

# Family System Based Counselling in HIV/AIDS

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**Abstract:** AIDS (Acquired Immuno Deficiency Syndrome) is caused by multiple sexual contacts, unhygienic blood transfusions and intravenous drug abuse. It is now thought of as a chronic disease whose length is indeterminate and whose course is uncertain. It seems to be an expected diagnosis leading rapidly to death. As the disease is associated with the feelings of isolation and depression in the patients, psychotherapy to the people with this infection and their families is expected to play an important role in the alleviation of psychological symptoms. Family systems therapy leads to intervention of the disease to some extent with the effective counselling of the patient's family. The counselling goals include reconciliation of the ill person and his/ her family, mobilization of family resources, facilitation of ill person's participation in the on-going life and in the planning for its future. The family therapist explains to the AIDS infected person his/her responsibilities towards her/his spouse before death. He also tells how to cope with the grief after the death of loved one. The family counselor also makes his/her best efforts to continue communication with the family members after patient's death and suggests medical check-ups of the family members. Moreover, family systems approach in counseling help in understanding common patterns of couple relationships, empowers the family to believe in its own capacities for problem solution and illness management, maps the family illness structure so as to make it healthier and mobilizes extra familial support to the AIDS patients.

**Keywords:** AIDS, family systems counseling, counseling, goals

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## Introduction

The first clinical cases of acquired immunodeficiency syndrome (AIDS) were identified in 1981. The human immunodeficiency virus (HIV), the causative agent of AIDS, was discovered in 1983. It is estimated that almost two million Americans have acquired HIV infection. Although AIDS was initially diagnosed in the United States in a group of gay men, groups recognized as at high risk for infection in this country include a wider sector of the population -- intravenous drug abusers (IVDAs), haemophiliacs and heterosexuals who have sex with patients belonging to high risk groups. ). In 1983 an infectious agent, the Human immunodeficiency virus (HIV) was identified as the cause of AIDS. Since then world wide more than 7 million people have been diagnosed with AIDS, 4.5 million have died from HIV associated conditions, and probably around 21 million have been infected with HIV.

It affects people in every country in the world. The United Nations estimates that as of 2006 there are 39.5 million people worldwide with HIV. Each day the disease affects more individuals, families and communities. In the U.S., it is thought that up to 1.2 million people are living with HIV. India has the third highest number of estimated people living with HIV in the world. India has a population of one billion, around half of whom are adults in the sexually active age group. The first AIDS case in India was detected in 1986 and since then HIV infection has been reported in all states and union territories. HIV is increasingly recognized as an illness that affects couples and families, and not just the individual. This is not only because the virus can be passed on from one person to another, but also because for every person infected with HIV, there is a family and community that are also affected.

HIV is a blood-borne virus that can be spread through unprotected sex, sharing drug-injecting equipment and to a child during or shortly after birth from an infected mother. HIV cannot be cured, but can be managed by a combination of medications. However, if left untreated, the condition can progress until the person develops AIDS (acquired immune deficiency syndrome). Immune systems that are compromised are unable to effectively fight infection. People are then susceptible to a range of infections and can die from these.

## Family Counseling and HIV/AIDS

As with other chronic illnesses, partners and families often provide most of the physical and emotional care. This places a great strain on them and lead to individual stress and tension between members of the family.

- In relationships, the diagnosis of HIV may reveal aspects of a person's behavior that they may have wanted to keep private. This may include infidelity or sexuality (such as male homosexuality) or intravenous drug use. This can result in feelings of guilt, blame and lead to a relationship breakdown.
- The family may also have to face bereavement.
- With HIV, more than one person in a family may be unwell which can add to the burden of care and cause additional emotional and financial problems.
- Stigma and discrimination may mean the diagnosis is kept hidden. This can prevent wider support from extended family or the community.
- A family with an infected child will have to consider when and how to disclose this to them.
- Problems can arise where there are conflicts with people's religious or cultural beliefs about medication.
- Parents may find it difficult to discuss sexual behavior and risk with their young children. This could have prevention implications for the next generation.
- Poor access to information can result in people not taking their medication as prescribed by their physician or not coming to the hospital regularly. People in families may disagree about the best course of treatment.
- The stress of living with HIV causes some people to suffer from mental health problems such as anxiety and depression.

### **Systemic Therapy Model of Family Counseling**

Walker (1992) proposed a systemic family therapy model which emphasized upon the effective counselling. It was suggested that in order to make counselling effective the family therapist should conceptualize the family itself as a living system that provides care and must endure and heal itself after the death of a person with AIDS. The counselling goals include reconciliation of the ill person and his or her family, mobilization of family and net work resources, facilitation of ill person's participation in the life of family of origin or choice and in the planning for its future. Therefore a systems approach to AIDS views the family as the unit of intervention and entire course of illness as time frame for intervention. This model for HIV - infected people and their families stresses on the inherent resources coping skills and problem solving abilities of families both to manage the illness and to perform non illness related tasks. The family therapist, therefore, acts as a consultant so as to encourage the families to identify and change meaning of illness, define problem areas and effect solutions. AIDS counselling should be pragmatic and problem focussed. The therapist must encourage the family to focus on the tasks of everyday life so as to put illness in its place (Gonzalez, Steinglass & Reiss, 1987).

A system oriented counselor not only examines the level of patient and family experience but also attempts to create a holistic approach to intervention that coordinates both medical and psychosocial care for all the family members. The psychosocial functioning of individual family members who are not themselves ill may be affected by the disease, for example, an adolescent whose parent is dying from AIDS may begin to make trouble in school.

A family counselor working with a family in which a person has AIDS needs to examine his or her own values and biases. Family systems thinking tends to homogenize human relationships as it believes in normative family structure and human behaviour. Family therapists need to respect traditions and sexual practices of different cultures that have been most affected by the disease. They should conceptualize family in broad terms. Family may consist of a group of intimate friends, networks of kins and non-kinds or group of caregiving volunteers and professionals.

Professional counselors must remember that their own fears about contamination and stigma may distance them from clients thereby encouraging a defensively moralizing stance. In order to help the client face the anguish of AIDS, therapists must find what is positive, strong and effective in the client's experience. Counselors, thus, creates a therapeutic bond with the client as well as faces the intensity of emotions engendered by working with AIDS patients and their families. The counselor must help in the removal of social stigmas attached to the person with AIDS.

### **Principles of Family Systems Counseling**

There are a number of principles which family therapists may use to help a patient with AIDS.

#### **(a) Overcoming Resistance to Family Therapy**

The family systems model therapist should be sensitive to the issues that AIDS-infected patient brings to therapy and to realize that the patient may be reluctant to involve family members. The therapist must encourage the client to disclose either sexual orientation or HIV infection. The suggestions of couples counseling may also meet with resistance. The patient with AIDS may be terrified that beneath his lover's acceptance and compassion, he may find blame or anger or may find that the lover secretly wishes to protect himself or herself by leaving. Similarly, the lover without AIDS may be reluctant to enter counseling.

Drug users may also distance themselves from their families after diagnosis. They may deny their illness, increase their drug use or feel bitter that their family did not succeed in its promise of ultimate rescue. The family in turn feels overwhelming anger and impotence. In couples in which a partner has led at having betrayed his spouse.

Counselor, therefore, must be flexible and compassionate towards the fears of the patient and wish for secrecy. In couple therapy, therapist has a duty to protect the partner by informing his denial system of the patient because denial may be his or her best defense against illness itself or a psychological dysfunctioning.

**(b) Counselling as an Ongoing Process**

The family counselor should frame counselling as an ongoing process where nature and frequency depend upon the psychosocial demands of the disease. Counselling usually consists of intermittent, brief or intensive work as the family and patient undergo physical or emotional crisis. By placing the patient with AIDS or family members in support groups problems may be solved thereby alleviating the burden for the therapist. The family counselling may be conceptualized as following critical phases of course of disease. The first phase of diagnosis of HIV infection creates a crisis of acceptance and adaptation accompanied by intense grief or denial. At diagnosis, the HIV-infected person may experience a variety of emotions of anger, abuse, powerlessness. The therapist must help the client work through complex emotions including fear of rage and abandonment by the partner. Moreover, the client should be helped to find the strategies for keeping the partner safe from further risk of infection as well as to help the client again perceive himself or herself as a person of strength and courage. The necessity of disclosure of infection to other family members becomes the most painful experience for women especially as most of them depend upon social networks for a sense of well-being. The counselor should help clients practice safer sex and help the drug users to prevent blood borne infections. The clinicians should play a role to enhance reduced risk sex thereby helping the couple to discover new and creative avenues for sexual expressions and physical intimacy. The family members should be made alert to the signs of deteriorating health or the onset of infection. The therapist should ask the dying patient to participate in planning an optimistic future for those he or she will leave as the gradual introduction of a sense of future is healing. After the death of person with AIDS the family enters a period of bereavement and reorganization which may be a complicated process for family. The family therapist should remain in contact with the family as a counsellor and encourage it for period checkups.

**(c) Empowerment of Family**

The counselor should empower the family to believe in its own capacities for problem solution and illness management. The family should be encouraged to see illness as a deeply personal event.

**(d) Mapping Family Illness Structure**

The counselor maps the pre and post illness family structure to help the family return to pre-illness stage by carefully taking the history of family development and handling of crises in the past by family members. Pre and post illness functioning is mapped in such areas as school, work, marital satisfaction, parent-child relationships, extended family relationships and drug and alcohol use. Penn (1983) suggests that a very important aspect of understanding the family's pre-illness structure is the mapping of development of family coalitions. The therapist must try to make the structure of family more flexible so that the meaning of illness changes in the direction of alleviating psychological pain.

**(e) Identification of Family Resources**

The counselor should help the family identify resources both inside and outside of the family. The family or ill person is encouraged to analyze the interconnections among people in the system. The therapist can serve as an organizer and facilitator of meetings attended by representatives of various systems such as schools, health care professionals, child welfare professionals, home makers and volunteers.

**(f) Mobilizing Extrafamilial Supports**

As AIDS isolates, the therapist should encourage the family to become connected to community support systems to get relief from isolation. In a struggle with emotional issues unique to AIDS including guilt, shame and mutual blame, the families and individuals get alienated from normal social discourse. In order to convert despair into activism, certain political groups must help people develop strategies for living positively with illness.

**Specific Techniques and Process of Family Counseling**

- Conflict resolution and problem-solving techniques used in sessions can help everyone cope better.
- Emotion regulation skills help to manage negative psychological states like sadness, anger and anxiety. Mindfulness is one of the techniques of regulation of emotions.
- Clients can go and see a therapist on their own, with a partner, or together as a family.
- The therapist would make an assessment of the individual, couple or family's needs. Where children are involved, he or she will respect the wishes of the parents before including the children in sessions.
- Families coping with serious illness can feel stuck and not know how to move forward. Family therapists can assist in helping find ways to challenge this and find new methods of coping. Therapists can provide an open, caring and non-judgmental environment to do this.
- Therapy sessions can help the family plan for events that might be difficult to talk about such as illness, hospitalization, or telling children about HIV infection.

### Conclusion

Regulation of emotions and family counseling has important implications for health, as poor emotion regulation is associated with a variety of negative outcomes. Psychosocial, affective, and medical outcomes can be meaningfully improved in at-risk and clinical samples through interventions that focus on teaching emotion knowledge and regulation skills. Such interventions include more traditional psychotherapeutic- intervention, as well as more innovative techniques such as expressive writing. Emerging evidence suggests that some subsets of patients may receive increased benefits; more research is needed to identify factors critical to benefit, as well as characteristics (of individuals or the interventions) that facilitate or impede efficacy. Overall, however, the inclusion of emotion-regulation interventions in a wide range of clinical care contexts and settings holds potential as adjuvant treatment to promote and improve health and well being.

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