

AIDS: WOMEN AT RISK!

Little attention has been given to the increasing population of women exposed to the HTLV-III virus. The authors identify the unique issues facing these women who are high risk for AIDS and suggest strategies for improving service delivery.

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Categories: 14, 22 & 11.

AIDS: WOMEN AT RISK!

People with life threatening or degenerative disease face common threats to physical and psychological well-being. An individual with Acquired Immune Deficiency Syndrome has an additional, unique constellation of problems never before encountered by social workers. To facilitate the audience's full appreciation of the psychological impact of AIDS, the presenters will first review the disease process and definition. Content for this section will include reactive HTLV-III exposure, AIDS-Related Complex (ARC), and the Center for Disease Control's (CDC) case definition for AIDS.

Little or no information exists regarding the risks and issues that women face. Women are at risk when they fall into one of the following five categories: those who have received contaminated blood through transfusion, intervenous drug users and sexual partners of drug users, hemophiliacs, or gay/bisexual men. The authors will focus on the last group as they represent the largest population at risk.

A diagrammatical conceptualization will be presented which organizes women's specific concerns along five axes: psychological issues for women-at-risk, unit of intimacy, family/significant others, cultural reference groups, and community. Case examples will illustrate the problems which arise along the continuum of the disease process. Issues will include ambiguity of diagnosis, safe sex precautions, disclosure, procreation options, social stigma, and adjustment to terminal prognosis. The following questions

will be among those addressed:

Why did I have a gay/bisexual lover?

How could I have not known that I was putting myself at risk?

Why didn't he tell me he had had gay sex?

How do I know if I have AIDS?

Should I have a special medical examination and where?

How will people view me?

How do I tell friends and family?

Will people abandon me?

Can I be sexually active now?

Can I have children and what is their risk?

What's going to happen to me?

Social Workers must take a leading role in assisting this growing, vulnerable population. To do so requires an investment on two fronts: self awareness and mobilization of resources. Examining one's homophobia is necessary in order to recognize and ameliorate the often subtle obstacles we encounter or create in serving these clients. There are additional feelings that workers must confront including fear of contagion, moral or religious dilemmas, and stigma of being identified as an advocate for AIDS victims.

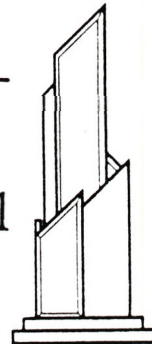
Across social work fields of practice, the authors will highlight generic intervention strategies and make specific recommendations. Based on the authors' current experiences, they will address counseling issues, educational programs with psychosocial content, and program development needs for those at risk, their significant others, and service providers. The

presentation will conclude with a question and answer period to assist participants in applying the content to their own practice arenas.

The APLA and the
Executive Board of the
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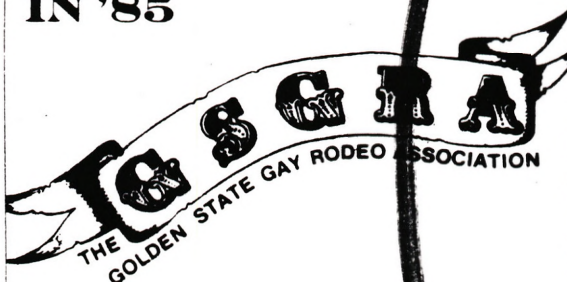


**Dignity Presents
"GAYS/LESBIANS IN
THEATRE AND FILM"**

DIGNITY/Los Angeles, a community for gay and lesbian Catholics, their families and friends, will have as its special guest speaker Jesse Jacobs, long-time dramatic performer and teacher, for the general membership meeting of Saturday, January 18, at 7:30 p.m. at the LACC Newman Center, 4665 Willowbrook, Ave., L.A. As a veteran of both on- and off-Broadway productions, as well as TV and motion pictures, Jesse Jacobs will bring his extensive expertise to *DIGNITY* to speak on the role of gays and lesbians in theatre and in film. He will specifically address the way gays are treated as members of a story, and how their gay image might fit into the context of the entire work. Having appeared in TV productions as diverse as *Davey Crockett* and *Knots Landing*, Jesse is sure to bring along many interesting anecdotes of the entertainment world to share with everyone.

The evening will begin at 7:30 p.m. with a potluck supper, and all attending are asked to bring an entree or dessert item to feed 400 people. All are welcome, and there is no

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**AIDS BENEFIT CONCERT
MOVED FROM L.A.**

The producers of *MUSICTHON 86*, the All Star Aid for AIDS Concert, announced at the end of December that they have decided to move the March 22, 1986 event from the Los Angeles Coliseum to Tampa Stadium in Tampa, Florida for the same date.

According to a spokesman for RJO entertainment, the production company promoting the concert, "We have decided to move the concert to Tampa for a number of reasons, primarily the excellent weather conditions in Florida in March, the technical capabilities of Tampa Stadium, and the hospitality of the State of Florida and the City of Tampa."

The benefit will be similar to the recent "Live Aid" and "Farm Aid" concerts with six hours of live musical entertainment to be broadcast worldwide via satellite and on a major cable channel, a network station, syndicated television, and radio. The concert will be aired simultaneously with a national telethon to raise funds for the International AIDS Foundation. The IAF was established to raise and distribute funds to various AIDS research, treatment and support organizations throughout the country in an effort to improve current services for persons with AIDS, to educate the general public about the disease, and to increase research efforts.

Classification system for manifestations of HTLV-III/LAV infection

INTRODUCTION: A classification system for HTLV-III/LAV infection will need to serve a variety of purposes. Uses include disease surveillance and reporting, epidemiologic analyses, clinical assessment of patients, and research studies. Other applications of a classification system are for disease recording systems (such as ICD-9) and health-care financing. These various purposes have different requirements and premises. Some may require a simple classification with limited categorization, while others demand a greater amount of detail regarding specific manifestations of disease. A single classification scheme satisfying all needs is therefore difficult to achieve. The proposed classification system below has been developed with four major categories, each having several potential subdivisions (Table 1). The appropriate classification is determined by the nature of the data available and the purpose to which the classification will be applied.

Patients are classified into one of four major categories, designated by Roman numerals I-IV. These categories, which are not necessarily mutually exclusive, correspond to: asymptomatic infection or early, self-limited "acute" disease (category I); persistent symptomatic infection (category II); "advanced" or "severe" disease without diagnosed opportunistic infection or cancer (category III); and disease manifested by diagnosed opportunistic infection or cancer (category IV).

Within each of these four categories, patients are further subclassified into one of three subgroups depending on laboratory tests of immune status. Assignment to these subgroups is designated by the numbers 0, 1, or 2, placed immediately after the Roman numeral (Table 1). Patients with laboratory findings of immunodeficiency, attributable to HTLV-III/LAV infection in the absence of other diagnoses to explain the findings, are designated as subgroup 2. Patients whose test results are not considered indicative of immunodeficiency are classified as subgroup 1. Patients whose immune status has not been evaluated by laboratory studies are assigned to subgroup 0.

Patients are then further subcategorized by the nature of their clinical presentation (Table 1). Assignment to clinical subcategories is designated by the alphabetic characters "A", "B", or "C" (Table 1). These letters acquire different meanings in different categories: In category IV, "A" represents immunodeficiency manifested by infections, and "B" is immunodeficiency manifested by cancer. In category III, "A" designates central nervous system disease, and "B" is severe constitutional disease. In category II, "A" is generalized lymphadenopathy, and "B" is autoimmune and/or immune complex disease, and "C" is chronic or persistent disease manifested by other signs and symptoms. In category I, "A" represents early retroviral syndromes, and "B" is latent infection.

CLASSIFICATION SYSTEM: For clarity, the classification system is presented in descending order starting with Category IV (immunodeficiency disease):

Category IV. Immunodeficiency disease: This category includes patients with clinical evidence of immunodeficiency not wholly attributable to other causes. This evidence includes: 1) the presence of an infection or cancer, the diagnosis of which is suggestive of underlying immunodeficiency, or 2) the presence of an infection or cancer, the presentation or course of which is clinically suggestive of underlying immunodeficiency.

Subgroups based on laboratory tests of immune status. Patients are classified are IV-0 (immunologic laboratory tests not done), IV-1 (immunologic laboratory tests not indicative of immunodeficiency) or IV-2 (immunologic laboratory tests consistent with immunodeficiency).

Subcategory A.* Immunodeficiency disease manifested by the diagnosis or presentation of an infectious disease.

Includes patients with infectious diseases, when the diagnosis or the clinical presentation of the infection is indicative of an underlying immunodeficiency, attributable at least in part to HTLV-III/LAV infection.

Subcategory B.* Immunodeficiency disease manifested by the diagnosis or presentation of a malignancy.

Includes patients with malignant diseases, when the diagnosis or the clinical presentation of the malignancy is indicative of an underlying immunodeficiency, attributable at least in part to HTLV-III/LAV infection.

Overall classification: Patients may be classified as category IV-0(A &/or B), category IV-1(A &/or B), or category IV-2(A &/or B) depending on clinical and laboratory assessment.

* Subcategories of Category IV are not mutually exclusive; e.g, a patient might have Kaposi's sarcoma and Pneumocystis carinii pneumonia.

Category III. Chronic, severe HTLV-III/LAV disease not manifested by clinical immunodeficiency.

Subgroups based on laboratory tests of immune status. Patients are classified are III-0 (immunologic laboratory tests not done), III-1 (immunologic laboratory tests not indicative of immunodeficiency) or III-2 (immunologic laboratory tests consistent with immunodeficiency).

Subcategory A.* Central nervous system disease.

Includes patients with encephalopathy or myelopathy attributable to HTLV-III/LAV infection, in the absence of coexisting infection or malignancy or other diagnoses to explain the findings.

Subcategory B.* Severe constitutional disease.

Defined as fever $>38.5^{\circ}\text{C}$ for >1 month, or involuntary weight loss ($>10\%$ baseline), or diarrhea of unknown etiology for >1 month, attributable to HTLV-III/LAV infection, in the absence of infection, cancer or other diagnoses to explain the findings.

Overall classification: Patients may be classified as category III-0(A &/or B), category III-1(A &/or B), or category III-2(A &/or B) depending on clinical and laboratory assessment.

* Subcategories of Category III are not mutually exclusive; e.g., a patient might have encephalopathy and severe constitutional disease.

Category II. Chronic HTLV-III/LAV disease includes patients whose findings are not attributable to other infections or to malignant diseases and do not meet the criteria for category III.

Subgroups based on laboratory tests of immune status. Patients are classified as II-0 (immunologic laboratory tests not done), II-1 (immunologic laboratory tests not indicative of immunodeficiency) or II-2 (immunologic laboratory tests consistent with immunodeficiency).

Subcategory A.* Generalized lymphadenopathy.

Includes patients with lymph node enlargement at 2 or more extra-inguinal sites for greater than 3 months, in the absence of other diagnoses to explain the findings.

Subcategory B.* Autoimmune or immune complex disease.

Includes patients with findings of autoimmune or immune complex disease attributable to HTLV-III/LAV infection, in the absence of other diagnoses to explain the findings.

Subcategory C.* Other findings consistent with chronic or persistent HTLV-III/LAV infection.

Includes patients with other persistent or recurrent signs and symptoms attributable to HTLV-III/LAV infection, in the absence of other diagnoses to explain the findings.

Overall classification: Patients may be classified as category II-0(A &/or B &/or C), category III-1(A &/or B &/or C), or category III-2(A &/or B &/or C) depending on clinical and laboratory assessment.

* Subcategories of Category II are not mutually exclusive; e.g., a patient might have generalized lymphadenopathy, immune complex disease, and other symptoms.

Category I. Early HTLV-III/LAV infection.

Subgroups based on laboratory tests of immune status. Patients are classified as II-0 (immunologic laboratory tests not done), II-1 (immunologic laboratory tests not indicative of immunodeficiency) or II-2 (immunologic laboratory tests consistent with immunodeficiency).

Subcategory A.* Acute retroviral syndrome.

Includes patients with self-limited signs and symptoms (e.g., aseptic meningitis, mononucleosis-like syndrome) attributable to recent HTLV-III/LAV infection, in the absence of other diagnoses to explain the findings.

Subcategory B.* Latent disease.

Includes patients with serologic or virologic evidence of persistent HTLV-III/LAV infection in the absence of clinical manifestations.

Overall classification: Patients may be classified as category I-0(A or B), category I-1(A or B), or category I-2(A or B) depending on clinical and laboratory assessment.

* Subcategories of Category I are mutually exclusive.

DISCUSSION: The proposed classification system presented in this document includes some elements of the other classification systems previously published (1,2). The development of a unified classification system will require extensive review and discussion within the scientific community, not only to ensure the appropriateness of the classification system but to ascertain its applicability to various purposes.

Several difficult issues related to classification in general need to be resolved. In addition, the classification system presented in this report contains some problems inherent in its attempt to be applicable in diverse settings. Among the issues we hope you will address are:

- 1) What is the proper role of serologic testing in assessing patients for the purpose of classification? What serologic tests should be used?
- 2) To what extent can the classification be a staging system, accurately representative of severity of illness, and to what extent should it try to make distinctions between the many different manifestations of HTLV-III/LAV infection?
- 3) Will a classification system which is accurate for staging disease and which distinguishes between many disease manifestations be too complex for widespread application?
- 4) What nomenclature should be used to refer to the different disease manifestations and syndromes? How should the terms "AIDS" or "AIDS-related complex" be applied to the classification system?
- 5) Which "opportunistic" infections and cancers, if any, should be specifically included in the classification system as evidence of clinical immunodeficiency? What criteria should be used to determine which infections and cancers are included? Should categorization of patients with those diagnoses be based on the specificity of association of the infection or cancer with HTLV-III/LAV infection or should it be based on the predictive value that the infection or cancer has for assessing the degree of immunosuppression and, presumptively, the patient's prognosis?
- 6) What is the appropriate role of immunologic testing in classification? If immunologic testing is included in the classification, what parameters should be used?
- 7) Is the classification system applicable both to children and adults?

Because our current level of knowledge regarding the clinical course of infection with the etiologic retrovirus of AIDS is incomplete, any classification formulated at this time will undoubtedly be only an interim system, useful as a framework for development of a more accurate classification. When an interim classification system is introduced, a mechanism for assessing and revising the classification criteria could be instituted by applying the classification system to long-term studies of patients with HTLV-III/LAV infection. The results of these studies could be used to redesign the classification system in the future.

REFERENCES

1. Haverkos HW, Gottlieb MS, Killen JY, Edelman R. Classification system for HTLV-III/LAV infection. *J Infect Dis* 1985;152:1095.
2. Redfield RR, Wright DC, Tremont EC. The Walter Reed staging classification for HTLV-III/LAV infection. *N Engl J Med* 1986;314:131-32.

Table 1
Relationship of disease categories
in the classification system, by level

	<u>Subgroups based on immune status</u>	<u>Subcategories based on clinical assessment</u>
Category I	I-0	I-0 (A or B)
	I-1	I-1 (A or B) ✓
	I-2	I-2 (A or B)
Category II	II-0	II-0 (A, B &/or C)
	II-1	II-1 (A, B &/or C)
	II-2	II-2 (A, B &/or C)
Category III	III-0	III-0 (A &/or B)
	III-1	III-1 (A &/or B)
	III-2	III-2 (A &/or B)
Category IV	IV-0	IV-0 (A &/or B)
	IV-1	IV-1 (A &/or B)
	IV-2	IV-2 (A &/or B)

* Subcategories of Categories II-IV are not mutually exclusive.

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DEPARTMENT OF CLINICAL SOCIAL WORK
UCLA HOSPITAL AND CLINICS
THE CENTER FOR THE HEALTH SCIENCES
LOS ANGELES, CALIFORNIA 90024

Dear UCLA Patient:

I am the Clinical Social Worker assigned to the immunology patients here at UCLA. My services are available to you, should you wish to discuss any questions or concerns.

Enclosed you will find some information about Acquired Immune Deficiency Syndrome (AIDS), your care at UCLA, and community programs that you may find helpful. Some of this information, however, may not relate to your specific situation.

If you have any questions about this material, or if you would like to discuss any other concern, please feel free to call me. I may be reached at (213) 825-5921 or (213) 825-7171, Monday through Friday from 8:00 A.M. til 5:00 P.M.

Sincerely,

Steve Buckingham

Steve Buckingham, MSSW
Clinical Social Worker

SB:mja

AIDS SOUTHWEST REGION

CALIFORNIA

AID for AIDS	(213) 461-6959	7985 Santa Monica Blvd., Suite 109-171 W. Hollywood, CA 90046
AIDS PROJECT/ LOS ANGELES	Hotline: (213) 871-1284 (213) 871-AIDS (800) 922-AIDS	937 North Cole Ave., Suite 3 Los Angeles, CA 90038
GAY/LESBIAN COMMUNITY SERVICES CENTER	(213) 464-7400	1213 N. Highland Ave., Los Angeles, CA 90038
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SHANTI FOUNDATION LOS ANGELES	(213) 874-2030	8568 Santa Monica Blvd. W. Hollywood, CA 90069
TRI-COUNTY AIDS PROJECT	(805) 967-2311 ext. 455	300 N. San Antonio Road Santa Barbara, CA 93110

TAKING CARE OF YOURSELF AFTER DISCHARGE FROM THE HOSPITAL

Larry Eppolito, R.N., P.A.C.
UCLA AIDS Clinical Research Center

The following are recommendations for precautions to be taken by you and other people.

1. Avoid intimate contact with individuals who have flu, colds or other know communicable diseases.
2. Sex. The decision to have sex with a regular partner involves a decision between you and your partner. The assumption is that you may be infectious (for AIDS) at this time. You should consider this fact. If you and your partner decide to continue with sexual relations the use of condoms is recommended. Consider alternate forms of activity that meet your needs for sex or intimacy that do not allow for the exchange of secretions. It is strongly recommended that you limit your sexual activity to one regular person whom you have informed that you have AIDS and that he also limits sexual activity. This is also a protection for you, since his exposure to multiple partners would increase the risk of infection for you.
3. Be sure your doctor knows that you have immune deficiency before accepting any kind of vaccination. Many vaccines have "attenuated" (living but altered) viruses which will not harm people with normal immune capabilities but which might be a problem for those with immune deficiency.
4. Avoid travel through areas of the world where communicable diseases are known to be more common.

5. Be sure that all meats, poultry and fish are well cooked.
 6. Avoid exposure to animal wastes, particles of which may be present in very dusty environments. Take extra precautions when handling the wastes of household pets, especially cats.
 7. Avoid the casual use of antibiotics. Take them only when your doctor (who understands that you have immune deficiency) directs you to do so.
 8. Eat a balanced diet with a full measure of vitamins, minerals, proteins and calories.
 9. Drink extra fluids, either juices or flavored beverages with the exception of alcohol.
 10. Avoid recreational drug use until more information is known about their possible contributions to immune deficiency.
 11. Avoid using shared toothbrushes and razors. As these procedures frequently involve small amounts of bleeding it is possible that blood on these objects may transmit possible infection.
 12. Advise your dentist that you have AIDS.
 13. If your doctor has told you that your platelet count is low avoid using aspirin which may aggravate bleeding tendencies.
 14. Avoid the sun.
 15. Do not donate blood.
 16. Reduce stress ... difficult for everyone, but it is a skill that can be learned just as any other. Stress have a profound effect on the ability of your body to heal itself.
- If you have other questions bring them to your next scheduled appointment.

If you have concerns about new symptoms - fever, shortness of breath, increasing cough, if you are on Bactrim report any rash - call 825-9412 and leave a message during daytime hours. In an emergency call 825-3718 during daytime hours. For a medical emergency during nighttime hours call 825-6301 and ask for the Clinical Immunology/Allergy fellow on call.

If you are a Kaposi's patient being followed at the Kaposi's Clinic by Dr. Mitsuyasu or Dr. Jacobs during the daytime and for a medical emergency after hours call 825-6301.

INFECTION PRECAUTIONS FOR PEOPLE WITH A.I.D.S.

LIVING IN THE COMMUNITY

Grace Lusby, MS, RN
Infection Control Coordinator, San Francisco General Hospital

Helen Schietinger, MA, RN
Director, Shanti AIDS Residence Program

San Francisco General Hospital Medical Special Care Unit and
San Francisco Bay Area Association for Practitioners of
Infection Control AIDS Resource Group

People with diagnosed AIDS who are able to care for themselves at home can safely live with both healthy individuals who do not have AIDS or with other persons with AIDS. Certain common sense hygienic measures protect both the person with AIDS as well as their housemates.

1. Care should be taken to not share body secretions, particularly blood or semen. In order for body secretions to be shared, there must be a point of entry into another person's body. Preventing this transfer of body secretions while still maintaining one's sexuality requires foresight and common sense. Risk reduction counseling for those who wish to remain sexually active is available through the San Francisco AIDS Foundation (San Francisco 864-4376) or Shanti Project (San Francisco 558-9644). This is important both to prevent possible transmission of AIDS to others and also to prevent acquiring other infections which may not be well tolerated by the person with AIDS.

There is no reason why persons with AIDS should not continue to have the usual casual social contacts with people that they have had in the past.

2. Maintaining a state of personal cleanliness is helpful to both the person with AIDS and others. This includes bathing regularly, washing hands after the use of bathroom facilities or contact with one's own body fluids such as semen, mucus, or blood, and washing hands before preparing food.
3. Kitchen and bathroom facilities may be shared with others. Normal sanitary practices in any household will prevent the growth of fungi and bacteria that may potentially cause illness to both immunocompromised and immunocompetent people. These include:
 - a. Clean kitchen counters with scouring powder to remove food particles. Sponges used to clean in the kitchen where food is prepared should NOT be the same sponges used to clean up bathroom type spills. Dirty looking

sponges should not be used to wash dishes or clean food preparation areas.

- b. Clean inside of refrigerator with soap and water to control molds.
- c. Mop kitchen floor at least once a week and clean up spills as they occur.
- d. Mop bathroom floor at least weekly and clean up spills. Bleach 1:10 strength (1 part to 9 parts water) can be used to disinfect floor and shower floor (athletes foot is caused by a fungus which bleach will kill). 1:10 bleach can also be used in the sink. A little full strength bleach can be poured into the toilet bowl for disinfection. Any spills of body fluids or waste (blood, urine, stool, vomitus, etc.) should be cleaned up first and then the surface disinfected with 1:10 bleach.
- e. Sponges used to clean the floor or any body fluid spills SHOULD NOT BE USED TO WAS DISHES OR CLEAN FOOD PREPARATION AREAS. Mop water should NOT be poured down sink where food is prepared. Sponges used to clean up spills should not be washed out at sinks where food preparations occur. Sponges and mops can be disinfected by soaking in 1:10 bleach for 5 minutes (longer may disintegrate sponge).

People with AIDS who are able to handle their own body secretions and excretions are able to live at home without any special precautions. Those listed above are considered good hygiene for any household.

- 4. Dishes may be shared with others provided they are washed in HOT soapy water hot enough to require gloves. A disinfectant does not need to be used.
- 5. People with AIDS can safely cook for others provided they wash their hands before beginning. It's also a good idea to not lick the fingers or taste from the mixing spoon while cooking. (Advice for everyone)
- 6. Since unpasteurized milk and milk products have been associated with Salmonella infections in the past, these should not be included in the diet. Salmonella infections are not well tolerated by people with AIDS.
- 7. If organically grown food is used (composted with human or animal feces), food should be cooked or be fruits that can be peeled. "Organic" lettuce is not safe.
- 8. Towels and wash cloths should not be shared without laundering in between people. Toothbrushes, razors, enema equipment and sexual toys should not be shared.
- 9. Trash disposal should be the same as for any household. Body wastes are flushed down the toilet. Other trash may be adequately handled by normal means (weekly trash pickups from cans lined with a plastic bag and a tight fitting lid

to keep out rodents). In the event of large amounts of sputum, wound drainage, etc. on kleenex or dressings, it is a good idea to collect them in a lined trash can in the house.

10. Pets - gloves should be used when cleaning cat litter boxes (Toxoplasmosis). Tropical fish tanks may contain organisms in the Mycobacterium family which are not well tolerated by persons with AIDS. Get someone else to clean your tank.
11. Keep living quarters well ventilated. Airborne diseases are less likely to be a problem when diluted by lots of air.
12. Persons with AIDS who are coughing should cover their mouths with tissues or handkerchiefs.
13. Persons with AIDS living together can do so safely by observing the same common sense hygiene practices discussed above. The opportunistic infections acquired by persons with AIDS are caused by organisms commonly found in the environment. The risk of becoming sick from one of these infections is based on the amount of immune system impairment, not on casual household contact.

8/24/83 revised 2/7/84

AIDS PROJECT LOS ANGELES

APLA is a non-profit organization serving the greater Los Angeles area whose services are provided primarily through the efforts of volunteers

AIDS – Acquired Immune Deficiency Syndrome

SUPPORT SERVICES

Home Health Assistance
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Legal and Financial Counseling
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AIDS-RELATED TERMS

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) An acquired defect in immune system function which reduces the affected person's resistance to certain types of infections and cancers. Although the cause is unknown for certain, it is thought to be a virus which is transmitted through sexual contact or exposure to infected blood. AIDS has been termed the number one health problem in the United States by the U.S. Public Health Service.

Once immune deficient, a person with AIDS becomes susceptible to a number of opportunistic diseases.

CANDIDIASIS A yeast-like infection caused by *Candida albicans* which affects mucous membranes, skin, and internal organs. Oral infections are called thrush and exhibit creamy white patches of exudate or inflamed and painful mucosa. Common sites are the nailbeds, axilla, umbilicus, around the anus, the esophagus, and the vaginal area. It may occur systemically and affect the heart and the meninges. This infection has become a standard problem seen in immune depressed people.

CRYPTOCOCCOSIS An infectious disease being seen in AIDS patients which is acquired via the respiratory tract with a primary focus in the lungs and which characteristically spreads to the meninges, but which may also spread to the kidneys and skin. It is due to the fungus *Cryptococcus neoformans*. Meningitis with headache, blurred vision, confusion, depression, agitation, or inappropriate speech is the most common form. It may be fatal.

CRYPTOSPORIDIOSIS An infection caused by a protozoan parasite found in the intestines of animals. Once transmitted to man, by direct contact with the infected animal, it lodges in the intestines and causes severe diarrhea. It may be transmitted from man to man. While this infection seems to be occurring more frequently in immuno-depressed people, one study reports incidence in healthy persons as well.

CYTOMEGALOVIRUS (CMV) A virus that is related to the herpes family, CMV infections may occur without any symptoms or result in mild flu-like symptoms of aching, fever, mild sore throat, weakness, or enlarged lymph nodes. Severe CMV infections can result in hepatitis, mononucleosis, or pneumonia even in non-immune suppressed people. CMV is very prevalent--found in as many as 54% of straight men and 94% of gay men studied--but is usually mild and self-limiting. CMV is "shed" in body fluids: urine, semen, saliva, feces, sweat. At present CMV is being researched as a possible cause of the immune suppression in AIDS patients.

DIFFUSE, UNDIFFERENTIATED NON-HODGKINS LYMPHOMA (DUNHL) A rare B-cell lymphoma that is difficult to distinguish from Burkitt's lymphoma. Its relationship to AIDS is uncertain at present and is being investigated. The DUNHL patients exhibit generalized lymphadenopathy and enlarged spleens. This cancer is usually fatal.

EPSTEIN-BARR VIRUS (EBV) A herpes-like virus that causes one of the two kinds of mononucleosis (the other is caused by CMV). It lodges in the nose and throat and is transmitted by kissing. EBV lies dormant in the lymph glands and has been associated with Burkitt's lymphoma, a cancer of the lymph glands. This is the clearest link to date between viruses and cancer.

HERPES SIMPLEX VIRUS I (HSV I) The virus that results in cold sores or fever blisters on the mouth or around the eyes. Like all herpes viruses, the virus may lie dormant for months or years in nerve or lymph tissue and flare up again under stress, trauma, infection, or immuno-suppression. There are no cures for any of the herpes viruses.

HERPES SIMPLEX II (HSV II) Causes painful sores on the anus or genitals. Sexually transmitted, it is the second most common venereal disease.

HERPES VARICELLA-ZOSTER VIRUS (HVZ) The varicella virus causes chicken pox in children and may reappear in adulthood as herpes zoster. Herpes zoster, also called shingles, are small very painful blisters on the skin that follow nerve pathways.

KAPOSI'S SARCOMA (KS) A tumor of the walls of blood vessels. Usually appears as pink to purple, painless spots on the skin but may also occur internally in addition to or independent of the skin lesions. Death occurs from major organ involvement. Originally seen in elderly men or in equatorial Africa as a slow growing, benign lesion, it is now occurring in young men, 80% of whom are gay, and is rapid and frequently fatal in its course.

LYMPHADENOPATHY Swollen, firm, and possibly tender lymph nodes. The cause may range from a temporary infection such as the flu, to lymphoma, which is cancer of the lymph nodes. (disease of the lymph nodes)

OPPORTUNISTIC DISEASES Those diseases which are caused by agents that are frequently present in our bodies or environment but which cause disease only when there is an alteration from normal healthy conditions, such as when the immune system becomes depressed.

PERSISTENT GENERALIZED LYMPHADENOPATHY Chronic, diffuse, non-cancerous lymph node enlargement that recently has been found to be prevalent among gay men. It typically has been found in those with immune system disturbances who develop frequent and persistent bacterial, viral, and fungal infections.

PNEUMOCYSTIS CARINII PNEUMONIA A lung infection seen in immuno-suppressed people. It is caused by a protozoa present almost everywhere but which is normally destroyed by healthy immune systems. It is air-borne. Once a person develops PCP, he or she is susceptible to recurrence of the disease, and the outcome is often fatal.

T-CELLS (HELPER/SUPPRESSOR) T-cells are lymphocytes (white blood cells) which are formed in the thymus and are part of the immune system that has been found to be abnormal in AIDS patients. The normal ratio of helper T-cells to suppressor T-cells is about 2:1. This becomes inverted in AIDS patients.

TOXOPLASMOSIS A disease due to infection with the protozoa, toxoplasma gondii.

QUESTIONS AND ANSWERS ON
ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)

Q. What is acquired immunodeficiency syndrome (AIDS)?

A. Acquired immunodeficiency syndrome (AIDS) is the name given to a recently reported complex of health problems. All patients with AIDS have developed a particular defect in their natural immunity against disease, leaving them vulnerable to illnesses that would not otherwise be a threat. These illnesses are referred to as opportunistic diseases.

Q. Who is at risk of having AIDS?

A. Nearly all cases have been reported from four distinct groups: homosexually active males, intravenous drug abusers, Haitians living in the United States, and persons with hemophilia. Special studies are under way with each of these groups. AIDS does not appear to be a threat to the general public, but because its cause is unknown, this is not yet certain.

Q. What are some of the diseases affecting AIDS patients?

A. About 85 percent of the AIDS patients studied have had one or both of two rare diseases: a type of cancer known as Kaposi's sarcoma, and Pneumocystis carinii pneumonia, a parasitic infection of the lungs. However, the basic underlying problem is a specific defect in the body's immune system. Other opportunistic infections which this immune deficiency allows to occur include unusually severe infections with yeast, cytomegalovirus, herpes virus, and toxoplasmosis. Milder infections with these organisms do not suggest immune deficiency, and are not considered "opportunistic."

Q. What is known about these opportunistic diseases?

A. The opportunistic diseases seen with AIDS are not new. Kaposi's sarcoma (KS) was described over 100 years ago. Prior to 1980, KS primarily affected elderly men and was very seldom fatal, even 5 to 10 years after diagnosis. It is also seen among children and young adults in some parts of equatorial Africa and in a few other locations. Pneumocystis carinii pneumonia affects a few hundred adults and children in the United States each year, but usually is seen only in patients with a severe underlying illness (such as leukemia) or in patients receiving therapy with drugs known to suppress the immune system (such as in kidney transplant patients to prevent organ rejection).

Q. What are some of the characteristics of patients with AIDS?

A. About 95 percent of the victims identified so far in the current AIDS investigation have been males; three-fourths of them have been homosexual or bisexual. The age group affected is primarily in the range of 25-44 years. All races have been affected.

Q. How serious is acquired immunodeficiency syndrome?

A. AIDS has a very high fatality rate, ranging from 20 percent to more than 50 percent depending upon the opportunistic disease and the time from diagnosis. CDC investigators do not know of any patient with AIDS who has regained lost immunity. Thus, AIDS patients continue to be at special risk of disease. Some are being studied to determine whether normal immune function does return.

Q. What causes AIDS?

A. Investigators have not yet been able to find the cause, or causes, of this loss of immunity. The occurrence of the syndrome among hemophilia patients suggests the possibility of transmission of an agent through blood products, but this has not been proved. One leading hypothesis is that the causative agent is a virus which can be transmitted sexually or, less commonly, through blood-products and blood. Risk factors that have been suggested from studies to date include an increased number of sexual partners for homosexual men and sharing of needles for those using illicit drugs, but as yet there is no definitive explanation.

Q. How common is AIDS?

A. Investigation of the syndrome began in June 1981, and by April 9, 1984, 4,023 cases had been reported to CDC.

Q. What is the geographical distribution of reported cases?

A. The distribution has been unusual, with about 40 percent of the cases reported from New York City and about 20 percent from California. AIDS cases have been reported from 44 states, the District of Columbia, Puerto Rico, and more than 20 foreign countries.

Q. Are there any symptoms specific for AIDS?

A. There are no clear-cut symptoms that indicate the loss of immunity, but many patients with AIDS have had symptoms of fever, loss of appetite and weight, extreme fatigue, and enlargement of lymph nodes (sometimes called "glands"). These often occur over a period of months before the patient's condition becomes severe enough to develop the specific observable diseases, such as Kaposi's sarcoma (KS) and pneumocystis pneumonia. KS is a form of cancer that usually occurs anywhere on the surface of the skin or in the mouth. In early stages, it may look like a bruise or blue-violet or brownish spot. The spot persists, grows larger, and may ulcerate. It may spread to other organs, including lymph nodes, causing them to enlarge. Pneumocystis pneumonia has symptoms similar to any other form of severe pneumonia, especially cough, fever, and difficulty in breathing. Some AIDS patients have had KS and pneumocystis pneumonia at the same time.

Q. Is there a laboratory test for AIDS?

A. There is no specific test for diagnosing AIDS. The specific immune defect in AIDS has not been identified, but many patients show a decrease in the number and function of certain white blood cells called T-helper lymphocytes. Although the number and function of these cells can be measured, these tests are not generally available, they are not 100 percent sensitive or specific, and they are very expensive. They are usually done in major research centers. However, other tests may help the physician in establishing the diagnosis of AIDS and its associated diseases.

Q. What can be done to prevent AIDS?

A. Although the specific cause of AIDS is unknown, the U.S. Public Health Service has made several recommendations for AIDS prevention.

- o Everyone should avoid having sexual contact with persons known to have or suspected of having AIDS.
- o Members of high risk groups should be aware that having multiple sexual partners increases their chance of contracting AIDS.
- o As a temporary measure, members of groups at high risk for AIDS should refrain from donating blood or plasma.

Department of Health and Human Services
Public Health Service
Centers for Disease Control
April 1984

TAKING CARE OF YOURSELF

The following is a discussion of common concerns and questions that may be of help to you.

Kaposi's sarcoma is a reflection of an underlying immune weakness. It is the immune system's job to kill not only foreign viruses and bacteria (germs) but also abnormal cells (mutant or malignant cells) that probably occur often in everyone. Therefore treatment may be two-fold.

1. To strengthen the immune system.
2. To kill the abnormal tumor cells.

STRENGTHENING THE IMMUNE SYSTEM:

General health care measures include:

1. Adequate rest - this means learning to listen to your body - in general you can do what you have the energy for. If you become fatigued by a particular activity you should consider decreasing or eliminating that activity.
2. Nutrition - a well balanced diet to include adequate calories, protein, carbohydrates, fat, and vitamins. Plenty of liquids, especially juices. Supplemental Vitamin C may be helpful (up to 3 grams/day - 1000 mg = 1 gram). High doses of A and D can be toxic. Do not take more than 100,000 units of Vitamin A or 400 units of Vitamin D. If you have fevers or diarrhea, extra calories and supplemental nutrients are a necessity. If decreased appetite is a problem, small frequent nutritious "snacks" may help. Also, commercially prepared nutritional supplements such as Sustacal or Nutramagen and many others are available in drug stores without prescription and may be of help. Use these liberally if your appetite is depressed.

AVOIDING THINGS THAT CAN WEAKEN THE IMMUNE SYSTEM

Avoid toxic substances which may weaken your immune system such as alcohol, cigarettes, and recreational drugs. The positive effect on your emotional outlook of a glass of wine or occasional marijuana cigarette may outweigh possible negative effects. This is something that each individual must decide for themselves.

MANAGING STRESS

Part of dealing with any illness is promoting a positive emotional outlook: a very potent medicine. Likewise a negative emotional outlook further weakens your body's defenses. Certainly dealing with a serious illness such as Kaposi's can cause some depression. Let your medical provider know you are feeling depressed. They will help you deal with these normal feelings before they become a serious problem.

Supportive psychological help is available should you need or desire it. The LA AIDS project is also available to you and is a valuable resource in providing supportive services of many kinds. Their telephone number is 871-1284.

SEX

The decision to have sex with a regular partner involves a decision between you and your partner. The assumption is that you may be infectious (for AIDS) at this time. You should consider this fact. If you and your partner decide to continue with sexual relations the use of condoms is recommended. Consider alternate forms of activity that meet your needs for sex and intimacy that do not allow for the exchange of secretions. It is strongly recommended that you limit your sexual activity to one regular person whom you have informed that you have AIDS and that he also limit his sexual activity. This is a protection for you since his exposure to multiple partners will increase the risk of infection for you.

THERAPY

In addition to supporting your immune system the second line of attack is therapy aimed at killing Kaposi's tumor cells. Several agents are available at UCLA.

1. INTERFERON - An experimental substance that is produced in the body. Large doses are manufactured and injected under the skin. The data are not complete but there is evidence that the interferon has tumor killing ability.
2. CHEMOTHERAPEUTIC AGENTS - have tumor-killing properties.
 - a) VePesid (VP16-213) (IV infusion) - administered by intravenous over 30 minutes for 5 consecutive days. This is repeated every 2-3 weeks depending on your blood count.

- b) Velban - administered intravenously. Can be given depending on your blood count.
- c) Vincristine - administered intravenously. Can be given weekly.

FURTHER RECOMMENDATIONS

1. Avoid using shared toothbrushes and razors. As these procedures frequently involve small amounts of bleeding it is possible that blood on these objects may transmit possible infection.
2. Advise your dentist that you have AIDS.
3. Avoid using aspirin which may aggravate bleeding tendencies.
4. Avoid the sun.
5. Do not donate blood.

HOW TO GET HELP

You will be seen regularly in the Kaposi's Center for treatment and for periodic evaluations. Most of your concerns will be dealt with on these occasions. You are encouraged to continue your care with your regular doctor if you desire. We will be glad to coordinate your care with him/her. For questions that cannot wait until your next appointment call either Larry Eppolito, 825-9412 or Susie McCarthy, 206-6046.

For after-hours medical emergencies call the UCLA page operator (825-6301) and ask for Dr. Mitsuyasu or Hematology-Oncology Fellow on Call.

Laboratory results in general will not be given by phone. They will be discussed at your next appointment.

file Steve Buckingham

LOS ANGELES: UCLA MEDICAL CENTER
THE CENTER FOR THE HEALTH SCIENCES

May 7, 1985

TO: Michael Gottlieb, M.D.
Associate Professor of Medicine
Acting Chief, Department of Clinical
Immunology and Allergy

FROM: Steve Buckingham, M.S.S.W.
Clinical Social Worker

This memo is pursuant to our conversation of May 1 regarding a referral protocol for social work consultation with AIDS patients in the Clinic.

In order to provide our patients with more comprehensive psychosocial services, I would like to suggest a more routine assessment of their situation upon entering our system. This would include financial/insurance screening, assessment of their social supports, and routine referrals to community agencies. Attached is the suggested protocol.

It is important to note that this protocol for brief routine assessments does not preclude my deeper involvement with patients who present with more involved concerns or needs.

I would also like to take this opportunity briefly to list the services I am able to provide: obtain social histories, formulate indepth psychosocial assessments of patients and significant others, coordinate discharge planning, provide psychotherapy to patients and significant others, make referrals to appropriate community resources, provide advocacy, and provide consultation to the medical staff.

I believe my early social work intervention and introduction may prevent possible problems later. Hopefully this will prove to be beneficial to both our patients and UCLA as we continue to serve this growing population.

Any suggestions or comments you may have regarding this protocol would be appreciated.

SB:adm
Attachment

SUGGESTED PROTOCOL

Routine Social Work consultation should be provided to:

- 1) Newly diagnosed patients;
- 2) New patients who are transferring their medical care to UCLA from another facility or physician;
- 3) Patients who have specific questions or concerns regarding insurance, financial assistance, or community services;
- 4) Patients who present with any psychosocial concerns, i.e., anxiety, depression, etc.

SB:adm
Department of Clinical Social Work
05/07/85

LOS ANGELES: UCLA MEDICAL CENTER
THE CENTER FOR THE HEALTH SCIENCES

August 26, 1985

To: Michael Gottlieb, M.D.
Acting Chief, Division of Immunology and Allergy

From: Steve Buckingham, M.S.S.W. *SB*
Clinical Social Worker

After our discussion in clinic this past Wednesday regarding the social work profession and its role in the emotional care of our patients, I wanted to take this opportunity to further outline the expertise that social workers have to offer.

Briefly, social workers are one of the three major groups offering psychotherapy in institutions and the private sector, the others being psychologist and psychiatrists, with the bulk being provided by social workers. I have attached an article that further explains and outlines the various providers of mental health services.

Just as we are all aware of the psychosocial needs and concerns that AIDS has engendered, it is equally important for us to understand the services available to help manage these needs and how to go about matching patients with appropriate services.

The Department of Clinical Social Work here in the medical center provides a variety of services to inpatients, outpatients, and their families aimed toward appropriate utilization of health care, adjustment to diagnosis, and maximizing functioning. After evaluating the psychosocial aspects of each case, clinical social workers offer therapeutic treatment and mobilization of hospital and community resources as needed.

More specifically, as the social worker assigned to the immunology patients, I am able to: obtain social histories, formulate indepth psychosocial assessments of patients and significant others, coordinate discharge planning, provide psychotherapy to patients and significant others, make referrals to appropriate community resources, provide advocacy, and provide consultation to the medical staff.

There are two key services which are of particular importance with this population which require social work involvement. They are psychotherapy/crisis counseling, and discharge planning.

Psychotherapy/Crisis Counseling

It is well known in the psychiatric literature that perceived threat or loss can precipitate a psychological crisis in any mentally healthy individual. The diagnosis of AIDS or ARC is a obvious example. Less obvious are crises precipitated by

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loss of control over one's environment (e.g., hospitalization), role changes, and threat to one's employment or career identity.

Hospitalization is a major blow to the patient's functioning, especially AIDS patients who typically are accustomed to being in control and having the human as well as financial resources to function with dignity and independence. Their anger can be acted out through noncompliance with medical regime, presenting management problems for staff, or directing their anger at staff, family, self, or other significant others. Depression, expressed through behaviors such as hypochondriacal responses, extreme dependency, or suicidal ideation, is a common response which can lead to poorer prognosis.

A real case example highlights the need for social work:

Mr. L is a 32 year-old gay male new to Los Angeles with little family support. He was recently diagnosed with ARC and reported feeling depressed and anxious. After being referred for a concrete concern around insurance the patient began to identify many other issues such as feelings of anger, unresolved feelings toward his mother and father and a general sense of disappointment in his work situation. His medical situation forced many concerns to the surface which has prior to diagnosis has been less priority.

I have been meeting with the patient weekly to assist him in his adjustment to ARC by providing him with clear and accurate information, helping him problem solve various concrete problems, and encouraging his exploration of feelings around AIDS, illness and death. During our work together Mr. L has begun to look at his family relationships and identify unfinished business which he now wishes to work on. Our sessions have enabled the patient to come to terms with his medical situation, address family concerns and make real moves toward career goals.

It is the social worker's role to intervene in the crisis, offer short-term counseling, and direct the patient to a reliable resource person or agency in the community for follow up as needed.

Discharge Planning

At present, the lack of community facilities that will care for the AIDS patients after discharge from the hospital necessitates the often complicated task of patching together other community resources to provide adequate care at home. This is a very time-consuming process and requires specific knowledge of the various AIDS-related agencies that will provide different components of the needed discharge plan.

A case in point:

Mr. W as a 35 year-old hospitalized gay male with KS. The

referral was for discharge planning at the patient's request to die at home. The patient was end stage with multiple medical problems which complicated the task of discharge planning. He had only minimal insurance provisions for home care, lived in Orange county outside the geographic boundaries of APLA, lived with an ex-lover who was apprehensive about assuming the responsibility of taking the patient home, had no family supports, and required I.V. therapy.

After several meetings with the patient, his roommate, and the medical staff I began to piece together a discharge plan that would enable Mr. W to die at home. This plan required the involvement of several gay organizations in Orange county, the VNA, DPSS, UCLA and variety of friends who volunteered to sit with the patient when he would be alone.

By early involvement and careful coordination Mr. W was enabled to die at home with friends and family as he had wished.

Hopefully this information will be helpful to you in better understanding social work and the provisions for psychosocial services. I would like to meet with you to further discuss any questions you may have as well as begin strategizing for my continued involvement with you and the AIDS situation.

June 13, 1985

TO: Susan J. Rehm, Director of Medical Center Clinical Social Work

FROM: Richard J. Steckel, M.D., Director
Jonsson Comprehensive Cancer Center

SUBJECT: Social worker for AIDS patients

Dear Sue:

I enjoyed the opportunity to talk with you and with Bernice Sokol the other day, together with our Deputy Director Jim Ruckle. We are continuing to meet with some of the caregivers on inpatient and outpatient services, to determine the best means to use limited Cancer Center funds to augment the psychosocial care of our cancer patients. Clearly, social work is a focus which deserves attention, in view of the prior cutbacks that were occasioned by Hospital financial problems.

A particular area of interest that arose at our meeting with you, was the one concerning AIDS patients at UCLA. I think that the six-month demonstration involving Mr. Stephen Buckingham has been eminently successful, from all that I can gather in talking to you and other people who have been involved in this. In fact, the demonstration has probably made an excellent case for a full time social worker to serve the needs of this difficult (and growing) group of patients. As I mentioned to you, our own resources are limited and we will have to establish a priority list of needs in order to decide how best to make a modest impact with a corresponding modest infusion of funds. I am equally impressed that the Bowyer Clinic social worker needs help and, if possible, augmentation of her own time component which now stands at 80% of full time. Even in these difficult times, my hope is that the Hospital will be forthcoming with new assistance in the form of a modest increment in social work assistance for some of our most needy patients, and in particular I believe that the Hospital should take a careful look now at establishing a full-time social work position for the AIDS patients. If there are any opportunities for recharging third parties for social work consultation on this or on other services, perhaps this can be exploited too. I will be back to talk with you about how the Cancer Center might best contribute to our common purpose of augmenting social services somewhat for UCLA cancer patients, although it is clear that we will not be able to reach the optimal level with funding available. I am equally hopeful that the Hospital will make a new contribution to ameliorating these problems, and I hope you will let me know how I might be helpful in making a case for social work augmentation in some of the areas of greatest need.

Very sincerely,



Richard J. Steckel, M.D.

cc: Bernice Sokol
James Ruckle

cc: MICHAEL GOTTLIEB