

SUPPORTIVE-EXPRESSIVE GROUP THERAPY

FOR PEOPLE WITH HIV INFECTION:

A PRIMER

**José Maldonado, M.D., Cheryl Gore-Felton, Ph.D.,
Ron Durán, Ph.D., Susan Diamond, M.A.,
Cheryl Koopman, Ph.D., and David Spiegel, M.D.**

**PSYCHOSOCIAL TREATMENT LABORATORY
STANFORD UNIVERSITY SCHOOL OF MEDICINE**

**This research was funded by the National Institute of Mental Health (NIMH)
Grant #MH54930 (Principal Investigator, David Spiegel, M.D.).**

**Stanford, CA
1996**

INTRODUCTION

PSYCHOSOCIAL ASPECTS OF HIV INFECTION

Prevalence of HIV infection

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), hemophiliacs, and heterosexuals who have sex with patients belonging to high risk groups.

Compared to earlier epidemics, there is a great deal known about HIV. Prior virology studies and the data gathered during this epidemic has allowed us to identify the etiologic agent (HIV), develop a set of diagnostic tests for the presence of the virus, recognize a number of opportunistic infections associated with the primary illness, and develop a number of pharmacotherapeutic approaches to serve as antiviral agents to slow the progression of the illness. More recently, the goal of much HIV/AIDS-related research has been to develop a vaccine that may prevent the rapid spread of the disease.

HIV as a disease

The central effect of AIDS is a dramatic depletion of a specific subset of T lymphocytes known as the CD₄ T cells. AIDS, however, is not simply a virus affecting the immune system. It may also refer to a neuropsychiatric disorder. HIV and AIDS patients develop neurological and psychiatric symptoms which are believed to be due to a direct infection of the brain by HIV. AIDS patients may sometimes demonstrate affective, cognitive, and motor symptoms even before the diagnosis of AIDS is made.

Emotional Effects of HIV/AIDS

Despite the fact that advancements in HIV diagnosis and treatment of opportunistic infections are made daily, infected patients face the prospect of a chronic, debilitating illness which invariably confers an early death. In general, the level of distress exhibited by HIV patients depends upon their present health status, and it often parallels the physical pains and changes associated with the progression of the disease.

The emotions associated with the diagnosis of HIV seroconversion are largely a reaction to a multiplicity of factors such as a radical alteration in one's sense of self, chronic somatic preoccupation, fear of development of illness, anger and frustration, the need for changes in sexual practices and behaviors, a decrease in self esteem, fear of abandonment, isolation and social ostracism, the uncertainty surrounding disease progression and treatments, and the prospects of death at an early age. Most patients experience a profound existential and interpersonal crisis. Fears of becoming ill, infecting others, and the multiple changes brought about by the disease all threaten the patient's world view. HIV infected patients, as many terminally ill patients, commonly experience a mixture of powerlessness, isolation, anger and fear.

Family members and friends share these feelings, but they also struggle with their own

adaptation to the devastating changes through which their loved ones go. As supportive as they may want to be, friends and relatives must deal with their own fears of contamination with the deadly virus. Often they feel inadequate about how to relate to the patient. This is frequently translated into various forms and levels of withdrawal, leaving patients feeling even more isolated.

Some studies have reported that notification of positive HIV serostatus is often accompanied by depression, suicidal ideation and attempts, anxiety, somatic complaints, and other symptoms. Additional studies have indicated that there may be an increased risk of suicide among patients diagnosed with AIDS. A so-called "secondary epidemic of AIDS-related bereavement" has been described in people with HIV disease, particularly in gay men who have sustained multiple, repetitive losses of both lovers and friends. Grief reactions experienced by gay men losing lovers or close friends to AIDS are similar to those of bereaving spouses and parents. Not only do AIDS patients need to deal with their own mortality, but they are usually grieving for those loved ones they have lost.

The progression of HIV disease consists of relatively distinct transition points: a) diagnosis (seroconversion); b) adaptation to a physically asymptomatic period; c) transition to a symptomatic disease; and d) clinical AIDS. The psychological responses of waiting and coping with this disease are similar in many ways to those observed in patients suffering from other chronic, life-threatening diseases such as cancer.

Social Support in Treatment

Even with the recent advances HIV research, our technology can provide us only with treatments that slow viral replication, promote health, and prevent opportunistic infections among HIV+ persons. Unfortunately, at this time, there is no cure for HIV infection or AIDS.

Psychosocial interventions, such as support groups, have been shown to play an important role in enhancing the quality of life for patients suffering a wide range of medical illness. This has already been demonstrated by Spiegel and colleagues with breast cancer patients. We expect to achieve similar responses in HIV+ infected individuals. The goal of this project is to enhance the quality of life among individuals living with HIV, improve social support, promote good relations with health care providers and, if possible, enhance health.

Social support has been shown to be an important mediating factor in dealing with stressful life events. The importance of social support was demonstrated in a study which found higher mortality rates in the first year after the death of a spouse. The same study also showed longer survival rates for married cancer patients compared to unmarried ones. Brief group therapy for depressed persons with HIV infection has already been shown to produced reductions in symptoms of emotional distress.

There is strong evidence to suggest that a social structure, such as a support group, provides individuals with meaningful support, encouragement for the expression of relevant emotions, and a buffer from stress. Groups have the potential to impact positively on both adjustment to illness and, ultimately, the course of the disease. Psychosocial interventions have proven efficacious in helping breast cancer patients cope better with the illness and live more fully. The use of group therapy in a sample of depressed HIV infected men has been found to produce significant reductions in symptoms of distress.

Spiegel and colleagues undertook a prospective study on the effect of psychosocial intervention on quality of life and survival time of 86 patients with metastatic breast cancer. The group met on a weekly basis for ninety minute sessions of supportive-expressive group therapy. The group focused on problems of terminal illness, including improving relationships with family,

friends, and physicians, and living as fully as possible in the face of death. The treatment group was found to have lower levels of mood disturbance, fewer maladaptive coping responses, and fewer phobic responses than the control group. Indeed, treatment patients improved in mood over the course of the year, while control patients worsened. Aided by the use of self hypnosis techniques, patients in the treatment group reported half the pain of those in the control group at the end of the initial study year.

An analysis of the content and affect in 14 support group sessions demonstrated that the deterioration or death of a member affected the content of the groups but not their affective quality, leading investigators to conclude these groups do not demoralize members. The most startling finding of the supportive-expressive therapy group studied by Spiegel was that the 50 treatment patients lived significantly longer (18 months on average) than the 36 control patients from the time of study entry. This finding is currently being tested in a new sample of metastatic breast cancer patients in our laboratory, as well as other samples in the United States, Canada, and Europe.

It is clear from Spiegel's research that the expression of relevant emotions and direct discussion of difficult subject matter enhances rather than hinders quality of life and may actually increase the life expectancy of people with terminal illnesses, such as HIV disease. The group experience offers patients a place to belong and to express feelings. By sharing a common dilemma, group members experience an intense bonding and a sense of acceptance. This may serve to counter the social alienation that often divides HIV patients from their well-meaning (albeit anxious) family, friends, and society in general. A support group has the beneficial effect of moderating the patient's sense of isolation by providing a new social network. The group becomes a powerful medium for restoring the patient's homeostasis in that the very experience which seems to separate him/her from the rest of the world is what bonds him/her with the group. Being with others who have the same illness and who share similar experiences mitigates the anxiety of facing the illness on one's own and normalizes disease-related feelings and experiences. Involvement in a group allows patients to better mobilize their existing resources, as well as to develop new coping strategies and sources of support. Furthermore, effective coping has been associated a decrease in high risk behavior, such as unprotected sex, among HIV+ individuals.

PATIENT POPULATION

The target population participating in this study are HIV positive men and women, regardless of their mode of transmission. The study sample will include both asymptomatic seropositive patients and those experiencing clinical complications associated with AIDS. Patients will have very specific issues to deal with in relation to their HIV infection. For example, issues arising for HIV-infected heterosexuals will not be identical with those arising for infected gay men and individuals infected through I.V. drug abuse. Women, as a group, will have yet a different set of challenges, including pregnancy and child rearing issues.

All patients will invariably express fears and fantasies around their own mortality and the very real threat to their lives due to the diagnosis. They will be faced with new physical and emotional challenges which require new coping strategies.

Even though HIV was initially described among gay men, intravenous drug abusers (IVDAs) and the heterosexual partners of bisexual men and IVDAs are at increasing risk and are

becoming the fastest growing population of HIV infected individuals.

Underrepresented populations

Latinos and African Americans represent about 40 percent of AIDS cases in the United States (CDC,1992). Twenty-nine percent of these cases are among African Americans and 16 percent are among Latinos. Relative to their proportion of the total population, African Americans and Latinos have an incidence of AIDS two or three times higher than homosexual/bisexual white males and over twenty times higher than white heterosexual males. Women comprise approximately 11 percent of AIDS cases nationally and African American and Latina women constitute about 74 percent of all female cases of AIDS in the nation. Women who are diagnosed with AIDS tend to die twice as quickly as men with the same diagnosis, and 63 percent will die of HIV complications without ever having been officially diagnosed as having AIDS. As a rule, the women most likely to be infected with HIV are generally low-income, belonging to an ethnic minority group, drug users, or partners of drug users.

GROUP LEADERS

Therapist Ability and Training

Each supportive-expressive therapy group is led by two therapists. Each therapist should have training and experience in psychotherapy or group therapy, as well as training and experience in psychosocial support for patients with life-threatening illnesses or medical management of HIV disease. In addition, they should also have at least minimal knowledge of HIV infection natural history, modes of transmission, stages of disease progression, opportunistic infections and medical complications and treatments, as well as treatment side effects. This knowledge is crucial -- not so much for the therapist to impart it to group members, but rather to enhance the therapist's own understanding of what it's like to live with this disease. The leader's function is not to provide their own opinions regarding the transmission, natural course, or treatments for AIDS but to foster an environment where the group members can provide support, hope, and knowledge to one another.

A potential group leader should be someone who has the ability to establish and maintain rapport, instill confidence in his or her ability, and display appropriate warmth and caring. Therapists must be comfortable with, or at the very least capable of tolerating, existential issues -- chief among which is the recognition of one's own mortality.

Therapists may share experiences with the group members along one or several dimensions: gender, sexual orientation, age, HIV seropositivity status, marital status and experience with the illness. The presence of common experience can be constructively shared if the therapists feel comfortable doing so in those areas in which the information is not evident. Such therapist transparency can be useful in establishing an atmosphere of openness and trust. At the same time, therapists are there for their skill in running the group: structuring the discussion, encouraging emotional expression, avoiding scapegoating, acknowledging emotional risk-taking, and providing support.

A therapist's decision to disclose or conceal personal information must be made after a

careful evaluation of the needs of group members. It must not be based on the needs of the therapist. Both positive and negative therapeutic repercussions could result from such disclosure. The leader's timing and atonement with group needs, stages of group cohesion, and overall therapeutic rationale for such disclosure must be impeccably examined and thoroughly understood. Supervision or consultation around this issue for the group leader is recommended.

Group leaders will be expected to provide coaching and counseling to one another. Likewise, the study provides for weekly supervisory sessions where leaders can discuss any difficulties that may arise, sharpen their therapeutic skills, and receive support for their own efforts.

GOALS OF SUPPORTIVE-EXPRESSIVE GROUP THERAPY

When leading supportive-expressive therapy groups for persons with HIV infection, we try to accomplish the following goals: 1) facilitate mutual support among group members and reduce isolation, 2) improve social and family support/ decrease feelings of loneliness and guilt, 3) promote greater openness and emotional expressiveness both within and outside the group, 4) facilitate the integration of a changed self and body image into the patient's current view of self, 5) improve coping skills and normalization of experiences, 6) improve the doctor-patient relationship, 7) detoxify feelings around death and dying, 8) help patients develop a life project, 9) promote safer sexual practices, and 10) enhance quality of life and greater authenticity.

MUTUAL SUPPORT AND REDUCTION OF ISOLATION

A complaint often heard from HIV patients is that they feel stigmatized and isolated. Joining a support group can help reduce these feelings. The fact that all group members are facing the same disease becomes a powerful bonding force. Meeting with a group of people who experience similar struggles and who understand in a way that few can is of immeasurable importance. Although there may be a sense of "instant intimacy" which transpires among group members, the role of the therapist is to facilitate meaningful and supportive interactions within the group. This entails the creation of a safe place which promotes individual self-disclosure, as well as facilitates empathic responses from group members.

IMPROVED SOCIAL AND FAMILY SUPPORT

Although members receive support from the group, an important goal is to improve their social and family support and, thereby, decrease feelings of isolation outside the group. In order to recruit help and support outside the group members need to be able to disclose their status to people outside the group. For some, this is not easy. The reasons for this are complex and vary from patient to patient. In some cases patients just do not want to burden their family or are terribly concerned about the social stigma associated to the disease. Others need to deal with the complexities of revealing the source of their infection. This is particularly true of patients who have maintained risk behaviors secret, such as the IV drug abuser or the homosexual/bisexual patient. The decision to tell often involves a struggle between maintaining privacy and secrecy, and the

need for social support.

Family and friends can be a significant source of emotional and practical help to the patient. It is important that patients be able to make full use of that resource when it is available. The aim is to help them identify the kind of support they want, as well as learn how and when to ask for what they need. The ultimate goal is to improve communication between the patient and their support system, including family and friends. Patients should feel that they can be open and honest with loved ones. They should be able to express their concerns, wishes, and fears without having to worry unduly about psychologically protecting others. In reducing barriers created by fear and concern, patients can make full use of their social support system and in so doing find a source of sustenance to carry them through the HIV experience. A desired effect of self-disclosure and greater social support is positively related with improved psychological health.

GREATER OPENNESS AND EMOTIONAL EXPRESSIVENESS

Openness and emotional expressiveness is a central goal of this treatment. For a variety of reasons patients feel pressure to appear strong and able to cope with their situation. Often this means that they feel they cannot show their emotions and must maintain a "positive attitude". This can consume a lot of energy and often is ineffective.

There are many reasons why HIV patients feel the need to retain a strong and composed attitude. Some of these come from outside pressures. Partners and family members may unintentionally communicate the wish that the patient be strong, because it helps them to cope with their own feelings of helplessness and fear. More internal reasons for wanting to remain strong and in control may involve concerns about being overwhelmed with fear and anxiety. The goal of supportive-expressive group therapy is for these patients to be able to express all emotions, whether they be positive or negative. With unencumbered emotional expression, the patient experiences relief and encouragement as he or she finds that the emotions are tolerable. The task of the therapist, therefore, is to pursue affect and encourage its expression. In doing so, the therapist models that the group is a safe and appropriate place to work through difficult emotions and that nothing is too overwhelming to talk about.

INTEGRATION OF CHANGED SELF AND BODY IMAGE

The diagnosis of HIV infection, along with its various treatments, often has a profound effect on a person's self-esteem, sense of self, and body image. The shock of the diagnosis, the ensuing treatments, and the adjustment to a body image that is in constant flux leaves the patient little opportunity to integrate these changes into his or her basic self-conception. As the disease progresses, physical limitations set in. For many patients, being in a position of requiring help with what were once minor tasks can be upsetting. Other changes, such as those caused by physical wasting and opportunistic infections, can become shattering experiences which leave the patient with the sense of his or her body is unfamiliar or profoundly damaged.

Before HIV patients begin to integrate their changed sense of self, they must get over the initial shock and horror that has unfolded. Sharing these experiences and hearing the stories of other patients with HIV infection help to put the patient's own experience into perspective. Experiences, thoughts and feelings that had originally seemed aberrant become normalized and

easier to accept. In the context of the group patients learn that their responses are not exceptional but a normal reaction to an abnormal situation. The normalization of their experiences makes it easier for each patient to consider how being HIV+ has changed them.

Assisting individuals in working through the stigmatization of the disease is extremely important. Part of this process will be dealing with how the disease was transmitted. For individuals who were infected by a partner, there may be a great deal of anger, and feelings of betrayal. For patients infected by the use of illegal substance, the sense of guilt and shame is hallmark. Equally confused and angered are persons who acquired the disease in relative passive terms, such as patients receiving blood products (i.e., hemophiliacs) or in the performance of their duties (i.e., health professionals).

IMPROVED COPING SKILLS AND NORMALIZATION OF EXPERIENCES

As previously discussed, individuals infected with HIV have to contend with a miasma of new problems, and this is often coupled with a major shift in their support system. Coping strategies that may have previously been successful may no longer seem relevant or appropriate. The goal of therapy is to help patients expand and improve their repertoire of coping skills. One major source of inspiration is hearing how other patients have learned to cope in similar situations. By learning from each other this way, patients are often able to explore other options. Studies on persons living with HIV have repeatedly found that a useful coping style is one that is active and problem focused. Our goal is to help patients learn to identify their own needs so that they can devise a plan of action to meet them.

One specific coping mechanism is self-hypnosis. Patients can use self-hypnosis to help themselves better handle pain, overcome sleep disturbance, and reduce the effects of stress. It is also a strategy they can utilize to get more distance from their problems when feeling overwhelmed, as well as to consider alternative ways of coping.

IMPROVED DOCTOR-PATIENT RELATIONSHIP

The quality of the HIV patient's relationship with his or her physician is vital. Disease progression is accompanied by increased involvement with the medical community. The treatment of HIV infection is characterized by complex treatment regimes. The monitoring of medical interventions can be extremely disruptive to an individual's lifestyle, especially those patients who are asymptomatic or still healthy enough to continue to work. HIV-infected individuals have been shown to benefit from a number of treatment regimens, including antiretroviral agents such as AZT. Yet, despite the proven effectiveness of these treatments, many patients tend to delay initiating treatment until they have advanced disease. Studies have demonstrated that the length of delay is related to unemployment, low social support, and the use of wishful thinking as a strategy for coping with being HIV positive.

Effective treatment requires compliance and adherence to it. Treatment regimes for HIV infection and its sequelae are usually cumbersome -- requiring complex dosing schedules, multiple drug regimes (and side effects), and indefinite periods of treatment. Because a considerable portion of the treatment is prophylactic, asymptomatic patients are likely to feel

better not taking the prescribed medications. Studies show that in recent trials of asymptomatic patients, about 30% of the subjects withdrew from treatment. Psychological distress presenting in the form of anxiety about being HIV-positive, feelings of isolation, depression, self blame and the lack of definitive information about treatment efficacy have been associated with treatment adherence problems.

The goal of the group is to help HIV patients develop good working relationships with their physicians by helping patients move toward an active role in their care -- where they become partners in their own treatment, as opposed to passive and dependent recipients. This can be accomplished by enhanced communication between patients and doctors which allows the patients to state what they want and need, to ask questions, and to feel more fully a part of their own treatment decisions.

DETOXIFY DEATH AND DYING

Thoughts of death and dying evoke primitive and intense feelings in everyone. Most people, however, use a "functional denial" to put these emotions aside so that they can continue to live their lives. Despite their constant presence, patients invariably try to avoid these topics, because they are so painful and frightening. Well-meaning (but equally terrified) family and friends usually collude with this avoidance due to their own anxiety about losing a loved one. Consequently, patients are left alone with their worst fears and fantasies. In the absence of a place where the patient can reveal and contemplate these terrifying images, they will inevitably experience negative emotions that will compromise their emotional well-being.

Patients who are left to ruminate about their death are unable to fully participate in life or enjoy much of living. Addressing death and related issues in a direct manner has the effect of decreasing the fear and anxiety that normally go along with it. Through addressing these fears and anxieties, patients learn that they can both tolerate such thoughts and that there may be things they can do for themselves to moderate their anxiety. Patients frequently find it an immense relief to simply be able to talk about death and dying in an unrestrained, explicit way. Helping patients break this particular subject down into smaller, more manageable parts diminishes the fear and anxiety associated with it.

DEVELOPING A LIFE PROJECT

Being HIV+ and living with AIDS transforms a patient's perspective about life and the future. There is a tremendous sense of urgency to delineate clearly one's life goals or to achieve them. The objective is to help each patient develop and refine a life project. This involves clarification of one's life values and goals, as well as of how the patient wishes to use his or her remaining time.

Discussions of life goals can be illuminating in helping patients reframe the effect of their illness on their lives. It demands a reassessment of life values and an acknowledgment that patients need to act in the present because the future is in question. This helps patients develop new goals that allow them to live and enjoy life more fully in the present. They are encouraged to use their valuable time, whatever its length may be, as well as they can.

PROMOTING SAFER SEXUAL PRACTICES

All patients suffering from HIV infection will be confronted with the behavioral component of the disease, because it can be spread by engaging in high risk behaviors such as having unprotected sexual relations or sharing dirty needles. Discussing sexual issues is difficult in any case. It is important for therapists to allow each individual to express fears, concerns, and practices openly and honestly. It is vital that therapists facilitate the group process so that the membership feels they can find support from the group. Studies have shown that HIV+ subjects who continue to participate in high risk behavior (e.g., unprotected sex) did so as a way of coping with stress. On the other hand, social support leading to better adaptive behavioral coping strategies was positively associated with positive morale, decreased self-blame, and a reduction in high risk sexual behaviors.

GENERAL TREATMENT STRATEGY

DESCRIPTION OF SESSIONS

Group Preparation

In preparation for starting an HIV/AIDS supportive-expressive therapy group, prospective group members are briefed about what they might expect. Each subject will be individually screened by Michele Gill (Study Coordinator) in order to assess their appropriateness for participation in the study. As part of a research study, subjects will be expected to complete a number of questionnaires and interviews.

The Study Coordinator will explain the purpose of the group to those subjects randomized to the group condition. She will discuss issues of confidentiality, stress the need for regular attendance, the need to call and inform leaders of absences, and provide preliminary details about the group format, including the presence of two leaders and audiotaping equipment. Group leaders are expected to review these issues of confidentiality, attendance, and format during the initial group sessions. Members are told that the purpose of the group is to help them better cope with all aspects of the HIV/AIDS experience. They are informed that the group is a place where members are encouraged to share and explore the various ways HIV has affected them. They are also told that the group is a place where they will be able to give and receive support from other persons living through similar experiences.

Initial Meetings

Initial meetings are critical, because they set the stage for what is to follow. Members again should be reminded about the aims of the group and how it will proceed. This is also the time to have the group members and therapists introduce themselves to one another, inviting the members to talk as openly as possible about their personal story, their feelings about their experience with HIV/AIDS and their particular goals in the context of the group.

While some of the discussion may be repetitive to what was provided in the initial contact,

it is helpful to repeat it. Group members should be told that they are a group of unique individuals, each with their own set of concerns regarding their disease, but that they have one vital thing in common: each is there to deal with the impact of the HIV infection on their lives. By coming together in a group they have presented themselves with the opportunity to meet various goals. The group is a place where they are encouraged to raise all issues, concerns, thoughts, and feelings that they have about any aspect of their disease and its consequences for them. Hopefully, the group will be a place where each of them will feel safe and supported by one another. The role of the group leaders is facilitate and support each group member in this endeavor.

After a brief introduction by the therapists, members are invited to introduce themselves to the group. By way of introduction, they are asked to state who they are, provide a brief history of their disease, and then to say what it is they hope to get out of the group. The introductions generally take up most of the first session. Sometimes it is necessary to complete introductions over the course of the next couple of sessions.

Following the introduction, leaders should summarize what they have heard. The intention is to summarize the themes that have emerged. This represents the first opportunity to reinforce some of the feelings and topics that are important in the group. The leaders can summarize by stating that some of the issues that most of them seem to be struggling with include their fear of dying from their disease, adjusting to a new way of life, and so on. It is likely that not all the common themes outlined earlier will be mentioned. These will naturally unfold over time as group trust is built and group cohesion increases.

The First Session: Ground rules

The first session is crucial in establishing an atmosphere of trust and safety among group members. Among family and friends, trust is either ascribed by social convention or earned over time. Within a therapy group setting, however, trust among strangers is contracted through social agreement to follow established ground rules. Even before members introduce themselves in the first session, therapists need to introduce fundamental "rules of the road" which include confidentiality, attendance, and participation.

Confidentiality. A discussion of confidentiality should begin with the therapist describing its importance and giving examples of liberal and conservative levels of confidentiality. A liberal level of confidentiality could be that members are free to discuss what happens in the group to outside non-members. A conservative level would be that nothing leaves the room. Something that falls in the middle of these two extremes would be that the general content of the session may be discussed with non-members, but individual group members may never be identified.

After the therapists introduce confidentiality, they should then invite each member to briefly describe the level of confidentiality with which he or she is most comfortable. Explain that the most conservative level of confidentiality expressed will be adopted by the group. Therapists may want to keep an ear out for potential dilemmas as people speak, such as when persons are not comfortable with keeping secrets from spouses or when someone may feel threatened with being the topic of gossip. Therapists should reflect or paraphrase each person's statement. They should then provide a summarization of the group's sentiments with clear verbalization of the most conservative level of confidentiality.

When new members are admitted to the group, they ideally should be advised of the confidentiality ground rule before entering the group. Alternately, new members may be advised of the confidentiality ground rule as they are introduced to the group.

Therapists should briefly remind participants of the boundaries to confidentiality in the study. For example, although every session is recorded (audio or video), all information from the recordings will remain within the confines of the study and will be used for supervision and research purposes only. Therapists attend weekly supervision sessions (name Dr. Jose Maldonado, Dr. David Spiegel and Dr. Catherine Classen as supervisors) to discuss not only the progress of participants, but to make certain that therapists are following the protocol. Therapists should also remind subjects of the limits of confidentiality as mandated by ethics and law. Specifically, confidentiality may be bridged when a participant is determined to be of imminent harm to him/herself or to others, or when there is reason to believe that persons who cannot take care of themselves (i.e., children, the elderly, or the disabled) are being abused.

Attendance. When screened for the study, participants are asked to make a good faith effort to participate in the groups for one year. Group cohesion hinges on attendance, and therapists should make it clear that every member's presence in the group is important. Certainly, people become ill, have transportation problems, or run into extenuating circumstances which may prevent them from participating for periods of time, but we ask for a good faith effort to attend.

A sudden drop in attendance may indicate that people are somehow unhappy with or threatened by the group. It is very important that this issue is brought immediately to supervision.

If a group member cannot attend a session or knows that he or she will be gone, we ask that they let the therapists or one of their fellow group members as soon as possible. Because groups become concerned about absent participants, informing the therapists or another member of an absence is a courtesy we ask that all extend to the group. When a member is absent and does not call, one of the therapists may want to call later to check on him or her.

Participation. In addition to attendance, therapists should encourage active participation from every group member. The problem with the silent member is that no one knows for certain what he or she may be experiencing. The silent member may be perceived by other participants as judgmental or hostile, when, in fact, the silent member may be confused, hurt, amused, or perfectly comfortable. One of the key roles of the therapist is to note who has spoken and to give members who have been silent the opportunity to speak.

Middle Meetings

Every meeting starts with taking stock of and recording which group members are present and which are absent. Also each meeting begins by asking if there are any new and urgent concerns that any members need or want to share. The bulk of the meeting is geared towards the provision of a supportive atmosphere in which the members can share their concerns about their situation with others who are experiencing similar circumstances.

While the general treatment strategy remains the same throughout treatment, there are certain issues that leaders should be sensitized to at various points in the treatment. During the first half of the treatment the main task is to facilitate the expression of thoughts and feelings about HIV/AIDS and any implications this may have for the members individually or for the group process. Leaders should remain alert to any of the themes that may emerge so that they can be made explicit and directly focused upon.

At this juncture, leaders may also begin to introduce themes that they feel have been implicit in the group. For example, they might remark that guilt has not been addressed, even though they get the impression this is an issue for several members. This process comment might

be all the group needs to mobilize around an important, albeit avoided, issue.

Sometimes, however, it is necessary to be more direct. If the group has not raised some of the common topics it can be for any number of reasons. One possibility is that some particular topic is not relevant to the group. Another reason may be that the group is finding some issues particularly threatening to deal with. Or, in the natural evolution of the group, they simply may not have arrived there yet. The therapists' job is to determine which of these alternatives is correct and to make the appropriate intervention. Certainly, if a particular topic truly does not seem important for the group, it need not be addressed. However, if it is a situation where the group is actively avoiding a topic or needs some help in getting to it more quickly, then the therapist must take an active role.

It is not uncommon for those suffering with AIDS to have a number of people in their lives they know are suffering from the same disease or who have died from the disease. Group members may want to talk about these experiences. It is important that therapists relate these experiences back to the group in an effort to facilitate each group member's concerns about their own illness and death.

Group members will invariably be at different stages in their disease progression and treatment. It is important for therapists to keep this in mind and check in with group members as to how they are feeling about seeing other members become symptomatic. Group members may be absent because they are too sick to make it to the group. These group absences present the therapist with the opportunity to facilitate expression around fear, anxiety, loss, and grief. Some group members will not be comfortable expressing how they are feeling about another member's illness and relating it to their own. It is important for therapists to encourage patients to share as much as they can but to also respect boundaries over how much they want to share.

Final Meetings

Therapists should intermittently remind the group about termination. The group should be asked to reflect on their thoughts and feelings about the impending end. It is not uncommon for the group to ask why the meetings have to end or whether it is possible to continue in some way. This needs to be addressed directly, but should also serve as a catalyst to discussing the underlying issue which is, ultimately, termination. The ending of the group is yet another loss for the person with HIV disease. It may feel like a tremendous one. Bringing the feeling of loss to the forefront enables the group to work on it actively. There will inevitably be a wealth of feelings activated by thoughts of termination, particularly if the group has become cohesive. Termination raises issues that are of direct relevance to their HIV infection concerns, especially grieving losses and having to get on with their lives in spite of these. The experience of termination may activate feelings associated previous losses. It is important that each group member is given the opportunity to explore their issues around loss and termination.

Learning to live with dying is what living is all about, and is at the very heart of HIV/AIDS supportive-expressive therapy groups. The group allows its members the opportunity to take inventory of their lives and determine what is important, and how they wish to live the rest of their lives.

THERAPIST ISSUES

Some issues related to co-leading a group with this population include:

Countertransference: As in any form of therapy, therapists should be aware of their own emotional response to issues that emerge in the group. Emotional responses to the group process are natural. Therapists leading these groups will be faced with a wide range of intense human emotions. A therapist's ability to facilitate the group and illicit intense emotions, while at the same time being aware of his or her own internal emotions, is a skill that therapists must develop.

Debriefing: To a large extent, a positive group experience depends on how well group leaders work together. Co-therapists should try to be as open and candid with one another as possible. Following each group meeting, leaders should spend time reviewing what has transpired. This is an opportunity to review what has gone well, address concerns you might have about particular group members, plan for the next group, and discuss how the two of you are working together.

Feedback: One of your responsibilities as group leader is to provide feedback to one another. This will greatly enhance how you work together and will exponentially increase your learning experience. However, giving and receiving feedback can feel threatening.

So, we suggest the following guidelines: Reflect on the feedback you are planning to give. Give the feedback in a descriptive, not interpretive, manner. State your feelings about what happened, rather than drawing conclusions. Try not to overload your co-leader by stating everything you have to say all at once. Give the feedback in manageable chunks, preferably taking turns with your co-leader. Finally, don't forget to provide each other with positive feedback. A great method of learning is to review audiotapes of your sessions with your co-leader. This provides a much more objective perspective and enables you to see what you actually did or, more importantly, what you could have done.

Interacting in group: A few ground-rules about working together in the group will greatly enhance your working relationship. Whenever your co-leader makes an intervention, give the group time to respond. That is, do not immediately follow-up your co-leader's intervention with a different intervention. This has the effect of nullifying the first intervention. You and your co-leader will not always be on the same wavelength. However, when you are, it can be helpful to build upon each other's intervention when there is an important point to make. Interaction between co-therapists is enhanced by maintaining good eye contact. This is best done by sitting directly opposite one another.

PRINCIPLES OF TREATMENT

SPECIFIC GUIDELINES FOR HIV GROUPS

The hallmark of the HIV group is it is comprised of individuals who are having to deal with a major life crisis. The reason for their involvement in the group is specifically to deal with their illness. The patients are responding to an extreme stressor that would be of crisis proportions for anyone. The group's purpose is *not to alter deeply rooted personality traits*, but rather to help

patients adjust to their new circumstances and to cope with the accompanying psychological, social, and physiological changes they are experiencing. In contrast to traditional psychotherapy groups, outside contact between group members is supported and encouraged. This group is not simply a social microcosm for the patient, but serves as a buffer against the traumatic effects of facing HIV disease on one's own. This, in turn, fosters the patients' adaptation to illness by managing overwhelming affect and encouraging a return to premorbid (or improved) functioning.

Maintain Focus on HIV/AIDS

Talking about HIV/AIDS disease and the countless ways it affects one's life and one's sense of the future can be extremely intimidating. Consequently, group members frequently attempt to side-track the conversation onto less intimidating subject matter. When this occurs (and invariably it will), the task of the leader is to redirect the course of the discussion back to HIV/AIDS and how it affects their life. Generally, whatever the "non-HIV" material may be, it is somehow related to HIV/AIDS. Actually, the "non-HIV/AIDS" subject is often on the mark, although this may be masked and not obvious to group members. It is the group leaders' task to illuminate the link to HIV/AIDS so that group members can speak more explicitly and directly about the particular HIV/AIDS issue. At other times, the "non-HIV/AIDS" subject may be a way of avoiding some important HIV/AIDS issue. This, too, needs to be openly discussed so that group members deal with troubling material.

Expression and Exploration of Emotions and Thoughts

An HIV/AIDS diagnosis gives rise to any number of issues and feelings, most of which are experienced as difficult and are therefore actively avoided. The avoidance or denial of threatening thoughts and feelings has disastrous consequences, chief among these being the reinforcement of the sense of alienation and isolation. It also aggravates the sense that these particular issues are unmanageable and evokes underlying feelings of intense despair, helplessness, and hopelessness.

There are various reasons why patients attempt to suppress and control thoughts and feelings that are disturbing. One reason stems from the popular, but erroneous and damaging belief that a consistently positive attitude is essential to promote healing. Many HIV/AIDS patients have come to fear that experiencing painful feelings, expressing negative thoughts, or even thinking negatively will cause their disease to progress in some way.

Another pitfall is a fear of being overwhelmed, or of overwhelming others, with their problems. The group provides an ideal environment for testing this belief. HIV/AIDS patients need to learn that they can tolerate their emotions. Here, the role of the therapist is critical. Leaders must demonstrate that they can tolerate any and all thoughts or feelings that emerge in the group, so that group members will take the risk of exploring their own frightening feelings and thoughts.

The expression and exploration of all emotional states and thoughts gives the patient the sense that no thought or feeling is too terrible to face. It can also be immensely validating to find that one's negative feelings and troubling thoughts are frequently shared by others. By sharing honest feelings and concerns with others in a safe and supportive environment, patients come to recognize that they are not alone. Thoughts and emotions that are potentially overwhelming can be defused and detoxified within the context of the group setting.

Facilitate Supportive Interaction Among Group Members

A primary aim of supportive-expressive group therapy is group support. This develops by being with other people who share similar experiences. Group support consists of relatedness

between members. This provides the opportunity for free expression, giving and receiving support, and reducing feelings of isolation.

The therapist's task is to encourage the development of a supportive, safe and open environment where patients can freely express all aspects of their experience. In early group meetings, it is particularly important that the therapist set the tone by demonstrating warmth and understanding. Supportive behaviors and attitudes can continuously be encouraged and reinforced by the therapist's empathic comments or observations. Finally, while it is important that therapists be supportive, it is crucial to facilitate group members support of one another. Therapists can assume an active position here by frequently calling on the group to provide feedback.

Mutual support stems from sharing significant personal experiences with others, and common concerns such as treatments, self-image or doctor-patient relationships. It involves both the giving and receiving of support. This, in turn, builds rapport and mutual caring, both in the group session and beyond. The potential for continued support outside the group meetings increases as members begin to share information, commonality of experiences, and help one another with both practical and emotional support.

Focus on Personal, Concrete Issues

When dealing with a life-altering and life-threatening disease like HIV/AIDS, people naturally attempt to shield themselves from it. One way of doing this is by talking about their disease in abstract and impersonal terms. This provides the illusion of keeping the HIV/AIDS at a safer distance.

A basic principle of supportive-expressive group therapy with persons with HIV/AIDS is to focus on the present, with emphasis on the development of an authentic relationship to one's life situation. The examination of self-image, life goals, and values is useful in helping people clarify assumptions they have about their lives which may impede them from living the remainder of their lives to the fullest.

The objective of the group, therefore, is to help patients live as fully in the present as they possibly can by addressing and expressing current concerns openly and honestly. Therapists can approach this directly by pursuing a patient's feelings and thoughts about given concerns or problem.

Facilitate Active Coping

As group members grapple with coping with their disease, leaders encourage the use of active, problem focused coping. With a chronic disease such as HIV, patients can be left feeling that there is little they can do to improve their situation. Some people become resigned, assuming a passive or avoidant stance. The types of coping that have been found to be most useful and which we try to facilitate include taking positive steps toward improving their quality of life, understanding their illness and its effect, and taking appropriate steps to deal directly with their disease. Patients are encouraged to become more involved in their treatment and in monitoring their disease. This involves learning about HIV, closely monitoring symptoms, working in collaboration with their doctor, or seeking second opinions as needed. For emotional and interpersonal issues, patients are encouraged to seek the support they need from people around them, both within and outside of the group.

Therapists invite patients to approach problems in their lives from the perspective that they

can do something to improve the situation, including those instances in which there seems to be very little one can actually do. Therapists encourage patients to break problems down into smaller, more manageable pieces. They may find that the best way to cope with certain aspects of their problems is to share their feelings with others. At other times, patients may need to recognize that there are courses of action they can take to modify the situation. In some cases, this may simply involve learning acceptance.

Relaxation and Self-Hypnosis

One important technique used to facilitate self-mastery is self-hypnosis. Hypnosis is an altered form of concentration. It can be used to help patients relax, to manage pain, or to problem-solve and explore a variety of issues while remaining in a state of relaxation. This offers patients the opportunity to appreciate their present situation, set realistic goals which would improve their quality of life, and develop ways to make this transition within the framework of their lives.

Self-hypnosis exercises are conducted at the end of each group meeting by one of the therapists. After a number of guided self-hypnosis sessions, patients can begin to use the method at home on their own. Typically, therapists lead the group through different hypnotic exercises pulling out a salient theme in each session and, when appropriate, focusing on symptom relief such as pain management. The exercise is approximately five to ten minutes in length and generally leaves the patients with a sense of restfulness and completion (see section "Using Self-Hypnosis" below).

GUIDELINES FOR LEADING GROUPS

Creation and Maintenance of the Group

The study's Study Coordinator, Michele Gill and the Medical Director, Jose Maldonado, are responsible for the creation of the groups. They set the time and place as well as make the initial contacts and arrangements with the potential members

The study coordinator will screen all potential group members. Any potential member whose difficulties extend well beyond coping with HIV/AIDS may be better served by individual therapy and will be referred appropriately. Additionally, some potential group members may be too physically ill to participate in a group, and still some patients may become too ill to attend once the group has started.

Once the group has started, therapists have primary responsibility for the day to day operations of the group. They will address any problems that have the potential of undermining the integrity of the group. This includes chronic lateness, frequent absences, or otherwise disruptive behavior.

While it is important in any group to address member absences, it is particularly important in groups for persons with HIV/AIDS. If members' absences are not commented upon and inquired into, this can lead to an underlying fear among the members that each of them can slip away unnoticed. In HIV groups an absence can evoke deep concern and anxiety about the absent member's health. It is important for these reasons that any absence be followed up on by the leader before the next group meeting and that the members be informed at the next meeting about the reason for the absence.

Empathy and Unconditional Positive Regard

Carl Rogers (1957) considered empathy, unconditional positive regard and authenticity as "necessary and sufficient conditions" for therapeutic change. We hold the position that these conditions are necessary for reaching our goals in supportive-expressive group therapy for persons with HIV disease. However, they are not, in themselves, sufficient.

Empathy is at the heart of any psychotherapeutic approach. It involves having an accurate

understanding of the patient's viewpoint and experiencing it as if it were your own. It is important to emphasize that it is "as if" the patient's experience were your own. Maintaining this "as if" posture ensures that the therapist does not get lost in the patient's experience or confuse his or her own experience with the patient's. An empathic reflection involves sidestepping much of what has been said in order to reflect the deeper meaning. An empathic response conveys to the group member a sense of being accepted and understood.

A therapist is experiencing unconditional positive regard for a group member if she or he feels a warm acceptance of all aspects of that person's experience. There is a caring for the person and an acceptance and appreciation of him or her as a unique human being. Unconditional positive regard does not mean that the therapist approves of everything the patient says or does. However, there is an abiding respect for the patient as a separate and valuable person. Both empathy and unconditional positive regard are critical elements that lend themselves to an environment of safety such that group members can expose their deepest fears and anxieties surrounding their experience of living with HIV/AIDS.

Therapist Genuineness

Rogers believed that therapist genuineness is necessary for successful therapy. Within the constraints of their role as group leaders, therapists should strive to be genuine. Rogers describes this as being congruent with one's own internal experience. Usually, it is not important or helpful that therapists share their internal experiences with the group, but it is essential that they are aware of it.

Self-disclosure and Culture Building

An essential element in beginning any group is establishing group norms, or "culture building". Group norms are the set of implicit and explicit behavioral rules by which a group conducts itself. These behavioral rules can be stated explicitly by the group leaders, although often they are imparted through role modeling. Group norms can also be introduced implicitly by the members. It is the job of the leaders to ensure that such behavioral guidelines are in the best interest of the group. The norms adopted should add to an environment of safety and acceptance. Conditions of safety and acceptance serve as the building blocks from which the group can go forward. These rules should also facilitate the free and spontaneous interaction of members with one another.

Members must show a non-judgmental acceptance of each other. Any differences that exist among members are to be tolerated. In this regard, the therapist may need to intervene occasionally to protect a group member or to facilitate a dialogue between members who are in conflict. If underlying tensions exist, it is crucial to work them through sufficiently so that they do not create an unsafe working environment.

Self-disclosure is another important, if not the most important, norm to be established in groups. Without self-disclosure there would be no material to work with in the groups and, ultimately, no benefit. Self-disclosure is a subjective phenomenon and therefore difficult to assess objectively. What is extremely self-revealing for one person may not be for another. Thus, it is the subjective assessment of self-disclosure that is critical. The most important aspect of self-disclosure, according to Yalom, is that it is an interpersonal act. Yalom believes that what is self-disclosed is less important than the fact that it is told to others. Consequently, when there is self-disclosure it is important to explore the person's thoughts and feelings around the disclosure as well as the reactions of others.

Related to the issue of self-disclosure is group participation at a more general level. All members are expected to participate in discussions. Certainly, some members will be more active than others. With silent or near silent members, the therapist should turn to them occasionally to elicit their thoughts and feelings about the group.

Rules should also be established around attendance, beginning on time, and informing the group leaders about absences. The central norm is that members view the group as important and, therefore, deserving of respect and consideration.

Practical Applications

One of the active ingredients in group therapy is working in the here-and-now. Accessing and working with one's immediate experience is far more potent than dealing with abstractions or experiences one has had in the past. For people with HIV/AIDS talking about the history of their disease, its diagnosis and treatments, is not only unavoidable but essential. The task of the therapist is to shift the focus of these discussions to the present. This is possible since any experiences that are brought in from the past will elicit emotions in the present, as well as have implications for how one chooses to be in the future. The role of the therapist is to help the group attend to their various immediate experiences. For supportive-expressive HIV/AIDS groups, this presents opportunities for each patient to express his or her immediate thoughts and feelings, as well as to provide support for each other.

The task of the leader is to help the group move beyond the abstract, intellectual level toward a more experiential level. Working in the here-and-now provides opportunities for members to work with a problem experientially. Whatever the issue under discussion, there is always an emotional response for each person. By shifting the discussion to the here-and-now, the member is helped to access his or her emotional response to the topic. To explore it experientially is to help the members track their internal emotional experience as it unfolds. Once patients have immersed themselves in their internal experience in the group, they are then encouraged to step back from that experience so that they can learn from it. Real discoveries about one's experience will only occur if one is in touch with and explores the experience as it emerges. For instance, the nuances of a person's fears about dying can only be discovered if the person is experiencing the fear while she or he actively explores it.

COMMON THEMES

RAGE

The uncertainty of the future, a compromised lifestyle, a sense of living on "borrowed time", the anxiety of wondering when the next opportunistic infection will occur, and the fears of living with a fatal disease all add fuel to a terror so unspeakable that it is often translated into rage. Some patients have described this as a feeling state that is so all-consuming that it obscures all other feeling or logic. In the group setting, this kind of rage may present as either verbally assailing the leader or other group members for no apparent reason, and/or angry withdrawal from the group discussion and possible sudden and impulsive termination from the group.

This kind of rage can be detrimental and ultimately destructive to both HIV/AIDS patients and their loved ones as it promotes alienation. The therapeutic task is to make a place for it to be

discharged and managed appropriately. The leader must set the stage for exploring and expressing these feelings within the context of the group.

SHOCK, DENIAL AND PERSONAL STORY

Recounting the diagnosis is normal during the initial sessions. For group members to tell his or her tale in the shelter of the group helps desensitize the shock and trauma of what most people with HIV/AIDS consciously or unconsciously believe is "being handed a death sentence."

By the time the individual has negotiated the process of actually making it to the first group session, some of the initial shock will have been mitigated; but it will, for the most part, have been done alone.

Empathic listening as each member recounts the story of their diagnosis is invaluable. Therapists' consistent, dedicated attention is essential. Other group members will focus in varying degrees on one member's story, being reminded of their own experiences, feeling empathy, and/or being overwhelmed with anxiety.

REALIZATION OF MORTALITY

For most HIV/AIDS patients, the diagnosis of HIV/AIDS is the first confrontation with their own mortality. The trauma of this realization can leave the patient overwhelmed and immobilized with fear and anxiety.

There are a number of issues and concerns that are raised for patients suffering from a life threatening illness such as HIV disease. Chief among them is wondering when the next opportunistic infection will strike. In addition to fear and anxiety, patients often experience such feelings as anger, frustration, sadness, and despair. Some of these feelings may be in relation to death themselves or sadness about leaving loved ones behind. Other feelings and issues associated with this process are fears of abandonment, loss of autonomy and dignity, or uncontrolled pain.

The therapeutic task is to facilitate members in detoxifying death and dying. In addition to facilitating the expression of emotions and providing emotional support, therapists help patients break down this devastating topic into separate and more manageable issues.

Therapists aim to facilitate members in giving voice to their anxieties and fears, with the full acknowledgment of one's essential aloneness in facing one's own mortality.

LACK OF CONTROL, HELPLESSNESS, UNCERTAINTY

Most people diagnosed with HIV disease make conscious or unconscious assumptions about having been handed a "death sentence." Whereas in other life-threatening diseases there is often some comfort in varying statistics for cure, disease management, remission, these possibilities feel much less certain for persons with HIV/AIDS. As shock and denial dissipate, group members will address issues of lack of control, helplessness and uncertainty toward their diagnosis and the scenario of inevitable health decline and imminent death. As tempting as a problem-solving approach at this point might be for both the leader and group members, the leader needs to maintain a focus on exploring and facilitating verbalization of the uncomfortable, frightening aspects and individual scenarios that arise from feeling that one has lost, or will

imminently lose control and become helpless.

DOCTOR-PATIENT RELATIONSHIP

Patient-doctor relationship needs to become a central focus of attention. The doctor becomes a messenger of good and bad news, as well as the provider of treatment. In the ideal situation, doctor and patient understand each other, the patient feels supported and there is room for questioning. In reality, patients often feel dependent and powerless in relation to their doctors. They are often afraid to ask questions, particularly since they have recently received a terrifying answer to a question regarding their HIV status.

Sometimes patients have unrealistically high expectations of doctors. We want them to know everything. Inevitably doctors will disappoint or anger patients because they can not give the patient a "cure" or a definitive answer. Because of the literal life and death nature of struggling to live with HIV/AIDS, the relationship between patients with AIDS and their doctors needs to be one of communication and trust.

One of the main goals of the group is to help patients with HIV develop a collaborative relationship with the doctor. To facilitate this, it is important to examine what may lie at the root of poor communication between doctor and patient. Often, the patient displaces anger and frustration about the HIV infection onto the doctor. Fear about the disease can interfere with hearing information correctly.

Helping patients identify the source of their feelings towards doctors is the first step towards working them through. The feeling that one's health hangs on the doctor's expertise may be difficult for some patients and may result in unhealthy communication and attitudes. Therapists should encourage a collaborative doctor-patient relationship and to take an active stance towards their treatment. This active attitude is characterized by collaboration in the decision making and treatment process. An aspect in which the group can be helpful is by providing a different perspective on treatment options which then patients are encouraged to discuss with their physicians.

TREATMENT RELATED CONCERNS

Trying to stay afloat in the ocean of information, misinformation, and uncertain information may elicit the sensation of helplessness and drowning in individual group members. The ratio of what is known versus what is unknown about HIV disease remains heavily tipped toward the unknown, despite recent advances in medical research.

The psychosocial impact of both the disease process and its treatments can be immensely frightening. Actual and/or anticipated pain, disfigurement, and debilitation can be daily issues in the lives of group members.

Group leaders need to remain a consistent listener, attentive to both verbal and non-verbal expressions of feelings. Leaders need to allow group members the opportunity to share the concrete details of their particular medical treatments. Some members may be involved in clinical trials of new drugs. Others may be using alternative treatments. As group leaders we need to make our position clear: the patient's primary physician must be consulted about, or at least

informed of, the patient's desire to include adjunctive treatments. Additionally, it is important to assist the members in identifying emotions surrounding choice of treatments. Furthermore, it is important to allow group members to share particulars of what seems to have helped or not helped them. This allows the group to serve as somewhat of an information-sharing place. By engaging in these strategies, therapists will have assisted in transforming feelings of overwhelming helplessness and frustration into more manageable feelings and more "empowered" decision-making skills regarding treatments for group members.

SELF AND BODY IMAGE

Because of the wide array of opportunistic infections and HIV-related conditions, radical changes in physical appearance can occur relatively quickly. Kaposi's Sarcoma (KS) can result in the socially-stigmatizing purplish lesions anywhere on and inside the body. Chemotherapy for non-Hodgkin lymphoma results in hair loss/baldness. The wasting syndrome (MAI) associated with AIDS results in an emaciated, concentration-camp survivor-like appearance. Central line catheterization (through the chest), not usually noticeable when a person is clothed, may have a dramatic impact on physically intimate relationships. Extreme fatigue, caused by HIV, opportunistic infections, medications, depression, or any combination of these which may require the use of canes, walkers, or wheelchairs, can also be socially stigmatizing for group members. Symptoms such as chronic diarrhea, nausea, and pain (headaches, neuropathy, etc.) present their own dilemmas.

Self-identity issues are intimately related to these physical changes. Actual or anticipated sickness, pain, disfigurement, and/or debilitation profoundly affect group members' self/body images. These affect how the individual perceives him or herself simultaneously with the feedback about how s/he is perceived by others.

Exploring the myriad of ways each individual's view of him or herself (physically and psychologically) has been altered is important. Leaders may need to gently direct them more toward the heart of the matter. The role of the therapist is to help make these implications explicit. Often this can be accomplished by redirecting the discussion toward how these actual or anticipated changes affect the member's sense of self-identity.

EFFECT OF ILLNESS ON LOVED ONES & FAMILY

Being diagnosed with HIV affects not only the patient but their families and loved ones as well. Psychological distress in family members and significant others has been found to be as high as in HIV-infected persons.

There may be group members who have not disclosed their sexual orientation to their biological family and now faces the dilemma of whether to disclose to their biological family both their sexual orientation and HIV status. Even for an individuals who have already "come out", the decision whether or not to disclose serostatus to their family is painful. The stigmatization of people with HIV/AIDS and homosexual people often complicates the "normal" issues which families experience when confronted with the illness and potential death of a family member. If the family has been previously supportive of their gay member on the basis of sexual orientation, clinical experience indicates that their tendency will be, once again, to rally their support for their gay, HIV-infected member.

One of the group goals is to improve communication between the patient and the family. The therapeutic task is to explore the problems and difficulties patients encounter in dealing with their families with the aim of reducing the fear of hurting or scaring family members. By not talking about HIV/AIDS, the family is communicating that the topic is too terrible to be discussed. Just as is modeled in the group, open and honest communication reduces fears and anxiety. Even extremely sad and painful truths will relieve the anxiety of too much uncertainty, and frequently serves to bring the family and patient closer to each other thereby reducing feelings of isolation. This enables patients and family members to truly support each other and to enhance the quality of their time together.

There is no clear answer on how to balance the needs of family members with the needs of the HIV-infected patient. As the disease progresses, needs will continue to shift in an on-going basis. Assisting patients explore and clarify their feelings in order to decide what and whom to disclose their diagnosis is valuable in the group because all members benefit.

REORDERING LIFE VALUES, PERSONAL GOALS

In facing HIV/AIDS, fundamental questions about one's life are bound to arise. As patients lives are transformed, their priorities shift accordingly. Patients develop a clarity about where they want to devote their time and energy. Other things that once felt important may abruptly seem irrelevant. As patients' energy fluctuates, they are confronted with the need to make choices.

Discussions of life goals can be important in helping patients restructure the impact of the illness on their lives. It forces an evaluation of life's values and a recognition that putting off important goals until a later time will not do, because there may not be a later time. However, before patients can move on to new solutions, they must grieve their losses and talk about their sadness over these changes. This will enable them to develop new goals and sometimes discover that they are able to live and enjoy life more fully.

Therapists encourage patients to set their priorities. Therapists should help group members identify and explore what is important to them and to separate this from what the environment dictates they do. With support from one another, group members can bolster each other to live according to their life goals and values and to not get trapped by things they do not want to do. Helping patients focus on the reality of living with a life threatening illness can result in a dramatic

change in time perspective.

SOCIAL RELATIONSHIPS

Patients with HIV infection generally engage in a complete reevaluation of life, particularly in the area of relationships. Along with reordering life values and goals, patients with HIV reassess what they get from existing relationships and discover they need.

HIV infection also frequently impacts the way others view the infected person. Sometimes the person with AIDS finds that friends or co-workers respond to him or her differently. The difference may involve stigma, social exclusion, or devaluation.

Therapists should help members to share their social experiences with other members of the group. In sharing stories about one's experiences with others, there is a pull towards an external focus, for instance, complaining about a friend's behavior. The task of the leader is to help patients access their emotional response. This is essential in order for patients to come to understand what they need from relationships and are not getting.

These social changes need to include behavioral changes in the area of sexuality. The issue of disclosing HIV status with prospective and current sexual partners need to be addressed. Likewise, the group should be encourage to discuss safer sex practices and how to deal with high risk behaviors. Therapists are advised against imposing their own judgment value to the discussion. Yet, therapists should encourage all members to participate and contribute to the discussion helping group members contain those who may have a despondent attitude toward "safety".

COPING WITH PROBLEMS AND LEARNING FROM EACH OTHER

People develop various coping styles over time, and these styles are generally more clearly delineated in the face of an HIV/AIDS diagnosis. Some may use a repressive style which involves avoiding the stressor as much as possible, including any thoughts or feelings that may be associated with it. Others may employ a more vigilant or monitoring stance where they try to learn everything they can about the disease and constantly are monitoring their bodies for any sign of disease progression or new symptomatology. Another style may be an extremely reactive or helpless stance where the person may be overwhelmed and constantly seeks help and support from others. In attempting to cope with HIV/AIDS, patients can learn a great deal from one another. Collectively, the group offers a wide range of coping strategies and strengths from which to draw upon and learn.

The therapists' role is to involve the entire group by encouraging them to share experiences. The exchange of information and history can serve to reduce anxiety, promote commonality and foster a sense of normalcy. Patients realize that they are not alone, nor is their experience abnormal. Listening to the problems and attempts to cope on the part of other group members enables each member to recognize resources they already possesses, as well as learning new coping strategies. The experience of learning from and being helpful to other group members promotes ego enhancement. It provides a means of enhancing self-esteem through the members' realization that they can knowledgeable and compassionately help others with a similar problem.

WHY ME?

This is a common question patients with serious illnesses ask themselves upon receiving their diagnosis. Some may feel that life is unfair and that they have done nothing to deserve their illness. Others may identify HIV/AIDS as a punishment; while yet some one else may see their illness as a "test". Therapists should facilitate the exploration of members' belief systems regarding their diagnosis. Sometimes assumptions or deep-rooted motivations are revealed that patients were unaware they held. When patients become aware of their assumptions and underlying motivations, they can then evaluate them both emotionally and intellectually. This process allows group members to reclaim a sense of control.

USING SELF-HYPNOSIS

Hypnosis is a psychophysiological state of attentive, receptive concentration, with a relative suspension of peripheral awareness. Hypnotic phenomena occur spontaneously, and the alteration of consciousness which hypnotized individuals experience has a variety of therapeutic applications. Hypnotizability is a stable and measurable trait -- not everyone is hypnotizable. A therapist inducing hypnosis is merely serving as a coach for the patient to maximize his or her hypnotic capacity. As such, all hypnosis is self-hypnosis. The therapist helps the patient use his or her own hypnotic capacity to undergo a trance state. Hypnosis is not therapy. The mere entry into a hypnotic state does not have any therapeutic effects of its own. Therapeutic change comes not from the state itself, but from what happens during it. In this regard, hypnosis is not a treatment itself but rather a facilitator of a variety of treatment strategies. The state of intense concentration elicited in hypnosis can facilitate attention to a variety of strategies which enhance control over somatic function, reduce pain, and provide control over a number of bodily functions and mental states.

Hypnosis can be helpful as an adjunctive tool for treating anxiety symptoms because of its ability to help patients control their somatic response to anxiety-provoking stimuli. This enables them to attend to the stimuli long enough to alter their point of view about them and achieve a sense of mastery over them. Most of the strategies used in the treatment of anxiety syndromes employing hypnosis combine instructed physical relaxation with a restructuring of cognition, utilizing imagery coupled with physical relaxation. As in the treatment of anxiety disorders by systematic desensitization or progressive relaxation, patients are instructed to maintain a physical sense of relaxation (i.e., floating), while picturing the feared situation or stimulus. It is important that the 'relaxation' instruction utilize an image that connotes reduced somatic tension, such as "floating" or "lightness," rather than being a direct instruction to "relax." This latter more cognitive term may actually induce more anxiety, while affiliation with a somatic metaphor usually produces some reduction in tension.

Initially, the use of hypnosis in the session can help in demonstrating to patients that they have a greater degree of control over somatic responsiveness than they had imagined. It is often useful to begin by teaching the patient to create a place in their "mind's eye" where they feel safe and secure. On occasion, it help the subjects to learn how to project their image onto an imaginary screen. Later they can learn to manipulate the screen by either making it bigger or smaller, having

the screen being nearer or farther away, as needed.

After they have learn to manipulate the screen and their own physical sensations, patients may be ready to do therapy work. They may, for example, learn to recreate the physical state of relaxation, while projecting onto the screen the fearful situation. This then, becomes a very useful procedure by which to control and obtain mastery over anxiety-producing situations by dissociating the somatic from the psychological response to the feared stimulus. Initially the patient is asked to recreate the physical feeling of relaxation. Then, the patient projects onto the screen images associated to the feared situation, only this time the somatic reactions associated to anxiety do not develop. On occasion it helps for patients to foresee likely physical sensations or situations associated to a fearful experience in order to master them.

Patients may also use the trance state as a means of facing their concerns more directly. They can achieve this by placing an image of an upcoming performance or fearful situation on one side of the screen; on the other side, testing out various strategies for mastering the situation.

Other approaches using hypnosis have included instructing patients in a trance to imagine that they are literally somewhere else, away from the fearful stimulus, thus separating themselves from the anxiety producing experience.

Insomnia

As we have discussed earlier, hypnosis is a state of increased concentration and awareness. From this point of view, the hypnotic state is far from sleep, although both are restful altered mental states with reduced awareness of the peripheral environment. So, it might seem paradoxical to use hypnosis to help people fall asleep. Nevertheless, hypnosis can be helpful for inducing a state of physical relaxation that is at least compatible with sleep. As in the treatment of anxiety, a relaxing trance state may diminish the sympathetic arousal usually associated with anxious preoccupation and could facilitate the entering into a restful sleep. Patients can be instructed to enter a state of self-hypnosis, then to induce a sense of floating and physical relaxation.

Once this is achieved they may use one of many different mechanisms to "put worries or thoughts on hold for tonight, knowing that they can always deal with them tomorrow". For example, they can project these thoughts onto an imaginary screen. Then, they can become a kind of 'traffic director' for their own thoughts, dealing with them on the screen, thereby dissociating them from the physical response to them, while remaining in a quiet and relaxed state.

Another useful method is to have patients imagine themselves lying restfully in a comfortable and safe place, while they see themselves "placing the disturbing thoughts onto the clouds, watching the breeze slowly carrying them away", or even imagining their worries to be like "leaves floating in the surface of a river, observing them flowing with the current" rather than holding on to any particular thought. Such approaches can be helpful in conjunction with standard sleep hygiene practices, which include keeping the bedroom as a place to sleep, avoiding working and other anxiety-arousing activities in bed, and avoiding looking at the clock when awakened. It is also important to distinguish routine insomnia due to situational reactions and anxiety from the more severe forms that are associated with major depression, an anxiety disorder, or an exacerbation of their physical condition.

Medical Procedures

Since hypnosis can be used to produce a state of relaxation and as a method to reduce anxiety, it have proven to be valuable as an adjuvant to medical procedures. Once patients have

been trained in the use of self-hypnosis, they can use it both in preparation to a hospital visit and while in the clinic or hospital. Once in that state they can imagine themselves being somewhere they enjoy and feel safe, thereby dissociating their mental experience from the physical (and possibly painful or unpleasant) aspects of the procedure. It can also be used as a way of mastering the anxiety associated to potentially threatening procedures, either diagnostic (i.e., CT-scans or bone marrow aspirations) or therapeutic (i.e., chemotherapy).

For example, a 43 year old HIV-infected woman who suffered several episodes of convulsions refused to undergo Magnetic Nuclear Resonance (MRI) testing, needed for the accurate diagnosis of its etiology, because of feelings of claustrophobia. On two previous occasions she agreed to try, but even after several milligrams of diazepam, she was unable to relax sufficiently to lie comfortably during the procedure. Finally, she accepted a referral to psychiatry. In my office (JRM) she proved to be highly hypnotizable (a 9 out of 10 on the HIP, a clinical measure of hypnotizability)). Under hypnosis we explored the associations between the scanner and her anxiety. Images of a coffin came to mind. These were then followed by memories of her father lying in the funeral home -- he had died of a massive stroke. We then proceeded to explore her anxiety as it related to fears to what the test may show, including the possibility of a malformed blood vessel or other pathology that may affect her brain, as it happened to her father. Once this was discussed, she felt that it "was better to know than to avoid". She was trained in self-hypnosis. After inducing a relaxed state she was instructed to "create in your mind's eye a place where you can feel safe and comfortable, knowing that sounds and people in the room will not disturb you". We also "practiced" going to the scanner room by having her imagine that she was both the patient in the room and the technician operating the machine. In this fashion she felt more "in control" of the situation.

The next day, we met her at the scanner room. Once she was on the imaging table, the patient followed the procedure we practiced. Once the test began, we left the room with the agreement that the technician would let her know when the test was over. She imagined herself walking through a forest and crossing a river. As she walked to the riverbank, instead of floating she sank slowly as she followed the contours of the river. Once on the bottom she held on to some algae. When she exhaled her breath it formed a gigantic bubble or cocoon which allowed her to breathe underwater and be safe. As the magnets in the MRI shifted in position she imagined that this was the clanking sound of motorboat engines in the surface. She remained in this state for approximately 2 hours, while both non-contrast and contrast test were performed. She tolerated the procedure well and easily came out of the trance state once the signal was given.

Pain Control

Pain is always a psychosomatic phenomenon, combining somatic with subjective distress. It never exists in a vacuum, and it always represents a combination of both tissue injury and the emotional reaction to it. Despite the organic factors causing pain, it is clear that psychological factors are major variables in the intensity of the pain experience. Beecher demonstrated that the intensity of pain was directly associated with its meaning. For example, to the extent that pain represented threat and the possibility of future disability.

Hypnosis can facilitate an alteration in the subjective experience of pain. Several techniques can be used to achieve this goal. Most techniques involve the production of physical relaxation coupled with visual or somatic imagery that provides a substitute focus of attention for the painful sensation.

The specific technique employed may depend on the degree of hypnotic ability of the subject. For example, patients can be taught to develop a comfortable floating sensation on the

affected body part. Highly hypnotizable individuals may simply imagine a shot of novocain in the affected area, producing a sense of tingling numbness similar to that experienced in previous dental work. Other patients may prefer to move the pain to another part of their body, or to dissociate the affected part from the rest of the body. As an extreme form of hypnotically-induced, controlled dissociation some patients may imagine themselves floating above their own body, creating distance between themselves and the painful sensation or experience.

To some, more moderately hypnotizable patients it may be easier to focus on a change in temperature, either warmth or coolness. A sensation of warmth could be elicited while imagining they are floating in a warm bath or applying a heating pad to a given area of the body. A cooling sensation can be elicited by imagining that the afflicted extremity is immersed in an ice cold mountain stream or in a bucket of ice chips. Temperature metaphors are especially effective. This may be related to the fact that pain and temperature fibers run together in the lateral spinothalamic tract.

The images or metaphors used for pain control employ certain general principles. The first is that the hypnotically controlled image may serve to "filter the hurt out of the pain." They also learn to transform the pain experience. They acknowledge that it exists (the pain) but that there is a distinction between the signal itself and the discomfort the signal causes.

The hypnotic experience which they create and control helps them transform the signal into one that is less uncomfortable. So patients expand their perceptual options by having them change from an experience in which either the pain is there or it is not, to one in which they see a third option, in which the pain is there but transformed by the presence of such competing sensations as tingling, numbness, warmth, or coolness.

Finally, patients are taught not to fight the pain. Fighting pain only enhances it by focusing attention on the pain, enhancing related anxiety and depression, and increasing physical tension which can literally put traction on painful parts of the body and increase the pain signals generated peripherally.

For patients undergoing painful procedures, such as bone marrow aspirations, the main focus is on the hypnotic imagery *per se* rather than relaxation. This works especially well with children since they are so highly hypnotizable and easily absorbed in images. Patients may be guided through the experience while the procedure is performed or a given scenario suggested and later have the patient undergo the experience hypnotically while the procedure is underway. This enables them to restructure their experience of what is going on and dissociate themselves psychologically from pain and fear of the procedure.

Even though the precise mechanism for hypnotic analgesia is not known it is suspected to have components of two complementary mechanisms: physical relaxation and attention control. Patients tend to splint the painful area instinctively, which in turn increases muscle tension around the painful area often resulting in increased pain. Therefore creating a state of hypnotically induced relaxation may easily decrease their experience or perception of pain.

This can be more easily achieved by creating images that facilitate a relaxing response, such as a warm bath, floating on an air mattress in a pool, or just floating out in space. Second, and probably more important, since hypnosis involves an intensification and narrowing of the focus of attention, it allows patients to pay selective attention to the action or ideas contained in the metaphor or images therefore placing pain at the periphery of their awareness. It thus diminishes the amount of attention they pay to painful stimuli. A third possible mechanism affecting the pain experience may be related to the psychological meaning of the pain itself. Some patients have been in pain so long that pain has become an intrinsic part of their existence.

Take for example the case of a 62 year old woman referred to me (JRM) with hopes that hypnosis will help alleviate her experience of chronic pain associated to cancer. A formal test of hypnotizability demonstrated that she was in the highly hypnotizable range. Under hypnosis she was instructed that all the pain would "go away" or at least she would be able to block it. But as soon as she exited the trance state the pain returned. Because of the curious dynamics of this phenomenon we decided to explore the meaning pain had for her. She told us how her oncologist had warned her that "she would be in pain as long as she were alive". It became clear that she associated pain to "being alive". And that she would only be "pain free" the day she died.

Having explored this, and after discussing it with the patient, she decided that it "was not fair that after suffering so much, I still have to deal with the pain". She "gave herself permission to live without pain and to enjoy as many of her remaining days as she could". She ended her trance experience and discussed it. Shortly afterwards she left the office, inadvertently leaving her cane behind. A few hours later she called to inquire if it was there. When we told her it was, she replied "you can keep it as a souvenir".

Regardless of the underlying mechanism, there is no doubt about the efficacy of hypnotic analgesia. Hypnosis has been shown to be superior to an attentional control condition for analgesia among children undergoing painful procedures. Furthermore, in a randomized prospective study, a combination of hypnosis and group psychotherapy was shown to result in a 50 percent reduction in pain among metastatic breast cancer patients (Spiegel and Bloom, 1983). This was accompanied by a significant reduction in mood disturbance.

The Induction Process

A simple self-hypnosis exercise consists of the following:

1. Induction into self-hypnosis: The first step is to help the members enter a safe and comfortable state where they are floating, free of tension and pain. It begins with an eye roll.

"Begin by getting as comfortable as you can... then look all the way up to the top of your head, as high as you can. Take a deep breath and hold it... Then, close your eyes and exhale the breath, and as you're exhaling the breath, let your body float..."

"Imagine that you're floating in a bath, a lake, a hot tub or maybe just floating in space..."

"Imagine the sensation of your whole body just floating right down into the chair, taking deep and easy breaths. Concentrate only on your breath, letting yourself notice how light it is, how it keeps you either warm or cool, and how it keeps you comfortable so that you can continue to float effortlessly during this time and fully immerse yourself in this soothing sensation of relaxation. And if you're aware of any pain or discomfort at this time, imagine a sense of either warm or cool tingling numbness and wrap it around that part of your body that's in pain or experiencing discomfort, so that it becomes a filter and filters the hurt out of the pain."

2. The split-screen technique:

"As you continue to float, picture in your mind's eye an imaginary screen. This can be a movie screen, a TV screen or just a piece of clear blue sky. First picture on this screen a pleasant scene, perhaps a place you enjoy being..."

Let yourself enjoy the image, keeping in mind that this is only one of any number of images that you hold in your store of memories that you can access any time you need to, simply by letting your body float the way you are right now. Then let that image fade and once the screen is clear again, divide it in two..."

The left side of the screen represents the problem state: Members are instructed to place a problem state on the left side of the screen. The type of problem the members are instructed to place on the screen is based on material that emerged in the session. For instance, if a theme in the group was control then the therapist might say:

"On the left side of the screen let yourself picture something about the HIV that you can't control or something you would like to change."

Maintain comfort state: After holding the picture in their mind for about a minute, members are instructed to focus on maintaining their state of physical comfort where the body is floating comfortably, unaffected by what they're seeing on the screen.

"Now focus on the comfortable feeling of your body floating, taking deep and easy breaths,

remembering that even if you're reacting to what you're seeing on the screen that your body doesn't need to."

The right side of the screen represents the problem-solving/comfort state: Members are instructed to place a problem-solving or comfort state on the right side of the screen. For instance, something about the HIV that you can control.

"Now on the right side of the screen let yourself imagine one thing about the HIV that you can control or change... (or better yet) imagine new ways in which you could address ... (the problem projected on the left side of the screen)..."

Reinforce comfort state.

"Remember... focus on the comfortable feeling of your body floating, taking deep and easy breaths... Remember that even if your mind seem to react to what you're seeing on the screen, your body doesn't need to... In fact, your body will continue to be relax and at ease"

Look at both screens side by side.

"As you look at both images sitting side by side, take a few moments to reflect on what they mean to you in a private sense."

3. Suggestions for future use of self-hypnotic states:

"You can use this exercise as a way to make your body feel more comfortable and as a way of dealing with problems by placing them in a new perspective... When you're ready, bring yourself out of the state of self-hypnosis by counting backwards from 3... On 3, get ready. On 2, with your eyelids closed roll your eyes up to the top of your head..., and on 1, open your eyes slowly feeling fully awake and alert."

Alternative Hypnosis Exercise: A Safe Place

Because all hypnosis is self-hypnosis, the induction used to facilitate entrance in the trance state is not as important as what patients and therapists can achieved during their trance experience. The following is a different self-hypnosis exercise. It uses the eye-roll technique for induction, but offers a variation to the split screen technique. It allows for patients to have more freedom during their hypnotic experience rather than being directed or guided by the therapist.

After induction of a hypnotic state (section 1 above) you can facilitate the creation of a safe place where patients may "want to go to" in order to escape unpleasant physical experiences, facilitate induction into sleep, or simply to relax:

"Now, as you continue to relax, more and more deeply, just allow yourself to float across time and space.. In a moment, your unconscious mind is going to take you, to a very special place, that's associated with tremendous feelings of peacefulness, and tranquility.

It may be a place you have been before, or some special place that you find yourself in for the first time...

And you can allow such a place to spontaneously come into your awareness now... And as you find yourself there, give yourself the opportunity, to experience all the refreshing feelings associated with this wonderful state...

And I'm not really sure whether you'd rather sit back and relax, and look at everything around you... or if you rather walk around some, and explore this special place, that's here right now , just for you...

And I don't know for sure the things that will stand out for you... whether it will be the sounds in this special place, a color, a shape, or the beauty of the place. Perhaps you'll especially enjoy the sensations and feelings as you touch things, and maybe even the smells will be unusually pleasant...

And I wonder if you have already begun to notice the fact, that as you just experience , and enjoy this special place, you soak up and absorb these tranquil feelings. And you can just allow these feelings of deep contentment, and peace, and calm, to flow... all through you,.. to all parts of you... allowing all of you to experience these soothing feelings...

And as each moments passes in this special place, these wonderful, invigorating feelings increase, and become more a part of you... And you can savor this place, and your enjoyment of it can be heightened with every moment that you spend here...

And as you rest here, you can recharge your batteries... This experience may remind you of other places and experiences, where you've felt happy, and contented, and filled with peaceful feelings... And in this special place of serenity and security, things can come into perspective... You can become aware of actual feelings, with a correct sense of proportion free from the distortions of a mood or set of circumstances...

As you rest in this place, things come into proper perspective... And in this special place,

independent of anything that I say, you can receive what you most need right now... Your unconscious mind knows what you most need.... And I don't know exactly how you'll receive that... It may be that you gain a new perspective or just find yourself feeling differently...

And in a moment now, I'm going to count backwards from 3... and on one you will find yourself been fully awake and alert... But you will know that you can return to this special place of yours, whenever you need to or want to. You will know that whenever you need to rest, or replenish your strength and energy, that you can put yourself into a deep and peaceful self-hypnotic state, and return to this place...

Now... as I count backwards, allow yourself to drift back across time and space, bringing these wonderful feelings, and this sense of perspective with you. And you will awaken feeling well; refreshed, alert and clear headed. And what you have experienced can remain with you, after you have awakened... On 3, get ready. On 2, with your eyelids closed roll your eyes up to the top of your head..., and on 1, open your eyes slowly feeling fully awake and alert..."

GROUP PROBLEMS

DISEASE PROGRESSION AMONG GROUP MEMBERS

In a supportive-expressive group for persons with HIV/AIDS, it is a virtual certainty that the disease will progress for one or more members of the group. From the perspective of the person whose disease has progressed, being in the group can be vitally important. The group may be the only place where members can speak openly about what is happening for them. Members should be encouraged to stay both for their own sake and for the good of the group.

From a medical point of view, HIV infected patients will go through a number of stages depending on the progression of the disease and the adherence to prophylactic treatment. The following is the staging system published by the Center for Disease Control (CDC):

Stage I: indicates acute infection, usually experienced as a flu-like or mononucleosis-like syndrome (most individuals will remain free from an AIDS-related complication for a mean of 9+ years).

Stage II: usually characterized by a relatively prolonged period of latent infection. Individuals are infectious, but they experience no AIDS-related medical problems.

Stage III: similar to stage II, but the presence of persistent lymphadenopathy (swollen lymph nodes) in at least two extrainguinal (outside of the groin area) sites is noted.

Stage IV-A: represents the development of constitutional symptoms such as persistent diarrhea or fever and weight loss.

Stage IV-B: indicates HIV-related neurological disease (i.e., dementia, neuropathy, myelopathy).

Stage IV-C: indicates the presence of opportunistic infections secondary to immunosuppression.

Stage IV-D: lists cancer indicative of a defect in cell-mediated immunity (i.e., Kaposi's sarcoma, CNS and non-Hodgkin's lymphomas).

Stage IV-E: includes diseases not listed in other categories but could be attributed or complicated by HIV infection.

Besides the obvious signs of physical illness such as weakness, fatigue and muscle wasting, patients may experience a number of mental syndromes. Many of these problems are not just the patients psychological response to being HIV infected but a direct effect of the viral activity in the brain. The majority (3/4) of those who die with AIDS will show significant evidence of CNS (central nervous system) pathology. The majority of focal CNS damage is caused by a wide variety of opportunistic infections.

When HIV infection is seen as a chronic life-threatening illness, we notice that the psychological reactions to HIV/AIDS progression consist of four relatively distinct transition points following the stages of progression in the body: a. diagnosis (seroconversion), b. adaptation to a physically asymptomatic period; c. transition to a symptomatic disease, and d. clinical AIDS .

WHEN MEMBERS LEAVE

Occasionally members will decide to leave the group. This can occur for any number of reasons. Two of the more common reasons are that they are not getting their needs met, or that they find the group too frightening. In any case, it is important that their reasons for leaving be determined and, if possible, addressed in the group before they leave. The decision to leave may reflect entirely their own issues. However, more often than not it is also a reflection of the group.

The decision to leave may be because there is someone else in the group who is demanding too much attention or derailing the focus of the group. This kind of situation can occur if it is a psychologically heterogenous group. That is, where some members are psychologically healthy while others are more vulnerable and in need of more attention. If this is the situation, it is important that the problem be addressed because it is bound to be affecting other members as well.

Some individuals will leave because they find it too threatening to talk about the HIV virus and how it has affected them. Before a member leaves for this reason, it is important to talk about how the discussion is affecting them. Raising this issue with the group provides an occasion to address the fear and anxiety that is generated for all members when talking about various AIDS-related topics. These fears and anxieties should be acknowledged as valid and real, but the leaders can simultaneously use this as an opportunity to reiterate the philosophy of these groups. For instance, we believe that the best way to cope with the fear and anxiety about HIV disease is to talk about all the ways in which people are affected by it. The main principle in dealing with a member's decision to leave is to face it head on.

If there are problems in the group, then they should be addressed. At the end, whenever anyone decides to leave, every effort should be made to have the person return for one last

sessionso that everyone has the opportunity to say goodbye. This gives group members the opportunity to learn to say goodbye in a caring manner, and it gives a message that no one will slip away unnoticed.

CONFRONTATIONS AMONG GROUP MEMBERS

Confrontations among group members are rare in supportive-expressive groups,because the focus of these groups is on providing support to one another. Occasionally, however, confrontations will occur among group members. In such situations the task of the leader is to function as a mediator and to help facilitate caring and supportive communication. At times of conflict it is the role of group leaders to help members realize that the purpose of the group is to explore the impact AIDS has had on each of the members and to provide support to one another.

SCAPEGOATING

Scapegoating is a way of deflecting attention away from an uncomfortable issue and displacing the negative affect that issue evokes onto to someone else. If scapegoating occurs in supportive-expressive groups, it can be concluded that the group is engaged in a major attempt to avoid dealing with some anxiety provoking topic. Scapegoating is destructive, and the leaders must protect the person who is being scapegoated, as well as help the group to recognize the real issue it is avoiding. If scapegoating is not dealt with and eliminated, it will undermine the integrity of the group and all members, not just the person being scapegoated, will suffer.

THE MONOPOLIZER

A common problem in groups is the monopolizing patient. This is someone who finds it very difficult to be quiet in the group, jumps to speak at every opportunity, and has a hard time giving up the floor. Not only do these patients tend to monopolize the conversation and make it difficult for others to speak, but they typically do not speak about things of real substance or importance. The main reason for the constant verbiage is anxiety. The monopolizer is anxious if silent and so talks in order to quell it.

It is important that therapists intervene early on in the evolution of the group so as to circumvent the development of a problem. There are two goals: to help the monopolizer; and to protect the group. As Yalom (1985) describes it, the aim is not to get the monopolizer to speak less, but to speak more. Eventually, the therapist will have to interrupt the person and help him or her to speak from a more meaningful place. In order to do this, the leaders will need to attend closely to what he or she says and also in what context. You may notice that he or she tends to claim the floor immediately after someone has said something distressing. In a case like that, an appropriate intervention would be to interrupt him or her and to ask the person howhe or she felt about what he or she had just heard. If it is difficult for the monopolizer to access his or her immediate experience, it may be necessary to follow the question with an interpretive statement such as "*I'm wondering if you felt a need to change the topic to something that is not so upsetting*".

Another strategy in dealing with a monopolizing patient is to elicit reactions from the rest of the group. The strategy is to ask for reactions in a way that will facilitate the expression of supportive statements. The person who is monopolizing needs to feel that the rest of the group wants to hear about his or her concerns, feelings, and anxieties. Whenever this individual reveals thoughts and feelings of any importance this presents a perfect opportunity to elicit reactions from the group. This approach will help the group member feel heard and valued as a person and will encourage him or her to communicate at a meaningful level.

THE SILENT MEMBER

Silence can be an expression of any number of things. It may be due to fears about performance, feeling intimidated, feelings of superiority, fears about opening up the dam within, or discomfort in being self-revealing.

The goal with a silent patient is to help the person break through his or her silence. For some silent patients being called upon to speak can be distressing. Consequently, it is important to be careful in how you invite his or her participation. In the early stages of the group, an open question about group reactions can be asked in the group such that it does not single out particular individuals. If your silent members do not respond they can be turned to directly. If someone remains relatively silent for the first two or three groups, it will be necessary to address him or her directly. The therapist can comment on his or her silence and inquire about how s/he has been finding the group. The hope is that this will enable him or her to break the ice and begin to participate. In all likelihood leaders will need to continue supporting the patient as they draw him or her out. If over the course of time these approaches fail, the leaders may choose to address the question more directly in the group. Alternatively, the leaders may want to speak with the person on an individual basis in an effort to understand the problem.

As in the case of the monopolizing patient, the group can be drawn on to support the silent member. They can be asked for their reactions to her silence. The aim is to create as supportive and caring an environment for him or her as possible. The more the other members can be utilized to do this, the more effective it will be.

THE 'SPECIAL' MEMBER

The 'special' patient is the patient who feels set apart, different from the rest of the group. They use the differences that they see between themselves and the group to detach. This way they are able to disengage emotionally from topics they find difficult.

There are many ways in which a patient can decide to see themselves as special and set apart from the group. They might compare their disease to other group members and conclude that theirs is not as serious. Therefore, many of the issues that the group is concerned with are not relevant to their situation.

Therapists must remember that the ways in which these patients see themselves is motivated by anxiety. By agreeing to join the group in the first place, they made it clear that they had issues similar to the other members. However, once in the group their anxiety mounts, causing them to distance.

By listening carefully to these members, therapists can reinforce the similarities between

them and other members. The main strategy is to help this individual tolerate their anxiety and connect with the rest of the group. By joining the group in this shared journey of self-exploration and mutual support, they will feel less isolated and able to face their particular fears and concerns in the context of a supportive and caring environment.

THE HELP-REJECTOR

The help-rejector is someone who insists he or she is looking for help, if only he or she could find someone competent enough to give it to him or her. No one in the group, neither the members nor the leaders, can ever provide him/her with quite what s/he needs. Lodged in every reply he or she gives to others' responses to his or her appeals for help is a "yes, but..."

These individuals believe their problems are so complicated and difficult that there is really nothing that can be done for them. Underlying the belief that their problems are too complex lies a lack of desire to change. One possibility is that they receive gratification from being someone in eternal need of help. Alternatively, the intricacy of their problems may be their way of establishing a sense of superiority. Underlying this need to feel better than the rest are feelings of inadequacy and inferiority. By rejecting the help of others, they can keep people mystified about how to help them. The complexity of their needs is a way of keeping people from getting too close.

Rejecting help can also be a way of expressing anger. They may be feeling enraged at the unwarranted blow life has dealt them. The anger is preventing them from seeing any way to improve their life.

The therapists' task is to bypass their help-rejections in order to access the underlying emotions. These patients are working hard to maintain distance from others and their own feelings. It takes a sensitive and empathic orientation to help them to soften so that they can attend to what is really going on inside.

Paradoxically, help-rejectors are people in need of a lot of help. Not only do they need help in coping with HIV/AIDS but they also need help in maintaining relationships with others. They are trying to push people away and are often quite successful at it. Leaders must be careful that they not become alienated from the group. When the help-rejector rebuffs another member's suggestion, it is often useful to ask the member how it feels to have their advice rejected. Initially this can be threatening to both members but it will enable the help-rejector to respond to the other member as a person rather than another piece of advice they must fend off. By helping these individuals "join" the group, they will benefit from the support they receive and the group will benefit from having been supportive.

THE PSYCHIATRICALY DISTRESSED

HIV disease has no respect for age, race, socio-economic status, education level, geography, or gender. Thus, there is no reason to think it would not cut across personalities. There is a wide array of psychiatric problems that someone can bring to the group. These problems can include depression, anxiety disorders, personality disorders, and drug abuse. Admission criteria to participation in group therapy clearly excludes thought and dissociative disorders.

Ideally, the study coordinator will have assessed each potential member for psychiatric problems during the initial interview and anyone who was clearly inappropriate for a supportive-

expressive group has been referred elsewhere. Even with the initial screening, occasionally there will be someone who has joined the group requiring special psychiatric needs. Leaders should try to attend to these needs as much as possible without it being disruptive to the group. Therapists must be responsive to the special needs of this person but, at the same time, must keep in mind the needs of the rest of the group. Therapists should use their experience and expertise not to allow the troubled patient to derail the group.

It is important to create as supportive an environment as possible, partly by helping other members provide support for the patient. The therapist should bear in mind, however, that for some disorders there exists a bottomless pit that no amount of group support could ever fill. Leaders should be alert to this possibility and not allow the group to become depleted by or resentful of the person's neediness.

If attempts to support the individual meet with failure, it may be appropriate to recommend in a private conversation with that patient that he/she receive individual assessment and treatment in addition to the group. If it becomes clear that the special difficulties of this patient cannot be managed in the group and are disruptive, s/he may need to be removed from the group and referred for individual therapy.

Psychiatric Disorders and HIV:

a. Adjustment disorders

These have generally been detected in only 10-20% of HIV diagnosed cases. The once predicted high rates of suicide upon discovery of seroconversion have not developed.

b. Anxiety disorders

Episodes of anxiety lasting for one to several months are prevalent. Some reports suggest lifetime prevalence rates exceeding 40% in both seropositive and seronegative homosexual men, with the majority of onsets being related to seroconversion or commencing after the advent of the AIDS epidemic. During a period of 2 years of follow-up, about 20% of seropositive homosexual men described brief generalized anxiety, with the rates being comparable for seronegative men.

c. Mood disorders

Rates of a current major depression in HIV populations are elevated about two times above those in healthy communities, and usually are in the range found for individuals with other chronic illnesses (e.g., 5-8%). In hospitalized HIV patients rates are much higher and may approach 40%. Depression syndromes can be expected to occur in about 10-25% of seropositive homosexual men during the course of a 2-year follow-up. Somatic (i.e., weight loss, fatigue) and/or neurologic (i.e., psychomotor retardation, impaired memory, decreased concentration) symptoms may complicate the differential diagnosis in the physically ill individual with HIV/AIDS. Therefore, the more psychological symptoms of depression (i.e., sad affect, depressed mood, loss of interest, worthlessness, and suicidal ideation) are used to make the diagnosis.

d. Manic syndromes

Organic mood disorder, or secondary mania, may arise in HIV patients as a complication of a neuromedical disease (i.e., cryptococcal meningitis) or pharmacologic intervention (i.e., steroids, ziduvine (AZT), or ganciclovir). Manic syndromes also have been associated with HIV infection itself.

e. Psychotic disorders

A full-blown psychosis may appear in HIV-infected individuals in the absence of delirium, iatrogenic sources (i.e., due to treatment), or substance abuse. It is usually found in late stage illness, with a prevalence rate of 0.1 to 5%. Psychotic processes associated to HIV present with elaborated delusions, hallucinations (auditory, visual and tactile), and thought disorder.

f. HIV Dementia & other neurocognitive disorders

Due to HIV infection of the CNS, a portion of HIV-infected patients will develop cognitive disorders.

The most common has been termed *Mild Neurocognitive Disorder* (MND). Symptoms include subtle impairment in cognitive functions, particularly reduction in speed of information processing, impairment in attention, and difficulty in learning and recollecting new information. It has been estimated that approximately 50% of patients with frank AIDS will meet criteria for MND.

HIV-associated Dementia (HAD) represents the more advanced cognitive disorder associated with HIV-1 infection. The signs include marked impairment in ability to attend, concentrate, and process information quickly and flexibly; marked impairment in acquisition of new information and recall of such; and disturbance in language abilities including naming and fluency. Psychomotor slowing can be a prominent feature, and can be accompanied by incoordination and ataxia. Affective changes can also be present, ranging from depression to inappropriate or markedly labile affect. Irritability and violent outbursts can occur. Some patients may progress to a state of severe withdraw, apathy and mutism. Some late cases of HAD may be accompanied by psychosis and delirium.

g. Delirium

As in most illnesses, the causes of delirium are multifactorial, including the burden of the systemic disease, CNS impairment, and medication effect. Delirium can present with a hyperactive/agitated state or a hypoactive/withdrawn picture. We are rather use to the delirium presented in the hospitalized patient, but most physicians miss the cases presented by ambulatory patients. Many anti-infective, antineoplastic, and psychoactive agents in HIV can produce hallucinosis, organic mood disturbances, or frank delirium.

h. Pain

Along with delirium, pain represents one of the most underdiagnosed and undertreated phenomena associated with late-stage HIV disease.

i. Substance abuse

Lifetime rates of alcohol abuse in high-risk homosexual men (both sero+/-) approach 40%, a 2-3X increase above community prevalence rates. In general, alcohol abuse begins long before HIV infection. So far, the stress of the disease does not appear to increase rates of developing an alcohol abuse problem de novo. Conversely, infection with HIV may bring an adaptation of a healthier lifestyle, in which psychoactive substances are avoided.

RECOMMENDED READING

Callen, M., (1990). Surviving AIDS. San Francisco: Project Inform.

Dilley, J.W., Pies, C., Helquist, M., (1989). Face to Face, A Guide to AIDS Counseling. San Francisco: AIDS Health Project.

Monette, P. (1993). Last watch of the night. Harcourt & Brace Company.

Project Inform, (1994). Guidelines for doctor-patient relationships. Harperperennial.

Spiegel, D. (1993). Living beyond limits: New hope and help for facing life-threatening illness. New York: Times Books Random House.

Yalom, I.D. (1985). Theory and practice of group psychotherapy, (3rd ed.). New York: Basic Books.

Zegans LS, Coates TJ (Eds) 1994. Psychiatric Manifestations of HIV Disease. Psychiatric Clinics of North America. WB Saunders.