective of sexual orientation; heterosexual, homosexual or bisexual. This is important for people with multiple sexual partners practising unprotected penetrative sex (now or in the past), sexual partners of these people, drug users who share injecting equipment, and recipients of unscreened blood products and donated organs, especially before the introduction of routine screening of donated blood. Others needing counselling are people who may have been exposed to infection through previous invasive medical and surgical procedures from traditional or orthodox practitioners. As well, people seeking help because of past or current sexual behaviour which has put them at risk should be given priority. Others seeking help

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include pregnant women who are HIV-positive, health practitioners with occupational exposure, and people who have been sexually abused, assaulted or raped. Others include people considered to be special high risk groups, such as sexually active teenagers and commercial sex workers, and people at different stages of illness from HIV infection. When traditional care-giving within the family becomes inadequate, it is time to seek the help of professionals to supplement the efforts of the family. Informal caregivers of people with AIDS are often lovers, spouses and other family members. These people stand to benefit significantly from counselling as they are prone to experience what DE Carlo and Folk man (1996) call 'compassion fatigue' or burnout from caring for a sick person for a long time or losing loved ones after a period of physically and emotionally demanding caregiving. Additionally, sexual partners who are also caregivers need counselling to encourage the adoption of safer sex practices. The fact that different types of people require counselling to achieve specific but diversified goals points to the variation required in counselling procedures

6. COUNSELLING-METHODS AND TIMINGS

Guidelines for counselling are derived from the need for primary, secondary and tertiary prevention of the spread of HIV and the need for care which will enhance the quality of life of people already infected. These guidelines also indicate when and how people affected by

HIV or AIDS should be counselled. Three main times for guidance and counselling are before testing or screening; in the post-screening period; and when the client has been confirmed as having the infection.

> Pre-test counselling:

Pre-test counselling must take place before the client is screened. This provides education as well as guidance to the client.it helps to prepare the client to test for HIV, explains the implications of knowledge of HIV, and facilitates discussing ways of coping with knowing one's HIV status. It is important that the client be properly informed before giving consent to the test so that he or she can understand the result of the test and not see it simply as a test for AIDS. This saves the health practitioner the problem of disclosing a positive result where the consent of the client had not been sought before sample collection. A major component of pre-test counselling is the completion of risk assessment. The client's last exposure to risk needs to be discussed in a way that will help the client understand the possible results. Also, the social consequences of the result need to be explored, bearing in mind the practical realities (McCreaner 1989; Miller and Bor 1991; Perakyla 1995). Confidentiality would be a concern to anyone contemplating having the HIV test. The pre-test counselling session should handle this adequately, addressing the issue of who can and who cannot gain access to the results of the test. This is usually a very sensitive area, especially when the question arises of informing sexual partners or referring them for tests.pre test counselling is important for the client's understanding of the implications of a positive or negative test result.pre-test counselling lays the foundation of post-test counselling and test result provision.

The following issues should be addressed by a counsellor during pre-test counselling:

- > Reason for testing
- ➤ Knowledge of HIV/AIDS
- ➤ Level of understanding of the client
- Correction of misconceptions
- Assessment of personal risk
- Information on HIV test
- > Discussion of possible results
- > Capacity of the client to cope
- > Potential needs and support of the client
- > Personal risk-reduction plan
- > Taking informed consent from the client
- ➤ Making arrangements for follow-up

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> Post-test counselling:

Post-test counselling helps the client understand and cope with the HIV test result. The immediate post-test face-to-face counselling session (usually very emotional when the result is positive) is not only to give the result but to address the implications to the client and the significant others. The client must be helped to understand the difference between being HIV-positive and having AIDS. His or her immediate concerns should be analysed with the purpose of advising a shortterm plan of action. This requires the counsellor to discuss concerns, to ask questions and to review available care and support facilities. The post-test counselling period is a real challenge and is often emotionally demanding even for the practitioner when the client's result is positive. Other times when people affected by HIV or AIDS need counselling are when the HIV positive client is becoming ill, when the client is showing signs of AIDS related conditions, when medical management is being considered, and when neurological impairment is manifesting. The form of post-test counselling will depend on what the test result is. Where it is positive, the counsellor needs to tell the client clearly, and as gently and humanly as possible, providing emotional support and discussing with the client on how best to cope, including information on relevant referral services. On-going counselling will help clients accept their HIV status, and take a positive attitude to their lives. Through on-going counselling the infected person may choose to invite a trusted family member to share confidentiality and participate in the counselling—enabling the family to start practising family level counselling. But counselling is also important after a negative result. While the client is likely to feel relief, the counsellor must emphasize several points. First, because of the "window period", a negative result may not mean absence of infection, and the client might wish to consider returning for a repeat test after 3-6 months. Second, counsellors need to discuss HIV prevention, providing support to help the client adopt and sustain any new safer practices. (For further information on counselling related to testing, see Key Materials, Source Book for HIV/ AIDS Counselling Training, WHO, 1994.) Counselling becomes indispensable whenever any form of crisis for the client or other close contacts arises. The terminal phase of the illness when the client and significant others have to contend with imminent death and all the issues involved calls for intensive emotional support by the counsellor. Bereavement counselling of persons significant to the client is also an essential component of AIDS care.

The needs assessment schedule is a good framework for the content and nature of the counselling sessions at different periods and stages of the illness. The major aims of the counselling process are information giving, promotion of risk reduction strategies and provision of emotional support. The counsellor should be able to determine which of the areas should receive the most attention depending upon the stage of the disease. Counselling sessions must give information to the person infected about the following:

- 1. Taking care of self: the client must get to know more about the infection and should be assisted in adopting attitudes, beliefs and actions which will protect the body's immune system (Lindsay, Fevens and Gee 1996).
- 2. Enhancing, improving and modifying nutrition as necessary.
- 3. Promoting physical fitness and rest.
- 4. Avoiding substances, events and actions that threaten the body.
- 5. Reducing stress and strain that compromise the physical, mental and psychological welfare of the body.
- 6. Seeking and giving support for self-care.

The caregivers, as well as sharing knowledge from the identified areas listed, need guidance on caring for people with the disease, coping with changes and managing resources.

They also need help to manage the stress that may arise in their caring for persons with HIV/AIDS. The caregivers should at all times direct their counselling towards enhancing positive living, meeting the medical, social and emotional needs of the client and supporting the family. Several factors affect how the counsellor should approach issues to be handled during the counselling sessions. One is the gender of the client and the implications of this on the ability to negotiate safer sex especially within the Indian socio-cultural context. Other factors include access to care and caregivers, socio-economic status, the occupation, social position and roles in the social network (at work, at home, and in other social gatherings), and financial status. Factors that also seem to be important include age, personality, philosophy of life, beliefs and practice of religion; cultural values about life and death; satisfaction with life achievements; and the perception of economic self. How some of these factors could influence the levels of success in the Indian context may be understood from the case studies which follow.

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7. EVOLVING CONSTRUCTIVE RESPONSES AND SUPPORTIVE ENVIRONMENT FOR HIV/AIDS COUNSELLING

I have found a blend of several conceptual or theoretical frameworks quite useful in attempting to arrive at constructive responses and provide supportive counselling for people affected by HIV or AIDS. These include doing everything possible to preserve the dignity of the infected person as well as to respect the individuality of each client. A supportive environment is achieved by genuinely accepting people with HIV/AIDS with no reservations and emphasizing positive living at all times. No one knows when they will die and what will be the direct cause of death. This makes it important to live every day in the best possible way. These are some of the philosophical or humanistic views that are useful along with some theoretical frameworks guiding counselling in HIV/AIDS care. The theoretical frameworks found very useful are the life cycle, the developmental approach to crisis management and the family systems theory. Applying Miller and Bor's (1991) summary of three subdivisions of the developmental framework, consideration is given to the stage of HIV infection or AIDS, the individual's stage of development and the family's stage of development. This framework helps the counsellor to determine specific issues that will be of concern to the client at their age of contact. It also helps to review issues about HIV/AIDS that have a bearing on the relationship of the client with his or her family. It encourages seeking facts about the stage of the client's illness that could help the counsellor address the effect on the client's significant others. The framework also helps in hypothesizing anticipated responses of significant others when the client's health deteriorates. It assists in determining other factors that add to the stress of living with the infection. These might include the availability or otherwise of human and material resources and existing problems that could worsen the client's status. Difficulties for carers in the treatment environment, home-based or in hospital are also analysed within the framework.

The Family Systems Theory of the Milan Centre for Family Therapy is the other framework that has been useful in HIV/AIDS counselling. While discussing this theory is beyond the scope of this paper, three identified aspects of the theory that are useful in HIV/AIDS counselling are presented here. These are the systemic view, the technique of counselling, and the use of hypothetical questioning. These are future-oriented through encouraging clients to describe their lives and relationships in hypothetical future situations. The systemic view looks at the problems and postulates what can be done about helping the clients function within the system of which they are a part. The technique makes use of 'circular questioning' in highlighting the clients' different feelings about the problems. This is done by one counsellor with direct contributions from other counsellors who stay in the background. Essentially, the ability of the counsellor to provide a supportive environment is dependent on certain qualities. The counsellor must be without prejudice and fear, and must be well informed but not ashamed to acknowledge limitations or seek more information when unsure. He or she must personally have come to terms with the disease and should not be judgemental, should not make assumptions and should be capable of respecting the clients' ways of coping with the infection. The counsellor must be willing to share responsibilities with other people in the team caring for the clients. It may be useful from experiences in the field to illustrate how responses could become supportive

8. WHAT SHOULD BE IMPLEMENTED?

Health care delivery systems and the rights of clients within the system may be seen at various levels. To start with, counselling should be a fundamental right of the client in health care, irrespective of the nature of the disease or health needs that bring the client in contact with the system. This is not to say that every health practitioner should be made to undergo training as a counsellor for all terminal illnesses. It may be unrealistic to expect that present training of health professionals could be extended to include health counselling. However, there are signs of deficiencies in the training of almost all health practitioners; they lack skills to help clients manage sensitive issues related to their well-being. Major areas that require review are those of sex, dying and death. There is a need to look into the changing patterns of familial structures and interactions in Delhi, and to how functional and supportive the extended family can be. Whatever problems the extended family system may have, there seems to be much to gain from it as a social collective. Many people dying of AIDS, even when abandoned by spouses, friends and employers have been cared for by members of the extended family who may not have played an active part in their lives while they were in good health. After their death, it is usually the same family members who take responsibility for the nuclear family, or orphans left behind. There is a need to see how this old phenomenon of kinship can be improved upon to help the family cope with the crisis of AIDS in the absence of government social services. As a matter of urgency, there is a need for anonymous counselling facilities. These for a start

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could be in the big cities and towns and possibly linked to all health units. It is also important to demand an improvement in the telecommunications system in Delhi. Accessible phone booths are indispensable to people urgently seeking information as NACO has launched 1097 (toll free HIV/AIDS Helpline). Some of the standard answers are available online but further clarifications and personalised counselling are also available by dialling 1097.

9. CONCLUSION

Counselling is a very important mode of behavioural intervention in HIV/AIDS especially in the absence of an effective vaccine or a curative treatment. It consists of dealing with a variety of issues such as medical, psychological and social. HIV/AIDS counselling is the skill of helping people to take important decisions about their life, relationships, dying and death. When the skill is well learnt it is adaptable to managing all health-related problems. The health and illness patterns of the world's population are changing, especially with the emergence of ageing populations and increasing life expectancy. There are changes in the patterns and forms of existing diseases as well as the emergence of new ones. The orientation to health and illness has gone beyond thinking of cure as the only major motive of caring. Life involves accepting limitations and living positively within them. Counselling is caring that goes beyond curing. The issues brought to light by the needs of people with HIV and AIDS, and the people affected by their relationship to those infected, go beyond the disease itself. We are all affected; otherwise the whole world would not be talking about it.

Some of the goals of counselling are to help young people understand their sexuality;

- > To make people aware of their rights for sexual negotiation, especially where there are problems related to gender differences
- > To help find solutions to economic problems and to encourage an improved socio-economic status for women.

As well, counsellors will aim to facilitate premarital and intramarital communication, and to help in family crises which are part of HIV Prevention and control.

Counselling can greatly help in the problems that accompany HIV and AIDS, especially in achieving the effective communication so greatly needed to attain reconciliation with the realities of living, dying and death.

The findings also revealed gender differences in treatment adherence strategies. For those receiving ART, counselling reinforced treatment adherence. The findings also revealed gender differences in treatment adherence strategies. ART was described to reduce disease symptoms and restore physical health allowing them to resume their daily activities. Those that were not receiving ART bore myths and misconceptions about the effectiveness and side effects of ART, delaying the decision to seek treatment. Stigma and the attached concern of HIV/AIDS-related swift death, is a major barrier for ICTC (integrated counselling and testing centre). Based on this study's findings, ensuring the provision of quality assured and gender conscious ICTC and ART delivery services will enhance positive living and enforce compliance to ART programmes.

The findings of the study shows that Counselling also enhancing the patterns and ways of living to a remarkable level.

Counselling helps in

- > Acceptance to have a HIV infection
- Understands about HIV and AIDS
- > To understand the difference between HIV and AIDS
- > Boosting the emotional behaviour of the client
- > Motivation to fight with the HIV
- > Psychosocial support
- ➤ Adherence for ART
- > Removing myths and misconception about HIV and AIDS
- > To connect HIV positive clients with the mainstream

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- > To generate enthusiasm in the clients to move forward in their life
- > To live normal as usual life with all their joys
- > To active participation of HIV positive clients in the society
- Adoption of a Risk reduction plan for better prospects
- ➤ Motivated for Self-care activities

Appeals must be made to the government, philanthropic organizations and individuals to help existing counselling groups to train more people. There is an urgent need to expand the scope of coverage to reach many more people affected, not only by HIV or AIDS, but by other terminal diseases.

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