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Needs assessment: patient education for men and women living with HIV/AIDS

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NEEDS ASSESSMENT: PATIENT EDUCATION FOR MEN AND WOMEN LIVING WITH HIV/AIDS

A Thesis
Presented to
The Faculty of the Department of Health Sciences
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In Partial Fulfillment
of the Requirements for the Degree
Master of Public Health

by
Sohini Sengupta
August, 1994

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ABSTRACT

NEEDS ASSESSMENT: PATIENT EDUCATION FOR MEN AND WOMEN LIVING WITH HIV/AIDS

by Sohini Sengupta

This thesis examines the need for a comprehensive patient education program that emphasizes self-help/self-care for adults living with HIV/AIDS. Data were collected using a self-administered, written questionnaire.

Participants were recruited from agencies in northern California. This study revealed that 59 of 70 respondents were relatively satisfied with the services, including patient education, available in their community. Of the 70 respondents, 69 felt there was a need for a comprehensive patient education program. The study's findings illustrate both distinct differences and commonalities between the experiences and perceived needs and priorities of male and female respondents.

These findings will help HIV/AIDS service agencies re-structure their health education programs and assist in patient education program development. Future research in this area needs to address the perceived needs and priorities of different subgroups living with HIV/AIDS.

For Michael, May 1952 - June 1994

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CHAPTER 1: OVERVIEW

Over the last 30 years, the principles of self-help and self-care have become integral to the field of health education. Patient education has been particularly effective in teaching self-help and self-care strategies for managing acute and chronic diseases (Lorig, 1992). As a result, many individuals have adopted new health behaviors that directly enhance the quality of their lives, while bringing the added benefit of reducing the rising costs of health care (Holzemer, 1992).

Although self-help and self-care strategies have similar long-term benefits, there are important differences between the two concepts. Self-help aims to change health behaviors in order to improve health status (Lorig & Holman, 1993). Self-care aims to enable health care consumers to perform medical procedures traditionally done by physicians (Parcel, Bartlett, & Bruhn, 1986). Research has shown that patient education, incorporating both self-help and self-care strategies, can empower individuals with chronic diseases to learn coping skills, symptom management, and assertiveness techniques. In doing so, people with chronic diseases may have a greater chance to live longer and healthier lives (Lorig & Holman, 1993; Lorig, Laurin, & Gines, 1984).

Within the spectrum of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) care, patient education programs emphasizing self-help and self-care have been introduced but not consistently implemented by most service organizations, especially in moderate to low incidence areas (Crystal, 1989; Lenker, Lubeck, & Vosler, 1993). One of the factors inhibiting full implementation is that HIV infection and AIDS are not yet treated as chronic diseases by parts of the health care system, including some HIV/AIDS service organizations (Fee & Krieger, 1993). In many cases, the epidemic is still perceived as it was in the early years when individuals were not diagnosed with AIDS until they were dying of AIDS-related illnesses (Curran, 1985). From this perspective, self-help and self-care programs for long term health maintenance are irrelevant.

However, in recent years, the previously short window between diagnosis and death has been extended. Greater awareness of AIDS as a public health emergency and HIV-antibody testing during the initial stages of disease are cited as the primary reasons for this important change (Fee & Krieger, 1993). As a result, more people are living longer with an HIV seropositive or AIDS diagnosis. This phenomenon makes it necessary to recognize HIV infection as a chronic disease that can be controlled, often for significant periods of time, through close monitoring of symptoms and positive health promoting behaviors (Sarti, 1990).

However, living longer with HIV/AIDS does not necessarily mean that one's quality of life is improved. Patient education, incorporating self-help and self-care strategies, may offer HIV-infected individuals information, skills, and confidence to improve the quality of their lives through self-management of their condition.

Purpose

The purpose of this needs assessment research was (a) to determine the extent to which HIV-infected men and women perceive a need for a comprehensive patient education program, and (b) to determine the self-help and self-care priorities that should be included in a patient education program for adults living with HIV/AIDS.

Statement of the Problem

As the AIDS pandemic enters its second decade, AIDS continues to be the leading cause of death among many groups. AIDS has become the third leading cause of death among adults between the ages of 25 and 44, with minority groups significantly affected (Centers for Disease Control [CDC], 1993). Moreover, AIDS is one of the top five causes of death for women of childbearing age (CDC, 1993). In fact, AIDS has taken a disproportionate toll on Black and Hispanic women who comprise 53% and 21%, respectively, of this nation's women with AIDS (Kelly & Holman, 1993).

Current data indicate that the national pattern of HIV infection and AIDS is changing. The percentage of AIDS cases attributed to heterosexual contact increased by 21% between 1990 and 1991 (CDC, 1993). Conversely, among white, gay and bisexual men, the percentage of reported AIDS cases decreased slightly from 82% in 1990 to 74% in 1991 (Holzemer, 1992).

Since the emergence of AIDS as a public health problem, a majority of the research funding has gone to understanding the epidemiology of the disease and the development of new drugs and vaccines that will treat the clinical symptoms of AIDS or slow their onset (Brown, 1990; Fischl et al., 1990; Hirsch, 1990; Katzenstein et al., 1992). In comparison to basic research, fewer federal dollars have been allocated to AIDS prevention, specifically at primary and secondary intervention levels.

The goal of primary prevention is to reduce exposure to HIV, the causative agent of AIDS (Dorfman, Derish, & Cohen, 1992; Quirk, Godkin, & Schwenzfeier, 1993). Methods to achieve this goal include HIV education in various settings (e.g., schools, worksites, and health care facilities).

Secondary prevention aims to detect and diagnose HIV infection at an early stage through testing and various medical procedures. Examples of secondary prevention include voluntary HIV testing and intra- and postpartum care for pregnant women at risk (Acosta et al., 1992; Allen, 1990).

For individuals already infected with HIV, tertiary prevention is needed to delay disease progression. Currently, tertiary prevention methods include clinical trials, support groups, and HIV/AIDS-related seminars. Major AIDS epicenters, such as New York City, Los Angeles, and San Francisco, have an abundance of community-based organizations that offer these resources to HIV-infected people. However, in moderate and lower incidence areas, services are lacking and are not as well organized (Lenker et al., 1993). Even in high prevalence areas, social and medical services are not disseminated in a systematic manner. This makes it extremely difficult for individuals to gain the breadth of knowledge necessary to fully understand the complexity of this disease and the appropriate maintenance of their condition (Crystal, 1989).

In addition to the lack of services, there are enormous disparities in the distribution of HIV/AIDS services within different communities. In Los Angeles, New York City, and San Francisco, white, gay and bisexual men have often been the primary consumers of HIV/AIDS services. Anecdotal evidence suggests that these groups have greater access to social and medical resources. Minorities from low socioeconomic backgrounds, particularly women and their children, do not even have easy access to primary and reproductive health care (Wofsy et al., 1992). As a result, they often cannot act promptly to delay the progression of their disease, supporting the perception that being HIV seropositive, or having AIDS, is nothing more than an immediate death sentence (Williams, 1992).

Providing services to all HIV-infected individuals becomes an even greater challenge as more AIDS funding goes toward molecular and cellular research, with less dedicated to prevention, especially at the tertiary level (Aiken, 1989). For this reason, it is necessary to develop tertiary preventive interventions that are cost-effective and do not impose a heavy financial burden upon the present HIV/AIDS delivery systems.

Patient education programs emphasizing self-help and self-care should be key components of tertiary prevention. These programs have demonstrated their cost-effectiveness and can assist individuals with self-management techniques that can result in healthy attitude and behavior changes (Lorig & Gonzalez, 1993; Webber, 1990).

Attitudinal and behavioral changes will become increasingly important as more people live longer with an HIV seropositive and/or an

AIDS diagnosis. In fact, recent research and anecdotal data suggest that infected gay and bisexual men are developing sets of HIV-specific, self-help and self-care behaviors that are maintaining their health or delaying disease progression (Lovejoy, Paul, Freeman, & Christianson, 1991). These self-help/self-care guidelines include cognitive strategies, nutritional information, stress reduction techniques, symptom surveillance, and alternative therapies. Patient education programs that focus on some of these self-help and self-care approaches can motivate HIV-infected individuals to adopt healthy behaviors, increasing the quality, and perhaps, the length of their lives.

Today, AIDS remains a public health problem. A comprehensive patient education program emphasizing self-help and self-care may be an innovative approach at the tertiary level to deal with HIV infection and AIDS as chronic diseases. Past research on chronic disease self-management demonstrates the cost and social benefits of using patient education to enhance quality of life. This well-developed area of health education can be easily extended to HIV/AIDS care. This needs assessment was designed to explore the perceived need for a comprehensive patient education program for people living with HIV/AIDS.

Objectives

This study was designed to meet the following objectives:

1. To determine the perceived need for a comprehensive patient education program designed to teach self-help and self-care strategies to men and women living with HIV/AIDS.

2. To determine which self-help and self-care topics were perceived as important in a patient education program for people living with HIV/AIDS.

3. To provide an assessment of self-help and self-care needs and priorities to community-based organizations that offer HIV/AIDS-related services.

4. To provide HIV-infected men and women the opportunity to express their views and concerns about living with HIV/AIDS.

Methods

A total of 200 men and women was invited to participate in this needs assessment research. Selection criteria required potential participants to be over the age of 18, with a self-reported HIV seropositive and/or AIDS diagnosis. The sample was drawn from agencies in a small area of northern California that offer services for people living with HIV/AIDS. Potential participants were contacted in clinical settings, support groups, and HIV education seminars.

The design of this study was descriptive assessment research. Data were collected through a written, self-administered questionnaire. The original survey instrument explored respondents' attitudes about living with HIV/AIDS, and perceived needs and priorities for patient education.

Since the questionnaire consisted of both closed and open questions, it generated both quantitative and qualitative data. The closed questions provided quantitative data on the sample demographics, perceived need for a patient education program, and respondents' perceived self-help/self-care priorities. The open questions allowed respondents to share their feelings and express comments about any areas not specifically addressed in the questionnaire. The subsequent qualitative data were analyzed to identify salient themes about living with HIV and AIDS.

Limitations

There were several limitations in the research design. They included the following:

1. In order to protect the confidentiality of people with HIV/AIDS, the questionnaire was distributed by collaborating AIDS service agencies. Data collection and follow-up were therefore dependent on the efforts of busy, over-extended staff members at the participating agencies. As a result, the researcher had minimal direct influence on sample recruitment or response rate.

2. In general, written questionnaires are less sensitive instruments than interviews for collecting data (Oyster, Hanten, & Llorens, 1987). In this study, the written questionnaire lacked the benefit of obtaining in-depth information from the respondents, especially concerning each of the self-help/self-care priorities.

3. Since there were no known standardized needs assessment instruments on patient education for people living with HIV/AIDS, an original questionnaire was developed for this research. Without a standardized instrument, questionnaire reliability and validity cannot be verified.

4. There may have been problems inherent in the self-administered

survey instrument. Discrepancies may exist between the researcher's understanding of particular questions and the perspectives or interpretations of the respondents. These differences may have affected the validity of the data analysis.

5. The sample consisted of HIV-infected individuals who sought HIV/AIDS services from selected agencies in northern California. The results cannot be generalized to all HIV-infected individuals.

Significance of Study

Despite its limitations, this study has significance to the broad fields of health and patient education, and to the more specific area of AIDS education and treatment.

The study results clearly indicate that the respondents perceived a need for a comprehensive patient education program for people living with HIV/AIDS. Each respondent agreed that patient education was important and most had clear opinions about their priority self-help/self-care topics. Health educators can use these data to design patient education programs that will supplement the services already available to people living with HIV/AIDS.

Self-management, support groups, and nutrition were perceived as highly important self-help/self-care priorities by both male and female respondents. Childcare was perceived as very important by female respondents. These priorities, and the differences between men and women, provide valuable data for planning patient education programs. Incorporating this new information in future programs may assist HIV-infected individuals to participate in support services, to acknowledge their condition more completely, to better monitor their own health, and to adopt new attitudes and behaviors that may improve their quality of life.

The findings from this study revealed some of the ways that men and women think and feel about living with HIV/AIDS. The salient themes identified in the qualitative responses introduce a myriad of issues HIV-infected people are dealing with on a daily basis. These responses highlight similarities and differences between men's and women's perceptions about their diagnoses and their primary concerns about living with HIV/AIDS. The findings provide a significant foundation for designing patient education programs as well as other services for people living with HIV/AIDS.

Lastly, the study has significance for HIV/AIDS service agencies, particularly community-based organizations. It is hoped that the findings will assist them in improving their services either by identifying unwanted and costly efforts, or by introducing new interventions which are cost-beneficial and health promoting.

CHAPTER 2: LITERATURE REVIEW

Overview

The history of AIDS is part of a cultural process of attempting to come to terms with a new and often terrifying series of events: young people dying before their time, and the intermingling of sex and death. In order to respond to this crisis more effectively, health educators, health professionals, and policymakers must focus their attention to the AIDS epidemic in a new direction; a path that emphasizes human beings living with AIDS rather than dying from opportunistic AIDS-related infections.

With this outlook, new and innovative approaches for dealing with the HIV/AIDS epidemic must be developed and implemented. A review of the current AIDS literature indicates the need for programs that are cost-effective, health promoting, and population-specific. These criteria take on particular relevance in the context of the demographic trends and increased demand for HIV/AIDS-related health and social services. This review will describe these new concerns and priorities. Additionally, sections on the impact of self-help, self-care, and patient education on the field of health education are included. This is the conceptual framework for considering the possibility of patient education programs that teach self-management strategies to people living with HIV/AIDS.

AIDS and the Public Health System

In the United States, the Acquired Immunodeficiency Syndrome (AIDS) epidemic has overburdened all facets of the public health system. The continual accretion in numbers of Human Immunodeficiency Virus (HIV) infections and AIDS cases reported annually, along with the escalating costs of HIV/AIDS-related health and social services, are two major areas in which the burden is monumental. Additionally, the health care system must not overlook the needs of long-term survivors as it becomes more sophisticated in dealing with acute problems related to HIV infection.

The epidemic's increasing numbers and cost, as well as the needs of long-term survivors, require health promotion and health policy attention. Health policies need to be promulgated that benefit all individuals living with HIV/AIDS. Similarly, feasible and cost-effective interventions need to be developed and implemented in the changing climate of health care reform.

Demographics of HIV/AIDS

Currently, AIDS is one of the most serious health problems in the United States. As of February, 1994, 339,250 cases of AIDS had been reported by the Centers for Disease Control (CDC), with 204,390 deaths recorded since the syndrome was identified ("The toll," 1994). Moreover, one million to 1.5 million Americans are estimated to be seropositive for HIV, the causative agent of AIDS ("The toll," 1994). Gay and bisexual men, minority groups, and women are predominantly represented within these figures.

There have been important demographic changes since the inception of the epidemic. Since AIDS was first identified in 1981, it has become one of the leading causes of death in both men and women between the ages of 25 and 44 (Noble, 1991). HIV infection grew rapidly in the early 1980s, particularly among gay men, and peaked in the mid-1980s (Brookmeyer, 1991). Although the 10-year median incubation period makes it is difficult to predict when these men were initially infected, this portion of AIDS history is known as the first wave of infection. Data from the landmark San Francisco Health Department study revealed that HIV antibody prevalence nearly tripled in a cohort of gay men during this time period, from 24% in 1980 to 68% in 1984 (Curran, 1985).

However, the proportion of all AIDS cases diagnosed among gay men decreased subsequent to 1985. In the state of California alone, the cases dropped from 82% of all cases in 1990 to 74% in 1991 (Morbidity and Mortality Weekly Report [MMWR], 1992). This decline is partially attributed to increased awareness and adoption of safer sex behaviors (Aiken, 1989; Dilley, 1990). In addition, other behavioral changes to improve quality of life have allowed many of these men to live longer and healthier lives. Known as long-term survivors because they have lived with HIV infection for five years or more, these individuals seem to suffer from fewer complications, and have more positive attitudes concerning their prognosis (Hardy, 1991; Rabkin, Remien, Katoff, & Williams, 1993).

Surprisingly, younger gay men between the ages of 18 and 25 have not successfully adopted low-risk sexual behaviors as have the older members of their community. In San Francisco, previous data suggest that young gay men with a primary partner had lower perceived risk (Stall et al., 1992). The researchers concluded that this may be due to the fact that younger gay men are less concerned about AIDS risk. Lowered risk perception may contribute to an increase in the prevalence of HIV infection and AIDS cases among younger gay men.

Concomitant with the decline of AIDS cases in gay men is the gradual rise of AIDS cases reported in heterosexuals, particularly women in minority groups (CDC, 1993). This cohort represents the second wave of infection. Between 1991 and 1992, larger proportionate increases in reported cases occurred among women (9.8%) than among men (2.5%) (CDC, 1993). For women, incidence rates were higher for Blacks and Hispanics (31.3 and 14.6 per 100,000 population, respectively) than for Caucasians (1.8 per 100,000 population) (CDC, 1993).

By 1990, AIDS was the second leading cause of death in Black women between the ages of 25 and 35 (Porcher, 1992; Smith, 1992). The incidence of AIDS in both Black and Hispanic women of childbearing age (i.e., 15 to 44 years) directly correlates with the incidence of AIDS in infants due to vertical transmission of HIV (Kline & Shearer, 1992; Porcher, 1992). In California, more than one third of the estimated 400 HIV-infected women delivering live babies annually are Black, and nearly one third are Hispanic (Capell et al., 1992). Of these women, the reported chances of perinatal HIV-transmission range from 13% to 55% (Kelly & Holman, 1993).

Several factors can explain the increase in infection rates in women. Many of these women may be intravenous drug users (IVDUs), and may have sexual partners that are bisexual and/or IVDUs (Chu, Peterman, Doll, Bushler, & Curran, 1992; Goldsmith, 1991; Singer, 1991). Bisexual male partners are a significant risk factor because they may engage in unsafe, high-risk sexual behaviors with gay men (Bennett, Chapman, & Bray, 1989; Wood, Krueger, Pearlman, & Goldbaum, 1993). Injection drug use poses yet another problem in the second wave of HIV transmission, especially in low-income communities where drug abuse is rampant. In fact, injection drug use is the presumptive origin of HIV infection for most of the cases in Black and Hispanic women (Gayle, Selik, & Chu, 1990).

There are special concerns regarding women living with HIV/AIDS. Disease progression is more rapid in women than in men. Women are especially prone to certain gynecological infections, including cervical dysplasia, vaginal candidiasis, pelvic inflammatory disease, and cervical cancer (Laga et al., 1992; Nanda & Minkoff, 1992). These symptoms are often present in the absence of HIV infection and thus frequently overlooked by physicians, or attributed to other causes. As a result, many women, especially those who are poor or have no health insurance, do not seek medical attention during the early stages of HIV infection when treatment and care are most effective in delaying progression of disease (Kelley & Holman, 1993; Wardrop, 1993; Wofsy et al., 1992). Many women already have AIDS-related symptoms by the time they discover their HIV status (Lindsay et al., 1993; Pizzi, 1992).

Costs of Medical Care Associated with HIV/AIDS

As the number of AIDS and HIV cases continues to rise in stigmatized and disenfranchised subpopulations, so do the costs of health services needed to care for these individuals. Studies that review the projected

AIDS-related health care costs usually include only personal medical care costs associated with treatment and inpatient care (Hellinger, 1988). Costs associated with research, education, HIV testing, and other indirect services related to AIDS are most often excluded.

Projecting the total costs of treating a person with AIDS is difficult because of the successes and failures of the many palliative medications available. To date, zidovudine (AZT) continues to be the drug of choice for most individuals with HIV/AIDS. The cost of AZT for one patient is approximately $10,000 per year, representing a significant proportion of the total medical care cost of treating this individual (Hellinger, 1988; Penny, 1993). This estimated figure does not include the additional costs required to treat the multitude of side effects associated with the long term use of AZT. In fact, no current information is available on the overall costs of treating AIDS with AZT, or any medical drug for that matter.

Estimated lifetime costs of treating an AIDS patient rose to $61,800 in 1991 (Lenker et al., 1993). This figure includes hospital stays, diagnostic tests performed within the hospital, and treatment for opportunistic infections. No data were available pertaining to the costs associated with outpatient care, such as ambulatory physician visits, long-term care, and outpatient diagnostic tests. Surprisingly, inpatient care costs have decreased over the past several years. The average lifetime cost for all Medi-Cal AIDS cases through September 1985 was $90,000, compared to the 1986 average lifetime cost of $70,000 (Hellinger, 1988).

Overall, health care expenditures in the United States have increased more than 14-fold over the past 25 years. The personal medical care costs of those diagnosed with AIDS have increased from $2.2 billion in 1988 to $8.5 billion in 1991 (Lenker et al., 1993). In comparison, the cost of medical care in 1986 for all infectious diseases was only $7 billion (Crystal, 1989). A large proportion of the current costs are paid for by the federal government, especially in states which include cities that are epicenters of the epidemic. In California, at least 25 percent of AIDS-related medical expenditures are paid through the federal Medicaid Program (Lenker et al., 1993). To add fuel to the fire, the number of Americans without health insurance increased to an estimated 37 million over the past decade. Although this rise occurred independently from the emergence of AIDS, it has had serious implications for the quality of health care available to low-income people living with HIV/AIDS (Aiken, 1989).

Increased Demand for HIV/AIDS Services

Increases in the number of reported HIV infections and AIDS cases have meant sharply increased demands on health care resources in both medical and non-medical settings. Unfortunately, the demands outweigh the availability of both public and private funding for innovative health care services that would respond to the needs of HIV-infected communities. HIV-infected individuals need a continuum of services. This continuum includes medically-related services, such as physician and hospital care, as well as services that are socially based, such as support groups and HIV education seminars (Lenker et al., 1993). Responding adequately to these needs will require changes in organizational and financial arrangements within the current sociopolitical context. Currently, these critical services are fragmented under the administrative authority of different governmental and non-governmental agencies (Aiken, 1989).

The paucity of primary care physicians and under-enrollment in medical specialties, such as infectious diseases, immunology, and dermatology, cannot compete with the overwhelming number of HIV seropositive and AIDS patients within the health care system (Aiken, 1989). Besides the shortage of physicians, there is an even greater concern regarding the declining number of nurses (Aiken, 1989). For these reasons, the health service needs of people living with HIV/AIDS must be supplemented by, or redirected to, organizations outside of the medical arena.

The Role of Community-Based Organizations

Over the past decade, community-based organizations (CBOs) have played a significant role in responding to the demand for more social services and alternative health care for people with HIV/AIDS (Howell, 1991; Santa Clara County Health Department, 1990-1992). Social services include case management, emotional and practical support, support groups, housing assistance, and hospice services. Alternative health services denote types of care not traditionally provided by the current health care system, including alternative treatment resources (e.g, acupuncture, meditation, and herbal remedies), mental health counseling, HIV testing/counseling, and needle exchange programs.

Historical Significance

In writing the history of AIDS, many scholars have shown that the escalating public sense of crisis was met with governmental indifference to a disease that was killing gay men. The confrontation between the federal policy establishment and gay community and public health leaders prompted many to become involved in demonstrations, lobbying, and the creation of alternative health and social services (Fee & Krieger, 1993; Freudenberg, 1991). As a result, new CBOs came into existence and have been at the vanguard of providing AIDS education and social services, as well as advocating accessible and sensitive medical care (Dilley, 1990).

Even today, CBOs offer needed services for people living with HIV/AIDS outside of the hospital or clinic. The organization and mobilization of resources by the gay community earlier in the epidemic has provided models for other communities to emulate. In fact, many CBOs have evolved with the trends in the epidemic by either developing new and innovative programs that respond to emergent needs, or by extending their services to other communities newly-affected by HIV/AIDS (Howell, 1991).

Prevention Strategies of CBOs

Community-based organizations offer many types of preventive services. Some emphasize primary prevention, administering programs that will reduce exposure to HIV or alter the susceptibility of the individual at risk. Two examples are HIV testing and pre-/post-test counseling. These services identify individuals who are HIV seropositive, and educate HIV seronegative populations to reduce their risk of becoming infected (Duke & Omi, 1991; Quirk et al., 1993). Many CBOs have also implemented safer sex workshops to encourage the practice of healthy sexual behavior as another means of reducing the risk of transmission (Miller, Booraem, Flowers, & Iversen, 1990). In urban Black and Hispanic communities, primary prevention has been an even greater challenge for CBOs because of fewer social resources and other existing social problems compounding the issue of AIDS (Freudenberg & Trinidad, 1992; Quirk et al., 1993).

Community-based organizations also provide interventions that work at the secondary and tertiary levels of AIDS prevention. Secondary prevention is the detection and diagnosis of disease at an early stage, usually through screening procedures. Interventions at this level focus on individuals identified as being at risk for HIV disease. For example, CBOs offer HIV-infected pregnant women free HIV-antibody screening to determine the potential risk of transmitting HIV to their babies, if they decide to continue pregnancy. Intrapartum and postpartum education and care are secondary interventions that can help to prevent pediatric HIV infection, depending upon the health of the mother and her clinical stage of HIV infection (Acosta et al., 1992).

Tertiary prevention aims to prevent impairment and disability, and helps HIV-infected individuals manage their condition (Penny, 1993). Early diagnosis of HIV infection is critical in helping people delay disease progression through a combination of treatment, patient education, self-help, and self-care.

Even with the monumental effort demonstrated by CBOs in responding to the social and health service needs of people living with HIV/AIDS, there are still enormous deficiencies and limitations within the HIV/AIDS care delivery system. Allocation of funding for AIDS education and prevention services is less than the amount of money dedicated to research and development of new drugs (Fee & Krieger, 1993; Freudenberg

& Trinidad, 1992). Secondly, numerous CBOs provide the same types of ancillary services; this duplication of efforts places a heavy toll on the AIDS dollar (Lenker et al., 1993). Lastly, for many people living with HIV/AIDS, CBOs are the only hope of attaining direct access to services. Unfortunately, the number of functioning CBOs cannot keep pace with the demand for more services, or the growing number of HIV seropositive/AIDS cases each day (Aiken, 1989; Dilley, 1990). For these reasons, CBOs and medical institutions must link their efforts so that a comprehensive and widespread distribution of services can be offered to all people living with HIV/AIDS (Crystal, 1989; Wardrop, 1993).

The Emergence of HIV/AIDS as Chronic, Disabling Conditions

The health service needs of people living with HIV/AIDS, like those of individuals suffering from other chronic and disabling conditions, are a poor match for this nation's health care system, which is organized around acute health care services. It is important to note the distinction between an acute versus a chronic condition. Western societies' conceptions of illness have evolved around an acute disease model in which discrete agents (i.e., HIV) cause disease. The condition known as AIDS fits well within this framework. Physicians working within the acute disease model often discourage active patient participation and place minimal treatment responsibility on the patient (Turk, Holzman, & Kerns, 1986). Moreover, patients are not socialized to believe that they have control over their physical and emotional problems; control is relinquished to the health care providers (Duke & Omi, 1991; Turk et al., 1986).

Within the realm of AIDS care, the shift from an acute to a chronic disease model became necessary as more people with HIV/AIDS were living longer. The chronic disease paradigm satisfies some new assumptions concerning AIDS etiology and prevention/treatment. The first assumption is that HIV progression occurs over an extended period of time due to quantitative and qualitative detriments in immunologic functioning (Aiken 1989). Secondly, preventing the deterioration of the immune system requires illness management. The self-management process deals with controlling the symptoms. This involves dealing with issues that pertain to living with a disability and adapting to the psychological and social changes associated with it (Corbin & Strauss, 1991).

Since AIDS also fits the chronic disease model, HIV/AIDS health care delivery systems need to consider how everyday life activities can affect the choices individuals make about illness management, and how these activities ultimately have consequences for the direction taken by the illness course. In the past decade, the health care system has paid relatively little attention to understanding the complex societal factors affecting the epidemic. Instead, most of the attention went into examining the mechanisms of HIV disease within the body (Fee & Krieger, 1993).

As a result, the health care system has not been fully equipped to meet the new and very different service needs of long-term survivors living with HIV/AIDS, as well as the increasing number of newly diagnosed, HIV-infected individuals prevalent in marginalized communities. This includes increased need for patient education in the form of seminars, classes, or workshops that provide information on how to manage the condition (Penny, 1993). Secondly, self-help/self-care programs need to be developed that assist individuals in making healthy lifestyle changes (e.g, eating a balanced diet, and abstaining from smoking and alcohol). Lastly, more psychosocial support groups are needed for heterosexuals, women, and intravenous drug users to offer safe and culturally acceptable environments in which to share experiences and concerns (Ribble, 1989). Community-based organizations are well-positioned to provide more of these services in collaboration with the health care system.

Conceptual Framework

Self-Help

Over the past 15 years, there has been an increased awareness among the public and health professionals of the benefits of involving the consumer more actively in health care programs (Parcel et al., 1986). This strengthened involvement is considered not only preferable, but even essential to achieving desired behavioral and health outcomes. Evolving from principles in both health education and health psychology, the concept of self-help (also known as self-management) refers to the "performance of preventive or therapeutic health care activities, often in collaboration with health care professionals" (Tobin, Reynolds, Holroyd, & Creer, 1986, p. 29). The goal of learning self-help skills is to empower individuals to gain a sense of control over their lives. Empowerment expresses itself at the level of patients' feelings, ideas about self-worth, and ability to make a difference in the world around them, both physically and spiritually (Rappaport, 1986).

The conceptual framework used in health education programs that focus on self-help incorporates theory and techniques from both the social and behavioral sciences. The Health Belief Model (HBM) is a value-expectancy theory that attempts to predict and explain health behavior (Parcel et al., 1986). The HBM acknowledges that health behavior is based on the beliefs of personal susceptibility to a disease, seriousness of the disease, and the efficacy of the treatment (Lorig, Cox, Cuevas, Kraines, & Britton, 1984). In the past, the HBM has been used to study preventive health behavior (Rosenstock, 1974) and chronic illness (Kasal, 1974). However, its application is limited, and has decreased over the years as a result of the development of newer and better behavioral change theories.

The PRECEDE model has been applied to numerous educational interventions in recent years. The acronym, PRECEDE, stands for "predisposing, reinforcing and enabling constructs in educational diagnosis and evaluation" (Parcel et al., 1986, p. 18). Application of the PRECEDE model provides a systematic way of assessing the appropriate self-help behaviors and planned intervention techniques that can be used for each step of a health education program (Green, Kreuter, Deeds, & Partridge, 1980).

Another theory highly utilized in dealing with chronic illnesses within the fields of health education and health psychology is Social Learning Theory (SLT). The central tenet of SLT is that new information is insufficient to ensure that new health-related behaviors will be performed (Tobin et al., 1986; Valdiserri, West, Moore, Darrow, & Hinman, 1992). There are three principal therapeutic goals in SLT through which the self-management of a chronic illness is achieved: (a) Self-control skills are learned, (b) self-efficacy beliefs that will likely promote changes in health behavior are enhanced, and (c) environmental conditions that promote the self-control of a chronic illness are created (Bandura, 1984). For example, training in self-control of digital temperature in response to cold stimuli is often sufficient for the self-management of Raynaud's disease (Tobin et al., 1986).

An expansion of SLT is Self-Efficacy Theory. Perceived self-efficacy refers to "people's beliefs in their capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands" (Gonzalez, Goeppinger, & Lorig, 1990, p. 133). In other words, self-efficacy is concerned with the level of confidence one has in performing a certain health-related behavior, rather than actually performing that behavior. There is a growing body of research which demonstrates that health education interventions can change self-efficacy, and that changes in self-efficacy are associated with changes in behavior and health status (Lorig & Holman, 1993; Lorig et al., 1989; O'Leary, 1985; Strecher, McEvoy-DeVellis, Becker, & Rosenstock, 1986).

Self-Care

Parallel to the concept of self-help is self-care which emphasizes individual participation in changing health-related behaviors. Self-care programs have re-emerged in the last decade with the growth of the consumer movement and dissipating public confidence in medicine (Starr, 1982). Self-care theory is defined as a "process whereby a layperson can function effectively on his or her own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system" (Parcel et al., 1986, p. 17). Self-care theory has been effective in the use of oral agents by individuals with diabetes mellitus. Research indicates that self-monitoring and self-regulation of symptoms caused improvement in blood glucose levels (Holzemer, 1992).

Besides being cost-effective, self-care programs are considered comprehensive because they present information about prevention of specific conditions, and instruction about performing services that health care providers traditionally perform. Self-care programs enhance laypersons' abilities to make decisions regarding their health care, and to recognize and exercise options of care.

Patient Education

Definition of Patient Education

Changes in the health care system and provision of care in hospitals mandate that attention be refocused on empowering patients to function at home, away from hospitals and other clinical settings (Villejo, 1993). Recognizing the value of empowerment, and the key role it plays in chronic disease management, has prompted numerous studies evaluating patient education programs (Pizzi, 1992).

Several studies concluded that practicing self-management can significantly affect the activities and health status of people with chronic conditions, and reduce the costs of expensive inpatient/outpatient care. Goodall and Halford indicated that the cause of improved glycemic control for people with diabetes was self-management rather than insulin treatment (1991). In an arthritis self-help study, people with severe forms of arthritis increased their knowledge about their condition and learned self-management behaviors, while decreasing their pain (Lorig & Holman, 1993).

The studies evaluating patient education programs also delineate their effectiveness in relation to the specific types of interventions being offered. To understand how effectiveness is measured, it is important to identify the common principles of patient education. These principles include the individualization of education, explicit feedback on learning, and reinforcement of a new behavior (Mullen, 1993). Consistent with these principles, patient education programs relying exclusively on informational approaches to increase knowledge show lesser effects than programs which contain behavioral and skill-training approaches (Garrity & Garrity, 1985; Goodall & Halford, 1991; Mazzuca, 1982).

Use of Self-Efficacy Theory in Patient Education

Patient education programs that emphasize motivational skills and cognitive resources often use self-efficacy theory as a basis for their interventions. Self-efficacy theory has a strong research base, has been proven useful in changing health behaviors and health status, and has specific strategies through which it can be integrated into patient education practice. One study measured self-efficacy as a predictor of pain management during childbirth (Manning & Wright, 1983). The results indicated that women with higher self-efficacy for managing a medication-free labor did so more often than women with lower self-efficacy.

An arthritis self-management program used an arthritis-specific self-efficacy scale to measure patients' self-efficacy before and after the self-management program intervention (Lorig, et al., 1989). The program intervention included specific self-efficacy strategies, including skills mastery, modeling, reinterpreting physiological signs and symptoms, and persuasion (Lorig & Gonzalez, 1993). The findings indicated that the patients' self-efficacy was enhanced as a result of the intervention. More importantly, increased self-efficacy, unlike increased practice of self-management behaviors, was associated with improved health status.

Designing Patient Education Programs Through Needs Assessments

Many patient education programs use the PRECEDE model as a basic framework for community analysis and program development (Green & Kreuter, 1991). This model can also be used to assess the behavioral and educational needs of a specific population. The needs assessment can be conducted using surveys, interviews, and focus groups of the population of interest (Marti-Costa & Serrano-Garcia, 1983). Needs assessment is a vital step in patient education program development because it further defines the patient/client population, the needs of the patients directly, and the cultural factors and barriers of the population of interest (Villejo, 1993). Furthermore, needs assessment provides insight into factors that will facilitate, and those that will impede, future planning, implementation, and evaluation of the patient education program.

Application of Self-Help and Self-Care in HIV/AIDS Education

During the 1980s, many HIV/AIDS prevention programs and interventions were established. However, program planning gave little consideration to theoretical models for implementing health promoting interventions (Wardrop, 1993). Health promotion is essentially the process of enabling people to increase control over their health. Patient education using self-help or self-care strategies is a practical and feasible approach to health promotion for HIV-infected individuals as their condition becomes chronic (Lovejoy et al., 1991).

Traditionally, patient education has been utilized in hospitals and Health Maintenance Organizations (HMOs) to provide information to individuals on how to manage their chronic or acute illnesses (Villejo, 1993). These programs are limited in the sense that their primary focus is relaying knowledge about the disease of interest, rather than teaching cognitive skills to motivate self-control behaviors (Mullen, 1993). Patient education programs like these are often developed in the form of HIV education seminars hosted once a month, or every two months, at HMOs, such as Kaiser Permanente Medical Center in California. Unfortunately, no evaluation research on the content and effectiveness of these seminars could be found in the current AIDS or patient education literature.

CBOs' Role in Providing Patient Education to People with HIV/AIDS

Many of the limitations in HIV/AIDS-related health education and disease prevention programs within medical institutions are a direct result of the increasing numbers of HIV-infected patients, as well as the increasing demand for social and medical services (Fee & Krieger, 1993). Community-based organizations have consistently responded to these demands by providing specialized HIV interventions that address primary, secondary, and tertiary levels of prevention (Freudenberg, 1991). Patient education programs act as a tertiary preventive measure to combat the progression of HIV disease and disability. These programs can help people with HIV/AIDS cope, take care of themselves, and perform activities of daily living (Wardrop, 1993).

Surprisingly, the AIDS-related literature on patient education and self-help/self-care programs is small in comparison to other chronic diseases. However, the role of CBOs in offering health education and psychosocial support to people living with HIV/AIDS underscores the effort AIDS service organizations have made in providing preventive services at the tertiary level.

Support groups for people with HIV/AIDS are frequently used as a tertiary preventive strategy to address the psychosocial issues across the disease spectrum. One study examining the effectiveness of support groups for individuals with HIV/AIDS suggests that participation in a support group may help individuals decrease their level of anxiety and hopelessness, while helping them cope better with their illness (Kenneally Nicholas & Webster, 1993). Additionally, the Special Health Education Program of the Los Angeles Shanti Foundation was developed to assist HIV-infected, gay and bisexual men through the bereavement process after having lost loved ones to AIDS (Gorman & Mallon, 1989). The evaluation of this program concluded that sharing experiences and information allowed group members to alleviate stress, and take responsibility for their own lives and health.

In fact, the relationship between psychological variables (i.e, mental depression, perceived loss of control, feelings of helplessness) and altered immune functioning has been documented. The data suggest an association between psychosocial stress and the progression of HIV infection (Antoni, Schneiderman, Fletcher, & Goldstein, 1990). Most studies observing psychosocial stress in association with HIV progression have used HIV seropositive gay men as their subjects. However, there are common elements that cross sex and ethnicity relating to psychosocial disruptions, particularly loss or severe strain on existing social systems, and financial distress (Bendell, 1990). The way in which women respond to these elements needs to be further investigated.

With the emergence of HIV infection as a chronic condition, adopting healthy lifestyles has become a treatment emphasis. Many CBOs have been involved in sponsoring HIV/AIDS education seminars emphasizing self-help and self-care (Fee & Krieger, 1993). These seminars are replete with reminders about living a "balanced" life by eating nutritious food, sleeping adequately, and exercising. As an adjunct, CBOs in collaboration with local health departments have developed Early Intervention Programs (EIPs) for individuals who have been newly infected with HIV (Penny, 1993; Santa Clara County Health Department, 1990-1992). Through EIPs, individuals can understand the elements of the disease process at an early stage so that they are better able to deal with the impact of HIV infection on their work, diet, fitness, and relationships.

Despite the progress made by CBOs in responding to this epidemic at a tertiary prevention level, comprehensive patient education programs for people living with HIV/AIDS have not yet been fully developed. HIV infection and AIDS are still viewed by the medical community and mainstream society as acute, terminal diseases (Aiken, 1989; Fee & Krieger, 1993). As a result, most AIDS prevention efforts have concentrated on high-risk, HIV negative populations (Wardrop, 1993). Most of the currently available patient education programs emphasizing self-help and self-care are one-dimensional, information-oriented, and short-term. Moreover, the range of HIV/AIDS preventive programs becomes less innovative as less funding is dedicated to health education, and as more costly services are duplicated between organizations (Crystal, 1989; Lenker et al., 1993).

Patient education has not been readily available to all HIV-infected individuals. Community-based AIDS service organizations have their origins in the gay community, and while many of these CBOs have taken steps to make themselves available to other communities, most still provide only nominal services to non-gays (Wong-Rieger & David, 1993). Fortunately, other groups representing women, people of color (i.e., Blacks, Hispanics), and intravenous drug users have formed CBOs that respond to their specific needs and concerns (Freudenberg & Trinidad, 1992; Ting & Carter, 1992).

Assessing the Need for Patient Education for People Living with HIV/AIDS

Conducting a needs assessment is one method to determine whether patient education is perceived as important by HIV-infected communities (Manderson & Aaby, 1992). Several different needs assessment techniques can be used to generate qualitative and/or quantitative data. One of the most common forms of a quantitative needs assessment is a questionnaire checklist (Lorig, 1992). The advantages of this method are that it is easy to administer and tally, and can obtain quite specific information.

The disadvantage with this technique is that it usually reflects the interests of the researcher, and not necessarily those of the participants. Secondly, the relationship between researcher and participants is minimal during data collection, leaving the researcher with less control over the quantity and/or quality of the data (Marti-Costa & Serrano-Garcia, 1983).

On the other hand, qualitative needs assessments can gather more information directly related to the concerns and needs of participants. The data are generated through in-depth interviews or focus groups using open questions (Scrimshaw, Carballo, Ramos, & Blair, 1991). This approach is capable of providing valuable insight into the complexity and range of human attitudes, values, and behaviors. Open questions can be used to complement a fixed-question survey. They are also useful in identifying the salient beliefs and primary concerns of people living with HIV/AIDS.

At this point in the AIDS epidemic, it is important to recognize not only what has been accomplished by the medical establishment and CBOs in providing treatment and care to people living with HIV/AIDS, but what still is lacking. A comprehensive patient education program for people living with HIV/AIDS may help lower the costs of HIV/AIDS-related health care, consolidate services so that they are not duplicated from one organization to another, and empower individuals to believe that they can live with HIV as a chronic and manageable condition. A formal needs assessment was an important next step in determining whether such a program might help fill the gap in health and social services for people living with HIV/AIDS.

CHAPTER 3: METHODS

Objectives

This study was designed to meet the following objectives:

1. To determine the perceived need for patient education designed to teach self-help and self-care strategies to men and women living with HIV/AIDS.

2. To determine which self-help and self-care topics were perceived as important and should be included in a patient education program for people living with HIV/AIDS.

3. To provide an assessment of the self-help and self-care service needs of men and women living with HIV/AIDS, which can be used by community-based organizations that offer HIV/AIDS-related services.

4. To provide HIV seropositive men and women the opportunity to express their views and concerns about living with HIV/AIDS.

Questions

The research questions addressed in this study were:

1. Is a patient education program designed to teach HIV-related self-help/self-care strategies perceived as a need by men and women living with HIV/AIDS?

2. What are the self-help/self-care topics that are perceived as most important by men and women living with HIV/AIDS?

3. What are the salient themes common to HIV seropositive

individuals that need to be incorporated in a patient education program?

Definitions

The following terms are defined to avoid ambiguity. They are categorized as either conceptual or operational definitions.

Conceptual Definitions

AIDS - The acronym for Acquired Immunodeficiency Syndrome. It is a condition that results from a compromised immune system, especially due to the destruction of CD4 lymphocytes by HIV.

Asymptomatic - A healthy condition in which no symptoms of AIDS are observed, but P24 antibodies indicating the presence of HIV are detected in the person's blood. Under the new CDC definition (1993), asymptomatic individuals can be diagnosed as either being HIV seropositive, or having AIDS.

Bisexual Men - Men whose sexual orientation is towards both men and women. Sexual transmission of HIV is mainly through anal, vaginal, and/or oral sex with either men or women.

Community-Based Organizations - Agencies outside of the HIV/AIDS health care delivery system, which provide unique HIV/AIDS-related services to HIV-infected individuals. These services include seminars or classes on HIV-related topics, support groups, and early intervention programs. Other names for community-based organizations include AIDS health projects and AIDS service organizations.

Gay Men - Men whose sexual orientation is towards other men. Sexual transmission of HIV is mainly through anal and/or oral sex.

HIV - The acronym for Human Immunodeficiency Virus. It is the etiologic agent for the condition known as AIDS.

HIV Seropositive - The condition of having antibodies that are specific to HIV P24 antigen in a person's blood. To determine the HIV status, the blood is analyzed by diagnostic tests called the P24-antibody ELIZA and Western Blot.

Patient Education - A form of health education that teaches patients/clients skills and information on how to manage their acute or chronic conditions in order to improve the quality of their lives.

Self-Care - "A process whereby a layperson can function effectively on his or her own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system" (Parcel et al., 1986, p.17).

Self-Help - A concept which refers to "the performance of preventive or therapeutic health care activities, often in collaboration with health professionals" (Tobin et al., 1986, p. 29).

Transgender - An individual who cross-dresses. If it is a man, he can identify himself as either a man or a woman. Conversely, a woman can identify herself as either a man or a woman.

Operational Definitions

Alternative Therapies - Palliative remedies or treatments used by HIV seropositive individuals alone or in concert with clinical drugs to prevent the progression of HIV disease, or to treat any symptoms of AIDS. These therapies include herbal remedies, acupuncture/acupressure, and the use of a chiropractor. They are considered "alternative" because they are not scientifically proven to respond to, and/or regulate HIV. Alternative therapies are included in the self-help/self-care categories listed in Part 2 of the questionnaire (see Appendix A).

COBRA - The acronym for Consolidated Omnibus Budget Reconciliation Act of 1985. This plan allows all individuals to obtain medical coverage for up to 18 months after leaving their employer (for any reasons other than gross misconduct). This service is one of the choices listed under the self-help/self-care topics in Part 2 of the questionnaire (see Appendix A).

Domestic Partners - A relationship in which two individuals (man or woman) are monogamous and living together. This relationship status is one of the choices indicated on Question 8 in Part 3 of the questionnaire (see Appendix A).

Having AIDS and Asymptomatic - Under the new CDC definition (1993), any HIV seropositive individual with a CD4 lymphocyte count less than 200 is diagnosed as having AIDS, regardless of health status. In this study, having AIDS and being asymptomatic were self-reported on Question 3 in Part 3 of the questionnaire (see Appendix A).

OBRA - An extension of COBRA that provides an additional 11 months of medical coverage to only those individuals who left their employer because of any disability or health reason. This service is one of the choices listed under the self-help/self-care topics in Part 2 of the questionnaire (see Appendix A).

Primary Relationship - A relationship status in which two individuals are intimate but may also see other people on an intimate level. These individuals are not necessarily living with each other. In this study, primary relationship was one of the choices on Question 8 in Part 3 of the questionnaire (see Appendix A).

Self-Help/Self-Care Topics - Subjects of importance which could be potentially included in a patient education program for people living with HIV/AIDS. Potential respondents were asked to rate 20 self-help/self-care topics in Part 2 of the questionnaire (see Appendix A). Some examples were nutrition, exercise, stress-management, and the use of medical services.

Methodology

The need for a comprehensive patient education program for people living with HIV/AIDS was assessed using a written, self-administered survey. The survey questions explored whether or not patient education classes were a perceived need for people living with HIV/AIDS. The questions also asked about self-help/self-care topics men and women living with HIV/AIDS valued, and explored their thoughts, feelings, and concerns about living with HIV/AIDS.

Study Design

The design of this study was descriptive research, using a written, self-administered questionnaire as the method for exploring the patient education needs of people living with HIV/AIDS. A survey had the benefit of gathering a wide range of information from the subjects in a short period of time. For this study, the information included (a) thoughts, feelings, and concerns of people living with HIV/AIDS, (b) opinions on different self-help/self-care strategies, and (c) demographic information. Individuals who were HIV seropositive and/or who had an AIDS diagnosis were selected as subjects for this study.

Survey Questionnaire

Data were collected through an original needs assessment questionnaire. The questionnaire was four pages in length and consisted of three parts (see Appendix A). To protect confidentiality, potential participants were not asked to provide any identifying variables (e.g., address, county, social security number, or phone number) on the questionnaire.

Part 1 used open questions to explore the attitudes people with HIV/AIDS may share. Specifically, three questions asked the participants to express (a) their thoughts about living with HIV/AIDS, (b) how their lives had changed since the diagnosis, and (c) their concerns and frustrations about living with HIV/AIDS.

Part 2 explored the need for a comprehensive patient education program for people living with HIV/AIDS. Participants were asked to rate 20 self-help/self-care topics that could potentially be included in the program. The 20 topics that the respondents rated can be organized under the following four categories:

1. "Use of financial services," which included benefits planning, COBRA/OBRA, and private insurance.

2. "Use of medical services," which included communicating with

doctors, reading medical charts, clinical drug trials information, and medication/treatment information.

3. "Alternative therapies," which included herbal remedies, acupuncture/acupressure, and chiropractic services. Space was provided for the respondents to add and rate any other alternative therapies which were not listed on the questionnaire.

4. "Community resources," which included support groups, childcare services, and HIV/AIDS-related seminars.

Part 3 addressed demographic characteristics, such as age, sex, sexual orientation, HIV status, ethnicity, level of education, relationship status, number of children, and type of health care provider. On page 4 of the questionnaire, respondents were invited to (a) participate in a focus group at some later date to assist with the specific design of a patient education program, and/or (b) obtain a summary of study results. These options were included in order to provide a follow-up for those wishing greater involvement in the study, and to ensure the participants that the disclosure of the findings would be accessible to them.

Each potential participant received a questionnaire packet. The packet included a cover letter, a needs assessment questionnaire, and a stamped, self-addressed envelope. There was no financial compensation of any kind. Participants mailed completed questionnaires back to the researcher's home.

The cover letter explicitly stated that participation in this study was completely voluntary. Specific clauses were included explaining the purpose of the study, the expected benefits of participation, and the process of protecting the potential participants' confidentiality.

Preliminary Review

A focus group of six HIV-infected people helped re-phrase questions and simplify sentences on the questionnaire so that anyone with a high school literacy level would be able to understand it. In addition, questionnaires were given to an HIV-infected friend who pilot tested them on 10 HIV-infected members of his support group.

A complete research protocol, consisting of the purpose, research questions, and methodology for this study, was submitted to the Human Subjects-Institutional Review Board (HS-IRB) at San Jose State University (SJSU). The protocol provided information about the procedure for selecting subjects, expected benefits and/or risks to participants, and the process of protecting the confidentiality of study subjects. In addition, copies of the questionnaire and its cover letter were included. The research protocol was approved by HS-IRB on September 1, 1993 (see Appendix B).

Sample Selection

To be eligible to participate in the study, participants had to have a self-reported HIV seropositive and/or AIDS diagnosis, and be over the age of 18. The sample of men and women was recruited from agencies in northern California that offered services to people living with HIV/AIDS. The researcher found these agencies' phone numbers from a mailing list provided by Women Organized to Respond to Life Threatening Diseases (WORLD).

Survey Distribution

Upon approval of the research protocol, the surveys were distributed at agencies and an HIV education seminar sponsored by Kaiser Permanente Medical Center. Through the agencies, potential participants were contacted in both clinical settings and support groups. In clinical settings, the receptionist handed out the questionnaire packets to HIV seropositive clients who were interested in participating in the study. During HIV seropositive support groups, facilitators were asked to distribute the questionnaire packets to group members. The researcher was not in direct contact with these potential respondents at any point in data collection.

However, a small number of participants were recruited directly by the researcher at a public HIV education seminar sponsored by Kaiser Permanente Medical Center. The researcher was invited to the seminar to explain the objectives of the study, and distribute questionnaire packets to individuals interested in participating.

Data Entry/Analysis

A codebook was developed for the questionnaire (see Appendix C). The questionnaire asked both closed and open questions. Answers to the closed questions were coded directly, using pre-assigned values (i.e., 1 = yes, 2 = no). The open questions were read by the researcher and one HIV seropositive volunteer for the purpose of identifying themes. As themes were identified, they were monitored to determine how frequently they appeared in participants' responses.

The coded data were entered into a microcomputer and analyzed using the statistical program EPI-INFO. Statistics describing the demographic information (Part 3 of the questionnaire) were calculated. In addition, male and female group comparisons were performed using an R X C contingency table to determine the percentages of the respondents' ratings for each of the questions regarding the self-help/self-care topics.

Assumptions

This research was based on several assumptions concerning the survey instrument, collaborating agencies, and the sample population.

Survey Instrument

It was assumed that a self-administered, anonymous questionnaire was an appropriate tool to conduct a needs assessment because it could obtain a great deal of information from the sample population in a short period of time.

Secondly, it was assumed that the instrument would access adequate quantitative and qualitative data to express the concerns, priorities, and needs of men and women living with HIV/AIDS.

Lastly, it was assumed that providing a self-addressed, stamped envelope with the questionnaire would make the return process more convenient and increase the overall response rate.

Collaborating Agencies

Data collection was dependent on the help of collaborating agencies in distributing questionnaire packets to their clients. It was assumed that these agencies would be willing and interested in participating in the study since the results could provide useful information regarding their own services.

A second assumption was that the staff at the agencies would have their clients complete the questionnaires on site, and subsequently send them to the researcher.

The last assumption was that there were not many patient education services emphasizing self-help or self-care available at these agencies, especially in low to moderate incidence areas. Therefore, it was assumed that staff would welcome the opportunity for a needs assessment of their clients.

Sample Population

The researcher also made several assumptions about the nature and distribution of the sample population. Because of the stigma attached to being HIV seropositive and/or having AIDS in mainstream society, it was extremely important to protect confidentiality. For this reason, it was assumed that no direct access to the sample population would be permissible.

The second assumption was that equal numbers of men and women would be interested in participating in the study. Due to the diversity of the greater San Francisco Bay Area, it was assumed that participants would represent the ethnic and cultural diversity of the HIV/AIDS community at large.

A third assumption was that men and women would have different needs in terms of living with HIV/AIDS.

The final assumption had to do with financial compensation. It was assumed that no monetary incentive would be necessary as there would be substantial interest from both men and women about the concept of patient education for people living with HIV/AIDS.

Based on these assumptions about the questionnaire, participating agencies, and the potential respondents, it was assumed that data collection would take one month and that an adequate sample (50% response rate) would be obtained.

CHAPTER 4: RESULTS

The data collection period was from September, 1993, to February, 1994. During this time, the sample of men and women with a self-reported, HIV seropositive and/or AIDS diagnosis was recruited from agencies in northern California that offered HIV/AIDS-related services. A brief description of each agency's services is provided in Appendix D. A total of 180 questionnaire packets was sent to 10 community-based organizations and 20 additional packets were handed out at an HIV education seminar at a health care facility. Questionnaire distribution is detailed in Table 1.

A total of 72 questionnaires was returned to the researcher. Two questionnaires were eliminated from the final sample. In both cases, none of the questions were answered, and notes were attached stating that the questionnaires were too painful to complete. The other 70 returned questionnaires were complete, and the respondents fit the criteria for inclusion in the study. The final response rate was 35.0%.

Each collaborating agency contributed to the final sample (see Table 2). Of the 70 completed questionnaires, most were from clients of agencies which provided support groups as opposed to other HIV/AIDS-related services (e.g., clinical, or alternative healing). Nearly one-fourth of the completed questionnaires were from clients of Most Holy Redeemer (21.4%), which primarily offers AIDS support group services. The least number of respondents came from clients of health clinics, such as Planned Parenthood ($\underline{n}$ = 3) and the Santa Cruz AIDS Project ($\underline{n}$ = 4).

Table 1

Questionnaire Distribution at Collaborating Agencies

Agency	No.	Location
Tri-City Health Center	35	Fremont
Aris Project	30	Campbell
Most Holy Redeemer	30	San Francisco
The Center	20	Pleasanton
Kaiser[a]	20	Oakland
ESO	15	San Jose
Center for AIDS Services	12	Oakland
Planned Parenthood	10	San Francisco
Center for Attitudinal Healing	10	Tiburon
Santa Cruz AIDS Project	10	Santa Cruz
WEL support group	8	San Francisco
Total	200	

[a] Kaiser sponsored the HIV education seminar.

Table 2

Source of Completed Questionnaires

	Respondents (N = 70)	
Source	n	%
Most Holy Redeemer	15	21.4
Aris Project	11	15.7
Kaiser Permanente	8	11.4
Tri-City Health Center	7	10.0
The Center	7	10.0
Center for Attitudinal Healing	5	7.1
Santa Cruz AIDS Project	4	5.7
Center for AIDS Services	4	5.7
ESO	3	4.3
Planned Parenthood	3	4.3
WEL Support Group	3	4.3
Total	70	100.0

Description of the Sample Population

A total of 52 men and 18 women with a self-reported HIV seropositive and/or AIDS diagnosis participated in the study. No transgenders participated. Male respondents were between the ages of 26 and 58, with a mean age of 40 years. The women were between the ages of 24 and 54, with a mean age of 41 years.

Both male and female respondents had at least a high school education (see Table 3). One of the women in the sample completed the 11th grade, but noted on the questionnaire that she received a General Education Degree (G.E.D.). The mean educational levels for men and women were 14.83 and 13.39 years, respectively, indicating some years of post high school education.

Table 3

Education level of Sample

	Grade level			
Respondents (N = 70)	Mean	SD	MIN	MAX
Male (n = 52)	14.8	4.2	12.0	17.0
Female (n = 18)	13.4	1.7	11.0	17.0

Note. MIN = minimum value; MAX = maximum value. The range of values was between 11 (11th grade) and 17 (five years post high school).

Health Care Provider and HIV Status

Descriptive statistics regarding health care providers and HIV status are provided in Table 4. Respondents reported a variety of health care providers. More than one-third of the respondents belonged to an HMO (34.3%), approximately one-fourth received their health care through Medi-Cal (20.0%), and less than one-fourth had private doctors (15.7%). The remainder of respondents reported a combination of health care providers.

Fully 60.0% of the sample had a self-reported AIDS diagnosis and were also symptomatic, compared to 8.6% who had an AIDS diagnosis but were asymptomatic (see Table 4). Nearly three-fourths of the males (73.1%) and over half of the females (55.6%) had been diagnosed with AIDS. The remainder reported that they were HIV seropositive.

Respondents were asked to provide the date that they tested HIV seropositive, and if applicable, when they were diagnosed with AIDS (see Appendix A). Of the 70 respondents, 63 gave the approximate date that they were tested HIV seropositive (48 men and 15 women). Of these 63 individuals, 43 gave the date that they were diagnosed with AIDS (see Table 5).

The male respondents had been living longer with HIV than the females (see Figure 1). Thirty-five (72.9%) of the 48 men had been HIV seropositive for more than five years; one of them had been HIV seropositive since 1982. Four men from this group of 35 had lived with AIDS for more than five years.

Nearly two-thirds (60.0%) of the 15 women had been HIV seropositive for longer than five years (see Figure 1). Four of the 9 women had lived with an AIDS diagnosis for more than five years. Nearly half (46.7%) of the 15 women were diagnosed with AIDS within a year of testing HIV seropositive, and 3 (42.9%) were diagnosed with AIDS at the same time they found out they were HIV seropositive.

Table 4

Health Care Provider and HIV Status

	Respondents			
	Men (n = 52)		Women (n = 18)	
Variables	n	%	n	%
Health care provider				
HMO	20	38.5	4	22.2
Medi-Cal	8	15.4	6	33.3
Private doctor	8	15.4	3	16.7
Other	16	30.8	5	27.8
Total	52	100.0	18	100.0
HIV status				
AIDS				
symptomatic	33	63.4	9	50.0
asymptomatic	5	7.7	1	5.6
HIV seropositive (no symptoms)	14	26.9	8	44.4
Total	52	100.0	18	100.0

Table 5

Number of Respondents Giving Dates When Diagnosed

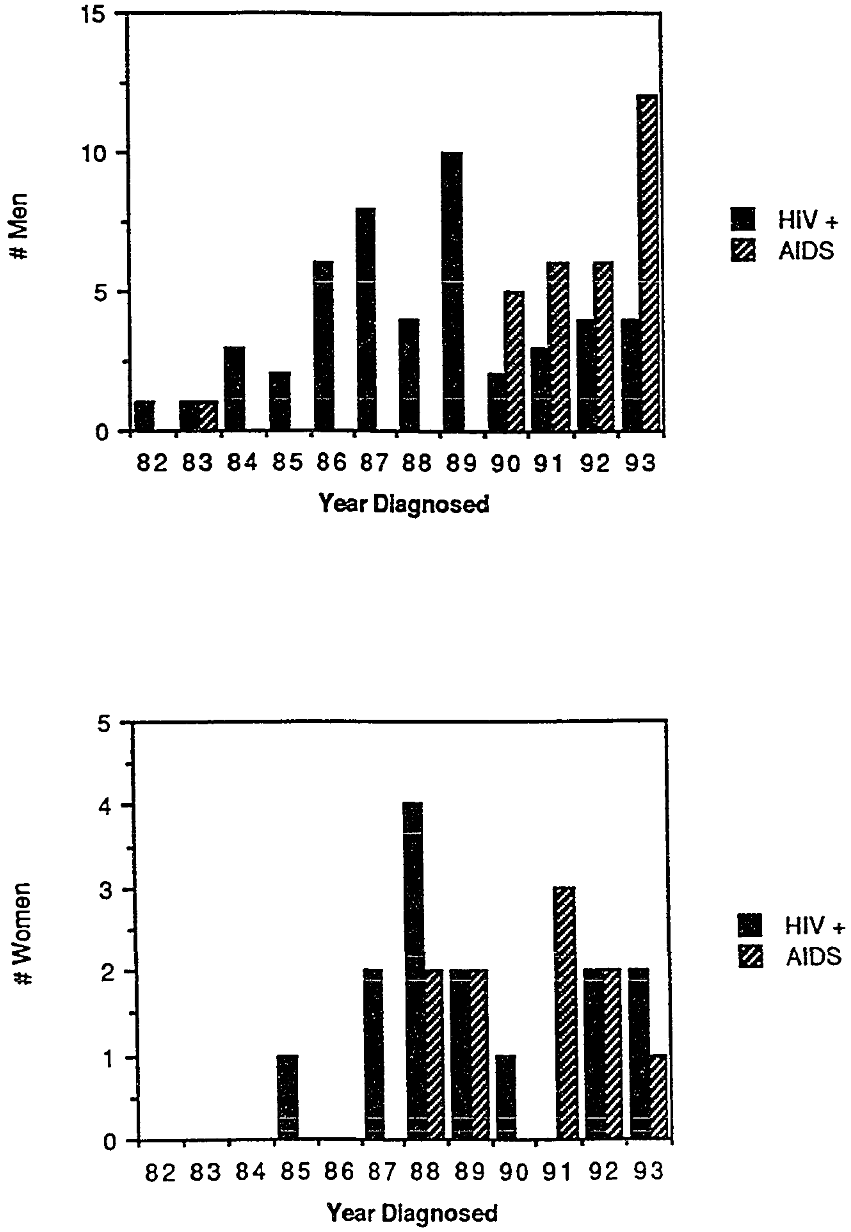
Diagnosis	Respondents (n = 63)	
	Males (n = 48)	Females (n = 15)
HIV seropositive	48 (100.0%)	15 (100.0%)
AIDS	33 (68.8%)[a]	8 (53.3%)[a]

[a] Percentage based upon the number of respondents who gave dates when they tested HIV seropositive.

Ethnicity and Sexual Orientation

There was greater ethnic diversity among male respondents than among the females (see Table 6). When ethnicity and sexual orientation were combined, the largest subgroup of the sample was gay, white males (47.1%). The women were equally divided into two ethnic groups: Caucasian and Black. Sixteen of the 18 women identified themselves as heterosexual.

Figure 1. Number of male and female respondents as a function of the year diagnosed as HIV seropositive and/or with AIDS.



Relationship Status and Sexual Orientation

The question on relationship status offered the following response options: single, married, domestic partner, and primary relationship. A large proportion of the male respondents were single (see Table 7). Of the 38 gay male respondents, nearly two-thirds said that they were single (63.2%).

Similarly, 14 (77.8%) of the female respondents were single, but of these individuals, 12 (66.7%) were heterosexual (see Table 7). Only 3(16.7%) of the heterosexual women were married.

Table 6

Association Between Ethnicity and Sexual Orientation

Ethnicity	Sexual orientation (N = 70)			
	Gay	Lesbian	Bisexual	Heterosexual
Men (n = 52)				
Caucasian	33	--	7	2
Latino	4	--	0	2
Black	0	--	3	0
Asian	1	--	0	0
Total	38	--	10	4
Women (n = 18)				
[a]Caucasian	--	1	1	7
[a]Black	--	0	0	9
Total	--	1	1	16

[a] Women were represented by only two ethnic groups, Caucasian and Black. Therefore, other ethnic groups were not listed.

Table 7

Association Between Relationship Status and Sexual Orientation

Status	Sexual orientation (N = 70)			
	Gay	Lesbian	Bisexual	Heterosexual
Men (n = 52)				
Single	24	--	5	3
Married	0	--	4	1
Domestic partner	9	--	1	0
Primary relationship	5	--	0	0
Total	38	--	10	4
Women (n = 18)				
Single	--	1	1	12
Married	--	0	0	3
Domestic Partner	--	0	0	1
Total	--	1	1	16

Children

Only 27 (38.6%) of the 70 respondents had children (see Table 8). However, two-thirds of the 18 female respondents had children. Nine of these 12 women (75.0%) were Black. Ten of the 12 women (83.3%) had their children living with them. Only one of these 10 women had three or more children.

In contrast, less than one-third of the men (28.8%) had children. Eleven of these 15 men were Caucasian (73.3%). Interestingly, 11 (73.3%) had their children living with them. More than three-fourths (86.7%) of the men had no more than two children.

The majority of the male and female respondents who had children were single (see Table 9). Seven (46.7%) of the 15 men were single as opposed to 5 (33.3%) who were married. The majority of the 12 women with children were single (66.7%).

Table 8

Association Between Having Children and Ethnicity

	Ethnicity (n = 27)			
	Caucasian	Black	Latino	Asian
Men (n = 15)				
Children	11	2	2	0
No. of children				
1 or 2	11	1	1	0
3 or more	0	1	1	0
Total	11	2	2	0
Live with respondents	9	1	1	0
Women (n = 12)				
Children	3	9	0	0
No. of children				
1 or 2	3	8	0	0
3 or more	0	1	0	0
Total	3	9	0	0
Live with respondents	2	8	0	0

Note. Values based upon number of respondents who had children.

Table 9

Association Between Having Children and Relationship Status

	Relationship status (n = 27)			
	Single	Married	DP	PR
Men (n = 15)				
Children	7	5	2	1
No. of children				
1 or 2	6	4	2	1
3 or more	1	1	0	0
Total	7	5	2	1
Children live with respondent	3	5	2	1
Women (n = 12)				
Children	8	3	1	0
No. of children				
1 or 2	7	3	1	0
3 or more	1	0	0	0
Total	8	3	1	0
Children live with respondent	6	3	1	0

Note. DP = domestic partner; PR = primary relationship.

Note. Values based upon number of respondents who had children.

Perceived Need for a Comprehensive Patient Education Program for People Living with HIV/AIDS

Previous and/or Current Access to Patient Education Services

On the questionnaire, patient education was defined as "a form of health education that teaches you any knowledge and/or skills that help you manage living with HIV/AIDS" (see Appendix A). Following the definition, participants were asked if they had received any patient education. Of the 70 respondents, 59 (84.3%) said they had received some form of patient education. Male respondents were generally satisfied with the patient education services available in their communities (see Table 10). However, nearly one-fourth (20.0%) of the female respondents were not satisfied with these services.

Table 10

Level of Satisfaction with Current Patient Education Services

	Respondents (*n* = 59)[a]			
	Men (*n* = 44)		Women (*n* = 15)	
Satisfaction level	*n*	%	*n*	%
Satisfied	22	50.0	7	46.7
Somewhat satisfied	20	45.5	5	33.3
Not satisfied	2	4.5	3	20.0
Total	44	100.0	15	100.0

[a] Value represents respondents who received patient education.

Respondents were asked to indicate the sources of patient education they had received. Participating agencies had helped compile the list of sources during questionnaire development. Response options included HIV education seminars/classes, group counseling/support groups, county AIDS Health Projects (AHPs), Early Intervention Programs (EIPs), and AIDS Service Organizations (ASOs). Space was provided to write any other patient education sources.

Table 11 shows where the male and female respondents reported receiving patient education. Nearly all of the men (90.9%) had attended group counseling and/or support groups. Agencies, such as AIDS service organizations (ASOs), have traditionally provided support group services. This may be why close to three-fourths of the men (72.7%) also reported patient education from ASOs.

Of the female respondents, 13 (86.7%) of the 15 had received patient education through group counseling/support groups. As with the male respondents, nine (60.0%) reported receiving patient education from ASOs.

Further analysis was done to identify any differences between groups. Among the males who had received patient education, 26 (59.1%) of the 44 respondents were Caucasian and gay (see Table 12). In contrast, most of the women who had received patient education were either Caucasian heterosexuals (40.0%) or Black heterosexuals (46.7%).

Table 11

Sources of Patient Education

	Respondents (n = 59)[a]			
	Men (n = 44)		Women (n = 15)	
Sources	n	%[b]	n	%[b]
Group counseling/ support groups	40	90.9	13	86.7
ASOs	32	72.7	9	60.0
Seminars/classes	26	59.1	6	40.0
AHPs	19	43.2	5	33.3
EIPs	14	31.8	2	13.3
Other	12	27.3	4	26.7

[a] Value represents the respondents who received patient education.

[b] Because the respondents were able to choose one or more sources of patient education, percentages do not total 100%.

Table 12

Association Between Patient Education, Ethnicity, and Sexual Orientation

	Sexual Orientation ($\underline{n}$ = 59)[a]			
Ethnicity	Gay	Lesbian	Bisexual	Heterosexual
Men ($\underline{n}$ = 44)[a]				
Caucasian	26	0	7	3
Asian	1	0	0	0
Latino	4	0	0	1
African American	0	0	2	0
Total	31	0	9	4
Women ($\underline{n}$ = 15)[a]				
Caucasian	0	1	1	6
African American	0	0	0	7
Total	0	1	1	13

[a] Values represent the respondents who received patient education.

Perceived Need For a Comprehensive Patient Education Program Emphasizing Self-Help/Self-Care

Overall, 69 of the 70 respondents felt there was a need for a comprehensive patient education program for people living with HIV/AIDS. Self-help and self-care strategies that needed to be covered in the patient education classes were rated from very important (5) to not important (1).

Priority Self-Help and Self-Care Topics

A mean was calculated for each of the 20 self-help/self-care topics (see Table 13). The means for the topics were ranked in order from the highest to lowest. Overall, the 69 respondents identified stress management (M = 4.8) as the highest priority, followed closely by support groups (M = 4.7). Informative topics, such as nutrition (M = 4.6) and medical therapies (M = 4.5), also had high ratings. The alternative therapies were rated the lowest; chiropractic services (M = 2.9) had the lowest rating of the 20 topics listed.

There were differences in self-help/self-care priorities between male and female respondents, especially in the higher ratings (see Table 14). Among the men, stress management was considered the highest priority (M = 4.7), followed by support groups (M = 4.6).

The female respondents gave generally higher ratings to each of the self-help/self-care priorities. Each of the 18 women gave support groups the highest priority rating (M = 5.0). Childcare services (M = 5.0) were also rated the highest by the sample of women. Even though some of the men in the sample had children, they did not rate childcare services (M = 4.3) as highly as did the women. The second highest priority for women was stress management (M = 4.9).

Financial services and alternative therapies were rated similarly by the male and female respondents. These topics received relatively low ratings, with alternative therapies receiving the lowest ratings. However, men gave higher ratings than the women to the financial service topics, such as private insurance (M = 3.9) and COBRA/OBRA (M = 3.5).

Table 13

Rank Order For Each of the 20 Self-Help/Self-Care Topics

Self-help/self-care topics	n[a]	M	SD	MIN	MAX
Respondents (n = 69)					
Stress management	69	4.8	0.8	0	5
Support groups	69	4.7	0.7	2	5
Nutritional information	69	4.6	0.9	0	5
Communication with doctor	69	4.5	0.8	2	5
Medication/treatment info.	69	4.5	0.8	2	5
Childcare services	61	4.5	1.9	0	5
HIV/AIDS-related seminars	69	4.4	1.0	0	5
Discussion/problem-solving	67	4.4	1.2	0	5
Vitamin therapy	69	4.2	1.2	0	5
Exercise	69	4.1	1.1	0	5
Alcohol or drug use/abuse info.	68	4.1	1.2	0	5
Benefit planning	63	4.0	1.5	0	5
Clinical drug trials info.	69	3.9	1.1	0	5
Private insurance	61	3.8	1.6	0	5
Reading medical charts	69	3.7	1.1	0	5
Herbal remedies	67	3.6	1.4	0	5
Acupuncture/acupressure	66	3.5	1.4	0	5
COBRA/OBRA	57	3.4	1.8	0	5
Chiropractic services	63	2.9	1.5	0	5
Other alternative therapies	31	1.3	2.1	0	5

Note. The range of values was from 5 (most important) to 1 (not important). MIN = minimum value; MAX = maximum value.

Note. Information is abbreviated as info.

[a] Values represent the number of respondents who answered this question.

Table 14

Comparison of Men's and Women's Self-Help/Self-Care Ratings

	Respondents (n = 69)					
	Men (n = 51)			Women (n = 18)		
Self-help/self-care topics	n[a]	M	SD	n[a]	M	SD
Support groups	51	4.6	0.8	18	5.0	0.0
Childcare services	44	4.3	2.1	17	5.0	1.1
Stress management	51	4.7	0.8	18	4.9	0.5
HIV/AIDS-related seminars	51	4.3	1.1	18	4.8	0.5
Medication/treatment info.	51	4.4	0.8	18	4.7	0.6
Communication with doctor	51	4.5	0.8	18	4.7	0.7
Nutritional info.	51	4.5	0.9	18	4.7	0.7
Discussion/problem-solving	50	4.4	1.2	17	4.4	1.2
Vitamin therapy	51	4.1	1.1	18	4.3	1.2
Exercise	17	4.1	1.1	17	4.2	1.3
Alcohol or drug use/ abuse info.	51	4.1	1.1	17	4.2	1.3
Benefit planning	48	4.0	1.4	16	4.1	1.6
Clinical drug trials info.	51	3.8	1.0	17	3.9	1.3
Reading medical charts	51	3.7	1.1	17	3.7	1.4
Herbal remedies	49	3.6	1.5	18	3.7	1.3
Acupuncture/acupressure	49	3.5	1.4	17	3.6	1.5
Private insurance	48	3.9	1.5	14	3.4	2.0
COBRA/OBRA	46	3.5	1.7	12	2.9	2.2
Chiropractic services	47	2.9	1.5	16	2.8	1.6
Other alternative therapies	17	1.5	2.2	4	1.0	1.9

Note. Ratings are ranked from highest to lowest means based on the women's responses.

Note. Information is abbreviated as info.

[a] Values represent the number of respondents who answered this question.

Assessment of the Time Schedule for Patient Education Classes

To determine the feasibility of people living with HIV/AIDS attending patient education classes, a time schedule checklist was included on the questionnaire. Specifically, the checklist asked for the respondents' opinions on (a) the number of classes that were needed to cover the self-help/self-care topics of interest, (b) the number of hours per class, and (c) how often classes should be held. Respondents were also asked whether they would like health professionals and/or peer volunteers to teach these classes.

Table 15 lists the responses of both male and female respondents who felt there was a need for a patient education program ($\underline{n}$ = 69). Over half of the men (61.5%) felt that the classes should be ongoing. Even though the sample size for women was smaller than for men, the values for the number of classes was similar. Of the 18 female respondents, 12 (66.7%) felt that the classes should be ongoing.

However, there were slight differences between males' and females' opinions regarding class length and frequency. More than half (61.1%) of the women and nearly half the men (51.9%) felt that there should be two hours per class. Over one-fourth (27.8%) of the women and nearly half (42.3%) of the men felt that the classes should be held weekly.

The majority of both male (76.9%) and female (83.3%) respondents felt that health professionals and peer volunteers with and without HIV infection should teach the patient education classes (see Table 15).

Table 15

Preferred Time Schedule for the Patient Education Program

	Respondents (n = 69)			
	Men (n = 51)		Women (n = 18)	
Preferred schedule	n	%	n	%
Number of classes				
4 - 5	14	26.9	3	5.8
6 - 7	3	5.8	1	1.9
8 - 10	2	3.8	2	3.8
Ongoing	32	61.5	12	66.7
Total	51	100.0	18	100.0
Number of hours per class				
1	23	44.2	7	38.9
2	27	51.9	11	61.1
3	1	1.9	0	0.0
Total	51	100.0	18	100.0
How often				
Weekly	22	42.3	5	27.8
Every two weeks	19	36.5	8	44.4
Monthly	10	19.2	5	27.8
Total	51	100.0	18	100.0
Preferred teachers				
Vol. with HIV	1	1.9	0	0.0
H.P.s & vol. with HIV	10	19.2	3	16.7
H.P.s & vol. with/without HIV	40	76.9	15	83.3
Total	51	100.0	18	100.0

Note. *H.P.s* refers to health professionals and *vol.* refers to volunteers.

[a] Value represents respondents who felt there was a need for a patient education program.

Thoughts, Feelings, and Concerns of People Living with HIV/AIDS

Three open questions were asked to explore issues that were not covered by the closed questions on the questionnaire. These open questions were:

1. When you think of HIV/AIDS, what do you think about?
2. In what ways has your life changed since your diagnosis?
3. What are your biggest concerns or frustrations about living with HIV/AIDS?

Thoughts about HIV/AIDS

The respondents were asked to list up to 10 words that describe their thoughts about HIV/AIDS (see Appendix A). Of the 70 respondents, 44 men (62.9%) and 18 women (25.7%) answered this question. Overall, 27 words were identified that represent the 62 respondents' thoughts about HIV/AIDS.

Tables 16 and 17 present the words as positive or negative thoughts. One of the words, anger, is listed in both categories since anger can have both positive and negative effects, depending upon the individual and the context. Of the positive thoughts (see Table 16), over half of the respondents (67.7%) identified a healthy lifestyle change they had made. These changes included improved nutrition, safer sex, avoiding risks, and exercise. Other respondents thought about the people in their lives, such as family/friends (22.6%) and significant others (12.9%).

Of the negative thoughts (see Table 17), over half of the 62 respondents listed death (67.7%). Nearly half of the respondents listed words relating to sickness (45.2%).

Table 16

Positive Thoughts About HIV/AIDS

	Respondents (n = 62)[a]	
Words	n	%
Healthy lifestyle changes	42	67.7
Anger	30	48.4
Medications/therapies	18	29.0
Happy	16	25.8
Hope	16	25.8
Family/friends	14	22.6
Social/political issues	14	22.6
Life	13	21.0
Support	9	14.5
Money	9	14.5
Relationships/love	8	12.9
Self	6	7.0
Volunteering	2	3.2

[a] Value represents the number of respondents who answered this question.

Table 17

Negative Thoughts About HIV/AIDS

	Respondents (n = 62)[a]	
Words	n	%
Death	42	67.7
Anger	30	48.4
Sickness	28	45.2
Rejection	24	38.7
Fear	23	37.1
Sadness/despair	23	37.1
Loneliness/isolation	14	22.6
Pain/suffering	14	22.6
Helpless	7	11.3
Dirty	7	11.3
Guilt	6	9.7
Uncertainty	6	9.7
Anonymity	5	8.1
Dependency	4	6.5
Frustration	4	6.5

[a] Value represents the number of respondents who answered this question.

Changes in Outlook and Lifestyle Since Diagnosis

The second question in this series asked respondents to describe in a few sentences their circumstances, lifestyle, and attitudes subsequent to their HIV seropositive and/or AIDS diagnosis.

Only 40 of the respondents responded to this question. Of these 40 respondents, 32 (80.0%) were men and 8 (20.0%) were women. The 10 salient themes were:

1. Changes in life and/or lifestyle.
2. Complications due to illness.
3. Limitations and physical disabilities.
4. Financial worries as a result of job loss.
5. Feeling closer to family/friends.
6. Loss of family/friends.
7. Loss of sexual desire.
8. Uncertainty about the future.
9. Enjoying life; not taking life for granted.
10. The "double-edged sword" of having HIV.

Among the male respondents, losing their jobs ($\underline{n}$ = 25), primarily due to illness complications, was a frequently stated comment. Becoming unemployed at such an early age also made many of these men feel like senior citizens. As one man articulated, "Now at 58 years old, I have to accept social security and become a struggling almost-senior before my time." Five men had lost their jobs due to discrimination in the workplace. One man had taken his employer to court, describing how "the workplace became a hostile environment immediately following my disclosure of HIV." Losing their jobs led to the new problem of worrying about finances (n = 15); an issue that these men may never have had to deal with before HIV.

Twenty (50.0%) of the male respondents stated that becoming sicker and less physically capable had prevented them from performing otherwise normal activities, such as gardening (n = 2), dancing (n = 4), exercising (n = 7), and having sex (n = 13). In some cases, loss of sexual desire contributed to other problems in relationships. One married man wrote, "The first thing to go was sex with my wife. It is still the thing I miss the most." For others, loss of sexual desire meant confronting difficulties in meeting other people, and starting new intimate relationships. As one respondent mentioned, "It [HIV] has ruined my life in terms of having a relationship with anyone, and sexually my life has come to a halt."

All eight of the women wrote more positively of how HIV had changed their lives. Most of them said they had stopped taking life for granted (n = 7) because they felt so uncertain about their future. As one woman stated, "I don't take things for granted anymore. Before my diagnosis, I can say I was a procrastinator. Now I get things done and enjoy life to the fullest." In other words, life became a continual process of learning and re-connecting to oneself. This was exemplified by one woman who felt, "I am in much closer touch with my feelings. I understand more about love. I experience - not just look at - life more these days."

The ways in which the respondents experienced life were demonstrated differently. Fifteen (37.5%) respondents gave some examples. Some of them spent more time with their families (n = 8). Some of them created a social support network of new friends and loved ones, to replace their old friends who rejected them as a result of their diagnosis (n = 5). Other respondents became politically active in the AIDS arena (n = 3), while other respondents found more meaning in social causes such as helping others, like themselves, to cope with living with HIV (n = 7).

Both male (n = 15) and female (n = 5) respondents had taken an active role in changing their own health behaviors and lifestyles. For example, some said that they had gone to support groups and classes on living with HIV/AIDS (n = 6); some made an effort to change their diets (n = 4); some stopped smoking, drinking, or taking recreational drugs (n = 12); and some became more religious and spiritual (n = 4).

Lastly, a total of 10 male and female respondents described dealing with HIV/AIDS as a constant battle between good and evil. They described HIV as a "double-edged sword" in the sense that it brought out the best and the worst in people. Individual respondents articulated this theme in different ways. One man stated:

> Right now, I associate HIV with herpes, stigma, excess baggage I can never get rid of, something that has destroyed/limited my life's potential. I also associate it [HIV] with strength and maturation – because of HIV, I had to develop.

Another women stated, "My life has changed for the better in some [ways], but worse in others. Better: I teaching others about HIV+ and AIDS. Worse: My love life is worse than before."

Concerns About Living with HIV/AIDS

All 62 respondents who answered the first question also responded to the third question, regarding their frustrations and concerns about living with HIV/AIDS. Indeed, many of the thoughts that the respondents expressed in the first question were mentioned as a concern in the third question. For example, of the positive thoughts, medications and relationships were also mentioned as concerns. Of the negative thoughts, both sickness and death were reiterated. Table 18 summarizes these concerns.

A majority of the respondents were concerned with their sickness (77.4%). Two concerns frequently stated were money problems (41.9%) and confidentiality (38.7%). Death (32.2%) was mentioned less often than the other concerns.

Table 18

Concerns About Living With HIV/AIDS

Concerns	Respondents (n = 62)[a]	
	n	%
Sickness	48	77.4
Money problems	26	41.9
Disclosure/confidentiality	24	38.7
Medications/therapies	23	37.1
Uncertainty	22	35.5
Death	20	32.2
Other peoples' attitudes	18	29.0
Medical care	17	27.4
Relationships/sex	16	25.8
Pain/suffering	16	25.8
Burden/dependent	15	24.2
Health insurance coverage	13	21.0
Fear	10	16.1
Politics	9	14.5
Lack of education	6	9.7
Research community	6	9.7
Loss of loved ones	6	9.7
Acceptance	2	3.2
Legal matters	2	3.2

[a] Value represents the number of respondents who answered this question.

Participating in a Focus Group or Obtaining the Study Results

Because of issues surrounding confidentiality, no identifying information was asked on the questionnaire. However, the respondents were asked whether they would like to participate in a focus group to help with the design of a comprehensive patient education program. They were also offered an opportunity to obtain the results of the study.

Only a small portion of the respondents selected either of these options (see Table 19). Ten of the 52 men (19.2%) indicated an interest in participating in a focus group, and 8 (15.4%) asked to obtain the results of this study. Similarly, only 4 of the 18 women (22.2%) wanted to participate in a focus group, and 4 (22.2%) asked for the study results. More often than not, respondents who wanted to participate in a focus group also asked for the results of the study.

Table 19

Focus Group and/or Results of the Study

	Respondents (N = 70)			
	Men (n = 52)		Women (n = 18)	
	n	%	n	%
Focus group	10	19.2	4	22.2
Results	8	15.4	4	22.2
Total	18	34.6	8	44.4

Summary

The findings suggest that there is a perceived need for a comprehensive patient education program among this sample of HIV-infected men and women. There were important demographic differences within the sample and differences in many of the responses between men and women. The respondents indicated that patient education should emphasize specific strategies, such as stress management, and provide more services, such as support groups and childcare.

Lastly, salient themes were analyzed from the thoughts, feelings, and concerns in the open questions. Male and female respondents described both shared and distinct experiences relating to living with HIV/AIDS. Some of the salient themes, needs, and priorities of the study sample will be discussed in the following section.

CHAPTER 5: DISCUSSION

A total of 70 individuals (52 men and 18 women) with a self-reported HIV seropositive and/or an AIDS diagnosis participated in the needs assessment. Of the 52 men in the sample, nearly two-thirds (63.5%) were Caucasian and gay; 32 of the 52 men were single. Only 15 of the men had children; 11 of those had their children living with them. Of the 18 women, half were Caucasian and half were Black. Sixteen of the 18 women were heterosexual and 14 were single. Twelve of the women had children; 10 of those had their children living with them.

A total of 62 respondents answered the open questions asking them to describe their thoughts, experiences, and concerns about living with HIV/AIDS. A majority of the thoughts and concerns were related to sickness and death. However, many of the respondents identified positive attitudinal and behavioral changes they had made since their diagnosis.

There were some distinct differences between the men's and women's responses to the open questions. Only male respondents described changes in their financial situation. Additionally, more women than men mentioned how their lives had changed for the better since their diagnosis.

Over three-fourths (84%) of the respondents had received some form of patient education and most were relatively satisfied with these services. Even so, 69 of the 70 respondents felt that there was a need for a comprehensive patient education program for people living with HIV/AIDS. Of the 20 potential self-help and self-care topics, stress management and support groups were rated most highly.

Each of these key findings are discussed in the following sections. Subsequent sections will discuss limitations of the sample population and research design.

Interpretation of Findings

Living with HIV/AIDS

This analysis identified some salient themes about living with HIV/AIDS. Most respondents mentioned death in their answers to the open questions. This theme can be interpreted in various ways. Death could mean their own impending mortality. Death could also mean the gradual loss of acquaintances, friends, and lovers (D. Lang, personal communication, March 1, 1994).

Another theme centered on fears about getting sick or dealing with current illnesses. Nearly half of the respondents, especially the males, expressed these concerns. Fear of getting sick or the numerous AIDS-related illnesses themselves may cause severe limitations in activities. Indeed, half of the male respondents described concerns or fears regarding physical limitations that affected their ability to perform certain activities, including gardening, dancing, and having sex.

Interestingly, none of the female respondents expressed any particular fears or concerns regarding physical limitations. One factor might explain this finding. HIV-infected women often have different issues, such as caregiving responsibilities for children, than their single male counterparts. These issues not only affect the women's well-being, but the lives of those around them, especially if young children are involved. As a result, women with HIV/AIDS cannot always focus solely on their own illness and health status (Kelly & Holman, 1993; R. Dennison, personal communication, February 14, 1994).

Another theme was facing unemployment. Over three-fourths of the 32 male respondents had lost their jobs as they became more physically disabled. Becoming unemployed affected these men in different ways. For some, losing their jobs stripped them of their dignity. For others, losing their jobs meant, for the first time in their lives, having to worry about their financial situation. They were particularly worried about the medical and non-medical expenses that they felt would be needed to maintain their health. Specific medical expenses that were mentioned included medications, which were not always covered by health insurance. Non-medical expenses included alternative therapies, such as herbs.

None of the female respondents expressed concern about losing their jobs. Although questions about income level were not asked in this study, the female respondents may not have been as financially well-off as their male counterparts before they were diagnosed. Furthermore, HIV-infected women may have financial problems beyond the scope of HIV/AIDS. This may be especially true if they are single and raising children by themselves, as were the majority of women in this study (R. Dennison, personal communication, February 14, 1994).

Change in lifestyle was another important theme identified by 32 male and eight female respondents who answered the question asking how their lives had changed since their diagnosis. Over two-thirds of these respondents reported having made some attitudinal and/or behavioral change. Valuing life was an important attitudinal change expressed by all of the eight female respondents. In contrast, less than 10% of the men expressed this theme. Interestingly, the majority of the women described how HIV and AIDS actually made their lives better because they stopped taking life for granted. One example given repeatedly was that the women spent more time with their children, relatives, and significant others.

Both male and female respondents reported having made behavioral changes that included eating healthier food, practicing safer sex, abstaining from recreational drugs, and attending support groups. Some of these changes, particularly support groups, were also perceived as important self-help/self-care topics. In fact, research and anecdotal evidence suggest that support groups, along with friends and family, are influential in helping individuals make and sustain behavioral changes (Bendell, 1990; Ribble, 1989). Although it was perceived as a highly important self-help/self-care topic, none of the respondents mentioned practicing stress management as one of the lifestyle changes they had made.

Need for a Comprehensive Patient Education Program

Many of the respondents had been exposed to different types of patient education and were relatively satisfied with the existing services available in their communities. However, despite the range of current services offered to people living with HIV/AIDS, almost all of the respondents felt a need for more comprehensive patient education programs. The researcher has observed that many patient education services for HIV-infected individuals are highly didactic, topic-specific, short term, and lack self-efficacy skill building. Respondents may have noted similar limitations, and were therefore interested in a more comprehensive program. It is also possible that the respondents were satisfied with their patient education services, but still recognized the need for alternative patient education programs for HIV-infected individuals who do not have access to existing services.

Approximately 85% of the respondents had been exposed to some type of patient education. Over three-fourths of these individuals had attended group counseling and/or support groups. Support groups are therapeutic in the sense that they provide individuals the opportunity to exchange information, make friends, and share experiences (Gorman & Mallon, 1989; Kenneally Nicholas & Webster, 1993). The ultimate goal of support groups is to create a social network where people are encouraged to reciprocate emotional and practical support that is often deficient in their daily lives.

Based on the experiences of the researcher as a support group facilitator and anecdotal accounts from HIV-infected individuals (D. Lang, personal communication, March 8, 1994), HIV seropositive support groups can become an avenue in which individuals focus predominantly on their illness, death, and dying. Discussing these issues may be helpful, but may also lead to depression and even greater preoccupation with illness. Incorporating patient education into support groups, particularly self-efficacy skill building, may allow people to address more of the positive aspects of living with HIV/AIDS identified by this study's respondents.

HIV/AIDS-related seminars were another source of patient education reported by over half of the respondents. Seminars are typically 1-2 hour events, in which a guest speaker is invited to discuss a health-related topic (e.g., nutrition or safer sex) as it applies to being infected with HIV. The information is frequently given in lecture format with a question/answer section at the end. Seminars are extremely useful in conveying knowledge, but lack the intimacy of smaller group sessions in which promoting attitudinal and behavioral changes might be more successful.

There were important differences in the sources of respondents' previous patient education. Nearly two-thirds of the respondents had received patient education from AIDS service organizations, whereas less than half had received education from AIDS health projects. The distinction between AIDS service organizations and AIDS health projects is interesting to note. AIDS service organizations are community-based organizations that offer a range of services to their clients, including information, support groups, seminars, social activities, counseling, housing, and meal programs. Of the 11 agencies participating in this study, seven were AIDS service organizations.

AIDS health projects offer similar services as AIDS service organizations but are directly linked with larger medical institutions. For example, the University of California San Francisco (UCSF) AIDS Health Project offers services to individuals who seek medical attention at UCSF Medical Center or San Francisco General Hospital. AIDS health projects are generally more difficult to access for individuals who lack health insurance. Although several were invited to participate, only one AIDS health project collaborated in this study.

There are a couple of reasons that might explain why more of the respondents had received patient education services through AIDS service organizations. In northern California, in contrast to many other parts of the country, there are more AIDS service organizations than AIDS health projects. For this reason, it seems logical that more of the respondents in this study had been exposed to patient education services at AIDS service organizations. Secondly, local AIDS service organizations tend to be more willing than AIDS health projects to collaborate with others and allow an outside researcher to conduct a needs assessment of their clients. This practice of collaboration may actually make a wider range of services, including patient education, more available to their clients.

In recent years, many county health agencies have developed Early Intervention Programs (EIPs). The underlying goal of these programs is to provide patient education to newly-infected individuals (Santa Clara County Health Department, 1990-1992). Over one-fourth of the respondents had received patient education through an EIP. Early Intervention Programs will play an important role in the future of HIV/AIDS care because they focus on tertiary prevention through one-on-one counseling, and they offer information on a wide range of topics (e.g., nutrition, stress, exercise, and treatments). No formal evaluation of EIPs has been done to date, but based on anecdotal accounts, these new programs seldom follow up to see whether their clients have adopted specific health behavior changes.

Self-Help/Self-Care Topic Ratings

The two self-help/self-care topics that the respondents rated most highly were stress management (M = 4.8) and support groups (M = 4.7). The high rating of stress management is interesting to note as it was not expressed as a thought, lifestyle change, or concern in the qualitative responses. This suggests that even proactive and educated people with HIV/AIDS desire more information on how stress can factor into disease progression. They also may want to learn skills necessary to incorporate stress management into their daily lives.

Stress management will play a significant role in self-help and self-care for HIV-infected individuals. It has certainly done so in the maintenance of other chronic diseases (Corbin & Strauss, 1991). In fact, one study on cognitive therapy demonstrated that psychological variables, such as stress management, were important in the proper functioning of the immune system (Antoni et al., 1990). Teaching stress management techniques, such as relaxation or meditation, in a patient education class could enhance the physical and mental health of people living with HIV/AIDS.

Unlike stress management, attending support groups was a frequently stated lifestyle change the respondents had made subsequent to their diagnosis. Indeed, all of the female respondents rated support groups as the most important self-help/self-care topic. This is consistent with previous research, which found support groups to be the most popular self-help service for people living with HIV/AIDS (Dilley, 1990; Gorman & Mallon, 1989). A formal evaluation of psychosocial support groups has shown that they are able to help individuals cope with living with HIV/AIDS through discussion and problem-solving (Bendell, 1990; Ribble, 1989). Although discussion and problem-solving were considered slightly less important (M = 4.4) by the 69 respondents, they have been effective techniques in other chronic disease patient education programs, facilitating individuals to help each other with particular issues (Lorig et al., 1989).

Alternative therapies were rated the least important self-help/self-care topics by the respondents. Of the three therapies listed, chiropractic services were rated the lowest, with only slightly higher ratings for herbal remedies and acupuncture/acupressure. These findings were surprising as anecdotal evidence strongly indicated that alternative therapies have helped HIV-infected individuals manage pain and discomfort (D. Lang, personal communication, April 25, 1994). It is possible that alternative therapies have not been as well recognized by HIV-infected people as palliative treatments. Furthermore, Western therapies are almost exclusively promoted by the AIDS health care industry. As a result, AZT and other clinical drugs are the most common and familiar treatments for most people living with HIV/AIDS (Sanders, 1989).

One of the key findings related to self-help/self-care was that childcare services were rated as most important by all of the female respondents. This is not surprising since the majority of women in this study had children living with them. The implications of this finding become extremely important in the context of the lack of affordable or free childcare services for women with HIV/AIDS. These services are essential so that women can make their gynecological appointments, meet with their support groups, and attend HIV/AIDS education seminars.

Women with HIV/AIDS

Within the second decade of the AIDS epidemic, the numbers of women with HIV infection have increased dramatically (Kelly & Holman, 1993). Despite this phenomenon, minimal efforts have been undertaken by medical institutions and community-based organizations to address the growing need for reproductive, childcare, and other social services for women. This delay in response has prompted many women to seek HIV/AIDS-related services at organizations serving gay and bisexual men. In this study, two-thirds of the female respondents came from nine such agencies. Six women came from agencies serving women exclusively.

The majority of female respondents had received some form of patient education from AIDS service organizations. However, less than one-fourth were satisfied with these services. This finding suggests broader dissatisfaction among HIV-infected women at large, especially in low-income areas where HIV/AIDS-related services are not as readily available. Moreover, the women in this study reported less participation in HIV/AIDS education seminars, AIDS health projects, and Early Intervention Programs, than the male respondents. This might be because HIV-infected women are more inclined to seek services at more general women's health agencies (Acosta et al., 1992; Dorfman et al., 1992).

Another issue that many HIV-infected women have to confront concerns the delay in response between the time they test HIV seropositive and their AIDS diagnosis. In this study, more than half of the women were diagnosed with AIDS within one year of testing HIV seropositive. Three of these women were diagnosed with AIDS when they tested HIV seropositive. These findings are not surprising since numerous studies have shown that women have a much shorter window between the date they test HIV seropositive and the date they are diagnosed with AIDS (Kelly & Holman, 1993; Kline & Shearer, 1992; Laga et al., 1992).

This phenomenon has serious implications regarding the health status of HIV-infected women. Women have different HIV-related complications than men (Laga et al., 1992). These complications are not always detected at early stages of infection because they are clinical conditions that can also be present in the absence of HIV. Since early detection is uncommon, women seldom seek HIV-specific interventions prior to seeking treatment for AIDS-related symptoms (Allen, 1990; Laga et al.,1992). As a result, HIV infection frequently progresses at a much more rapid rate in women than in men.

In summary, the 70 men and women who participated in this study provided insight into living with HIV/AIDS and provided useful direction for patient education program development. Their responses identify priority topics, shared experiences, and central differences between the needs of men and women. These findings offer important guidance to health educators and health care providers serving the needs of people living with HIV/AIDS.

Limitations of the Study

Several limitations in the research design were recognized before beginning the study. During data analysis, additional limitations related to the final sample were revealed. Research design and sample limitations affecting the outcome of the study are discussed in the following sections.

Lack of Ethnic Diversity within the Sample

Opportunities to diversify the sample population were limited due to unforeseen obstacles concerning access and language barriers. It was difficult to attract minorities because many, such as Latinos, Asians, American Indians, and Pacific Islanders, do not utilize HIV/AIDS services at the mainstream agencies (e.g., Aris Project in the South Bay, and Most Holy Redeemer in San Francisco), which provided most of the final study participants.

When minorities need health services, they tend to seek agencies within their own communities. This was understood prior to designing the study. Effort was made to contact such agencies and programs, including the American Indian AIDS Institute (AIAI) in San Francisco, a support group for Latinas in San Jose, and a support group for Filipinos in San Francisco. With AIAI, insufficient personnel and time resources restricted participation in the study. Language barriers were a serious problem with the two support groups. As a result, these ethnic groups were not represented in the final sample.

Low Overall Response Rate

Despite the distribution of 200 questionnaires, only 70 individuals participated in the study. Low response rates are common in studies using self-administered, written questionnaires (Oyster et al., 1987). For this reason, a 50% response rate was anticipated for this study. However, as the study progressed, the researcher learned of additional reasons for the lack of participation by potential respondents.

People with HIV/AIDS must complete numerous surveys, evaluations, and other forms required of them in order to obtain services from their HIV/AIDS service agency or health care provider (Most Holy Redeemer, personal communication, April 18, 1994). This study may have seemed like one more survey in an endless series of demands. Completing this particular needs assessment questionnaire would have involved time away from other priorities, with virtually no immediate benefit.

Secondly, the topic of this study may not have been interesting to some potential participants. Similarly, a patient education program may not have seemed salient to their current health needs. As a result, the needs assessment instrument itself may have selected out those who did not perceive a need for a comprehensive patient education program. This inadvertent selection may explain why 69 of 70 respondents endorsed the idea of a comprehensive patient education program.

Lastly, the AIDS epidemic is a constant reminder to people living with HIV/AIDS that they have a finite future. This concept was vividly illustrated by many of the responses to the open questions. Indeed, two respondents indicated that they were not able to fill out the questionnaire because it elicited unnecessary pain. Most likely, other potential participants may have chosen not to participate for similar reasons.

Low Female Response Rate

Despite the efforts made to recruit women, only 18 women participated in the study. Several explanations support this result. In general, not many HIV-infected women have access to HIV/AIDS-related services in their communities (Gayle et al., 1990; Kelly & Holman, 1993). Lack of health insurance and transportation account for some of the barriers (WORLD, personal communication, April 26, 1994). In addition, there are simply not enough services specific to the needs and priorities of HIV-infected women, especially in low to moderate incidence areas (Lenker et al., 1993).

One of the services that continues to be overlooked by most concerned organizations is childcare. The low female response rate in this study could be attributed to the possibility that many HIV-infected women with children do not have convenient access to childcare. Therefore, they may have greater difficulty participating in ancillary studies or additional activities, such as this needs assessment.

Secondly, national statistics indicate that the majority of women with HIV/AIDS are also poor and minorities (Capell et al., 1992; Gayle et al., 1990). They are especially disenfranchised because there are too few health and reproductive resources for them in their communities. Furthermore, these women may not seek HIV/AIDS-related services because of language barriers and/or the stigma attached to HIV in their cultures. The best way to recruit these women into this study would have been some form of peer outreach. However, because of concern for respondent confidentiality, it did not seem appropriate to approach HIV-infected women in this manner.

Thirdly, it is possible that HIV-infected women were simply not interested in participating in this study, perhaps because the study did not offer any financial incentive. Based on conversations with members of WORLD, a women with HIV/AIDS support network, HIV-infected women have recently become over-studied in the field of AIDS research (R. Dennison, personal communication, February 14, 1994). In return for their efforts, very little or no compensation has been offered. Over time, many women with HIV/AIDS have developed distrust for the research community. These dynamics were not well understood prior to beginning the study.

Other factors besides access may have contributed to the low response rate among women. It was assumed that outreach to women would be most effective through support groups. A current list of support groups was obtained through WORLD. Unfortunately, when the recruitment began, most of the women's support groups on the list were no longer in existence. Moreover, the organizations which were contacted did not have the time or human resources to distribute questionnaires during their support group meetings. As a result, only WEL, a support group specifically for women, agreed to participate in this study.

Proactive Sample Population

The 70 study respondents appeared to be relatively well-educated about their condition and already utilizing patient education services. Even so, they were able to identify distinct and basic needs applicable to their circumstances that could improve or modify current patient education services.

However, the results of a needs assessment with a proactive sample of HIV-infected individuals cannot be generalized to all people living with HIV/AIDS. There may be a deep dichotomy between HIV-infected individuals who can utilize the HIV/AIDS delivery system towards their benefit (e.g., participants in this study) and those who are alienated by the system. The latter group includes people who are homeless, poor women, poor minorities, and many intravenous drug users. The proactive sample in this study offered insight and ideas that may be useful beyond the individuals they represent. However, determining the perceived needs of disenfranchised communities is also critical in order to develop a comprehensive patient education program that is relevant to the specific circumstances and lifestyles of a broader group of people living with HIV/AIDS.

Needs Assessment Questionnaire

An original survey was used as the data collection instrument for this study. This methodological decision was necessary because no psychometrically validated needs assessment instruments on patient education for people living with HIV/AIDS had been developed. This decision has implications for the validity of the findings.

The survey instrument was an anonymous, self-administered questionnaire. Anonymity was important to protect the confidentiality of participants. The primary advantage of a written questionnaire was that it had the potential of obtaining the data in a short period of time. The disadvantage was that a questionnaire with mostly closed questions would not gather subjective, in-depth information about HIV-infected individuals' patient education needs.

These limitations of the data collection instrument meant that certain nuances in the respondents' answers may have been lost. To minimize this limitation, open questions were included in the questionnaire as a means of attaining information that would have been missed if only closed questions were asked.

A self-administered questionnaire can also be an impersonal vehicle for truly sharing experiences, needs, and concerns. However, even with the little space provided to answer the open questions, the respondents poignantly expressed many ways in which living with HIV/AIDS had changed their lives.

Data Collection

The final limitation is with the data collection method. The researcher could not be in direct contact with any of the clients at the collaborating agencies during data collection because of confidentiality issues. Health educators and HIV coordinators were the primary contacts at the collaborating agencies. The HIV/AIDS education seminars were the exception because they were held in a public forum where any individual or group was allowed to solicit information, services, and research opportunities.

The contact people from the collaborating agencies were sent questionnaire packets to distribute to interested HIV-infected clients, with specific instructions to have the clients complete the questionnaires at the agency, if possible. There were unanticipated difficulties with this method of distribution. The contact people were unreliable in remembering to give the clients the questionnaire packets. In an attempt to circumvent these problems, numerous follow-up telephone calls to the contact people were made to expedite the data collection process.

Despite the study's limitations, this needs assessment was a timely investment as more people with HIV/AIDS are living longer with their condition. The questionnaire allowed the respondents to voice their thoughts, feelings, and concerns about living with HIV/AIDS as well as their opinions regarding the specifications of a patient education program. This study will assist collaborating HIV/AIDS service agencies in improving their own patient education programs. The information from the study will also be useful in the preliminary design and implementation of future patient education programs.

CHAPTER 6: CONCLUSION

This study explored the need for a comprehensive patient education program for people living with HIV/AIDS. In the following sections, recommendations for further research are discussed, as well as recommendations for health education practice.

Recommendations for Further Research

Further research should explore in greater depth the specifications of a comprehensive patient education program, as well as the services currently available for people living with HIV/AIDS. Particular attention should be addressed to the perceived needs and priorities of specific subgroups, such as poor women. Other studies should focus on individuals who have lived for long periods of time after diagnosis. Such research should explore the possibility that attitudes and behaviors can delay disease progression. These areas of study need to be pursued qualitatively so that the data will be based upon the interests and concerns of the participants, rather than those of the researcher.

This study identified a strong interest in a comprehensive patient education program, as well as specific self-help and self-care priorities, among a proactive sample of men and women living with HIV/AIDS in northern California. However, this research should not be used as the sole basis for a comprehensive patient education program for other communities living with HIV/AIDS. Other assessments among more diverse subpopulations will help determine whether the priorities and needs of this sample are different from others. Particular attention to cultural diversity, geographical location, and socioeconomic status, will be important.

These factors can be identified through focus groups or personal interviews. These methods encourage an active dialogue between participants. Both approaches have the ability to obtain information about needs and priorities concerning living with HIV/AIDS that is often lost when using quantitative methods. These data could help determine whether one comprehensive patient education program can serve the needs of all people with HIV/AIDS, or if different programs customized to fit group or community needs are more relevant.

Future research should also evaluate the HIV/AIDS services currently available for people in different communities. This needs assessment indicated stress-management programs, support groups, and nutrition programs as highly important for HIV-infected men and women. Women also perceived childcare services as very important. Subsequent studies need to explore these and other self-help/self-care priorities to determine whether or not these services are accessible or deficient in a given community. Focus groups or interviews are ideal methods for exploring such local barriers. Disenfranchised subgroups, including poor women, intravenous drug users, the homeless, and minorities, should receive particular attention as very little research has addressed their HIV-specific needs and priorities.

Lastly, studies are recommended that explore the attitudes and behaviors of long-term HIV/AIDS survivors. This needs assessment inadvertently identified some of the needs and priorities of long-term survivors since the majority of respondents had lived with HIV for more than five years. Further investigation is critical to explain why these individuals were relatively satisfied with their HIV/AIDS services, valued patient education, and prioritized certain self-help/self-care services over others. Such research might reveal a link between patient education, self-help/self-care, and the ability to delay disease progression. Health educators and allied health professionals could use this information to help other HIV-infected people who are having difficulties in managing their condition.

In any research involving human subjects, participants should be given an incentive and/or opportunities to help organize program interventions. Even though this needs assessment was conducted on a limited budget, the respondents were still given the opportunity to participate in a follow-up focus group (to be scheduled at a later date), and/or receive a summary of the results. However, possibly due to confidentiality concerns, less than one-fourth of the respondents were interested in either option. Offering these types of incentives helps build trust with participants. This is particularly important if the researcher or research group intends to work with the respondents in future research projects.

It is also recommended that researchers consider financial incentives for participants when preparing a project's budget, particularly if participants will be involved in an assessment or organizing activity. If the study involves participating in an intervention, it is recommended that services, such as childcare and transportation, be made accessible to program participants. These recommendations seem obvious, but surprisingly, have been ignored by numerous research groups in both small and large institutions. The findings from this needs assessment clearly suggest their importance.

Recommendations for Health Education Practice

Health educators and other health professionals are often faced with the challenge of developing programs that satisfy the wide range of medical and social service needs of long-term HIV/AIDS survivors and the growing numbers of HIV-infected individuals. Needs assessments are useful tools in identifying their perceived priorities, as well as recognizing the perceived strengths and weaknesses of services available in their communities. The findings from this needs assessment have immediate relevance to the field of health education.

Most of the agencies collaborating in this study were community-based organizations (CBOs). These agencies have a sincere interest in providing programs and services that are relevant to the particular lifestyles and circumstances of their client populations. This needs assessment will be useful to these agencies for several reasons.

The identified self-help/self-care priorities will provide the agencies with a list of topics and services that the study sample perceived as important. It is recommended that CBOs cross-check this list with the services they already provide. The priority list may suggest the need for further evaluation by agency staff and clients. Services may need to be expanded or re-structured so that they incorporate self-help and self-care techniques.

The list of self-help/self-care priorities may assist CBOs in comparing their services with those of other health care agencies in their community. It is recommended that CBOs collaborate with these agencies in providing a comprehensive system of care to avoid costly duplication of services.

Community-based organizations may utilize the findings to develop a patient education program for their clients. However, interested organizations must recognize that this needs assessment indicated general needs and priorities of HIV-infected individuals. It is recommended that health educators within CBOs design patient education programs that are culturally relevant to their clients' characteristics. For example, certain factors, such as ethnicity, income status, sexual orientation, education level, and age, may need to be considered before developing patient education programs for any subgroup.

This study's findings illustrate distinct differences between the experiences and perceived needs/priorities of male and female respondents. It is recommended that CBOs, especially those that have traditionally offered services to gay and bisexual men, use this information to make their services more accessible and relevant to women. For example, providing free childcare to HIV-infected women with young children is one way of reaching out to women in their community.

Lastly, additional information was identified through the positive and negative experiences related by HIV-infected individuals. One final recommendation is that health educators in an agency select some of the more positive themes as topics for discussion in support groups and/or HIV/AIDS education seminars. For example, topics that address valuing life and lifestyle changes, may stimulate conversations between individuals that focus more on living than dying.

This needs assessment, as well as future needs assessments, may improve the overall effectiveness of HIV/AIDS care by identifying and filling the gaps in critical services. These recommendations can be used by HIV/AIDS service agencies who participated in the study and any other interested organizations. Specifically, it is hoped that these agencies offer more patient education services emphasizing self-help/self-care, including some of the topics prioritized in this study. Alternatively, agencies may gain insight into the experiences of people living with HIV/AIDS from the salient themes identified in this study. In doing so, it is possible that more individuals will live longer and healthier lives in spite of their HIV status.

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APPENDIX A

Needs Assessment Questionnaire

NEEDS ASSESSMENT QUESTIONNAIRE

Part 1: Attitudes and Feelings About Living with HIV/AIDS

When you think of HIV/AIDS, what do you think about? (Please list up to ten different words)

1.________________	6.________________
2.________________	7.________________
3.________________	8.________________
4.________________	9.________________
5.________________	10.________________

In what ways has your life changed since your diagnosis? (please write your answer in the space below)

____

____

____

____

____

____

____

____

What are your biggest concerns or frustrations about living with HIV/AIDS? (Please list up to ten different words)

1.________________	6.________________
2.________________	7.________________
3.________________	8.________________
4.________________	9.________________
5.________________	10.________________

How satisfied are you with the HIV/AIDS services available in your community?

Satisfied ___ Somewhat Satisfied ___ Dissatisfied ___

Part 2: Needs Assessment of Patient Education for People Living with HIV/AIDS

"Patient education is a form of health education that teaches you any knowledge and/or skills that helps you manage living with HIV or AIDS."

Have you ever had any patient education? Y / N

If yes, please check all agencies where you have received patient education.

___ Seminars/classes

___ Group counseling/support groups

___ County AIDS Health Projects

___ Early Intervention Programs

___ AIDS Service Organizations

___ Other (please specify):______________________________

"One way of providing patient education is through a set of comprehensive classes that teach information and strategies that help people live with HIV/AIDS."

Do you feel there is a need for patient education classes for people living with HIV or AIDS?
Y / N

Which topics do you feel need to be covered in these classes?
(Please circle one number for the following topics):

	VERY IMPT.		IMPT.		NOT IMPT.
Exercise	5	4	3	2	1
Nutritional information	5	4	3	2	1
Vitamin therapy	5	4	3	2	1
Stress management	5	4	3	2	1
Use of financial Services:					
Benefit planning	5	4	3	2	1
COBRA / OBRA	5	4	3	2	1
Private Insurance	5	4	3	2	1
Use of medical services:					
Communicating with doctor	5	4	3	2	1
Reading medical charts	5	4	3	2	1
Clinical drug trials info.	5	4	3	2	1
Medications/treatments info.	5	4	3	2	1

	VERY IMPT.		IMPT.		NOT IMPT.
Alcohol or drug use/abuse treatment info.	5	4	3	2	1
Alternative therapies:					
Herbal remedies	5	4	3	2	1
Acupuncture/acupressure	5	4	3	2	1
Chiropractic services	5	4	3	2	1
Other	5	4	3	2	1
(Please specify):________________________					
Community resources:					
Support groups	5	4	3	2	1
Child-care service	5	4	3	2	1
HIV/AIDS-related seminars	5	4	3	2	1
Discussion/problem-solving	5	4	3	2	1

Any other suggestions? (Use the back side of this page, if needed.)

Time schedule:

1. How many classes do you think there should be to cover all the topics you are interested in?
   4-5___ 6-7___ 8-10__ Ongoing___

2. How many hours per class? 1___ 2___ 3___

3. How often should these classes be held?
   Weekly ____ Every 2 weeks ____ Monthly ____

Would you like peer volunteers, with and without HIV/AIDS, health professionals, or a combination of all to teach these classes? (Check all that apply)

Volunteers with HIV/AIDS _____

Volunteers without HIV/AIDS _____

Both volunteers and health professionals _____

Health professionals _____

Part 3: Background Information

Age:___ **Sex:** Male___ Female___ Transgender___

Circle whether you are: Gay / Lesbian / Bisexual / Heterosexual

HIV status Asymptomatic___ Symptomatic___ AIDS diagnosis___

When did you find out you were HIV seropositive? ____________________

If applicable, when were you diagnosed with AIDS? ____________________

Ethnicity (Please check one only):

Caucasian___	Latino/Latina___	Black___
Asian___	Native American___	Pacific Islander___

Other (please specify)____________________

Circle the highest level of education completed:
5 6 7 8 9 10 11 12 13 14 15 16 >16

Relationship status Single___ Married___ Domestic partner___
Primary relationship___

Do you have any children? Y / N
If YES: **How many?** 1___ 2___ 3 or more___
Do they live with you? Y / N

Health care provider: Private physician _____ Medi-Cal _____
HMO (e.g. Kaiser) _____ Other (please specify) ___________

****

If you would like to participate in a focus group to help design a patient education program for people living with HIV, please call the Investigator at (415)325-6662, OR write the address and/or phone number where you can be reached in the space provided.

If you would like the results of this study sent back to you, please call the Investigator, OR write the address and/or phone number where you can be reached.

Thank you very much for your support and time. Your contribution will be significant in helping to improve both social and medical services for people living with HIV.

APPENDIX B

Human Subjects Approval

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

Office of the Academic Vice President • *Associate Academic Vice President* • *Graduate Studies and Research*
One Washington Square • San José, California 95192-0025 • 408/924-2480

To: Sohini Sengupta
328 Pope Street
Menlo Park, CA 94025

From: Serena W. Stanford Serena W. Stanford
AAVP, Graduate Studies and Research

Date: September 1, 1993

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

> "Needs Assessment of Patient Education for HIV Seropositive Women of Child-Bearing Age, and Gay and Bisexual Men"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted. If you have questions, please contact me at 408-924-2480.

APPENDIX C

Codebook

NEEDS ASSESSMENT OF PATIENT EDUCATION FOR MEN AND WOMEN LIVING WITH HIV/AIDS

CODEBOOK

REVISED 11/2/93

Codes for each question are shown in brackets.

Agency or seminar attended {SITE}:

Kaiser HIV education seminar = 1
Tri-City Health Center = 2
Aris Project = 3
Most Holy Redeemer = 4
The Center (Pleasanton) = 5
ESO = 6
Center for AIDS Services = 7
Planned Parenthood Health Clinic = 8
Center for Attitudinal Healing = 9
Women Embracing Life Support Group = 10
Santa Cruz AIDS Project = 11

1. How satisfied {SAT} are you with the HIV/AIDS services available in your community?

No response = 0
Satisfied = 1
Somewhat satisfied = 2
Dissatisfied = 3
NOTE: If satisfied and dissatisfied checked, enter 2.

2. Have you ever had any patient education {PATED}?

No response = 0
Yes = 1
No = 2

3. Where patient education received.

Yes = 1
No response = 2

For each of the following types of patient education, enter 1 if checked; enter 2 if blank.

Seminars/classes {SEM}
Group counseling/support groups {GROUP}
County AIDS Health Projects {AHP}
Early Intervention Programs {EIP}
Aids Service Organizations {ASO}
Others {OTH} (If cannot be classified in one of the other groups)

4. Is there a {NEED} for patient education classes for people living with HIV/AIDS?

No response = 0
Yes = 1
No = 2

5. Topics to be covered in the patient education classes:

Very important =	5
	4
Important =	3
	2
Not important =	1
No response =	0
Not applicable =	9

NOTE: If two consecutive numbers are circled, choose the more conservative number.

<u>For each of the following topics, a rating must be given on a scale of 0 to 5 or 9</u>:

Exercise {EXER}
Nutritional information {NUTR}
Vitamin Therapy {VITA}
Stress management {STRESS}
Benefit planning {BENEF}
COBRA / OBRA {COBRA}
Private insurance {PRIV}
Communicating with doctor {COMM}
Reading medical charts {READ}
Clinical drug trial info. {CLINIC}
Medication / treatment info. {MEDS}
Alcohol or drug use/abuse treatments {ALCH}
Herbal remedies {HERBS}
Acupuncture / acupressure {ACUP}
Chiropractor {CHIRO}
Other alternative therapy {OTHER}
Support groups {SUPPORT}
Child-care service {CHILD}
HIV-related seminars {SEMIN}
Discussion / problem-sharing {DISCUSS}

6. How many {CLASSES} to cover all of the topics?
    No response = 0
    4-5 = 1
    6-7 = 2
    8-10 = 3
    Ongoing = 4
7. How many {HOURS} per class?
    No response = 0
    1 = 1
    2 = 2
    3 = 3
8. How {OFTEN} should these classes be held?
    No response = 0
    Weekly = 1
    Every two weeks = 2

Monthly = 3
NOTE: If two consecutive numbers are checked, enter more conservative choice.

9. Who would you like to {TEACH} these classes?
    No response = 0
    Volunteers with HIV/AIDS = 1
    Volunteers without HIV/AIDS = 2
    Health professionals = 3
    Both volunteers and health professionals = 4
    Volunteers with / without HIV/AIDS = 5
    Volunteers with AIDS and health professionals = 6
    NOTE: If all choices are checked, enter 4.
7. {AGE}?
    Enter number written.
8. {SEX}?
    Male = 1
    Female = 2
    Transgender = 3
9. {SEXUAL} orientation?
    Gay = 1
    Lesbian = 2
    Bisexual = 3
    Heterosexual = 4
10. HIV {STATUS}?
    No response = 0
    Asymptomatic = 1
    Symptomatic and AIDS diagnosis = 2
    Asymptomatic and AIDS diagnosis = 3
11. When HIV seropositive {HIVPOS}?
    Enter date written.
    If complete date given, enter mm/dd/yy.
    If only year given, enter 6/15/yy.
    If only month and year given, enter mm/30/yy.
12. When diagnosed {DIAG} with AIDS?
    Non applicable = leave blank
    If complete date given, enter mm/dd/yy.
    If only year given, enter 6/15/yy.
    If only month and year given, enter mm/30/yy.
13. Ethnicity {ETHN}?
    No response = 0
    Caucasian = 1
    Asian = 2
    Latino/Latina = 3
    African American = 4
    Native American = 5
    (includes American Indians and Alaskan Natives)
    Pacific Islander = 6
    Other = 7

14. Education {EDUC}?
    Enter level completed.
    NOTE: If two numbers are circled, choose the most conservative number.
15. Relationship {RELAT} status?
    Single = 1
    Married = 2
    Domestic partner = 3
    Primary relationship = 4
16. {CHILDREN}?
    No response = 0
    Yes = 1
    No = 2
17. If yes, how {MANY}?
    No response = 0; enter 0, if answered NO to Q.16.
    1 = 1
    2 = 2
    3 or more = 3
18. If yes, {LIVE} with you?
    No response = 0; enter 0, if answered NO to Q.16.
    Yes = 1
    No = 2
    NOTE: If both "yes" and "no" are circled, enter 1.
19. Health care provider {PROVIDE}?
    No response = 0
    Private physician = 1
    HMO = 2
    Medi-Cal = 3
    Other = 4
    Private physician and Medi-Cal = 5
    HMO and Medi-Cal = 6
    Other and Medi-Cal = 7
    Private physician and HMO = 8
20. {FOCUS} group?
    Yes = 1
    No response = 2
21. {RESULTS}?
    Yes = 1
    No response = 2

APPENDIX D

Description of Collaborating Agencies

1. Aris Project is the leading ASO in the South Bay. Located in Campbell, it offers support groups, HIV/AIDS education seminars, and housing assistance to its clients.

2. Center for AIDS Services is an ASO located in Oakland. It offers meals, social activities, and referral services to people living with HIV/AIDS in the Oakland-Berkeley area.

3. Center for Attitudinal Healing is an ASO that offers alternative therapy services to people living with HIV/AIDS in Marin County. Services include meditation, support groups, and seminars on alternative treatments. This organization is located in Tiburon.

4. The Center is an ASO located in Pleasanton. It offers support groups, mental health counseling, and seminars to people living with HIV/AIDS in Contra Costa County.

5. ESO is an ASO for African Americans located in San Jose. It offers drug rehabilitation and support groups to their clients with HIV/AIDS.

6. Kaiser Permanente Medical Center in Oakland provides monthly HIV/AIDS education seminars to the public (member or non-members) at no cost.

7. Most Holy Redeemer Church in San Francisco is an ASO that provides AIDS support services that include support groups, HIV counseling, and Seminars.

8. Planned Parenthood Care Clinic in San Francisco provides reproductive care to low-income women. A section of their clinic is dedicated to meet the needs of women with HIV/AIDS such as reproductive care, primary care, and HIV testing.

9. Santa Cruz AIDS Project is an AHP that provides a range of services to clients living in Santa Cruz County. These services include support groups, primary care, seminars, and HIV counseling.

10. Tri-City Health Center is an ASO located in Fremont. It provides low cost services to their clients living in the lower East Bay area. The HIV/AIDS services include support group, seminars, and primary care.

11. Women Embracing Life (WEL) support group is a group of women in San Francisco who meet weekly to discuss their experiences in living with HIV/AIDS.