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The Psychosocial Challenges of AIDS and ARC

Jeffrey S. Mandel, PhD, MPH

Perhaps the most striking and recurring theme that occurs when working with people with AIDS and ARC is the struggle to maintain hope. Helping people with life-threatening illnesses always presents a difficult challenge; the uncertainties about AIDS and the lack of treatments only compound this task. In addition, AIDS has become a powerful sociocultural event that involves mass hysteria, political and scientific battles, and a long history of association between homosexuality and mental illness. People with AIDS and ARC may present mirrors through which mental health professionals must face personal fears and thus cope with counter-transference issues. All these elements of the current AIDS environment complicate attempts to keep hope alive.

Reactions to Diagnosis

One focus of our study has been to document how people react to being diagnosed with AIDS or ARC. In comparing AIDS, malignant melanoma, and acute leukemia, we found a highly similar range of reactions in the two-month period following diagnosis. All groups showed mean clinical levels of distress, anxiety, and depression. We also found similarities on measures of self-esteem and locus of control.

We asked the men in our study what worried them most about having AIDS or ARC. Most commonly they reported concerns about protracted or more serious illness, about burdening or being dependent on others, and about the possibility of death.

What these results suggest is that in many ways we are seeing a typical human response to life-threatening illness. Thus, we may rely on the wide body of literature already available, as well as our own previous clinical experience, to guide our clinical work.

Assessment of Mood or Cognitive Disturbance

AIDS and ARC present complications to the assessment of mood and cognitive disturbances. Both AIDS and ARC have frustrating and unpredictable medical courses. People feel fine one day and terrible the next; their emotional states often fluctuate in tandem with the physical changes. Thus, the basis of clients' distress becomes difficult to determine.

Conversely, psychosocial factors may affect the perception of physical symptoms. The problem of distinguishing between the physical symptoms of AIDS and hypochondriasis is common. Hypochondriasis, founded on denial of emotional conflict, permits patients to express more comfortably their concerns, not

only about physical symptoms, but also about the adequacy of health care. People with ARC may have particular difficulty in getting their health care providers to take their concerns seriously.

Organicity presents another confounding problem. More than half of hospitalized AIDS patients show signs of organic mental disorders. While increasing attention focuses on the possible neurotropic nature of HTLV-3/LAV among hospitalized patients, the amount of organic involvement among non-hospitalized persons with AIDS and ARC is unclear. Organic involvement can have profound effects on mood and cognition and can frighten and confuse the client and the clinician.

Most people with AIDS or ARC adjust to their diagnoses without disabling psychosocial problems. In fact, most clients develop a very positive spirit. Clinicians may be surprised by their clients' positive approaches and hopefulness. They may interpret this spirit as denial and encourage their clients to experience what the clinicians assume is the real underlying pain. Those practitioners with limited experience in working with life-threatening illness are especially prone to make this common error. Often, clinicians project their own distress and fears onto their clients. For most people with AIDS or ARC, quality of life assumes utmost importance and they become expert at making the most of their precious time.

Attribution — The Search for Meaning

Our study has also focused on attribution, the theories about the causes of threatening events. Attributions are important in adjusting to illness because they create understanding and a sense of meaning and control. Naturally, people form theories about the origins and meaning of their illness. These theories are then related to the kinds of life-changes people make after being diagnosed.

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Dr. Jeffrey Moulton, a member of our project, found that most men with AIDS or ARC attribute the cause of their health problems to themselves. This self-attribution is also associated with greater distress. The opposite of self-attribution may be a belief that one's illness is caused by external sources, such as bad luck or the environment. This response seems to be emotionally protective.

We also studied post-diagnostic life-changes, such as changes in diet, exercise, and stress-reduction techniques. On the average, those men who make many life changes are less

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Editor: Michael Helquist; Medical Adviser: Stephen Follansbee, MD; Administrative Assistant: Joseph Wilson.
Director, AIDS Health Project: James W. Dilley, MD.

Psychosocial Challenges . . .

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distressed and feel more hopeful than those who make few changes.

These findings suggest a number of clinical applications. Clinicians may find it important to explore how clients seek meaning from their illness. Clinicians can also develop ways to encourage positive life-changes; in this way, they can help bolster clients' sense of mastery and control. Some therapists, especially those who have been trained analytically, feel conflicted about being openly directive. However, dealing with terminal illness requires a shift towards a more active technique.

Self-Disclosure About Health Problems

Our study analyzed the relationships among "coming out" as being gay, discussing health problems with others, and emotional distress. Most men (approximately 80%) had come out as being gay to their families and at work prior to being diagnosed. Two months after their diagnoses, however, many had not discussed their health problems with family members or with co-workers.

Not having come out yet was the most common reason for not discussing health problems with others. Most men who did discuss their health problems with others reported a positive experience while those who chose not to do so experienced more distress.

A diagnosis of AIDS or ARC brings with it a special set of problems including others' fear of contagion and the social stigma of homosexuality, drug abuse, or hemophilia. Gay men's adjustment to their diagnoses is enhanced by their comfort in being openly gay. The skills learned in coming out become useful again in handling the disclosure of an AIDS-related problem. Clinicians can anticipate greater distress among gay clients who have not come out to family members or to colleagues at work.

One thorny issue which arises in this area of self-disclosure is whether or not to tell one's sexual partners about health problems, or whether to be sexual at all. Some clinicians encourage safe sex as a bottom line, while others insist that it is an ethical obligation to tell all partners about health problems. Both clients and clinicians approach this issue with strong feelings. All practitioners have an obligation to explore their own feelings about sex and AIDS, so as not to burden their clients with their own moral or sexual prohibitions.

Underestimated Psychosocial Needs In ARC

An emerging theme in our study reveals that the psychosocial needs of persons with ARC have been underestimated. Men with ARC reported lengthy delays in seeking a medical evaluation for a suspicious symptom. When they finally consulted their physicians, they were often told that their symptoms were nothing to worry about. At other times the physician simply expressed uncertainty about the cause of the symptoms. Yet patients sometimes feel their fears are being invalidated by these well-meaning words or ambiguous reflections.

Sometimes patients and health care providers may collude in denial to avoid the uncertainty of the situation. Friends of the person with ARC might also cooperate in this "everything will be fine" scenario rather than empathizing with their friend's distress.

We found people with ARC more distressed than persons with AIDS. Many people with ARC choose not to discuss their health problems with others because they fear rejection. In our study half the men with ARC are sufficiently affected by their illnesses to be unable to maintain their employment. Without a clear diagnosis, however, many men said they feel guilty about taking time off from their jobs to recuperate from intermittent illnesses or to sort out personal affairs.

Supporting Hope

Searching for hope in the absence of definitive medical treatment, people with ARC and AIDS frequently seek al-

ternative therapies. Many physicians discourage or only tolerate questions about these treatments, pushing their patients to rely exclusively on the medical establishment, continue to search for these treatments clandestinely, or reject the medical establishment altogether. Some physicians, sensing the need for adjunctive treatment, suggest that patients see mental health professionals. Whether or not alternative treatments are of medical value, health care providers need to support their clients in their quests for some hope. There are many ways of bolstering that hope; alternative treatments are just one. At the very least, clinicians should encourage their clients to educate themselves about what is known about AIDS and to take active roles in their own health care.

Sometimes people speak of "false hope," but I am not sure such a thing really exists. Hopelessness is a dangerous place: a place in which people are depressed and withdrawn, one which often draws death about itself quickly. Hope, on the other hand, provides the motivation for people to enhance their health as best they can, draw friends around them, and maybe even live longer. With the media so full of misleading statements about the 100% mortality with AIDS, it is crucial that we as health care providers support clients in their struggle to maintain hope. By doing so, we are not colluding in our patients' defenses; rather we are supporting something vital to the quality, and maybe even to the quantity, of their lives.

Jeffrey S. Mandel, PhD, MPH, is director of the UCSF Biopsychosocial AIDS Project, a collaborative group of social scientists, immunologists, and physicians who have been working together since 1982 on several research and educational projects. A primary focus of their work has been a longitudinal psychosocial study of persons with AIDS and AIDS-Related Conditions (ARC). Dr. Lydia Temoshok serves as principal investigator of the study, which is sponsored by the National Institute of Mental Health. This article presents material delivered at the UCSF Conference on AIDS: Policy, Administrative, and Clinical Issues of Mental Health, September 1985. For more information about research projects being conducted by the University of California San Francisco Biopsychosocial AIDS Project, contact Jeffrey S. Mandel, PhD, MPH; Project Director, Biopsychosocial AIDS Project, Box 6-B; Langley Porter Institute, 401 Parnassus, San Francisco, CA 94143.

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Diagnosis/Treatment

The Role of Psychiatry in AIDS

Samuel Tucker, MD

Central Nervous System (CNS) dysfunctions frequently complicate AIDS diagnoses. Many AIDS patients suffer from well-defined and often treatable focal lesions in the brain, such as those resulting from toxoplasmosis, cryptococcosis, or a lymphoma. More common is a generalized encephalopathy, which includes dementia as a prominent feature. The dementing process begins with impaired concentration and mild memory loss and progresses to severe global cognitive impairment. Physicians and researchers now recognize dementia in the absence of opportunistic infections as a primary presentation of AIDS. HTLV-3/LAV is known to be neurotropic and is believed to cause this progressive dementia. Anecdotal reports indicate that as many as 50 to 70% of the patients seen in consult

demonstrate certain aspects of dementia.

When clinicians provide a psychiatric consult for AIDS patients due to mental status changes, they must rapidly assess the cause of the process and must differentiate deliriums from depression or dementia. All three conditions have overlapping symptoms.

A delirium is usually of rapid onset, occurring from a few hours to a few days. Delirious patients usually show increased or decreased psychomotor activity, such as agitated pacing or rocking. Their sleep-wakefulness cycle may also be altered with more alertness and activity at night. Psychotic sensory-perceptual disturbances, such as auditory and visual hallucinations, are not uncommon. A clouded sensorium, which makes cognitive testing impossible, is a hallmark of a delirious state. Deliriums often have a traceable and treatable etiology. For example, severe bi-temporal headaches of incipient cryptococcal meningitis or drug toxicity from one or several combined medications may foster a state of delirium.

If consultants can rule out a treatable delirium or focal lesion, they should next differentiate between a functional depression and dementia as the reason for the mental status changes. The diagnosis of major depression in patients becomes clouded because many of the symptoms of depression may be the result of the patients' medical illnesses. Fatigue, weight loss, difficulty with sleeping, and anorexia are common symptoms for both AIDS and depression. To differentiate between depression and a medical etiology, consultants should emphasize cognitive and affective symptoms and minimize patients' somatic concerns.

Diagnostic criteria for depression include low self-esteem, feelings of failure, loss of interest in relationships, suicidal ideation, inability to concentrate, and frequent crying spells. A history of major depression, previous psychiatric treatment, or suicide attempts help distinguish a functional depression from dementia.

The unexplained onset of depression in AIDS patients who have otherwise been coping adequately may herald the onset of a central nervous system process such as dementia. Dementing illnesses have an insidious onset marked by a clear sensorium in the presence of measurable cognitive deficits, such as confusion, the inability to retain new information, and disorientation with short- and long-term memory deficits. These parameters hold true for the organicity seen in AIDS patients.

Case reports describe confused patients who lack interest in personal appearance and hygiene, and who display inappropriate behaviors in public. The spectrum of presentation varies from passive cooperation and total unconcern to temper tantrums, inappropriate disrobing, irritability, anxiety, paranoia, hostility, and delusional and psychotic thought processes. Serial EEGs may demonstrate diffuse slowing, and CAT scans may show cortical atrophy with ventricular enlargement. Psychiatric hospitals report that many of these patients have no previous AIDS diagnosis. Only serial cognitive assessments, abnormal EEGs, and CAT scans permit the eventual diagnosis of a dementing process due to AIDS.

Treatment Interventions

Treatment of delirium entails addressing the underlying etiology. Polypharmacy, the presence of street drugs or alcohol abuse, must be ruled out for clients to clear their sensorium. In some functionally psychotic, severely agitated, delirious or demented patients, neuroleptic medications may be necessary. Preferred treatments to clear these states are high potency, low anti-cholinergic medications (such as haloperidol at minimal doses) because they reduce agitation and eliminate psychotic ideation without the side effects of excess sedation, orthostatic hypotension, or lowering the seizure threshold.

However, avoiding medication with anti-cholinergic activity is recommended because these drugs tend to exacerbate disorientation, increase memory difficulties, and produce a toxic psychosis. Anti-cholinergic activity also dries oral secretions that help inhibit the growth of opportunistic infections such as

thrush. Benzodiazepines, such as Diazepam, should be avoided in delirious patients since these drugs can increase confusion by depressing higher cortical functions. The treatment of depression also entails the use of the least anti-cholinergic medications. Currently, the drugs most commonly used are alprazolam and nomifensine.

Other Treatment Factors

This discussion of medication is not meant to minimize the importance of various interpersonal therapy techniques, such as supportive, insight, cognitive, and behavioral models. These help patients cope with the extremely difficult process that they are undergoing. In addition, education to properly recognize and care for dementing patients gives staff the ability to contain such inpatients and their behaviors. In-service programs about intervention strategies with dementing patients are imperative for the nursing staff. These are particularly important on medical wards for nurses who may not be accustomed to working with patients who have behavioral problems linked to organic developments. Nurses frequently do not expect such difficulties in AIDS patients, especially those patients who are very young.

For outpatients, the over-all strategy is simply to keep clients as functionally autonomous as is medically responsible and feasible. During the early period of disease symptoms, patients may be allowed to go home and function adequately with minimal assistance depending on their levels of cognitive impairment and physical stamina. Day care programs for demented patients need to be developed as other options.

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As the dementing processes continue, patients may require a 24-hour caregiver. But this supervision can be an overwhelming burden to lovers, family, and friends who are willing to provide this needed care; respite programs must be created to alleviate periodically the emotional and physical burdens assumed by the caregivers. They need information about the disease, what to expect, and how to use community groups. Support groups for caregivers can be especially valuable for coping with emotional demands.

Public health and home visiting nurses should make regular functional assessments as the patients' conditions progress; they should pay special attention to clients' self-care capacity and their personal safety in the home. Nurses should determine whether patients can take their medications, buy food, cook meals, feed themselves, count money, drive a car, and follow through with any given task. Reality orientation devices, such as calendars, appointment books, posted emergency numbers, and signs that identify rooms and their functions, will help keep patients safely at home.

Current photographs of the patients are useful for identification in case patients wander and get lost in the neighborhood. Demented people are frequently paranoid and may also be suicidal. Weapons should be removed to prevent patients from accidentally hurting themselves or others.

In conclusion, the goals of these interventions are to maintain people at their highest levels of adaptive functioning and to maintain their autonomy, personal integrity, and independence while attempting to diagnose and treat AIDS patients for any psychological processes.

Samuel Tucker, MD is an Assistant Clinical Professor of Psychiatry at the University of California San Francisco.

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BRIEFS

IN REVIEW

AIDS: PSYCHOSOCIAL FACTORS IN THE ACQUIRED IMMUNE DEFICIENCY SYNDROME. Gail Henderson Baumgartner, AB, MSW. Charles C. Thomas, Publisher; Springfield, Illinois, 1985; 113 pages. Although this volume offers an extensive review of the literature on the psychosocial impact of AIDS, the 60 pages of findings are sometimes jumbled with unrelated information lumped together with little context provided. The author does present a helpful discussion of the challenges faced by gay men and others who must now cope with safe sex activities, fears of intimacy, and pressures to pursue relationships. Also beneficial is her look at the impact on the families and lovers of people diagnosed with AIDS. The author concludes her review with a recommendation that the social worker's expertise be better integrated into the interdisciplinary care of people with AIDS.

PSYCHIATRIC IMPLICATIONS OF ACQUIRED IMMUNE DEFICIENCY SYNDROME. Stuart E. Nichols, MD and David G. Ostrow, MD, PhD (eds.) American Psychiatric Press, Inc., Washington, D.C., 1984; 137 pages, softcover, \$12.00. These 13 essays touch briefly, and perhaps too lightly, upon concerns important to anyone involved in AIDS care, services, or education. Three essays offer further insights into the aspects of AIDS presented in this issue of FOCUS. Carol B. Britton, MD provides the reader with a basic review of neurologic complications resulting from several of the opportunistic infections that accompany an AIDS diagnosis. Marshall Forstein, MD considers the AIDS anxiety of the worried well and emphasizes the importance of patients' control over their health status. James W. Dilley, MD discusses how clinicians can adopt different interventions to meet three general levels of care required by people with AIDS who are referred for consultation.

"International Conference on Acquired Immunodeficiency Syndrome, April 14-17, 1985, Atlanta, Georgia" (proceedings), *Annals of Internal Medicine*, November 1985, Volume 103, Number 5. AIDS research developments have become so dynamic that lectures and papers delivered nine months ago seem ancient. Nevertheless, these proceedings from last year's important Atlanta conference offer valuable basic information on the epidemiology, virology, and immunology of AIDS as well as the clinical and psychosocial care of patients.

A copy of these conference papers is available from the Business Department, *Annals of Internal Medicine*, 4200 Pine Street, Philadelphia, PA 19104. A single copy is \$7.00. A reprint of the 400 poster presentations from the conference costs \$4.00. The journal advises that checks should be made payable to *Annals of Internal Medicine*.

RECENT REPORTS

Risk Reduction with Condom Use. The San Francisco AIDS Foundation announced last month that laboratory tests have shown condoms to be an effective block to the transmission of the AIDS virus. With a grant from the local AIDS organization, UCSF researchers Jay Levy, MD and Marcus Conant, MD tested five different, commercially available brands including both latex and natural membrane condoms. All five prevented a fluid containing a high concentration of the virus from penetrating the fine membranes of the condoms. Conant said he believes that condoms, when used properly and in conjunction with a spermicidal jelly, are safe "100% of the time." Conant advised that health care providers and AIDS educators must now inform the public about the correct use of condoms. The research data will be published in a medical journal.

AIDS Virus Missing From Saliva of Most AIDS Patients. The AIDS virus has been detected in the saliva of only one of 71 men infected with the disease, according to researchers from Massachusetts General Hospital (*New England Journal of Medicine*, October 31, 1985, page 1606). At the same time, 28 blood samples taken from 50 of the 71 men yielded HTLV-3/LAV. The researchers said their study also revealed that the concentration of the virus in the one saliva sample was substantially less than that found in the blood samples. The Boston scientists concluded, "These results may be useful in allaying public concern regarding the casual spread of AIDS and HTLV-3 infection."

HTLV-3/LAV Infection of the Brain. Two articles that recently appeared in *The New England Journal of Medicine* (December 12, 1985) provide new findings about the effect of the AIDS virus on the central nervous system. David D. Ho, MD and his colleagues confirmed that the AIDS virus is neurotropic as well as lymphotropic and that the virus can be recovered from the cerebrospinal fluid, brain, spinal cord, and peripheral nerve of patients with AIDS-related neurologic complications. Ho also found that several patients had neurological problems as a result of HTLV-3/LAV infection but did not have clinical manifestations of immunodeficiency. He advised that the patients' atypical neurological presentations "serve to remind us that HTLV-3 may cause central nervous system syndromes yet undefined."

The article by Lionel Resnick, MD and associates outlines their efforts to define the role of HTLV-3/LAV in the pathogenesis of AIDS encephalopathy. One important finding reveals that HTLV-3/LAV can duplicate in the brain without causing clinical neurologic disease. They concluded that AIDS virus infection of neurologic tissue does occur in the majority of patients with neurological abnormalities associated with AIDS or ARC.

The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. This newsletter represents an attempt to place much of the data and press reports in a context that will prove meaningful and useful to its readers. Suggestions and comments are welcome and encouraged. Please address correspondence to Editor, AIDS Health Project; 333 Valencia Street, 4th Floor; San Francisco, CA 94103. For information about other AIDS Health Project programs, call (415) 626-6637.

NEXT MONTH

The Centers for Disease Control specify an exact set of diseases and symptoms to fit the surveillance definition of AIDS. The current epidemiological framework for AIDS fails to monitor the much more prevalent set of illnesses and conditions grouped loosely together under the name of "AIDS Related Conditions" or "ARC." A general estimate indicates that there may be ten ARC cases for each diagnosis of AIDS. According to this rule-of-thumb guide, more than 150,000 people in the United States may have symptoms and illnesses that can be classified as ARC.

People with ARC present health care professionals with a vast array of needs, interests, and challenges. In the February issue of FOCUS, John Acevedo, MSW and William Vitiello, PhD, clinical social workers of the AIDS Health Project, will discuss the implications of ARC for health care providers, their patients, and their clients. In addition, the estimated prevalence of ARC in San Francisco and the projected impact of ARC on the health care system will be presented.