Understanding ARC: The Broader Spectrum of AIDS

John Acevedo, MSW

Recent studies of people at risk for AIDS reveal several individuals who have conditions related to the immune disorder that are not included within the definition of AIDS itself. Physicians and researchers have yet to agree on a universal definition or name for these conditions, and much uncertainty exists for patients, caregivers, and service providers. The term AIDS Related Conditions or ARC has gained some prevalence as a working description of this spectrum of infections and conditions, but what constitutes ARC is not well-defined.

Many of the conditions referred to as ARC are as disabling as, or sometimes even more disabling than, those associated with some stages of AIDS. However, many people encounter great difficulty in qualifying for and receiving insurance coverage, disability benefits, and social services. Moreover, the uncertainties that arise from this confusion often exacerbate patient reactions.

The purpose of this report is (1) to help clarify for the mental health professional what is meant by a diagnosis of ARC, (2) to heighten awareness of the perspective of the ARC client, (3) to review successful clinical strategies in working with this population, and (4) to highlight issues raised while working with these clients.

A Variety of Descriptions

A brief historical review provides a perspective for understanding ARC. As early as the summer of 1981, physicians documented evidence of an acquired immune deficiency found initially in the male homosexual population. One gay newspaper popularized the term Gay Related Immuno-Deficiency (GRID) (1). However, once epidemiologists identified additional at-risk populations, such as I.V. drug users, hemophiliacs, and Haitians, the term Acquired Immune Deficiency Syndrome (AIDS) was established (2).

Important parallels exist between the evolution of the AIDS definition and the recent attempts to describe ARC. In 1981 Donald Abrams, MD, observed an increased incidence of diffuse lymphadenopathy (swelling of lymph glands) among gay men. He began a prospective and longitudinal study of the natural history of the condition in these men, many of whom were first seen and referred by community physicians. Abrams’ work paralleled studies underway in New York City and Los Angeles.

In May 1982, the Centers for Disease Control (CDC) recognized persistent generalized lymphadenopathy as having epidemicologic similarities to those men who had Kaposi’s sarcoma and Pneumocystis carinii pneumonia. These studies indicated other accompanying clinical symptoms, including fatigue, fevers, night sweats, and unexplained weight loss. Abrams, now a researcher and assistant director of the AIDS clinic at San Francisco General Hospital, observed a broader range of symptoms among his lymphadenopathy patients. These symptoms included headaches, sinusitis, pharyngitis, thrush, diarrhea, perirectal complaints, and skin complaints, especially herpes simplex and herpes zoster, tinea, impetigo, and condylomata. In addition, Abrams and other physicians noted psychologic complaints of anxiety, depression, and reduced libido.

As the number of case reports of AIDS increased, the vast majority of patients gave histories of these non-specific symptoms. Many physicians suggested the symptoms were prodromal; that is, they believed the appearance of such markers would be followed by an AIDS diagnosis. However, labeling all such patients as having AIDS prodrome clearly carried prognostic implications for which there was little evidence. During this period, the term “pre-AIDS” was popularized by both the media and some members of the medical community. To clarify this issue, the concept of an AIDS-related complex was developed. Community groups use the generic term, AIDS-related conditions (ARC). This term provides the clinician with a global picture of any medical condition that indicates a suppressed immune system, a person at-risk for AIDS or with evidence of AIDS viral infection, that does not meet the case definition of AIDS, and that ranges in acuity from mild to severe.

“The identification of ARC patients may help prevent early complications and prolong survival, may enhance research, and may facilitate the provision of supportive therapies.”

While ARC surveillance data has not been collected, health officials estimate that for every person with AIDS, there are ten persons with ARC (3). Although preliminary data from the studies of lymphadenopathy by Abrams and others suggests that 10 to 25% of diagnosed cases of ARC will progress to AIDS, the lack of a universal definition makes it difficult to compare their data.

The uncertainties about the ARC definition remain unresolved, and the need for mandatory reporting of ARC continues to be unaddressed. Accurate information is difficult to obtain due to concerns about confidentiality. Mortality rates of ARC patients are unknown at present, but anecdotal reports abound of deaths prior to formal AIDS diagnoses. The identification of ARC patients may help prevent early complications and prolong survival, may enhance research, and may facilitate the provision of supportive therapies.

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The current situation intensifies the complex psychological reactions to an ARC diagnosis by both client and practitioner. Given the current lack of information, the mental health care provider's initial reaction might be one of helplessness. However, my experience suggests that client reactions parallel those of other people facing terminal illness.

Role of Psychosocial Intervention

A thorough psychosocial assessment is essential for anyone who presents for treatment of psychological reactions to an ARC diagnosis. Practitioners must address pre-existing psychiatric disorders before attempting other interventions. In addition to standard medical and psychotherapy histories, a history of sexually transmitted diseases (STDs) helps to clarify at-risk status. The practitioner should also obtain a thorough history of substance use. Clients often present with confusion and ambivalence about their diagnoses; history-taking allows for client self-definition of illness.

The scope of psychological reactions reported in the literature on death and dying provides a valuable context for understanding the reactions of ARC clients. Shock, denial, fear, anger, sadness, depression, and bargaining are the norms for them. Interspersed throughout these approaches, practitioners need to take a more active, educational role. Referrals to appropriate resource agencies, to medical journals, and to individuals in the community are helpful to some clients. Providers who only present a blank therapeutic screen may exacerbate problems and alienate the client.

Cognitive-behavioral approaches have been effective in teaching specific skills and techniques to manage stress, depression, anger, and fear resulting from the uncertainty of the illness. These approaches are especially effective for addressing feelings of helplessness, alienation, and decreased or damaged self-esteem. They also provide structure and context to an otherwise chaotic experience.

Models for Empowerment

Mental health practitioners have used the following models to help ARC clients cope with their situations: (1) the continuum of withholding and disclosure, (2) personal and sexual identity, and (3) the impact of thoughts and feelings. These models apply to both individual and group settings. A brief description of each follows.

(1) Withholding and Disclosure. Withholding has two aspects: protection and denial. Clients may withhold information either to protect themselves or others, or to deny that a problem exists. Disclosure can lead to intimacy and trust, or it can bring about increased vulnerability. This model provides an understanding for confronting feelings and reinforces clients’ skills developed from previous disclosures. Clients are encouraged to discuss parallels between “coming out” as a sexual person and coming out as a person with ARC. Exploring this continuum often elicits other issues, such as independence and dependence, autonomy and merging, the real and the non-real.

(2) Personal and Sexual Identity. Personal identity and sexual identity are not static in relation to each other; rather, they emerge and dissolve at different times. Personal identity includes all of one’s strengths and weaknesses. Conscious sexual identity is viewed on a developmental scale with changes from childhood to adulthood.

For many gay men, sexual identity has been limited to participating in sexual activities without exploring other dimensions related to being gay. The advent of AIDS and the necessity for sexual behavior changes confronted many men with an apparent identity crisis. This model acknowledges the experience of loss — death and loss of community, the loss of sexual activities, and the existential loss of identity — and encourages the client to become aware of deeper issues such as homophobia, love and lovers, death, and the meaning of life.

Problem-solving, behavior changes, and the development of new meanings are directions for the client to take when ready.

(3) Impact of Thoughts on Feelings. For our purposes, I have defined feelings as immediate emotional reactions, and thoughts as sentences people tell themselves. Negative, destructive, and unnecessary thoughts contribute to feeling out of control and to attitudes of hopelessness and helplessness. Cognitive techniques can be used to teach clients the skills needed to redirect thought patterns into more positive and constructive modes. These thoughts contribute to a sense of control, hope, and responsibility.

Implications for Providers

The practitioner working with an ARC client faces a number of counter-transference issues. The primary one is homophobia. Providers who retain even subtle biases against homosexuality are apt to harm clients by reinforcing negative self-concepts. Clinical supervision can help the provider explore personal attitudes toward a gay client’s basic concept of self-worth and sense of power and control. Personal values about who is entitled to power in our society need to be addressed not only when working with gay clients, but also with blacks, addicts, and women.

Confronting death elicits major power and control concerns for the provider, and practitioners can expect to confront their own issues of loss. Acknowledging the powerful feelings of helplessness and the tendency to collude with ill clients is one approach to help keep separate the practitioner’s feelings from the client’s issues. Suicide raises ethical considerations; and providers may experience a range of reactions similar to those reported by their clients. Professional support groups, supervision, and individual therapy can help address these feelings.

In summary, the issues associated with ARC are multifaceted and complex. A thorough psychosocial assessment can provide the practitioner with the information necessary to help ARC clients. Pre-existing psychiatric disorders should also be addressed. Practitioners can employ both individual and group models to assist clients with their responses to ARC, for developing appropriate coping skills, and for changing at-risk behaviors. Providers should appreciate how different sexual identities, personalities, and ethnic and cultural influences may affect the individual response to ARC. The general goals of treatment include helping clients to recognize the control they can exercise over their lives, to develop strong, positive, and realistic senses of self; to deal with anger, anxiety, and loss; and to strengthen their support systems.

John Acevedo is a clinical social worker on the staff of the AIDS Health Project.

REFERENCES:


Diagnosis/Treatment

A Working Definition of ARC

To define AIDS Related Conditions or ARC is no simple task. A complete definition for these symptoms and conditions has eluded us for nearly four years, and researchers see no sign that the confusion will end in the near future. Ultimately, surveillance guidelines and a medical description of ARC must be formalized by federal health officials. In the interim, both researchers and physicians in private practice seek to develop a working definition to help them interpret the results of clinical studies and to follow more accurately the course of these conditions.

To help the practicing clinician make better sense of the uncertainties surrounding the medical diagnosis of ARC, FOCUS
A Proposed Definition of ARC

**REQUIREMENTS:** Clinical—Two major findings, or One major and Two or more minor findings, PLUS

Immunologic — One or more findings, PLUS

Other Laboratory — Two or more findings.

**CLINICAL**

<table>
<thead>
<tr>
<th>Major</th>
<th>Minor</th>
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<tr>
<td>Lymphadenopathy—nodes = or &gt; 1 cm. at 2 or more extragenital sites for at least 6 months</td>
<td>Night sweats for 3 months or more</td>
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<td>Oral thrush</td>
<td>Fatigue</td>
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<tr>
<td>Hairy Leukoplakia (white, corrugated oral lesions)</td>
<td>Pruritis (itching) for 1 month or more</td>
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<tr>
<td>Herpes zoster (shingles) under age 60</td>
<td>Extensive seborrheic dermatitis or eczema</td>
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<tr>
<td>Fever for 3 months or more</td>
<td>Refractory dermatophytosis (skin fungal infection not responsive to treatment)</td>
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<td>Weight loss of 10% or more of body weight or 15 or more lbs.</td>
<td>Bullous impetigo (bacterial skin infection)</td>
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<tr>
<td>Central or peripheral neurologic deficit</td>
<td>Extensive molluscum contagiosum (skin infection, small blisters)</td>
</tr>
<tr>
<td>Diarrhea for 3 months or more</td>
<td>Unexplained persistent sinussitis (sinus infection)</td>
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*Most symptoms may be intermittent or continuous for the period and must occur in the absence of any identifiable cause.

**IMMUNOLOGIC**

- Helper T-cell count under 400/cubic mm.
- Helper/Suppressor ratio of less than 1.0

**OTHER LABORATORY**

- HTLV-3 antibody positive
- HTLV-3 virus culture positive
- Leukopenia (abnormal decrease of white blood corpuscles) (<4000/cubic mm.)
- Lymphopenia (deficiency of lymphocytes in the blood) (< 1000/cubic mm.)
- Anemia (hematocrit 35 or <)
- Thrombocytopenia (abnormal decrease in number of blood platelets) (<100,000/cubic mm.)
- Serum globulins (proteins in the blood, associated with antibodies) 3.5 g/dl or >
- Sedimentation rate (a non-specific indicator of inflammation) 20 or >
- Serum cholesterol <135 mg

Individuals who want more information about the BAPHR definition can contact the organization at Box 14546, San Francisco, CA 94114 or call (415) 558-9353. Reprints of the Gottlieb classifications can be obtained from Dr. Harry W. Haverkos, Building 31, Room 7A49, National Institutes of Health, Bethesda, MD 20205.

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REFERENCES

BRIEFS
IN REVIEW

AIDS IN THE MIND OF AMERICA: The Social, Political, and Psychological Impact of a New Epidemic. Dennis Altman. Anchor Press, Doubleday; Garden City, NY. 1986; 228 pages. $16.95. Political scientist and author Dennis Altman provides the first comprehensive and authoritative analysis of the full impact of AIDS on the very fabric of American life. As an Australian who travelled extensively throughout this country to research this book, Altman brings an outsider's view to the unique American response to an epidemic so intertwined with sexuality, politics, and morality. Altman displays once gain his special ability to analyze events objectively while he also acknowledges his own strong feelings about the matter. This volume offers a particularly insightful analysis of the impact of AIDS on the gay and lesbian community, its aspirations, its fears, and its future. San Francisco readers can appreciate seeing the local experience placed in a larger comparative context.

RECENT REPORTS

AIDS Impact on Public Policy. Few institutions in this country remain untouched by the AIDS epidemic. Not only government, hospital, and school officials but also owners of restaurants, realty firms, and airlines have been pressed to develop polices related to AIDS. Speakers at last month's AIDS and Public Policy forum in New York City emphasized that state and federal governments must assume more responsibility in AIDS public policy issues. "There is no more pressing an issue for the government to face than AIDS public policy," Philip R. Lee, MD, director of the UC San Francisco Institute for Health Policy Studies and President of the city's Health Commission, advised the audience of hospital administrators and health officials. Lee emphasized that the most pressing issue is health care financing. Under the current "hodgepodge of financing mechanisms," Lee suggested that New York, San Francisco, and other cities will soon be hard-pressed to meet AIDS expenses. One positive development, he said, was the example set by people with AIDS and the thousands of volunteers across the country who work in AIDS programs. "They represent a birth of the concept of our community responsibilities as citizens." The two-day forum was co-sponsored by the UC San Francisco institute and the United Hospital Fund, an influential organization involved in public policy issues in New York.

Hospital Workers' Psychosocial Responses to AIDS. Researchers at New England Deaconess Hospital in Boston recently interviewed 237 professional and technical hospital employees to determine their feelings about their contact with AIDS patients. The study focused on health care workers at the major AIDS patient care facility in the state. At the time of the study, the hospital had admitted approximately 60 AIDS patients, nearly one third of all the cases in the state.

The researchers collected data on five dimensions of hospital staff responses: (1) the frequency and nature of contact with AIDS patients, their families, and friends; (2) their source of information about AIDS; (3) the accuracy of workers' knowledge about AIDS; (4) attitudes about AIDS and homosexuality; and (5) the workers' personal difficulties and stresses resulting from their contact with AIDS.

Led by Carl R. O'Donnell, ScD, MPH, the researchers found that technical workers had the most frequent contact with AIDS patients but that little social and emotional interaction occurred. The quality of contact appeared to be a primary determinant for levels of job stress, satisfaction, and fear of AIDS. Approximately 60% of the participants felt they had sufficient knowledge to deal with AIDS patients' physical needs, but only 42% felt equipped to cope with the emotional needs of patients, their families and friends. This factor caused considerable dissatisfaction for respondents in all job classifications.

A third of the respondents felt they did not have enough information about infection control measures.

More than half of the workers reported that AIDS makes their job a "high risk occupation", and 42% agreed that hospital workers should not be required to work with AIDS patients. Although a majority said they had thought more about homosexuality as a result of AIDS, the percentage who reported feeling more tolerant as a result is equaled by those who became less tolerant.

Three-quarters of the respondents felt that a special unit for AIDS patients would provide them with better care and would assure more stringent infection control, but only a minority (11%) said they would be willing to work in such a unit. The workers most often reported stress related to a sense of loss of control over their environment. Inconclusive information about AIDS, inconsistently followed hospital procedures, lack of acknowledgement for the increased emotional workload from AIDS care, and lack of information and sensitivity to issues of homosexuality and drug use contributed to the staff's discomfort.

The researchers concluded that hospitals must implement not only AIDS educational programs but also special support programs for the staff during regular working hours. Reprint requests can be addressed to: Carl O'Donnell, ScD, MPH; Pulmonary Laboratory, New England Deaconess Hospital; 185 Pilgrim Road; Boston, MA 02215.

The amount of research information now appearing in the medical and lay press staggerst 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

Treatments, vaccines, and cures are the watchwords of hope for everyone touched by the AIDS epidemic. And yet the frequent announcements of potential new treatments begin to blur with the many AIDS stories in the media every week.

In the March issue of FOCUS John Ziegler, MD, UCSF professor of medicine and associate chief of staff for education at the Veterans Administration Medical Center, will provide an overview of the spectrum of AIDS treatments now being used by researchers. Ziegler, who is also involved in a number of AIDS research studies, will consider the potential for existing and new anti-viral drugs, the role of immunomodulators, and the treatment implications of the autoimmune responses linked to AIDS.

In addition, Deborah Hahn and Roberta Wong, PharmD, will address the frequently asked questions about clinical drug trials in San Francisco. Which drugs are being tested? What are the results and side effects? How does a person enter, or leave, a drug trial program? How are specific drugs chosen for testing?

Both Hahn and Wong are involved in the AIDS program at San Francisco General Hospital. Hahn is the clinical trials coordinator and Wong is a clinical research pharmacist.