OVERVIEW OF PSYCHOLOGICAL ISSUES CONCERNING AIDS

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"As a psychiatrist at the Memorial Sloan-Kettering Cancer Center, I have the opportunity to interview, evaluate, and treat many patients with Kaposi's sarcoma (K.S.) and AIDS who are experiencing difficulties in coping with their illness. More than any other population of cancer patients, this one suffers a dramatic change in self-esteem, daily habits, and general life style in response to the onset of the illness.

"Psychological and social interventions are an integral part of treatment, for without adequate coping strategies and environmental supports, patients are easily lost from follow-up care."

Joseph Barbuto, M.D.
Psychiatry Service
Memorial Sloan-Kettering Cancer Center
(Letter reprinted from New York Times Magazine, March 27, 1983)

I. Social Isolation

A. Withdrawal of social supports.

1. Fear of mortality among friends, family.

2. Helplessness; inability to effectuate change
   a. Inability to "make patient feel better"
   b. Unrealistic expectations among friends, family.

3. Overidentification with patient
   a. Friends are typically of same age, exhibit same lifestyle, interests, daily habits
   b. Arousal of sense of vulnerability, fragility

4. Fear of contagion
   a. Conflicting, sometimes unscientific media reports
   b. Difficulty separating appropriate and inappropriate anxiety
   c. Hepatits B model

B. Isolation among hospital patients

1. Infection control precautions sometimes severe

2. Occasional homophobic reactions among hospital staff

II. Alteration in Quality of Life

A. Crisis, disruption, disorganization in thinking and daily habits.

B. Experiencing "bankruptcy", boredom, isolation, social withdrawal

1. Patients often too sick to work, too well to stay at home

2. Fatigue limits vocational, social participation

3. Medical restrictions
   a. Sexual practices limited, abstinence
   b. Social outlets withdrawn

4. View of self as leper in social, sexual void

III. Drop in Self-Esteem

A. Stigma of AIDS

1. AIDS as a sexually transmitted disease

2. Patients begin to feel guilty, dirty

B. Internal dialogue: "What did I do to deserve this?"

1. Surfacing of internalized homophobia
   a. "I have AIDS because I am gay"
   b. Bargaining — "I'll go straight, if only I am cured"

2. Self-condemnation concerning "life in the fast lane"

C. View of self as toxic to others

IV. Intensity of Emotion

A. Obsessive cognitive (thinking) style

1. Absence of customary diversions, distractions, daily habits

2. Void filled by ruminative (obsessive, repetitive) thinking

B. Emotional vacillation

1. Anger, guilt, rage, depression, fear, easy tears

2. Fluctuations frequent within course of day

3. "Roller Coaster" effect
   a. Alternation between hopeful highs and helpless lows
   b. Rapid alternation due to changes in medical condition, doctor's reports, media, etc.

C. Anger

1. At lack of justice, righteousness in life

2. In response to realistic, concrete frustrations
   a. Demand for answers, effective treatments, comparative outcome data not satisfied

b. Lack of effective governmental response
c. Victimization by medical establishment
d. Inability to retain control
e. Media hysteria
f. Abandonment by friends, family

V. Issue of Control

A. General sense of lack of control over disease, body, life

1. Reinforcement of passive, helpless patient role by medical establishment

2. Lack of effective treatment plan

B. Struggle to regain control

1. Scrambling from doctor to doctor for disconfirmation of diagnosis

2. Perceived sense of urgency to select treatment option

C. Relevance for counseling

VI. Denial

A. Defense mechanism

1. "Not me, it can't be true"

2. "I'll be the first to overcome this disease"

3. Denial as primitive but healthy buffer

B. Importance of denial in keeping patients intact

1. Helps patient to maintain positive quality of life

2. Allows patient to deny; patient must indicate readiness to deal directly, openly with prognosis

C. Denial to be challenged only when medical treatment is compromised

VII. Financial Stressors

A. Cost of treatment is exorbitant
1. Range: $50,000 to $100,000

2. Can reach one half million dollars

B. Importance of knowledge of third party reimbursement and government financial aid

EMOTIONAL STAGES OF THE DYING PATIENT

(As per Dr. Elizabeth Kubler-Ross)

In general, stages overlap, coexist. Patients may fluctuate from stage to stage, even daily.

The following are defense mechanisms and are necessary for adequate coping.

1. First Stage: DENIAL AND ISOLATION

   - Most primitive but healthy (buffer)
   - "Not me, it can't be true"

   Allow patient his denial; it must be up to him to indicate readiness to deal with his mortality.

   Avoid judgment.

2. Second Stage: ANGER

   - "Why me?"
   - Displaced and projected. Expect being a dartboard.
   - Empathy most important here. Do not take it personally.

3. Third Stage: BARGAINING

   - Only effective briefly
   - Demands replaced with bargains
   - Often associated with quiet guilt

4. Fourth Stage: DEPRESSION

   - Numbness and stoicism, anger and rage replaced by a sense of great loss
   - Two types important to distinguish
     - Reactive depression
     - Preparatory grief
   - Allow patient to feel sad

5. Fifth Stage: ACCEPTANCE

   - Almost all patients who have sufficient time experience this stage
   - Neither depressed nor angry -- void of feelings
   - How do we know if a patient is giving up too early?

GENERAL COUNSELING RECOMMENDATIONS

1. Treatment Goals. The goal of peer counseling with AIDS patients differs markedly from traditional psychotherapeutic treatment objectives. Stated simply, the goal is the establishment of an ongoing, accepting, open social relationship. Treatment is often just being with the patient, listening to him or her, and understanding what the patient is saying. Sharing intense emotions helps to dilute their negative effects. Good empathetic listening skills are therefore critically important. Because therapy with AIDS patients involves "being there", listening, and sharing, the best therapeutic style is the counselor's own personality. Counselors are advised to simply be themselves, to trust themselves. Fabrications are inappropriate and easily detected by patients.

2. Control Issues. Patients with AIDS tend to become passive recipients of medical treatment dictated by physicians and medical institutions. The medical establishment can be impersonal, frustrating, and lead to a sense of helplessness. Patients should therefore be encouraged to take as much of an active role in treatment as possible. They can participate in their treatment plan by learning about nutrition, stress management, relaxation skills, transcendental meditation, coping visual imagery, the "Simington Method", etc. Various self-help books focusing on these areas are available in bookstores.

3. Be helpful, but don't "overhelp". Assistance in the form of helping patients to do things that they can do themselves is NOT assistance. Overhelping can leads patients to develop a sense of passivity, dependency, helplessness. It can reinforce a sense of imminent decline. Patients should be encouraged to do as much as they can, taking into account medically prescribed limitations.

4. Maximize the quality of the patient's life. Patients should be encouraged to participate in as many social, recreational, leisure, and occupational pursuits as possible, given their medical status. Discourage the frequently adopted role of the "professional patient", whereby patients spend all of their time in support groups, with counselors, therapists, and medical practitioners. Suggest that the patient go to movies, theater, dinner parties, and the like. It is not inappropriate for counselors to accompany patients in recreational activities.

5. Encourage the patient to be vocal and expressive. The significant others in patients' lives often shrink away from the responsibility of discussing "heavy" issues. Patients are frequently told that they are being morose and depressing or that they are engaging in negative thinking when they initiate discussions involving their mortality. Don't assume that you can't or shouldn't talk about these issues with patients. It is important, however, that you let the patient take the lead and allow him or her to guide you into these topics.

6. Permit Denial. If the patient is obviously utilizing the defense mechanism of denial, let it be, as long as his or her medical care is not compromised as a result. The failure to accept one's prognosis is usually not damaging. Denial reduces stress, keeps patients happy, intact, coping, and helps them to maintain a positive quality of life.

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7. Encourage participation in groups. Group therapy is the treatment modality of choice for AIDS patients. Groups are safe and supportive places to discuss relevant issues and exchange information. They afford patients the opportunity to see examples of effective coping philosophies among other group participants. Furthermore, group therapy always has a social component, thus reducing isolation.

8. Reliability, consistency, and continuity. The support offered by peer counselors must be reliable, consistent, and continuous. Since therapy primarily involves "being there", it is important that counselors make commitments to themselves and ot their patients to be available. Patients should be advised far in advance of counselors plan to be out of town. Arrangements should be made for "back-ups". Additionally, patients should be followed-up on a regular basis to ensure continuity of care after they have been referred to other G.M.H.C. services. Referral does not imply termination of the counselor-patient relationship.

9. Be sensitive to the patient's social unit. Patients do not live in a vacuum. They are surrounded by friends, family members, roommates, and lovers. It is not unusual for patients to experience as much stress from significant others as they do from the disease itself. Counselors should obtain the patient's permission to consult with these individuals, to strengthen the patient's natural social supports, and to make referrals for significant others as needed.

10. Allow time for the therapeutic alliance to develop. It takes time to establish trust and to cultivate an ongoing, accepting relationship. Be patient.

11. Avoid statistics. Statistics are not helpful. Discussions of mortality rates can lead to pessimism, self-defeatism, and helplessness. Further, overall statistical data are not relevant for individual cases.

12. Maintain regular contact with the patient's primary physician. It is not unusual for patients to misconstrue doctor's statements. Anxiety often interferes with listening and comprehension. It is critically important that counselors obtain written permission from their patients to consult with physicians and hospitals concerning recommendations for diet, rest, leisure, work, sexual practices, etc.

13. Accept being used as a dartboard. Counselors should recognize their need for a "thick skin". Patients will find many reasons to become angry, and they will often direct this anger at whatever or whoever is present. Counselors should not personalize these attacks. When they occur, patients should be engaged in dialogue.

14. Give yourself permission to experience discomfort. Counselors should recognize, and refrain from, self-condemnation when they experience fear, anxiety, discomfort, or general self-consciousness with patients. Working with individuals who are facing a possible terminal illness is not easy. Remember that you are human and that it is natural to feel fragile, frightened. Counselors are encouraged to participate in support services designed for them by G.M.H.C.