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THE WORK OF LIVING WITH HIV: A STUDY OF BINATIONAL GROUPS

by

Christina Joy

A dissertation presented to the  
FACULTY OF THE PHILIP Y. HAHN SCHOOL OF NURSING  
UNIVERSITY OF SAN DIEGO

In partial fulfillment of the  
requirements for the degree  
DOCTOR OF NURSING SCIENCE

May 1997

Dissertation Committee

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## ABSTRACT

### The Work of Living with HIV: A Study of Binational Groups

The purpose of this investigation was to study the experience of individuals who live with and manage HIV infection and AIDS. The context of living with HIV/AIDS, the prevailing conditions, the actions/strategies used, and the consequences of the actions were considered using grounded theory methodology and dimensional analysis. A purposeful sample of 21 individuals HIV positive or diagnosed with AIDS from San Diego, California and Tijuana, Mexico were interviewed using semi-structured questions. Data were analyzed using open and axial coding, the constant comparative method, and dimensional analysis. The work of living with HIV emerged as the central dimension within the context of the HIV care system. Conditions influencing participants were societal stigma and social support. Taking care of self, which included involvement with HIV-related treatment activities, making changes, being willing to experiment, taking charge of one's health care, and being cautious, were undertaken with the goals of staying healthy - for the cure (San Diego participants) and living better (Tijuana participants). Of particular interest was the use

of clinical drug trials by a majority of participants from both groups as either a supplemental or essential source of HIV health care. The findings of this study have implications for nurse clinicians, researchers, and educators working in community and multicutural settings.

## DEDICATION

This dissertation would not be possible without the support, sustenance, and assistance of three individuals. My mother is the original source of the drive, determination, and persistence needed to complete such a effort. I am only sorry she is not alive to see the completion of the dissertation and the awarding of the doctoral degree. Without the on-going support and comfort from my dear friend, Pat, I could never have finished. And my co-worker and fellow nurse, Irene, made the inclusion of the participants from Tijuana possible and very much alive throughout the study.

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## Chapter 1

### Introduction

Since the first cases of HIV infection and AIDS were documented in the early 1980's, the global epidemic has continued to spread and intensify. As of December, 1996, 1,500,000 AIDS cases among adults and children were reported by countries worldwide (World Health Organization [WHO], 1997). At the same time, HIV infection among adults and children around the world was projected to be 22,600,000 (WHO, 1997).

In the United States, the Center for Disease Control (1997) identified as of February 28, 1997 a total of 573,800 persons, 13 years and older, with AIDS who had been reported to state and local health departments during the years from 1981 to 1996. Of the total 573,800 AIDS cases, 85% were male and 15% were female; 47% of the cases were white; 35% were non-Hispanic black; and 18% were Hispanic.

Unlike the early years of the epidemic in the U.S. during the 1980s, an increasing number of individuals

besides white gay men have become infected with HIV in the 1990s. From 1992 to 1996, non-Hispanic blacks, Hispanics, and women accounted for increasing numbers of individuals diagnosed with AIDS (Center for Disease Control [CDC], 1997).

In 1996, 41% of reported AIDS cases were non-Hispanic blacks, and 20% were women. This was the first year that the percentage of reported AIDS cases for non-Hispanic blacks was greater than for whites (CDC, 1997).

In 1995 and 1996, the number of AIDS opportunistic infections stabilized, and the number of deaths decreased (CDC, 1997). For non-Hispanic blacks and Hispanics, however, there was increased incidence of opportunistic infections (CDC, 1997). For the same time period, there was no decrease in numbers of deaths for women and those individuals infected through heterosexual sex (CDC, 1997).

The trend of increased survival for all reported AIDS cases is most likely due to earlier detection, use of combination antiretroviral therapy, and effective prevention and treatment of opportunistic infections (CDC, 1997; McCormick, Inui, Deyo, & Wood, 1991; Piette, Mor, & Fleishman, 1991). The increased incidence of opportunistic

infections in non-Hispanic blacks and Hispanics may reflect decreased access to health care which is associated with disadvantaged socioeconomic status, cultural factors, or language barriers (CDC, 1997).

With the delay of patients developing AIDS diagnoses and increased time of survival, HIV disease is now considered a chronic illness for many individuals (CDC, 1987; Barroso, 1997; Eubanks, 1989; McCormick, et al., 1991). The evolving chronic nature of HIV disease carries with it the ever-increasing importance of meeting long term health care, psychological and social needs.

Like other life-threatening chronic illnesses, the cumulative effects of HIV disease can invade and overwhelm every aspect of the lives of those involved. Many AIDS patients are "heavy users of health care and social services (Piette, Mor, & Fleishman, 1991)." The debilitating physical conditions, threatened financial security, altered personal relationships, strained living conditions, and stigma make AIDS a "nursing-intensive" disease (Sowell, Fuszard, & Gritzmacher, 1990).

### Statement of the Problem

The purpose of this investigation was to study the experience of individuals who are HIV infected or are diagnosed with AIDS as they live with and manage the disease. To better understand the experience of living with HIV/AIDS, it is of interest to learn about the conditions that influence infected individuals; the actions/strategies undertaken to deal with the disease; and the consequences that result from actions and strategies.

The complex and emotionally-charged care of persons who are HIV infected presents a tremendous challenge to nurses and other health care workers. In order to better assess, plan, manage and evaluate those who suffer with HIV/AIDS, it is imperative that nurses be aware of the patterns, behaviors, and approaches individuals use to deal with feelings, to seek help, and to care for themselves (Derdiarian & Schobel, 1990; Allan, 1990).

A review of literature (Larson, 1988) from 1983 and 1987 found no research papers pertaining to HIV/AIDS among 169 articles of nursing literature. From 1987 to 1990, 54 nursing research studies relating to HIV/AIDS were published (Larson & Ropka, 1991). The studies from 1987 to 1990

overwhelmingly concentrated on the attitudes and behaviors of nurses and nursing students in relation to patients with HIV/AIDS (Larson & Ropka, 1991). Of the 54 nursing studies, only 14 related to patient concerns, experiences, feelings, or nursing care.

During the 1990s, the number of nursing research studies concerned with HIV/AIDS increased. Investigators started to focus on patient experiences and concerns such as: hope and spiritual well-being (Kendall, 1994); psychosocial assessment (Derdiarian & Schobel, 1990; Laryea & Gien, 1993; van Servellen, Padilla, Brecht, & Knoll, 1993); coping (McCain & Cella, 1995); symptom management (Powell-Cope, 1996;); quality of life (Ragsdale & Morrow, 1990; Rose, 1993; Wilson, Hutchinson, & Holzemer, 1997); health concerns of women (Anastasio, McMahan, Daniels, Nicholas, & Paul-Simon, 1995; Rose, 1993); stresses of hospitalization (van Servellen, Lewis, & Leake, 1988); long-term survivorship (Barroso, 1997); and work-related activities to improve quality of life in HIV disease (Ragsdale, Kotarba, & Morrow, 1992).

Research studies in medicine during the 1980's and the 1990s focused on etiology, transmission, prevention,

treatment, pathology, pharmacology, and epidemiology (Larson, 1988; Siminoff, Erlen, & Lidz, 1991). Social science studies concentrated on neuropsychiatric and psychosocial factors and reactions, education, prevention, social services and the like.

### Lines of Inquiry

The lines of inquiry guiding this study are:

1. What is the experience of living and dealing with HIV/AIDS?
2. What are the differing conditions which influence individuals living with HIV/AIDS?
3. What actions/strategies do individuals use to deal with and manage HIV/AIDS?
4. What are the consequences of living with and managing HIV/AIDS?

### Sensitizing Concepts

Two sensitizing concepts (Strauss & Corbin, 1990) form the basis of this study. First, a growing number of individuals who are infected with HIV experience the disease as a chronic illness. As with other chronic conditions, health care, day-to-day living, social and psychological problems become more complex, greater in number, and more

difficult to manage. The "work" and effort of dealing with a chronic and life-threatening illness as described by Strauss (1975) and Corbin and Strauss (1988) can become an enveloping focus of one's daily existence.

The second sensitizing concept of this study is that individuals who are infected with HIV require intensive and expert care by professional nurses as the disease progresses and becomes more problematic. This is especially true for the disadvantaged and dependent who live within precarious social and financial situations. Living within disadvantaged circumstances increases the risks of HIV infected individuals for developing more disease-related problems, enduring more hardship and suffering, and furthering the spread of HIV.

As Smeltzer and Whipple (1991) emphasize, nursing has always advocated and intervened for those who are in need of care. This can be especially crucial for individuals with HIV disease. Because of fear and the stigma of the infection, HIV infected individuals are often rejected by their biological families. Members of the social support network may avoid or abandon individuals as the disease progresses because "the emotional and concrete demands are

too threatening, too time consuming, or too insoluble (Lennon, Martin, & Dean, 1990, p. 479)."

"Nurses are in a unique position to provide holistic care, to teach, to conduct and disseminate research about HIV and AIDS (Smeltzer & Wipple, 1991, p. 254)." This is possible because nurses provide the majority of the care and education to individuals with HIV/AIDS and their significant others. In addition, nurses have "traditionally" been concerned about health care promotion and making health care accessible to all members of society (Smeltzer & Whipple, 1991).

#### Significance of the Study

In 1988, the National Center for Nursing Research identified seven areas of focus for nursing research. HIV infection was identified as second in priority (Larson & Ropka, 1991). An HIV Advisory Panel was formed to more fully develop an HIV research agenda. The panel subsequently identified five priority areas for HIV nursing research: (a) prevention of HIV transmission; (b) physiological aspects of nursing care; (c) psychosocial aspects of nursing care; (d) delivery of nursing care; and (e) applied ethics (Larson & Ropka, 1991).



In 1992, the Conference on Nursing Research Priorities sponsored by the National Institute for Nursing Research selected five research priorities for the remainder of the 1990s: (a) community-based nursing models; (b) effectiveness of nursing interventions in HIV/AIDS; (c) cognitive impairment; (d) living with chronic illness; and (e) biobehavioral factors related to immunocompetence (National Institute of Nursing Research, 1993). The aim of research related to the effectiveness of nursing interventions in HIV/AIDS is to evaluate the effectiveness of biobehavioral nursing interventions; to foster health promoting behaviors of individuals at risk for HIV/AIDS; to ameliorate the effects of illness in those already infected; and to concentrate on women and individuals from different cultural backgrounds (National Institute for Nursing Research, 1993). The focus of studies related to living with chronic illness is the testing of interventions that increase individual and family adaptation to chronic illness (National Institute of Nursing Research, 1993)

The significance of this study is that information will be obtained to add to the growing body of knowledge about the experience, feelings, problems, and activities of

individuals living with and managing HIV disease.

Information about the personal situations, living conditions, and health care needs of individuals who are HIV infected or are diagnosed with AIDS may promote enhanced awareness, growing tolerance and acceptance by nurses and other health care professionals.

Increased knowledge through research may raise the consciousness and heighten the sensitivity of nurses who care for persons with HIV disease. Information, tolerance, and acceptance may help reduce fear and discomfort and improve management and delivery of patient care, especially in the home and the community.

#### Summary

HIV disease is increasingly a chronic condition for many individuals who live in various socioeconomic circumstances. Managing the pervasive and complex problems that can arise for HIV/AIDS individuals is difficult, multifaceted, and often overwhelming for those individuals who are infected and those who try to help.

As with other serious chronic conditions, nursing has much to offer in assisting with the management of the daily problems and work that is required by HIV disease. To be

able to provide knowledgeable, skilled and sensitive care, nurses must be aware of the daily trials, tasks, feelings, and concerns of those individuals who experience HIV disease and all of the associated complexities.

## Chapter 2

### Review of Literature

Living with HIV and the management of the disease as a chronic illness are discussed in this section. The experience of HIV as a chronic illness is viewed with respect to the socioeconomic and psychosocial problems and conditions which HIV infected individuals encounter. The management of HIV as a chronic illness is considered in terms of the use of various strategies and the consequences of engaging in those strategies.

### Chronic Illness

Chronic illnesses are prevalent conditions in Western societies as improvements in health care and technology have been developed, and large numbers of people live longer. Study and discussion of chronic illness conditions are common in many academic disciplines, medical and health care arenas, government and business sectors.

Corbin and Strauss (1988) identified chronic illness as the most prevalent form of illness in our society and the

major health problem facing our nation. Strauss (1975) in his book, Chronic Illness and the Quality of Life, used the definition of chronic illness proposed by L. Mayo in 1956 in an address to the Commission on Chronic Illness:

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care.

As Strauss explained, the chronically ill share many social and psychological problems, but each disease has a specific set of problems. Various diseases impact differently in terms of: management, medical regimes, and the effect on an individual's life and disease course.

Despite differences from disease to disease, chronic illnesses, according to Strauss (1975), present social and psychological problems for affected individuals, their families, care givers, etc. in the context of the specific conditions in which they live. The daily experiences, problems, living conditions, and management of illnesses by patients are as important for medical and health care providers to consider as etiology, diagnoses and treatment of symptoms:

We have seen these people attempting, with more or less success and courage, to manage their lives, often in the face of extreme adversity. Their management is their business (Strauss, 1975, p. 133).

A study by Derdiarian & Schobel (1990) supports the recommendations by Strauss (1975) of using the individual's experience of chronic illness in planning and providing care. The data suggested that patients are the best evaluators of changes and should be given opportunities to describe the changes associated with their illness. "To understand just how the patients experience the impact of this disease is key to designing their care (Derdiarian & Schobel, 1990, p. 445)."

To deal with multiple problems and varying conditions associated with chronic illness, patients must develop basic "strategies". These strategies include methods or techniques developed to have some degree of success. In many cases, patients need assistance from family, friends, acquaintances, or strangers, i.e. "agents", to carry out these strategies. To effectively implement basic strategies, "organizational or family arrangements" must be made (Strauss, 1975).

There must be coordination and organization of the efforts of everyone involved which requires trust, interactional skills, and financial, medical, and family resources. A myriad of physical, psychological, and social "consequences" result depending on how the patient, family, care givers, etc. have organized themselves to handle the various problems which develop (Strauss, 1975).

### The Experience of HIV as a Chronic Illness

Daily living problems of Chronic Illness. Strauss (1975, p. 7-9) proposed a framework from which to view and understand patients and their experiences. Chronic illness causes multiple problems of daily living:

1. Prevention of medical crises and management of the crises once they occur
2. Control of symptoms
3. Carrying out prescribed regimes and managing problems that evolve from the regimes
4. Prevention of or living with social isolation
5. Adjustment to changes in the course of the disease
6. Attempts at normalizing interactions with others and style of life
7. Funding - finding the necessary money to pay for

treatments and to survive, in the midst of partial or complete loss of employment.

The problems described by Strauss apply to HIV disease as well as other serious chronic illnesses such as ulcerative colitis, chronic renal failure, emphysema, and hemophilia. All of these diseases are life-threatening with no known cure. Physical problems include pain, fatigue, and various physiological dysfunction. Strict medical regimens must be balanced with periods of rest. Treatments may be time-consuming, expensive, and require special instruction to learn and skill to perform. Interactions with health care agencies are often frequent and lengthy.

Many HIV infected individuals and others with serious chronic diseases live within a spiraling downward disease trajectory which is different for each individual. The main burden of care is on the individual and/or those who are present in the home. The burden of care is more arduous for and often neglected by the poor, homeless, or substance abusers.

For women infected with HIV, self care needs are frequently complicated because of responsibilities for care of children who may or may not be HIV infected. In a



descriptive study (Anastasio, et al., 1995) of 10 HIV infected women who attended a large metropolitan outpatient clinic, participants reported that the "most burdensome health-related self care activities" were administering home treatments, adhering to special diets, and obtaining resources. The most burdensome "universal self care activities" were caring for children, physical activity, and seeking employment (Anastasio, et al., 1995).

Many of the daily problem areas of living with a chronic illness that Strauss (1975) identified are being studied and discussed in the 1990s in terms of living with HIV infection. Financial burdens often become more difficult or insurmountable. With HIV infection or other serious chronic conditions "...funding becomes an ongoing preoccupation, with dramatic force sufficient to compel the behavior not only of the patient and possibly his kin but often of the professional personnel involved in his treatment as well (Strauss, 1975, p.109)."

Many HIV/AIDS individuals are often unemployed with no health insurance except for state or government sponsored care, such as Ryan White federal funds for impoverished, uninsured HIV infected individuals. In a cross-sectional,

descriptive study of the healthcare needs of 386 positive HIV patients in hospitals and outpatient, long-term care, and home settings, the "most urgent" needs of patients in all settings were related to finances (Baigis-Smith, Gordon, Mcquire, & Nanda, 1995).

McCormick, et al. (1991), in a study of long term care needs of hospitalized white gay males with AIDS, highlighted the chronic illness nature of AIDS and the accompanying need of long term care resources. The characteristics of those who were most appropriate for long term care outside of the hospital setting were those individuals who: had impairment of two or more activities of daily living; lived alone; had dementia; were more likely to be covered by Medicaid; had lost 10% or more of their body weight; and had more frequent hospital visits.

Corless, Halloran, and Belyea (1994) compared 128 hospitalized patients with HIV infection and 79,345 patients hospitalized with other disorders from an urban health science center to identify nursing dependency needs of HIV patients compared to other hospitalized patients. HIV patients were more likely to be assigned nursing diagnoses relating to infection, fluid volume deficit, nutrition,

diarrhea, altered oral mucous membranes, impaired gas exchange, impaired mobility, potential for injury, prolonged disease/disability, activity intolerance, grieving, disturbed self concept, powerlessness, depression, social isolation, and impaired home maintenance.

Stage of illness, level of symptoms, and psychological functioning in 156 HIV infected individuals at various care and referral centers were investigated by Linn, Monnig, Cain, and Usoh (1993). Their findings indicated that stage of illness was not related to measures of psychological functioning of coherence, depression, and anxiety. Increased HIV symptoms were related to increased depression, anxiety and decreased coherence. The results emphasized the greater importance of perceived physical symptoms over stage of illness for psychological functioning in HIV infected individuals.

In a qualitative study of 9 homosexual male couples, Rose (1996) suggests a social context to symptom management. Couples in this study used "mutual protection" as a mechanism to prevent losses they could control and to let go in situations beyond their control. Independent, inter-dependent, and dependent symptom management was used by

couples in this study.

Other studies (Bowers & Dols, 1996; Cohen, Ferrans, Vizgirda, Kunkle, & Cloninger, 1996; Nokes & Kendrew, 1996) have considered nutritional and sleep needs in HIV infected individuals. Bowers and Dols (1996) assessed the nutritional status of 36 HIV infected individuals in an outpatient clinic setting by use of a revised Subjective Global Assessment tool. The most severely malnourished HIV patients showed more weight loss and gastrointestinal symptoms, a greater level of functional impairment and wasting, lower albumin and CD4 lymphocyte values. Use of such tools can assist nurses and dietitians in identifying which HIV patients need nutritional intervention (Bowers & Dols, 1996).

In a descriptive study of 50 subjects at an outpatient clinic in the mid-western United States, investigators (Cohen, Ferrans, Vizgirda, Kunkle, & Cloninger, 1996) assessed the sleep of persons with HIV infection. Greater than 50% of the subjects had difficulty falling asleep; 43% slept less than 6 hours or more than 10 hours a night; and most subjects awakened frequently during the night.

Nokes and Kendrew (1996) assessed the sleep quality of 56 HIV infected adults at a veterans hospital in New York. General well-being was correlated with sleep quality. Individuals who were intravenous drug users reported less sleep quality and well-being than others.

An exploratory study by Rose (1993) of 11 HIV infected women, 6 African American and five white, from urban agencies in the southeastern section of the U.S. identified multiple health concerns. Six of the women were diagnosed with AIDS; five were HIV positive but asymptomatic. Most had no financial to very limited financial income. Housing tended to be low-income and "unsafe" as described by the participants. Most reported lack of appetite and poor sleep. Cigarettes, marijuana, and alcohol were commonly used. Many felt "generally mistreated" and isolated from their families and friends. Concerns about care of children and suicidal thoughts were common among the participants.

In a grounded theory study of 29 homosexual men, Kendall (1994) identified wellness spirituality as a process that involved "appreciating and understanding life, fulfilling purpose, finding meaning and acceptance, and building meaningful connections with others." Building

meaningful connections were characterized by "belonging, sharing, gay bonding, confrontation, supporting, and touching."

Psychosocial experience of HIV. How the individual views, feels, and reacts to the illness is crucial to the quality of life experienced and the successful management of the condition and accompanying problems (Corbin & Strauss, 1988). Many of the "consequences" which Strauss speaks of in dealing with chronic illnesses are psychosocial in nature.

Ragsdale & Morrow (1990) studied 95 subjects who were in various stages of HIV disease, asymptomatic, symptomatic, or diagnosed with AIDS. Results indicated that HIV infection significantly affected quality of life, with the least impact on HIV positive individuals and the greatest impact on those persons with symptomatic disease. Another finding was that HIV disrupts psychosocial aspects of life the most.

Ragsdale & Morrow (1990) suggested that their findings supported previous research of terminal cancer and chronic renal failure. This research indicated that quality of life is a function of the patient's nearness to death. The

authors recommended that knowing which quality of life aspects change with disease progression can guide nursing care and case management.

In a separate ethnographic study, Ragsdale, Kotarba, and Morrow (1992) investigated the work-related activities used by 19 respondents to improve quality of life in HIV disease. Findings indicated that quality of life was enhanced when those infected were able to carry out activities they felt were important and when the healthcare team supported their work.

Strauss (1975, p. 9) described the experience for the chronically ill as, "...their illnesses are either always with them or, if quiescent, potentially lurking just around the corner." This description represents a departure from the typical medical model of viewing chronic illness as a disease, with an emphasis on physiological aspects, pathology, and treatment plans rather than on the person and the human experience (Morse & Johnson, 1991; Kleinman, 1988).

Kleinman (1988, p. 3) described illness as "the human experience of symptoms and suffering. Illness refers to how the sick person and members of the family or wider social

network perceive, live with, and respond to symptoms and disability." Chronic illnesses never really go away and may range from constant threats to vital functioning, to feelings of vulnerability and loss of control, to the comprehension of disfigurement, disability, and death. According to Kleinman, illnesses often have more than one meaning and become so entwined with the course and events of an individual's life that they "become inseparable from life history."

Recognizing the various meaning of illness that an individual has is important for understanding and ultimately providing effective assistance and care (Kleinman, 1988; Strauss, 1975; Toombs, 1992; Morse & Johnson, 1991; Allan, 1990; Derkearian & Schobel, 1990). Kleinman (1988) discusses symptom meanings, cultural significance, social and personal meaning of illness.

Symptom meanings have to do with the designation of various symptoms, such as pain, wheezing, and nausea as "disability or distress" which are culturally based. Certain symptoms and illnesses can be assigned meanings based on the cultural context, such as the stigma of HIV. The personal and social meanings of illness refer to the



transferring of significance from the person's life to the illness, the intensifying and/or exacerbating of life patterns, or the creating of new opportunities for existence.

Depending on the individual and their life history, various feelings and reactions are aroused in the day to day experience of chronic illness. Toombs (1992), a philosopher suffering from multiple sclerosis, provides a very personal and in-depth view of chronic illness as a lived experience. According to her account, chronic illness is experienced as a "disruption of a lived body."

Individuals live a disordered existence because dysfunction in the physical or biological sense is a disruption in the patient's being in the world." The body tends to become objectified as a "malfunctioning physiological organism and as a physical encumbrance." There is a forced attention to physical function and an awareness of impairment and pain on a daily basis.

With chronic illness, the individual is "irrevocably attached" to a malfunctioning body that has the potential to interfere or disrupt many or all activities and involvements. The illness is experienced as "world-

threatening", sometimes "life-threatening". Fear is paramount: fear of death, fear of not being able to function, fear of pain and suffering. Pain and discomfort of some kind are often ever-present (Toombs, 1992).

Toombs (1992) also identified multiple losses experienced by the chronically ill. Typical losses were: loss of control over one's body or the illness or one's life; loss of wholeness of bodily integrity; loss of sense of self; loss of relationships with others; loss of certainty of a personal sense of indestructibility; loss of independence; loss of the freedom to make choices about one's own situation; and loss of the familiar world, i.e. the activities, work, and play of the everyday world.

Many of the feelings and psychiatric symptoms of HIV disease are similar to those of other life-threatening diseases (Fullilove, 1989). Anxiety, apprehension, depression, helplessness, sadness, grief and suicidal thoughts occur frequently (Fitzpatrick, et al., 1984). A sense of an "existential aloneness" is part of the chronic illness experience according to Toombs (1992):

Nothing is quite so isolating as the knowledge that when one hurts, nobody else feels the pain; that when one sickens, the malaise is a private affair; and that when one dies, the world continues with barely a ripple (Murphy, 1987, p.63).

Complicating the experience of individuals with HIV disease is the prevalence of neuropsychiatric and psychological problems. Especially common for HIV infected individuals is the development of dementia which can limit the ability to live with the psychological stress of the illness and also to effectively follow treatment regimens (O'Dowd & McKegney, 1990).

O'Dowd and McKegney (1990) compared a group of AIDS patients with a group of non-HIV medical patients to compare psychological reactions, problems, and the need for in-patient psychiatric consultation. The investigators found that the groups of AIDS patients who were predominately male, Hispanic, and IV drug users exhibited equal rate of suicidal behaviors with the non-HIV group. Results also indicated that the AIDS patients needed more psychiatric visits and consults over the course of a year.

A descriptive study (Twinaime, 1993) of 80 individuals, 19 who were HIV positive and asymptomatic, 26 who were symptomatic, and 35 who were diagnosed with AIDS, was

conducted at a care center in Texas to assess the relationships between HIV status, depression, and suicidal intent. The HIV positive, asymptomatic group showed more suicidal intent but less depression than the other two groups. Analysis also revealed that African Americans and Latinos had greater suicidal intent than Caucasians.

In a study of seropositive HIV gay men in Australia, Viney, et al. (1991) found that the HIV positive men and their care givers exhibited psychological frailness in the form of anxiety, indirect anger, and helplessness. Psychological strength was evidenced by a greater sense of personal competence and a good feeling towards peers.

Lennon, Martin, & Dean (1990) in a study of the influence of social support on AIDS-related grief reaction in gay men found that AIDS patients frequently suffer from isolation and loneliness because they do not want to burden friends. Patients and others in their social network often talk of nothing else besides AIDS and tend to socialize predominately with people who are in the same circumstances.

In a descriptive study (Linn, Anema, Hodess, Sharpe, & Cain, 1996) of 255 HIV infected African American adults, depression was related more strongly to the individual's

perceived health status than HIV symptoms. Perceived health was based on HIV symptoms and resources (church attendance, income, etc.) available. Depression was more likely to occur if resources were inadequate.

Analysis of a descriptive study by Valente, Saunders, and Uman (1993) of 223 individuals from an urban outpatient clinic who had tested positive for HIV or perceived they were at risk revealed that symptoms of AIDS were predictive of depression for HIV positive men, but not for HIV positive women. The number of AIDS-related symptoms were associated with an increase in unhealthy behaviors, and depression was associated with more unhealthy behaviors.

In a correlational study (van Servellen, Brecht, & Knoll, 1993) of 30 male AIDS patients attending an outpatient clinic at a large medical teaching university, two-thirds of the participants showed clinical depression, and more than one-half demonstrated serious feelings of hopelessness. Depression was significantly related to stressful life events, physical health, and negatively related to satisfaction with social support and hope. Hopelessness was significantly negatively related to satisfaction with social support.

The effects of stigma on HIV. Herek (1990) stressed that AIDS-related stigma adds to the emotional burden and coping responses of living with a chronic and fatal disease. Persons with AIDS must deal not only with the disease and all of the problems but also societal hostility and suspicion due to stigma. As a result, anger, anxiety and depression are increased for individuals with HIV disease.

Anger can be intensified because of loss of employment or harassment, loss of health insurance, and the poor response of government, religious, and social agencies in helping individuals deal with the disease. Anxiety is amplified not only because of fear of the disease but also fear of the response of individuals. Depression can be worsened and can take the form of self-blame or internalized stigmatization.

The effects of stigma are extremely damaging to the emotional and social well-being of those infected with HIV and have an enormous impact on the experience and management of the illness. "It is in the social context of stigmatizing illness that individuals experience AIDS (Fullilove, 1989, p.5)."

For persons with AIDS, the stigma associated with the disease is often layered on other stigmatized identities, such as homosexuality, bisexuality, prostitution, IV drug abuse, homelessness, and ethnic heritage. Unfortunately prevention and treatment of the HIV epidemic has been hampered by stigma, like unwanted illnesses throughout history (Herek, 1990).

During the plague of the Dark Ages, individuals who were ill concealed the disease for as long as possible or fled to other areas, thus increasing the spread. In Britain in the 1880's, specialized houses were instituted because contagious diseases aroused disgust and fear, and because general hospitals would not accept certain types of patients, those with fevers, cancer, the mentally ill, pregnant women and children. The early fever houses were called "houses of recovery" so as not to frighten citizens who lived nearby (Herek, 1990).

During cholera epidemics of the 1980's in the United States, there was tremendous fear of contagion especially when the cause was not known. The poor, racial minorities, immigrants, and the sexually deviant were labeled as idle and intemperate, and because of their behavior, these groups

were held responsible for the disease and its spread. The general public attacked and avoided sick persons.

Quarantine measures were frequently advocated and used so that the sick could be isolated and kept in special hospitals (Herek, 1990).

The parallels between the early epidemics of infectious diseases and AIDS are striking despite hundreds of years in which many socioeconomic and technologic advances have been developed. However, stigma has existed at least since the Greek civilization and probably since people first formed social groups (Goffman, 1963).

The Greeks, according to Goffman (1963), originated the term, stigma, to designate bodily signs which indicated something unusual and bad about the moral character of an individual. Modern usage of the term refers more to the sense of "disgrace" rather than the bodily evidence of it (Goffman, 1963).

Individuals are stigmatized when they are perceived to possess personal or social "attributes" that are different or incongruous with the stereotype of what the public thinks they should be. These individuals can be viewed as different, less desirable, bad, dangerous, or weak; they are



reduced from a "whole and usual person to a tainted, discredited one (Goffman, 1963, p. 63)."

A "stigma-theory" or ideology is developed to explain and rationalize the individual's inferiority or danger to others. The stigmatized are seen as not quite human and thus can be discriminated against in a variety of ways and to a great extent. They are not accorded the respect, regard, and acceptance that non-stigmatized individuals in society are.

Individuals respond to stigma in characteristic ways. Goffman (1963) explains that the stigmatized individual has feelings of a normal human being but also agrees that he or she may not be what they really ought to be. Feelings of shame and self-betrayal are common. However, personal acceptance and self-improvement can also be a consequence.

Social contracts can be very tenuous between the stigmatized individuals and the rest of the public, with the natural reaction being avoidance of such situations by all involved. An accompanying sense of isolation with feelings of suspicion, depression, anxiousness, and confusion can result for the stigmatized individual.

When social interactions do inevitably occur, the stigmatized individual may be preoccupied with feeling unsure and self-conscious about what others think of him or her. If the stigma is particularly visible, there may be a sense of being exposed, that their privacy has been invaded. In anticipation of or reaction to the uneasiness of many social situations, stigmatized individuals may use "defensive cowering" or "hostile bravado" as responses, further adding to the discomfort and unease (Goffman, 1963).

Social support for persons who must suffer from stigma comes primarily from two different sources. The first and most significant group are those fellow sufferers who share the stigma. The second group of supporters are those individuals who are known as the "wise". These can be close friends, relatives, or normal individuals who are sympathetic to and accepted by the stigmatized group. Nurses who work with and come to know stigmatized individuals are often designated as "wise" (Goffman, 1963).

In studying the effects of stigma regarding HIV disease, Walkey, Taylor, and Green (1990) found in a study of attitudes towards AIDS that the stereotype of persons with AIDS is more negative than the view of individuals with

cancer and coronary heart disease. AIDS patients were rated as "more dangerous, dirty, foolish, and worthless" than the comparative groups of patients. This study indicated that persons with AIDS, like those with mental illness, are perceived less favorably than patients with cancer and heart disease.

Walkey, et al. (1990) felt that the negative stereotype and the stigma of AIDS is driven primarily by a fear of contagion. Important ramifications of the fear and stigma may be less care and concern afforded HIV infected individuals compared to others who are ill.

Siminoff, Erlen, and Lidz (1991) concur with Walkey, et al. (1990) that patients with HIV disease may receive substandard care because of fear and distress on the part of nurses and other health care professionals and personnel. The authors quote several studies (Douglas, Kalman, T.P. & Kalman, C.P., 1985; Kelly, et al., 1988; Katz, et al., 1987; Scherer, Haughey, & You-Wu, 1989; van Servellen, Lewis, & Leake, 1988; Wiley & Acklin, 1988; Wiley, et al., 1990) which focus on the attitudes about HIV/AIDS of nurses and health care professionals.

Indications from studies of the attitudes of health care providers about HIV/AIDS showed a significant percentage of providers who expressed reluctance or discomfort about coming into direct contact with individuals with HIV. Some of the providers expressed an opinion of their right to refuse to care for patients infected with HIV or diagnosed with AIDS.

Layea and Gien (1993) found in a grounded theory study of 25 HIV positive participants at an outpatient clinic in Newfoundland, Canada that fear of disclosure was "intense". Leisure activities and social lives were limited by fatigue and the fear of disclosure or fear of infecting others. Eighteen of the participants had experienced a negative change of attitude about themselves.

Goffman (1963, p. 5) stated that because a person with stigma is often viewed as not "quite human, a variety of discriminations occur through which we effectively, if often unthinkingly, reduce his life chances." The effect of stigma, as described by Goffman, can influence the illness experience, treatment, and survival of those with HIV disease.

## Management of HIV as a Chronic Illness

### Strategies and consequences

Without understanding a great deal about how the chronically ill get through their days outside of health facilities, health personnel will never understand what they really need to know in order to give effective care...(Strauss, 1975, p. 6).

Except during acute phases, the chronically ill typically live at home and manage their illness by themselves or with the help of others, usually in the midst of medical equipment, procedures, and drugs. As Corbin and Strauss (1988) explain, management of an illness at home is often difficult for all who are involved.

Chronic illness to these researchers (Corbin and Strauss, 1988) is a "sense of failed body" with a need to adjust to the disease and its symptoms of decreased performance, altered internal and external appearance, limited activity, and potential death. Managing illness and accommodation to changes in the body, self-image, relationships, and lifestyle on a daily basis requires a great deal of work.

From their study of various chronic illnesses, Corbin and Strauss (1988) have produced a theoretical scheme of chronic illness management. The scheme includes several

components: the contextual; the work and interactional; the biographical; and trajectory phasing. The scheme can be used for studying chronic illness or in working with patients to plan and manage their illness.

The contextual component consists of a conditional matrix which represents multi-level and multi-interactional conditions. These conditions are political and socioeconomic influences such as stigma; the bearing of the illness; life biographies; everyday situations; work processes and performances; competition for available resources; and interactions of all participants (Corbin & Strauss, 1988).

The biographical component includes all of the various biographical processes. These biographical processes are: contextualizing the illness into one's life; coming to terms with one's body; reconstructing one's identity; and re-doing one's biography.

The trajectory component is one of phases, comebacks, stability, instability, deterioration, and dying. These phases involve shifts in the illness course; the work of chronic illness; and various types of relationships,

marital, biographical, and work relations (Corbin & Strauss, 1988):

The concept of trajectory encompasses not only the course of illness but all of the associated illness work carried out through the work processes. Inclusive in this work and the work processes are types and lines of work and modes of articulating them, as well as various biographical processes that are set in motion by the illness course itself and the work of managing it and are affected and in turn affect the carrying out of work done via the work processes (Corbin & Strauss, 1988, p. 326-327).

Work is defined by the authors as the different kinds of tasks which need to be performed; how the tasks are done; who does the tasks; under what conditions are the tasks done; and the consequences of performing the tasks. Essentially work is a plan of action to manage one or several aspects of the illness and the lives of the ill persons.

The different types of work are illness work, everyday-work, and biographical work. Illness work includes the tasks and activities to control symptoms, the following of treatment plans, and interactions with the health care system. Everyday-work involves activities of daily living and maintaining social relationships. Biographical work means coming to terms with the illness.

Chronic illness management involves different types of work and the various interactions of the individuals doing the work with those who are involved, amid the context of trajectory, "the active role that people play in shaping the course of an illness (Corbin & Strauss, 1988, p. 34)."

Chronic illness work involves a constant juggling of time, space, energy, money, jobs, activities, and identities to maintain balance and to carry on in everyday life.

Individuals cope with chronic illness, according to Fitzpatrick, et al. (1984) in a variety of ways. Some do not adjust, becoming passive, dependent, and eventually giving up. Others use denial, either total or complete. According to these authors (Fitzpatrick, et al., 1984), denial is common among people who experience potentially lethal illnesses. Associated with denial is "middle knowledge", a state of ambivalence when the person recognizes he or she is dying but refuses to accept the idea of death. Also used is rationalization which helps to dilute the impact of the course and seriousness of the illness. Individuals often feel guilt for their own behavior or blame others for their situation and problems.



Fitzpatrick, et al. (1984, p. 242) point out, "there is an urge to control the uncontrollable by detailed knowledge." Patients try to know every detail of various drugs and treatment regimens. Or they question their health care providers about what is happening to their bodies or what will happen under certain circumstances. Some individuals refuse certain drugs or treatments, propose alternatives, or initiate various therapies themselves.

Other patients may develop a fighting attitude. "Many are buoyed up by defiance. They intend to survive and wish all those around them to support them in their battle (Fitzpatrick, et al., 1984, p. 243)." There are many people who will submit to new, untried procedures, painful or not, in hopes of relief or cure. Some individuals are able to achieve a positive acceptance of their condition and illness, often over time and with help.

Fitzpatrick, et al. (1984) also found that urban, gay men commonly organized formal networks to deal with the social, economic, scientific, and personal demands of HIV disease. Self-help groups for grieving individuals or for people trying to change risk behaviors also were formed.

These groups provided a supportive environment for exchange of information and helped to decrease a sense of isolation.

Lennon, Martin, & Dean (1990) found that the all important social support network which can be crucial in performing the work of chronic illness is often strained between HIV positive individuals who are well and those who are exhibiting symptoms and problems of HIV disease. The strain is often due to the fact that both need comfort and help in dealing with the demands of the disease. This situation is especially true for care givers who are HIV positive and who become less able to provide care because of their own increasing needs.

Barroso (1997) in an ethnographic study of 14 men and 6 women who had AIDS for at least three years, focused on the ways of becoming a long-term survivor. The author identified five dimensions that explained how survivors "reconstruct" their lives within the context of HIV infection. The five dimensions were: normalizing; focusing on living; taking care of oneself; being in relation to others; and triumphing.

Normalizing included maintaining a daily routine; realizing that AIDS conditions were episodic; and not

allowing AIDS to become the focus of one's life. Focusing on living involved: having a positive attitude; planning for the future; and having a focus for one's energy. Taking care of oneself was characterized by: discontinuing negative habits; undertaking health-promoting activities; being responsible for one's health; and decreasing stress. Being in relation to others included: dealing with one's family; renegotiating the friendship group; helping others with HIV; and developing a relationship with a higher power. Triumphant involved: believing that having AIDS was a blessing; re-establishing the priorities in one's life; discovering who they really were; and believing they could live with AIDS.

In a grounded theory study of 38 patients, 42% Hispanic, 32% Caucasian, 26% African American, 76 % male, and 24% female, with advanced-stage AIDS, Wilson, Hutchinson, and Holzemer (1997) identified the central experience, i.e. basic social/psychological problem, of "living with dying". Participants attempted to cope with "living with dying" through a three-stage process of "salvaging quality of life from remnants."

The first stage of "salvaging quality of life from remnants" was "preserving" which was characterized by: managing stigma; maintaining life function; juggling treatment and side effects; and participating in decisions. Strategies to manage stigma involved: "secrets" and silence; selective disclosure of partial information to chosen confidants; and full and open disclosure.

Hispanics were more likely to not disclose because of "fear of rejection from friends, family, or the church" and for fear of consequences of disclosure for their loved ones (Wilson, Hutchinson, & Holzemer, 1997, p. 85). By choosing not to disclose, the individual had to bear more of the burden of living and dying by himself or herself. Selective or open disclosure could result in isolation and rejection.

Maintaining life function involved continuing the current lifestyle; not focusing on AIDS; living day-to-day; thinking positively; establishing a routine of health-promoting activities such as exercise, diet, stress reduction, and recovery from substance abuse. Juggling treatment and side effects included: fighting for treatment by overcoming financial and logistical barriers to obtain health insurance; cautious experimentation meant

participation in clinical drug trials or use of alternative and holistic therapies; and body listening by "tuning into" one's own body responses. Participating in decisions involved becoming knowledgeable about the disease and the health care system; "shopping" for the health care provider that can best serve them; and asserting preferences regarding treatment options (Wilson, Hutchinson, & Holzemer, 1997, p. 87-90).

The remaining two stages of "salvaging quality of life from remnants" were "sustaining and redeeming". During "sustaining" participants used the strategies of recasting goals and "presencing of people", making connections with others, seeking interpersonal meaning, and reconciling with estranged family. The stage of "redeeming" involved: adjusting hope levels; death calculations; coveting time; preserving dignity; and resolving spiritual issues.

#### Summary

This study is concerned with how individuals live with HIV disease as a chronic illness on a daily basis. A broad view of chronic illness is used to focus on the various problems individuals encounter; the reactions to the disease, problems, personal circumstances and surrounding

conditions; the work that must be undertaken to manage the disease; and the consequences which result from the work.

Previous nursing studies of individuals with HIV/AIDS have focused on various aspects of living with the disease. Chronic illness concerns such as physical and psychosocial problems; psychological functioning; healthcare, self-care and dependency needs; symptom management; quality of life; long-term survivorship; and living with advanced AIDS were of interest. Men and women who are HIV positive and asymptomatic, symptomatic, or diagnosed with AIDS and who live in urban areas and small towns in the northeastern, southeastern, mid-western, Pacific Coast regions of the United States, as well as Nova Scotia in Canada have been studied.

This study views HIV/AIDS as a chronic illness and seeks information about the experience of living with the disease, which includes problems, reactions, strategies, work, and consequences rather than focusing on a particular aspect of living with the disease. Participants in this study, who are mostly men, are from urban areas of two nationalities, the United States and Mexico. The cultural differences of living and dealing with HIV/AIDS are compared

and contrasted.

Conclusions from this study may provide useful information about how individuals live with HIV disease as a chronic illness. Knowledge gained may be important for nurses and other providers in assisting patients who are U.S. citizens or of Hispanic heritage as they experience and manage HIV/AIDS.

## Chapter 3

### Method

This chapter includes discussion of the study methodology and research activities. A brief summary of the study methodology, grounded theory, is presented. The sample is described. Research activities of gaining entree, human subjects concerns, data collection, data management, and data analysis are discussed.

#### Research Methodology

Grounded theory was developed and introduced by Glaser and Strauss (1967). The grounded theory method is "oriented to discovery" (Benoliel, 1996) and representative of the reality of the persons studied (Strauss & Corbin, 1990).

Of interest to grounded theory investigators is the study of social problems to which individuals must adapt (Benoliel, 1996). The focus of analysis is to organize ideas that emerge from the data in order to explain the phenomenon being studied and to develop substantive theory.



Ultimately researchers using grounded theory strive to relate their work with other studies so that the theory will have a broad base of applicability and usefulness (Strauss & Corbin, 1990).

### Sample

For entry into this study, participants were required to be 18 years and older, could be male or female, and had to be HIV positive or diagnosed with AIDS. Individuals were selected based on their ability to meet study requirements, to give informed consent, and according to the on-going, emerging theory of the study.

To enhance the principle of constant comparison, individuals were sought from a wide range of social and cultural groups. Study participants from diverse backgrounds, personal circumstances, and various stages of HIV disease progression were of interest to better identify a broad array of similarities and differences characteristic of living with and managing HIV infection.

The sample consisted of ten (10) U.S. participants who lived in San Diego, California and eleven (11) participants who lived in Tijuana, Mexico. Basic demographic data of participants' age and sex and information about length of

time of HIV infection are presented in Table 1.

Table 1

	San Diego n=10	Tijuana n=11
Age Range	29 - 48 years	27 - 39 years
Males	10	9
Females	0	2
Length of years HIV Infected	1 - 11 years	7 months - 9 years
Mean time of HIV Infection	6 years	3 years

The ten participants in San Diego were all males. Eight were Caucasians, and two were African Americans. Ages ranged from 29 to 48 years old. The group of participants from Tijuana consisted of nine males and two females. Their ages ranged from 27 to 39 years of age.

The length of time for HIV infection for the San Diego participants was 1 to 11 years, with a mean time of 6 years. The length of time of HIV infection for the Tijuana participants was 7 months to 9 years, with a mean time of infection of 3 years.

### Research Activities

#### Gaining Entree

Entree to health care facilities and participants was facilitated by the investigator's work with subjects

involved in clinical drug trials at community-based research sites in San Diego and Tijuana. The U.S. participants were involved in several different pharmaceutical company drug trials conducted at a research site within the city of San Diego. The Tijuana participants all attended an after-hours special HIV clinic in the center of downtown Tijuana where they received primary HIV health care, counseling, information and were enrolled in a U.S.-sponsored, pharmaceutical drug trial. Both the principal investigator of the U.S. clinical trials and the Tijuana physician were in full knowledge and support of the participation of their patients in this study.

#### Human Subjects Concerns

Human subjects considerations guided the various research activities of informed consent, data collection, data management, and data analysis. Before commencing the study, approval of the study proposal and informed consent form were obtained from the University of San Diego Committee for the Protection of Human Subjects. A copy of the approval letter is included in Appendix A.

Individuals at the San Diego and Tijuana research sites were approached by the investigator about participating in

the study. The purpose of the study, study procedures such as audio-taping, the right to confidentiality, the right to withdraw from the study without jeopardizing current or future health care and research participation were explained. Any questions that arose were answered.

If participants agreed to participate in the study, the informed consent was reviewed and discussed, with additional emphasis placed on the right to confidentiality, the right to withdraw from the study, and the ways to contact the investigator. All consents were signed by participants prior to their involvement in any study-related activities. Each participant was offered a copy of the signed consent for their records.

The participants from Tijuana were provided with an explanation about the study, and questions were answered in Spanish by a bilingual nurse who was a staff member at the San Diego and Tijuana research sites. A Spanish language version of the informed consent was provided for the Tijuana participants. Sample English and Spanish consent forms are included in Appendix B.

### Data Collection

In grounded theory, data are collected from the field of study through the use of purposeful and theoretical sampling. Purposeful sampling is the selection of participants on the basis of theoretical needs, willingness to participate, and ability to describe thoughts, behavior, and insights (Strauss & Corbin, 1990). Theoretical sampling is directed towards obtaining data about events, incidents, and behavior that indicate categories that can be developed and conceptualized for ultimate theory development (Strauss & Corbin, 1990).

Both purposeful and theoretical sampling were used in this study to guide selection of participants and collection of data. The investigator was in contact with potential participants from San Diego and Tijuana, Mexico during the conduct of various pharmaceutical company clinical drug trials. These potential participants met the basic study entry criteria and expressed interest in talking about their experiences living with HIV/AIDS. In addition, participants from two nationalities presented the opportunity to gather information about cultural similarities and differences of dealing with the disease.

Several methods of data collection common to grounded theory such as interviews, participant observation, and on-going review of relevant literature (Glaser & Strauss, 1967) were utilized. Interviews were the major means of collecting data. Observation of study participants occurred during interviews. Review of pertinent HIV literature was on-going throughout the study.

A significant amount of participant observation also occurred prior to the commencement of this study as the investigator worked with HIV-infected subjects in various clinical drug trials. Through observations of individuals in their homes and during research visits, it became apparent to the investigator that HIV infected individuals were engaged in a great deal of activities and effort, i.e. "work" (Strauss & Corbin, 1990) trying to deal with the disease. These observations sparked the idea for conducting this study of how individuals live with, work and manage HIV.

Interviews. Data were collected from January 1993 through July 1994 by interviews in which participants described their experience living and dealing with HIV infection. An semi-structured interview approach was used,

employing use of broad, open-ended questions which allowed each participant the opportunity to describe their experiences, thoughts, and feelings. Probes and more focused questions were also used according to the emerging theory as participants described how they managed their illness in terms of problems, successes, actions, and reactions under various circumstances.

The open-ended questions developed for the interviews were guided by the lines of inquiry. A copy of these study questions is included in Appendix C.

Participants were interviewed primarily in clinic type settings at the research sites where they attended study visits. Two of the San Diego participants were interviewed in their home. Privacy was always maintained, and interruptions were kept to a minimum.

The interview sessions on average lasted about an hour. Interviews were conducted by first briefly explaining the study and answering any questions in either English or Spanish. All twenty-one interviews were audio-taped and later transcribed verbatim.

Each one of the Tijuana participants was interviewed in Spanish by the bilingual nurse who was a staff member at the

research site. The interviews occurred at the after-hours HIV clinic in downtown Tijuana after participants completed study visit activities for the U.S. pharmaceutical-sponsored clinical drug trial.

The investigator was not in attendance during the interviews for the Tijuana participants. The interviews were conducted by the bilingual nurse in the same clinic, but in a separate room, where the investigator was working with participants involved in another research study. The bilingual nurse was familiar with the purpose of the study, the interview questions and procedures. She would interrupt an interview to consult with the investigator if questions or problems arose.

Risk Management It was anticipated by the investigator that during an hour-long interview, participants might experience physical discomforts or fatigue because of HIV-related conditions. During the interviews, participants were continually assessed and asked, if necessary, about feelings of discomfort or fatigue. None of the participants demonstrated or complained of fatigue or any other physical discomfort.



Also expected was the possibility that participants might become emotionally upset while discussing their experiences and feelings related to being HIV infected. Plans were made to provide opportunities for participants to discuss feelings or concerns during the interviews or afterward. If necessary, referral for further discussion with mental health professionals was available. For the Tijuana participants, counselors were present at the after hours clinic to provide one-on-one and group counseling.

One of the Tijuana participants did become emotionally upset while talking about his feelings of being HIV infected. Additional time was taken during and after the interview to allow the participant to fully express his feelings and to provide support. He was also referred to one of several counselors who were working at the after-hours clinic.

Benefits. Participants may have benefitted from talking about their experiences and feelings associated with living with HIV disease and managing their illness. Some expressed a hope that their participation in this study and other research studies may be of benefit to others who are HIV infected.

### Data Management

Audio tapes of the interviews were transcribed verbatim. The Tijuana interviews were transcribed and then translated from Spanish to English by a court-certified interpreter. Brief field notes and research memos were written as data were collected. The transcribed interviews, field notes, and memos were maintained in separate files for the U.S. and Tijuana participants. All references to participants in the any of the written materials were identified by special codes.

### Data Analysis

In grounded theory methodology, as data are collected analysis begins. Categories of thoughts, feelings, behavior, incidents and other information are identified and labeled through open coding. Open coding is the "breaking-down", examination, comparison, conceptualization, and categorization of data (Strauss & Corbin, 1990). According to Glaser and Strauss (1967), the initial assignment of various data to categories can be based on the knowledge and experience of the researcher, i.e. what "looks or feels right".

As new data are collected, they are compared to data already accumulated and categorized through the constant comparative method (Glaser & Strauss, 1967). Theoretical sampling is used to target collection of data based on the emerging categories. Data continue to be collected until no new information or categories emerge (Strauss & Corbin, 1990).

During the process of coding, categorization, and comparison of new and collected data, memo writing is encouraged to discuss the questions and conflicts about the data and categories that arise (Glaser & Strauss, 1967). Memo writing also facilitates the identification of the various properties of categories. These properties can serve as "rules" for the assignment of new data to categories as replacement for the former "looks or feels right" criteria.

As categories and their properties are defined, relationships between categories become more evident. The relationships between categories are developed as the number of original categories is reduced and those categories remaining are integrated by means of theoretical sampling and saturation (Glaser & Strauss, 1967).

For this study, interviews were initially analyzed line-by-line by the use of open coding to identify key concepts. Similar concepts were grouped together and organized as categories. The linkages between the key categories were explored in a series of memos comparing and contrasting each of the U.S. participants with one another; each of the Tijuana participants with one another; and the two groups with one another.

Once key categories were established, relationships were identified and explained by axial coding (Strauss & Corbin, 1990) and dimensional analysis (Schatzman, 1991). Axial coding is a means of labeling and relating categories by means of a coding paradigm in terms of context, conditions, actions/interactional strategies used, and consequences of the actions and strategies (Strauss & Corbin, 1990, p.97).

Dimensional analysis, which was developed by Schatzman (1991), allows the researcher to "discover the meanings of interactions observed in situations" by identifying all of the parts and relationships of a situation or problem (Kools, et al., 1996, p. 317). Through the use of an explanatory matrix, dimensional analysis provides a

"framework that helps move analysis beyond description (as in axial coding) and into the realm of explanation" by furnishing "a structure for analysis and a context for explanation (Kools, et al., 1996, p. 317)."

Dimensions are the components of the phenomenon under study as identified by the researcher (Kools, et al., 1996, p. 317). Dimensions are organized within the explanatory matrix of **context** (the situation or environment of the phenomenon being studied); **conditions** (dimensions which facilitate or block or impact the actions of a phenomenon); **processes** (actions or interactions impelled by conditions); and **consequences** (the outcomes of the actions or interactions) (Kools, et al., 1996).

The placement of dimensions within the explanatory matrix is influenced by a central dimension, the **perspective**, that "provides the greatest explanation for the relationship among dimensions ( Kools, et al., 1996, p. 319; Schatzman, 1991)." Once the dimensions are organized within the matrix, relationships and patterns among the dimensions/categories can be described and explained.

### Credibility

The activities of prolonged engagement and peer debriefing (Lincoln & Guba, 1985) during data collection and analysis were used to promote credibility of study findings. Prolonged engagement was evidenced by the investigator's two years of clinical practice with HIV individuals in clinical drug trials prior to this study. Peer debriefing was accomplished through periodic discussions of the study design, procedures, data, and findings with several nurses involved with HIV primary care and research trials.

### Summary

Grounded theory methodology and dimensional analysis were used in this study of how twenty-one men and women from binational groups in San Diego, California and Tijuana, Mexico lived with HIV disease and managed their illnesses. Principles of informed consent, privacy, and confidentiality of participants were followed and preserved throughout the study.

## Chapter 4

### Findings

The findings of data collection and analysis for the San Diego and Tijuana groups of participants are presented in this chapter. The major dimensions and key linkages for both groups are discussed in terms of the context, conditions, actions, and consequences of living with HIV disease.

### Dimensions

Dimensional analysis (Schatzman, 1991) was used to determine the "perspective" and the major dimensions of the study phenomenon, living with HIV infection. The perspective from which the major dimensions were organized and explained was the **Work of Living with HIV**. The major dimensions were: **System, Stigma, Support, Taking Care of Self, Staying Alive - For the Cure** (San Diego subjects) and **Living Better, "de vivir mejor"**, (Tijuana subjects). The perspective and major dimensions are represented in the dimensional matrix (Schatzman, 1990) in Figure 1.

Figure 1:


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San Diego and Tijuana Participants			
<u>Perspective</u>			
Work of Living with HIV			
<u>Context</u>	<u>Conditions</u>	<u>Actions/Interactions</u>	<u>Consequences</u>
System	Stigma Support	Taking Care of Self	Staying Alive Living Better

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In dimensional analysis, perspective "provides the most fruitful explanation of the phenomenon under consideration" (Kools, et al., 1996, p. 318). Context refers to the situation or environment of the phenomenon being studied. Conditions impact on actions and interactions, either facilitating or impeding. Actions and interactions are intended or unintended and are driven by the existing conditions. Consequences are the outcomes of the specific actions and interactions (Kools, et al., 1996).

#### Work of Living with HIV

As Corbin and Strauss (1988) explain, the management of chronic illness and the adjustments to bodily changes and



states of health requires work. Work involves the various tasks that are performed, under various conditions, and in response to the problems presented by a chronic illness. The tasks and activities are performed to deal with "illness work, everyday work, and biographical work (Corbin & Strauss, 1988)."

Illness work is directed towards controlling symptoms, following treatment plans, and interacting with the health care delivery system. Everyday work involves the activities of daily living and maintaining family and social relationships. Biographical work includes the process of coming to terms with the illness.

In order to deal with being HIV positive, participants in this study were engaged in a number of activities to deal with actual or potential problems in regard to the disease. They also were actively dealing with problems associated with the various circumstances and conditions which existed for them, financial difficulties; lack of access to HIV health care and information; discrimination; strained or changed relationships with families and friends; changes in lifestyle, and so on. And many of the participants were deeply involved with coming to terms with their illness and

themselves.

The work of living with HIV was ever-present, multifaceted, frequently intense and consuming for participants. As one of the San Diego participants who was managing two AIDS-defining infectious conditions stated:

I think if you want to survive, you have to do all this stuff. HIV is so damned complicated There's a lot of work involved...

Participants in this study were in various stages of HIV disease progression. They either experienced no real symptoms of HIV infection, were mildly or moderately symptomatic, or were diagnosed with AIDS.

Typically, individuals infected with HIV live several years with no health problems or evidence of the infection except for positive HIV antibodies. Various factors such as the type, virulence, or resistance of the virus; the individual's immune response; and antiretroviral treatment regimens can influence the course of the infection. Some individuals are known as long-term survivors, living ten or more years. At the other extreme, some experience rapid onset and death from the infection.

Once the virus begins to affect the immune systems and major organs, multiple symptoms and HIV-related conditions

develop as susceptibility to infections increases. As with other serious chronic illnesses, increased HIV symptomatology and disability have profound and far-reaching effects on the ability of individuals to be active and productive members of society and to live a quality life.

Being HIV infected touched the lives of the participants in this study. All had some amount of work to do dealing with either symptom management, treatment regimens, or psychosocial reactions. For some, the opportunity and ability to be employed and self-supporting were severely limited. Interpersonal relationships with family, friends, spouses, partners, children, and others were often changed and challenged. Table 2 presents information about participants in terms of length of HIV infection, disease progression, use of antiretroviral therapy, and employment status.

Table 2

	San Diego n=10	Tijuana n=11
Length of years HIV infected	1-11 years	7 months - 9 years
Mean Time of HIV Infection	6 years	3 years
Asymptomatic	3	9
Symptomatic	2	1
AIDS Diagnosis	6	1
Antiretroviral Medications	10 (ZDV,DDI)	10 (DDI) ; 1 Unknown
Full-Time Employment	2	9
Part-Time Employment	4	1
Unemployed	4	1

All twenty-one of the participants were taking anti-retroviral medications such as AZT, DDI, or 3TC as HIV therapy or as study requirements for pharmaceutical HIV research studies. Some were receiving either AZT or DDI monotherapy, but a majority were taking some sort of combination antiretroviral therapy from the available FDA-approved medications, AZT, DDI, or DDC, and investigational drugs, 3TC or D4T.

Twelve of the participants in this study, three in San Diego and nine in Tijuana, were asymptomatic and described themselves as "healthy". Two San Diego participants and one from Tijuana were symptomatic, experiencing a variety of

symptoms which included intermittent lower extremity arthralgias, periodic gastrointestinal upset, and various types of skin rashes. All fifteen were able to carry on with the usual activities of their lives without any physical restrictions except when symptoms or other non-HIV illnesses occurred.

Eleven participants who were asymptomatic or symptomatic were fully employed and three were employed part-time. One of the Tijuana participants who was symptomatic was unemployed because he had lost his job as a bank teller when a pre-employment laboratory test for HIV was reported to his employer as positive.

Those working part-time included a San Diego participant who had been released from prison and was doing odd jobs. The other San Diego part-time worker was a waiter; he had chosen to quit work temporarily to care for his partner who was HIV infected and had been ill. The Tijuana participant who worked part-time was a full-time medical student.

Seven of the twenty-one participants, six from San Diego and one from Tijuana, were diagnosed with AIDS. Three of the seven, two from San Diego and one from Tijuana, were

classified as having AIDS because they met the CDC classification of CD4 lymphocyte counts less than 200 mm<sup>3</sup>. None of the three had been diagnosed with an AIDS-defining condition or opportunistic infection. They all felt well most of the time but experienced a variety of symptoms such as occasional bouts of diarrhea, fatigue, and weight loss (Tijuana participant) or recurring sinus infections and skin rashes (San Diego participants).

The other four San Diego participants with AIDS diagnoses had past or existing opportunistic infections for which they were receiving on-going treatment: one had recently recovered from PCP (*pneumocystis carinii* pneumonia); two of the three had CMV (cytomegalovirus), and one had MAI (*mycobacterium avium*) infection. Three of the four also had histories of other severe bacterial infections, including pneumonias other than PCP and sepsis from indwelling central intravenous catheters.

The participants with AIDS had major disruptions in their lives due to feeling ill and/or the various therapies and activities required for care of their illnesses. As one of the participants said, "HIV is a real complicated disease

because there are so many things you can get, i.e. infections, herpes, rashes, mouth sores."

For some there was the realization of the inevitable downward, terminal course of the infection, especially as the AIDS-related conditions develop:

If you have AIDS, you don't just have a life-threatening disease, you have a lot of problems that you probably never even thought about before all of a sudden, it's right in your face...It's like if you were in Vietnam and you were out there for six months, seeing the people die, seeing the agony, seeing the suffering, you yourself not being able to eat hot meals all the time, not being able to take a hot bath, not being able to take care of yourself. You always have the hope that someday that helicopter is going to come in and it's going to pick you up and take you out of there and you're going to go home. You're going to go back to all the sweet things you had before. That helicopter is not ever going to come for a person that has AIDS. It's not going to ever come for me.

Another participant commented on how the disease had impacted on his ability to do other work and be involved in activities he enjoys:

What I did in 1987 versus what I'm capable of doing today, I put in maybe two hours a day at work. You know something as simple as golfing, something I haven't done in a couple of months has been a real major frustration for me. I have been in the hospital four times in the last three months.

Of the seven participants in this study with AIDS diagnoses, one from Tijuana was fully employed as an

educational psychologist. Two of the San Diego participants with AIDS worked part-time. One of these continued to try to work as a bookkeeper even for only two hours a day. The other was an antique dealer who had been forced to decrease the amount of work he could do because of several recent hospitalizations for asthma and PCP.

The remaining four San Diego participants with AIDS were unemployed. Two of the four were unable to work because of their HIV-related conditions. One of these two stated how "frustrating" and upsetting it was to not be able to work and support himself:

It's real hard to justify an existence when I can't do anything. I can't work. I really can't take care of myself. I'm living at the mercy of other people.

Two participants with AIDS diagnoses chose not to work for a variety of reasons: to preserve their health; to "decrease stress"; or not being able to be insured. Both received state or federal disability payments as income. For one of these participants, going from a well-paying full-time job to disability was a major change and traumatic:

My self esteem went so far down. I went from standing in the 30,000 square foot retail store in suits to living on \$500 to \$600 a month with social security and being uninsurable. The main reason I never went back to work is that I'm



uninsurable. There is no way today, even at 8 years of being HIV that I can go out and get insurance, because of the pre-existing clause.

The four participants living on disability had expressed the most difficulty with managing finances since all had at one time worked and were used to living on more than \$800 a month (federal disability) or up to \$1000 a month (state disability). Trying to pay the usual living expenses and to access some of the local services offered by the city, county, or local AIDS organizations was often a challenge:

If you're living alone and you're paying utilities and so forth, all these things come directly out of your (disability) check. You can juggle around your income. There are things that you can do that when you go in and apply for the food bank (service sponsored by the San Diego AIDS Organizations), you already know the requirements and you make....it's terrible to say this but you cannot be totally honest and get into the system and get anything out of it. So if you want to go to the food bank and you know your income can't be any more than \$640 a month, then you have to show an income of \$640 a month. Otherwise they'll turn you down. And when you only get \$700 a month, you know that extra \$60 or whatever can keep you from getting a lot of benefits.

Another of the participants who was not working and receiving disability payments used similar creative financing:

So what it means to be a responsible, productive member of society when you are not in the mainstream? How do you do that? Especially when you feel O.K. and you feel like ripping off the system. Well I made peace with that.

Of the ten San Diego participants, three lived alone; one lived in a group home; one either lived in his truck or with family and friends for short periods of time; and the remaining five lived either with spouses, partners, or roommates.

One of the Tijuana participants lived with his wife and infant son. The two women participants lived with their children; one lived with her five children; and the other woman participant lived with her four children and her parents. One of the male participants lived with his family. Another lived with his partner. Two lived alone. The living arrangements of the other three participants were not determined.

For the San Diego participant who had no place to live, a real problem was loss of social security funds:

Social security said that I couldn't collect money unless I was a resident of the county. So I needed a place to live. And I was living in my car at the time and I told them I think I can stay with these people until things get squared away. So they considered me not being homeless because I had a place to stay even though it was a temporary setup.

They were taking away \$400 out of my SSI payments because I didn't have a place to stay.

Another San Diego participant who was on disability but with no acute health problems was concerned about making plans for in-home care in the future when he would not be able to take care of himself. Monies were available from the state to pay care givers who move into the homes of HIV infected individuals who required assistance:

Now when you start getting sick, I can pick the person that comes into my house. If you know the system, you can. If you don't know the system, they can decide who's going to come in and take care of you. And you got a stranger coming into your house. Doing all these things for you and you don't know who they are. But I can pick a friend that I know can do it.

A San Diego participant who lived alone, cared for his home, and managed all of his HIV-related problems spoke of the need for help, assistance, and caring when living with HIV:

I am fortunate, I do have friends, good friends. But it's not the same as having somebody there living with you that really is there for you. Although if I call these people, they'll come right over. I'll be honest, it's frightening. You know you're going to die, you don't know when. Sometimes you have an indication. But if you're out there by yourself, if you have somebody at home, say a lover, your wife, or whatever, that can really be the difference between wanting to live or not wanting to live, between quality of

life and not quality of life.

Several San Diego participants mentioned the impact of having HIV disease on developing close and intimate relationships:

As far as my relationships, since I've found out about me being HIV positive, my relationships are not the same. Before I had a relationship with a female, and I always explained the situation to her about me and it turned the key off and there was nothing there no more. Every once in awhile we get together and we talk but she says that when the time will come for a sexual relationship we will not have one...

A fear of possible spread of HIV to others was also expressed by one of the men from San Diego:

One of the things that really has slowed me down, it's been the idea that I really don't want to be extremely close to anybody because I don't want them to catch what I have, and it's a reluctance to open myself up to people... When I meet somebody the first thing I think is that I want everybody safe.

Others questioned the likelihood of an intimate relationship being possible with a terminal disease:

For myself AIDS means being alone forever. It means there's not going to ever be a bonding between another person because of all the uncertainty that's going on. I would love to be able to share an apartment with somebody that I got along with, just so we could help each other through this whole thing. But who's to say that I have a month, or if I have two months or three months and why would you want to build up a relationship that is only going to end in tragedy.

All twenty-one of the participants described emotional reactions such as fear, depression, etc. to being HIV infected. A participant from Tijuana stated, " I have constant stress thinking I'm going to die." Another Tijuana participant commented on the changes he had noticed in himself since he became aware that he was HIV infected:

Before I wasn't so sentimental. But since I know I am infected, every time someone speaks about my family I get very sentimental. I cry. I hope this is a phase because I don't want to be a cry baby. I feel embarrassed about crying but sometimes I can't avoid it.

After being hospitalized several times for recurrent asthma attacks and a severe episode of PCP, one of the San Diego participants commented on becoming more fearful:

Now I have a lot of fears, like with my cough, I got it before I got the PCP. I'm the one with it, I'm the one who has PCP and I have those horrendous fears that I'm going to be dead within a week, and I have to talk if I want to be cremated and all that. Even though you know it, your mind takes off with you.

Many participants from San Diego and Tijuana stated that when first diagnosed, they were in denial for a year or more. As one Tijuana participant said, "I didn't believe it. I thought it was a mistake. I insulted my doctor and told him it was a mistake." This was often followed by a desire

to learn as much as possible about the disease and the most promising drugs and therapies, with intermittent periods of not wanting to think about being HIV infected:

As far as my attitude, I've gone through stages about it and I've been more optimistic: support group stage; burn out; don't want to hear anything about it; mourning. (San Diego participant)

Several of the participants from both groups mentioned dealing with the disease one day, one event at a time and trying to maintain a positive attitude as much as possible:

I don't feel depressed about being HIV positive and I figure I take one day at a time and I just do what I have to do for that particular day and if it doesn't work, I take it as a challenge to look for something else that would work... I try to do things as they come and this has worked very well for me.

Some of the Tijuana participants spoke of their efforts to remain positive, calm and peaceful in an attempt to protect their immune systems and general health. One of the women from Tijuana stated:

They say that the more fear one has the more the disease develops. Therefore the more calm and serene one is, it is better, it is healthier than to keep on thinking in a negative way. On the contrary, one has to think positively.

Other Tijuana participants talked of giving up plans and goals for the future once they learned of being HIV positive:

All the plans that one has are not going to be carried out. Since the moment that I was told that I'm positive, all the projects that I've planned are gone. Every extra thing that I want to do, is not going to happen.

There were various ways participants viewed the effects of being HIV infected on their lives. Some felt there was a positive effect from having HIV disease. The San Diego participant who was married stated, " I think it strengthens us. We've had to face things. The disease has reduced a lot of stress - little things don't bother us anymore." Another San Diego participant said:

I'm really trying to make the best of a terrible situation. But all of a sudden having been diagnosed with AIDS, I right now am actually living better than I was when I was healthy and in control of my life. I now all of a sudden am sober, I am happy, I'm more responsive to other people's needs.

A third San Diego participant added, "So if there was a good part of being HIV+, it made me a better person emotionally. Stronger emotionally and just more responsible. Just being more comfortable with myself being gay." But another participant from San Diego disagreed:

I guess in certain respects I dislike intensely when I hear, 'Oh AIDS has been really good for me, and all this crap.' People say, 'Oh it's just been wonderful.' They feel that they're more compassionate or more caring, understanding or something. But every time I have been in a group, I just want to wring their necks. Because I have not felt that I'm thankful for having AIDS, that it's made me so much more compassionate and all this crap. Living with HIV is complicated; it's hard; it's lonely; and it's very frustrating.

### System

The context for participants in this study was **System**. System refers to the HIV care system of health care options, insurance coverages, clinical drug trials, social services, and information resources which were available to participants in this study.

Participants utilized some or all of these services and resources for the treatment and care of their HIV disease. The San Diego participants generally had more access to HIV information and treatment than those participants in Tijuana.

The System also influenced for many of the participants how they lived, worked, managed finances, and made disclosures about being HIV infected. Unless participants were free of financial concerns, they were often dependent on state or federal health care programs and community



social services. To be eligible for or to utilize these programs and services, income was usually limited to less than a thousand dollars a month.

Living within a limited income affected decisions about living arrangements, i.e. whether to live alone or with others. Dependence on disability payments rather than work was a decision for some in order to maintain a limited income. Others had to make decisions about using money to make monthly co-payments for health care and medication or for housing and food.

Some of the U.S. participants under-reported their monthly income to receive social services. Several Tijuana participants presented themselves as San Diego residents with a local address in order to be eligible for health care at U.S. federally-funded Ryan White clinics. Participants from both groups often used aliases to receive HIV-related care and to prevent disclosure of their HIV status to employers, insurers, or to the general public.

Table 3 presents the types of health care options available to the San Diego and Tijuana participants.

Table 3

	San Diego n=10	Tijuana n=11
Private Medical Care	1	NA
HMO Health Care	2	NA
VA Medical Care	2	NA
MediCal Health care	4	NA
Ryan White Health Care	NA	3
Government Health Care	NA	8
No Health Care	1	NA

Participants in San Diego had available a wide array of health care coverage plans, insurance carriers, social services, clinical drug trials, and information sources to select from. In comparison, Tijuana participants had limited HIV health care options, services, and information available. Tijuana participants who had legal immigrant status crossed the United States/Mexican border and sought access for care and information at Ryan White-funded clinics, community service organizations and clinical drug trial sites in San Diego.

Health care for the San Diego participants was extremely varied because of the diverse types of health care insurers, i.e. private or HMO, and coverage options, such as

the VA medical system, county, state, and federally-sponsored health care available in the United States. The type of health care coverage available depended for the most part on personal circumstances and employment status.

One San Diego participant had no health care coverage and was only beginning to arrange for San Diego County or Ryan White coverage because he had recently been released from prison. The San Diego participant with private medical care was able to have the coverage because his wife worked for the medical practice. One of the San Diego participants with HMO coverage continued to pay for the enrollment after he was not able to work; the other had HMO coverage through his full-time employment as a registered nurse. Two participants used the VA system. The four San Diego participants using MediCal were unemployed and on disability. The San Diego participant who was self-employed had no coverage.

One San Diego participant had a particularly complicated combination of health care options because of his own personal circumstances. He was enrolled in an HMO from which he received primary health care, specialty care from dermatologists or ophthalmologists, and hospitalization

coverage. He also was eligible to receive federal medicare disability coverage.

The HMO coverage for this participant did not provide any medications except for the intravenous ganciclovir and related supplies which were part of the outpatient/home health services provided by the HMO. He obtained all other medications through the San Diego County Health Department, through participation in research trials, or by paying cash at a private medical practice for consultations and other therapies such as vitamin and mineral supplements.

This participant also chose to become involved with a second private medical practice which accepted medicare patients to help build up its patient base. From the second private medical practice, he received lab evaluations and consultations to supplement the information and assessment provided by his primary health care provider.

Ten of the Tijuana participants who were employed were covered by the Mexican government-sponsored health care system. In Mexico all individuals employed are covered by the national social security health care system which includes medical care and hospitalization. The Tijuana participant who was not employed at the time of this study

did not have access to this basic health care system.

Four of the Tijuana participants were able to legally cross the Mexican-U.S. border. One who was mildly symptomatic and one with AIDS continued to live in Tijuana but crossed over to San Diego to gain access to HIV medications and health care at a Ryan White-funded clinic. Throughout the United States, such clinics receive federal funds from the Ryan White Care Act to provide primary care and antiretroviral and prophylactic medications for those individuals with HIV/AIDS who are uninsured and without health care.

In order to be cared for at a Ryan White clinic, the two Tijuana participants had to provide a local San Diego address where they were living. Both used addresses of friends or family in San Diego where they often visited and stayed for periods of time.

A third Tijuana participant who was asymptomatic and healthy lived and worked in Tijuana but also visited relatives in Los Angeles where he would access HIV-related information and social services. The fourth Tijuana participant who was a legal immigrant was making plans to attend a Ryan White clinic in San Diego. Although he was

asymptomatic and healthy, he wanted a medical evaluation and testing of his immune system to determine if he needed to be taking antiretroviral medications.

The remaining seven Tijuana participants who were asymptomatic and healthy were not legal immigrants and could not cross the international border to take advantage of the resources in San Diego and the United States. The reasons for not being able to obtain legal immigrant status were varied because the process and requirements for filing and acceptance were complicated and rigorous.

All of the seven Tijuana participants who could not legally cross the international border had no real access to HIV health care or medications in Tijuana. Most did not wish to use the government health system for HIV health care because of various reports about HIV infected patients being turned away from clinics or hospitals due to fear and discrimination by health care providers. In addition, HIV medications were difficult to obtain due to the expense and the bureaucracy of the government system:

Sometimes we have AZT. AZT is expensive in Tijuana and people who have coverage from the social service system can get the medicine, but there is a lot of bureaucracy, and they have to know where to go and who to ask. But legally they can get it. People that

don't work obviously don't have health coverage so it is difficult for them to get it. Most of the drugs related to HIV are very difficult to obtain in Mexico. Most of them are through donations from the U.S. and people in general. The people who can cross the border or that are U.S. citizens have more access to more services and programs. Depends on what health agency they get attention from.

Fortunately an after-hours HIV clinic had been organized by one of the local Tijuana AIDS organizations. At this clinic, patients could receive information, counseling, a medical examination, and a limited supply of HIV medications which were most often donated by various groups and individuals from San Diego.

Many of the San Diego participants in this study were less than satisfied with their health care options and providers. Several of the participants who had become informed about HIV disease and therapeutic advances felt that they were as knowledgeable if not more so than their physicians:

And I know enough about the medicines, like rifabutin. I had read about it, studied about it. I asked him (his doctor) about it and he didn't know very much. I knew more about it than he did. He had to go look up stuff in the books and then come back to tell me that it would be good for me.

Another complained about knowledge of hospital staff (including nurses) and their knowledge and familiarity with

HIV/AIDS patients, treatments, and drugs:

Those of us who are HIV positive are much better informed (than health care professionals/staff) about what needs to be done for us, e.g. accessing and flushing various types of peripheral and central IV lines. (When admitted to an ER with pneumonia) I had a computerized list of my meds, and the doctor pulls out a PDR and starts looking up my medications. I don't think he knew what any of them were for. You know it scared me.

One of the participants complained about his HMO, "It's like a factory":

They allow you 10 minutes per visit. When I go to see my doctor every 6 weeks, I'm allotted 10 minutes. I usually go in with a list of 10-12 things I want to discuss. I literally have to talk fast because he will try to answer my questions but he's also limited to when his next appointment is... I took this article to the opthamologist about alternating and combining anti-CMV medications and I asked him for his opinion. And the opthamologist looks at me and says, 'I have no opinion. I just diagnose. I don't treat. If you want to talk treatment, go talk to infectious disease.'

A San Diego participant who had state-funded MediCal coverage felt that for a particular ENT problem the surgeon may not have suggested the "gold standard" therapy of surgery because MediCal did not fully reimburse physicians for their time and work:

I question whether or not if I had that gold standard insurance, whether he would have immediately suggested that surgery (to repair



an elongated styloid process which irritates his throat) is an option here and 'if you would like me to fix it so you don't have the feeling of discomfort for the rest of your life.'

Other San Diego participants (the one with private medical care; one of those who used the VA; and the one who had attended Ryan White clinics) had no complaints about their primary health care providers. One of the participants who used the VA system stated that he was pleased with the care he received there:

I find it to be extremely good. They have their clinic strictly for people with HIV, two days a week. They're constantly there to answer questions and to do things for you. They have four nurses and a social worker, and you have your own doctor. It's consistent. You always see the same doctor.

The participant who had such difficulty with his HMO attended two private medical practices for consultations and various other kinds of therapies:

I have gone to two other medical clinics, both of which I think are more on the cutting edge of HIV treatments here in San Diego. At the one clinic, I receive vitamin shots once a month, and I get B-12 shots once a week. I honestly think that's helped. I also see the doctor occasionally, every couple of months. We just chat. They're always trying something new. So I'll ask if he has read about anything or heard anything about new medications... At the other clinic, I was very impressed. The first visit was for two hours, and it was not just for filling out paperwork. You were actually with a nurse or

a doctor for the whole two hours. He answered questions. He took the time and I was pleased with that.

Although ten of the eleven Tijuana participants were eligible for care with the social security health system, none had accessed any services within the system. This was because of many instances that the participants were aware of when other HIV infected individuals were discriminated against, received inadequate care, or were rejected by health care providers and staff:

Unfortunately, the Mexican government doesn't want to get involved with this disease. In fact, we're rejected from most hospitals as patients. I've received information from terminally ill friends that go the social security hospital where they are told to leave and die somewhere else because they need the beds, or the nurses visit the rooms covered from head to toe, like astronauts. They are misinformed that by just entering the room of a terminally ill patient, they will become infected. This makes one feel worse.

It's total discrimination against us... The majority of the doctors don't accept us as easily as they accept a patient with cancer or hepatitis, or one with pneumonia. They see us as being unusual. They cover themselves up with suits as if they were going to the moon and they disinfect the room where we've been. This is the most humiliating discrimination there is.

Because of the difficulties with discrimination and inadequate care in the social security health care system,

many of the Tijuana participants in this study first received care or evaluation for their HIV infection through the Organization SIDA Tijuana which organized the after-hours HIV clinic:

Things would be easier if the government could open more clinics where patients with AIDS could get good medical care by competent doctors and that all the discrimination that's going on now, wouldn't exist.

Also available to study participants in San Diego were clinical drug trials testing new antiretroviral, immune-enhancing, prophylactic and other HIV-related medications. A majority of these trials were sponsored by pharmaceutical companies and conducted at university medical centers, community-based research sites which were affiliated with such groups as the American Foundation of AIDS Research, and at physician offices and clinics.

San Diego and Tijuana participants used these clinical trials either to supplement the HIV health care they were receiving or to provide essential HIV care and drug therapy. Table 4 represents the numbers of San Diego and Tijuana participants using clinical trials for essential or supplemental HIV health care.

Table 4

	San Diego n=10	Tijuana n=11
Participation in Clinical Drug Trials (Supplemental)	3 of 7	4 of 11
Participation in Clinical Drug Trials (Essential)	4 of 7	7 of 11

Seven of the ten San Diego participants in this study were enrolled in a variety of clinical trials. Two were participating in open label studies of rifabutin and azithromycin which were being tested for prophylaxis of MAI and treatment of cryptosporidium, respectively. The open label trials were being conducted by pharmaceutical companies after the major safety and efficacy trials of the drugs had been conducted and during the interim period in which data was being analyzed and prepared for FDA submission. One participant was enrolled in a trial testing DDI and an IV medication to enhance the immune system. One participant was enrolled in a trial testing clarithromycin for prophylaxis against MAI infection. And three participants were enrolled in a trial testing AZT and a new drug, 3TC, in combination.

Three of the seven San Diego participants were enrolled in clinical trials to supplement their HIV health care at

the VA and at an HMO. These three were receiving basic antiretroviral therapy such as DDI and AZT and standard prophylactic medications such as bactrim for PCP from their health care providers, as well as regular laboratory monitoring and medical exams every one to two months. Participation in the drug trials was undertaken to supplement their HIV therapeutic regimens with medications which appeared promising but were not yet FDA-approved or available, except through the research studies.

One participant wanted access to the rifabutin as a possible means to start prophylaxis against MAI. The participant who had cryptosporidiosis enrolled in the open label azithromycin study in hopes of finding an effective treatment which so far he had not been able to receive from his HMO or find anywhere else. The third participant, with a CD4 count greater than 400 mm<sup>3</sup>, wanted to try the immune - enhancing medication and be able to track his CD4 count status by means of the monthly lab evaluations which were part of the study.

The remaining four San Diego participants used clinical trials as an essential part of their HIV health care. The participant who was involved in the clarithromycin study did

so because he was having difficulty with the amount of MediCal co-payments he was required to make, i.e. the first \$450 dollars a month of an income of approximately \$800 a month. Because the co-payments were so expensive, he was avoiding going to the physician despite being on AZT and needing regular lab and medical monitoring for hematologic and other side effects.

I missed three doctors appointments in November and December of 1992 because I didn't want to not have the holiday spirit (he had 2 teenage children) and I didn't go to the doctor because I couldn't afford it.

Participation in the clarithromycin study allowed him at least monthly to see his physician who was offering the study, to receive lab tests to monitor for drug side effects, to be cultured frequently for MAI, and to receive medication which might help protect him from MAI infection for which he was vulnerable because his CD4 count was less than 50 mm<sup>3</sup>.

The other three San Diego participants who used clinical trials as essential sources of HIV health care were involved in an AZT and 3TC study. One of these participants had just been released from prison and had no health care coverage. As he was trying to decide what to do for HIV

health care, he heard about the AZT and 3TC study. During this interim period, he was able to be enrolled in the research study, start on antiretroviral medications, and receive lab monitoring and medical exams every month. Soon after enrollment, he began the paperwork to arrange for Ryan White and San Diego County health care, with the possibility of MediCal coverage in the future.

Another San Diego participant in the AZT/3TC study was self-employed and in very good health but had no health insurance. Prior to the AZT/3TC study and despite being insured through his employment with the U.S. Attorney's office in San Diego, he had attended a Ryan White clinic for HIV health care, received HIV medications from San Diego county, and participated in another type of clinical trial. This participant did not use the health care insurance provided for by his employment because he did not want his HIV status revealed to his employer or the insurance carrier. Participation in the AZT/3TC trial provided him with antiretroviral medications, monthly lab testing, and medical exams which he used rather than having to attend the Ryan White clinic.

The other San Diego participant enrolled in the AZT/3TC trial was fully employed as a registered nurse and was enrolled in an HMO through his employer. This participant also did not want to risk revealing his HIV positive status to his employer or insurer but at the same time wanted to know what his CD4 count was and if he needed appropriate HIV therapy:

Primarily the reason that I enrolled, to gain access to a physician and also to get some protection (antiretroviral medication) in this interim period (starting a new job and health coverage). I would like to know how I'm doing right now. I just need a reinforcement of numbers to let me know how well or not I am doing. So basically this (drug trial) has been a resource for me.

All of the Tijuana participants were participating in U.S.-sponsored clinical drug trials at the time of this study. One participant was enrolled in a UCSD trial in San Diego. The other ten were participating in the same U.S. trial which provided an antiretroviral medication, DDI, weekly intravenous infusions of an experimental immune-enhancing drug, and on-going lab evaluations of the immune system.

The U.S.-sponsored DDI trial was available because of a relationship between a local Tijuana physician who was part



of the AIDS Organization Tijuana group and a community-based research group in San Diego. The San Diego group agreed to transport the DDI study to Tijuana and establish a satellite research site where the study drug and procedures could be administered and carried out.

Participation in the U.S. drug trial, especially for those who could not cross the border, allowed access to HIV information, medications, lab evaluations, and medical exams that they had not received from the existing government health care system.

The U.S. clinical trial provided treatment and evaluation for the ten Tijuana participants for a year. When the study was completed the participants were left with the same choices as they had before entering the study. For the ones who could cross the border, the prospects for further treatment and care were better than those who could not cross. One of the participants who could cross the border stated, "When all this is over, I'll try to cross to the U.S. to see a doctor." In contrast, one of the participants who could not cross the border had the following reaction:

I just finished with the treatment, and I feel insecure, insecure of me and my future. The treatment gave me a little assurance and strength. I will continue looking for other alternative treatments. I do not know where I'll find them, but I will search for the possible and impossible alternatives.

Social services were available to participants in San Diego through various public and private organizations and groups in San Diego county. The San Diego AIDS Organizations was one of the largest of these organizations and offered a variety of services and resources such as free legal work, case management, support groups, a buddy-system for newly infected individuals, a food bank, and transportation assistance. Being Alive was a local San Diego organization of HIV infected individuals that provided information, support groups, haircuts, massages, social events and outings. The Gay and Lesbian Center was a source for group and individual counseling, classes on HIV disease and therapies, information, and alternative therapies such as acupuncture.

San Diego County provided HIV testing, information and classes for newly infected individuals about basic antiretroviral and prophylactic medications and self care measures. Most of the services and resources at these

organizations were free.

In Tijuana, social services for HIV infected individuals were limited except for what was offered by a few AIDS activist groups and interested others. At the after-hours HIV clinic in downtown Tijuana which convened one evening every week, individuals with HIV could be tested for the virus, receive information and counseling individually and through support groups, medical exams, and medications, when available through donations. Most of those who staffed the clinic were physicians, psychologists, and others who volunteered their services. One of the participants in this study was one of the founders of the clinic:

There are other organizations that care for HIV patients (rather than the social security system) like "Organization SIDA (AIDS) Tijuana" which is part of Conocida. And there is another group which has similar services and has medicines. There are no restrictions to the amount of people we receive. Conocida reports to the national Ministry of Health. The clinic has been open for 5 years. An information Center has been open for 2 years. Some people are referred (to the clinic) by the Information Center or by the Health Center or by the social security system. Some people get information by calling some other organizations and also by word of mouth.

During the conduct of this study, the number and types of information sources in the dealing with HIV and AIDS

increased tremendously in numbers and became widely disseminated in the United States. Increasingly, HIV infected individuals, researchers, health care providers, the government, pharmaceutical companies, and individuals and groups both within and outside of the United States utilized the Internet to discuss information and new discoveries about HIV disease and therapies.

Other sources available to participants in this study were newspapers, local, state, national, and international; scientific and health care journals; government publications; national listings of available drug trials; books about HIV, drug therapies, caretaking; local, national, and international speakers including HIV infected individuals, physicians, researchers; private and public newsletters with varied information on such subjects as promising new drugs, use of government research monies by NIH and others, unapproved medications, and so on. Most of these information sources were available free of charge or for a small fee through the mail, on the Internet, in doctor's offices, in clinics, at the various AIDS organizations, on television, in libraries, to name only a few.

For the Tijuana participants, there was a lack of information available locally or throughout Mexico about HIV disease, treatment and care. One of the Tijuana participants decided to travel to Mexico City to obtain information when he learned he was HIV positive:

First we traveled to Mexico City and visited an office for AIDS care where they never helped me. We stayed in Mexico City from Thursday to Sunday. The only thing that I wanted was information and what we received were only closed doors. I traveled with my sister and when we went to the AIDS office requesting some information. They asked us to come back between noon and one o'clock because the person that provides the orientation was not in. And when we came back next day at the requested time, the person was not in yet. Then they sent us to another office, and the same thing happened. They didn't provide any information. We spoke with the director of the office of AIDS care, and he told me that he couldn't help me, that he would instruct somebody else to help me, but not until Tuesday.

Other Tijuana participants agreed with the lack of support and information from the Mexican government:

Here there is hardly any information, and I think it is due to the country's economic problems to create programs and distribute information for which money is required.

Most of the Tijuana participants in this study had not received much information about HIV until they became involved with the Organization SIDA Tijuana and the U.S. clinical drug trial:

The Mexican government doesn't provide any support. We haven't received any information in regard to AIDS. Rather we received support from the U.S. through this clinic.

Many would like to see multiple information sources in Tijuana and Mexico much like what exists in the United States:

It would be helpful for me if there existed detailed information on a massive scale. Something that would be on TV and in the newspapers. Information in public places, like restrooms, discos, and hotels. The type of information that exists in the U.S.

### Stigma

Participants from San Diego and Tijuana either experienced the stigma that can be directed towards people who are HIV infected, or they feared the repercussions of revealing their HIV status to friends, family, employers, insurers, or others in society. The San Diego participant who did not utilize his HMO coverage for HIV health care commented on his situation:

If I had cancer, I would feel a lot more comfortable to go to a physician and be treated but being HIV positive... I went to see the nurse practitioner and she felt my glands and asked, 'you always have big glands?' And I answered, 'Yes I always have.' But she didn't ask anything more. If she had asked me directly, then I would have told her my story. But she asked in a more general way, so I choose not to let her know.

A San Diego participant chose not to tell his boss about his HIV status which prevented him from receiving any possible support or understanding which he may have wanted or needed:

My boss always says to me that I'm usually optimistic and she said, 'Oh, G\_\_\_\_, you seem to have such an easy life, no worries, no nothing.' And I'm thinking, 'If she only knew...'

Another San Diego participant decided to avoid exposure during a more casual encounter with someone he did not know but who was judgmental of his behavior:

I had a guy at the golf course ask me, 'what's a young man like you riding in a golf cart for a nine hole course?' I said, 'I'm terminally ill, I've got cancer', because I just didn't feel comfortable getting into the whole thing with him.

This same participant and his wife stated that they had lost several friends, i.e. "heterosexual couples" when his HIV status became known to them.

Several San Diego participants related experiences of being rejected by others or being discriminated against because of their HIV status. One described an episode in a social security office:

The only time I felt like I had a disservice toward me was from employees of the social security who treated me less than honorably because of my HIV status, or because of their own

fear or homophobia or ignorance. In Missouri a lady asked me, 'Why are you here?' And I told her I was HIV+ positive and she backed up in her chair, and I asked for her supervisor and he apologized. The same thing happened here in San Diego.

Another participant from San Diego told of the reactions of some of his friends once they knew he was HIV positive:

My friends don't want to be around me. They think that they can catch something from me. They feel that if I drink a beer or whatever the situation is, they think that they can get the disease from me. It hurts because some of them were very special friends to me... One day my brother got angry and told everybody in the block that I was gay, which I'm not. Every time I go there, people look at me and say that my brother is saying that I'm gay...

The San Diego participant who was divorced but had two teenage children talked not only of the effects, real and perceived, of stigma for himself but also in terms of the effect on his children:

For my kids, to try to help them feel less threatened by the fact that I have AIDS, you almost have to be quiet about it...I tell them not to tell their friends at school...Especially with young girls. Girls really have a hard time growing up and they go through a lot of different things and to tell your personal secrets about a family member having AIDS could really put you in a social outcast situation.

And in terms of reactions to his HIV status by friends or others he had encountered, the same participant stated:



So really, it's hard to not just have cancer or to not just have been in an accident and be paralyzed or something like that...It's sort of bizarre, but the only real attack that I've come under for having AIDS has come from the church that my family goes to. I called one of my old friends to help me with my taxes this year because of the social security and state disability situation. I didn't want to make any mistakes. I told him I was receiving disability because I had AIDS. And it didn't really bother him at that time, I don't think. But after hanging up on the phone, he mentioned it to his wife. It was actually his wife who became very cynical and just said, 'I don't want him over here. I don't want anything to do with him. You're not going to see him, you know it's just like if we don't go around him then we're not going to get it. And like I said, I understand these things, but they took it a lot farther in the fact that they had to get on the phone and call these people from the church (which his ex-mother-in-law attends)...I know what it must be like for a black man to walk through a white neighborhood and feel different. I really feel different in the fact that I have this terrible illness that is not only debilitating but also a social disgrace. To have AIDS is really to be wrong.

All of the Tijuana participants spoke of the existence of discrimination in Mexico against persons with HIV and the effects of living with the stigma of being HIV infected. The government provided little to no information or support for programs for testing or to help people deal with the infection. Participants experienced job discrimination because of their HIV status. Others experienced a breach of confidentiality between the social security health care

system and employers. And most avoided revealing their disease to friends, co-workers, employers, and others for fear of rejection and loss of employment.

Several complained about the lack of government and public support and inaction, both in Mexico City and Tijuana, in regard to HIV disease:

Things would be easier if the government could open more clinics where patients with AIDS could get good medical care by competent doctors and that all the discrimination that's going on now, wouldn't exist.

The Mexican government is very bad. They don't give us any support. They don't care if people die. They don't have any opinion about this. They prefer to keep silent. They don't want to accept anything.

Tijuana participants spoke of the practice of many employers and companies who included HIV testing as part of the pre-employment requirements. One who had applied for a bank job commented on the reason for the testing, "banks believe that infected employees will represent a high medical cost; they want people without medical problems."

Pre-employment HIV testing by many banks and other employers was often performed without informing the applicants of the tests or obtaining their consent. None of the Tijuana participants who mentioned that they had been

tested by their employers had given their consent. In fact, many in this study learned of their HIV status because of the pre-employment evaluations. The laboratories or a doctor would contact them with the results.

I found out that I was infected when I applied for work at a bank. For some time, I was wanting to do a physical, so when I started to work at the bank, my employer requested a blood test. When I went to pick up the results, something was strange. When I asked the results, the nurse went to alert someone that I was there to pick up the results. The doctor was very pessimistic when he informed me about the results. I asked him for information as to where to go. He told me to go to another lab for a second opinion.

Unfortunately in some cases, the lab or physician also contacted the employers without the participants' permission. In those cases when the employers were informed of the test result, the participant lost the job:

I wanted to work in September for a cleaning company and I applied. They sent me to get a physical exam at the Ministry of Health. The nurse provided the company and the social security with my HIV status. There was no confidentiality, and I didn't get the job because I was HIV positive. They told me that was the reason why I didn't get the job.

Another participant who worked as a bank teller related similar experiences when he lost jobs in his hometown and in Tijuana:

I lost my work at a bank because they found out that I'm HIV positive. When I underwent hemorrhoid surgery, they withdrew blood and ran the HIV test without my permission. Then they alerted my employers about my HIV status, and they fired me under the threat that they would spread the word among all the employees so they could make my life miserable. After that incident, I came to Tijuana to live. I went to apply to another bank and they did a blood test. They told me that I passed all the psychometric tests, except for the blood test which showed that I'm HIV positive. They didn't hire me. I felt rejected.

Other Tijuana participants were fortunate that neither the lab or the physician informed the employers of the pre-employment test result. One participant was resourceful. Knowing that HIV testing would occur when he applied for a job at a bank, he sent a friend to the lab to provide a specimen for him in his place.

One of the Tijuana participant's wife had recently had a baby, and he felt she and the baby were singled out as HIV infected while in a government hospital during the birth of the infant:

When my son was born at a social service hospital, my wife was isolated because they said that she was infected without proof of that. I think what happened is that when she was pregnant, she went to get information about the AIDS test, and the social service took note of it... I even think that my son was marked by the social service hospital. They marked him on his ears. At births, babies who are infected or if the parents are infected, they are marked. My wife says that at birth, they put clips

in his ears, leaving them for half an hour and putting pressure on the ears. Later when the clips were removed, they left a scar.

Tijuana participants who did not directly experience rejection or the loss of a job because of their HIV status, feared that this might occur: "there are still false beliefs that just by looking at someone with AIDS or shaking his hand, one can become infected." One participant was fearful of informing any of his uninfected friends, "I haven't told friends that are not infected that I am. I believe if I told them that I'm infected they would reject or abandon me."

Most of the Tijuana participants were very guarded about informing friends, neighbors, co-workers, and especially employers because of the widespread fear and ignorance about HIV throughout Mexican society:

I would like to go to the E\_\_\_\_'s group (support group that meets at a coffee house). But I've been living here in Tijuana for 12 years, and I work as a cook. If I go to the group, I'll meet a lot of people, and I might come across friends that might recognize me and know I'm infected. I wouldn't like people to point me out on the street. I work as a cook in a restaurant, and I believe I could have problems at work. The people wouldn't like to touch me or allow me to touch anything. I believe I would get fired.

The experience of stigma for the participants in this study included actual or anticipated rejection and/or discrimination because of being HIV positive. Dealing with stigma was part of the work of living with HIV for the participants from San Diego and Tijuana.

### Support

San Diego participants reported receiving support from a variety of individuals and groups. The San Diego participant who was married admitted that his best support was his wife. Three of the participants mentioned their partners with whom they lived. Two participants spoke of 12-Step recovery programs as being a positive source of support.

Five San Diego participants stated that friends were helpful. Others utilized support groups at the various AIDS organizations, programs, or groups in the community. And one participant mentioned using therapy for depression which developed soon after he was diagnosed with HIV.

Two of the San Diego participants who were heterosexual attributed a great deal of support to the gay community. "I think a lot of heterosexual couples faced with this find it to be the case that they can find more information through

the gay community because the gay community's been dealing with it for so long." The other said, " Everything I do (except medical care) is through the Gay and Lesbian community support."

One of the San Diego participants who was part of a gay couple talked about the support available in the relationship, but if something happened to one or the other, there would be a change:

If D\_\_\_ gets sick and he leaves me and I get sick, I'm going to be by myself. Who is going to take care of me? D\_\_\_ has me to take care of him. I'll be by myself and going to the AIDS home, and I see that and it makes me depressed and makes me reaffirm that I have to stay well.

Four of the San Diego participants spoke of support or non-support from their parents and immediate family members. One participant was able to tell his parents about his gay lifestyle and being HIV positive and continued to receive their support. Another participant had a positive outcome with his father whom he had not been in contact with for several years:

My dad and myself hadn't talked in years and years just because of the way our life was when we grew up. And when I first got sick, I wrote him a letter and I asked him for money because I didn't have any other place to turn, and he sent it to me. And since then he calls me all the time.

For this participant, the relationship with his children was more difficult:

And so it's real hard to try to justify an existence when I can't do anything. I can't work. I can't really take care of myself. I'm living at the mercy of other people. I'm ruining emotionally everybody's lives around me. My daughter cries all the time. We talk openly about it and stuff like that, but little things like the neighbors around their house finding out is something that I went through over the past months.

For another San Diego participant who wanted his parents and other family members to know about his HIV status, it was a "struggle":

When I told them (parents) that one of the reasons I was there (visiting) was to tell my brother. I felt compelled to tell my brother face-to-face and they were against it. Like I'm not going to tell any other relatives but I feel I owe it to my brother to let him know. Even though we're not very close, I felt compelled to tell him about it. And my folks left the house. My folks have always made it clear to me the door is always open. If I were that ill, they would take me in, in a heartbeat. I'm convinced of that. But their dealing with it has been a struggle for the both of us (he and his wife).

The San Diego participant who had just left prison experienced difficulty with some family members but not others:

I have a lot of bad feedback from my sister. I tried to get some kind of support from her, which it turned out negative, and then I talked to my niece on the phone, and my niece gave me more



support than my sister. She wants to know everything that goes on in my life. My sister wouldn't allow it and didn't give me the address to where I could come to where she was. My sister said, 'Well you did it to yourself.' And I said, 'Look it is not what it was then, it is what it is now and I need your support, and the next thing I know she hangs up on me, and that screwed my head a little bit.'

Although Tijuana participants felt they received very little support from the government, the health care system, or society as a whole, many had informed some members of their family, i.e. parents, siblings, children of their HIV status. All of the participants who reported that they had told family members continued to receive understanding and support. The only exception was one of the women who was divorced:

When I told my oldest daughter, she cried, but I explained things to her so now she has more information, and she feels more at ease. My husband is the one that keeps saying to everyone that I'm HIV positive.

Many of the Tijuana participants stated that they received a great deal of support from other friends who were infected. Another source of support came from involvement with the AIDS Tijuana Organization:

Every Monday I used to go to a group where I was among people that shared the same situation. Everyone disclosed their own personal problems and in this way we began to know each other very well.

This helped me a lot because at the beginning, I was morally very down.

Tijuana participants also felt that they received a great deal of support from the other participants during the hourly intravenous infusions for the weekly research study visits:

Another thing that helped me was the guys from the group who without them I wouldn't be this well. Emotionally they helped me to know that there are other people that have the same desires that I do. When we chat, I feel very good. When you get home and think back on all the things that you have shared, it makes you realize all the help you can get from them.

One of the women from Tijuana felt the need for support groups among women and, with some additional knowledge and information, thought she could start a group for women:

I haven't seen a difference in the treatment of HIV for men and women, but women shut off more and don't seek treatment. Men are more open when it comes to looking for help. There is no psychological help to assist women with their anxiety. This means support groups for HIV positive women... It would be very helpful to have a women's group for moral support and information on the different stages of the disease to better understand. I think that with adequate information, I could put a group of HIV positive women together. I know I would be exposed for people finding out that I'm HIV positive, but I don't think it would affect me.

Sources of support varied for participants in this study. Sources which provided positive support included

parents, spouses, partners, siblings, friends, therapists, support groups, the gay community, AIDS organizations, and other HIV infected individuals. Other participants experienced difficulties with family, friends, spouses, or partners because of being HIV infected. The receipt of support as understanding, comfort, humor, and love often eased the work of living with HIV. The lack of support by key family members or individuals close to the participant could add to the emotional struggle and burden of living with the disease.

### Taking Care of Self

The various actions and strategies used by all of the study participants living with HIV infection were in some way aimed at taking care of self. The primary means of taking care of self in this study were related to engaging in HIV-related activities; making changes; gathering or seeking information; being willing to participate in experimental drug trials; and taking charge of health care planning and decision-making.

HIV-related activities included medication preparation and administration, symptom management, and coordination of HIV care appointments. Making changes involved changing

daily living habits such as diet and sleeping patterns, as well as undertaking philosophical, emotional and spiritual shifts in ways of thinking, attitudes, and behavior.

In order to be more knowledgeable of HIV disease and treatment options, San Diego participants gathered information from the multiple sources available to them. Tijuana participants constantly sought information about HIV/AIDS.

A majority of participants were willing to participate in clinical drug trials to gain access to promising new therapies and medications. Many sought to take charge of their health care by becoming as knowledgeable as possible and by seeking partnership roles with health care providers in planning and making decisions about health care options.

Typical HIV-related activities involved taking multiple oral and intravenous medications; preparing oral and intravenous medications by crushing and dissolving tablets (DDI) or mixing IV solutions (ganciclovir); caring for intravenous lines and insertion sites; performing regular physical checks of their bodies; attending various clinics, physician, and research appointments. The amount of involvement with HIV-related activities ranged from taking

antiretroviral medications three to five times a day and attending research study appointments once a month for the participants who were asymptomatic. Or, those participants with AIDS diagnoses and conditions took multiple types of medications several times a day and had one or two HIV-related appointments per week.

All ten participants from San Diego took antiretroviral medications. The five participants with AIDS diagnoses also took prophylactic medications for various opportunistic infections such as PCP, MAI, or cryptococcal medications, and other medications required by their physical conditions.

Two of the San Diego participants with AIDS self-administered intravenous medications (ganciclovir) daily for CMV retinitis. Both of these participants mixed the ganciclovir with saline solutions, prepared the IV tubing and set-up, and administered the medications to themselves. One participant lived alone and did everything by himself. The other participant's wife often helped him prepare and/or administer the intravenous medication.

Each of these San Diego participants with AIDS-related conditions were occupied every week with attending physician

or research appointments; obtaining medications and supplies, participating in support groups, and so forth . A listing of the routine HIV-related activities for one of these participants who had two AIDS-related conditions, CMV retinitis and cryptosporidiosis, provides an excellent example of all that was involved in their care:

- Every week - appointment with private physician for vitamin, mineral, gamma globulin injections and periodic consultations
- Every week - visit by home health nurse (HMO) to draw blood
- Every week - picks up medications and IV supplies at HMO pharmacy
- Every two weeks - dermatologist appointment to remove skin lesions, molluscum
- Every month - picks up medications at San Diego County pharmacy
- Once a month - research visits
- Every month - appointment with opthamologist to check eyes and vision
- Every 4 to 6 weeks - appointment with HMO primary care physician

Four of the San Diego participants performed daily routine checks of their bodies for any new symptoms or problems. One of these four stated that he checked himself physically every day for "any kind of marks or anything that looked not normal and to see if anything looked different." Another commented that he also checked for any changes but had no set routine:

Throughout the day, depending on the lighting, I might check the little spots from where I've itched myself, and I kind of check the condition, if they look like they're spreading and if I need to be more vigilant.

The San Diego participants who utilized clinical trials as the main source for their HIV health care made monthly study visits during which they received a supply of medications, had blood drawn, filled out questionnaires if appropriate, and received a medical exam. Usually at the start of the study, visits were more frequent than once a month while participants were being screened and baseline exams and lab evaluations were performed.

Like their counterparts in San Diego, the Tijuana participants took actions to take care of themselves in dealing with being HIV infected. The main HIV-related activities for all of the Tijuana participants involved taking antiretroviral medications daily. Ten of the eleven received their medications through the U.S. DDI clinical trial, and one received his from a Ryan White clinic in San Diego. Related to the actual taking of HIV medications was the time and effort that all Tijuana participants spent in obtaining their medications. For those who crossed the

border, there was the transit time back and forth. For the ten involved in the DDI clinical trial, there were weekly intravenous infusions of an experimental medication with once a month dispensations of DDI, the approved HIV antiretroviral medication.

Two of the four Tijuana participants who were able to cross the U.S./Mexican border sought HIV health care at a Ryan White federally-funded clinic. For one, the trip across the border was "not a burden":

It would be extremely serious if I wouldn't be able to cross into the U.S. to get my medication, since no one can get it for me. I take the trolley to get to the clinic and get the medication. This is part of my routine, and it's not a burden.

For the third Tijuana participant obtaining medications in the U.S. through a Ryan White clinic and a university-sponsored drug trial was more stressful and problematic:

I told them from day one that I wasn't an American citizen. I gave them my address and telephone number to validate that do have something here (San Diego). The problem was before when I tried to get into the clinic and I lied with some information. I didn't lie, but didn't tell the whole truth. I don't like to lie. It's very difficult for me to do that. What I did say was true; I never said I was an American citizen. I never said that I was always living here, but I said that I have a California address and a California telephone number and that I wasn't working, which is true - I wasn't working here in the U.S. Every time I went I felt



uncomfortable because, for example, they would ask me if I had an interview with a case worker and that they will help me if I needed something. I told them that I was living with a friend and that I was helping him out, English helps. I was under a lot of stress. I couldn't tell them about the help that I was receiving Tijuana (local support groups and friends).

A fourth participant who could cross the border to seek HIV health care had not done so prior to entering the DDI trial, but he stated that he would go to a doctor in San Diego for medications after the research study was over.

Many of the participants in the study, but especially those from Tijuana, took herbal or recommended foods to try to enhance their immune systems while receiving the antiretroviral medications. Descriptions of various regimens by two participants are as follows:

Every Saturday, I eat a grilled cactus with the juice of corn, salt and lemon. Daily I drink an aloe-vera shake, which is nutritious and cleanses your system while increasing your immunity. I believe this has increased my immunity. I've integrated to my regular diet raw cactus since I heard that it's good for the immune system. I drink a tea made out of a Filipino bitter melon leaves.

I also drink a boiled herb by the name of cat's claw, "una de gato", a shake of aloe vera with lemon, raspberries, and I take a lot of vitamin C capsules and multivitamins, and I'm injecting Bedojecta. I regularly inject myself with five ampules every two weeks, and I feel wonderful.

All of the San Diego and Tijuana participants mentioned making significant changes in their daily lives directed towards dealing with HIV and taking care of self. Four of the ten San Diego participants stated that they made concerted efforts to eat a more balanced diet, to sleep more regular hours, or to get more exercise. In addition to generally improving diet, rest, and exercise, three of the four also mentioned that they had stopped drinking and using drugs.

Another San Diego participant, whose long-term partnership had broken-up after he was diagnosed HIV positive, decided to make a real effort to meet other people and make more friends because his partner had been his main source of support. This participant attended support groups and became involved in volunteer work with two of the major AIDS organizations in San Diego.

Two of other San Diego participants stated that being HIV positive also had an impact on their usual ways of socializing. One had difficulties with being rejected by several friends and not being able to develop as intimate a relationship with a woman as he wanted. At the time of this study, he was trying to put his life together after being

paroled from prison. Another participant stated that he did not have sex with anyone anymore and that he was fearful of transmitting the disease to someone else which interfered with his being able to become "close" to very many people.

The San Diego participant who was married stated that he and his wife seemed to have overall less stress in their lives. They lived more simply on one income, and they tended to deal with one problem or crisis at a time rather than worrying about everything that could happen in the future.

One of the San Diego participants was able to end a relationship and move on to another, deal with depression through therapy, and become much more independent emotionally after starting to deal with his HIV diagnosis. As a result, he was able to talk to his parents about both his homosexuality and his HIV status and to retain their understanding and support:

Socially, I think I'm a better person since I found out I was HIV positive because when I found out about being HIV positive, I had to really look at a lot of issues in my life and why I'm the way I am... If I hadn't found out I was HIV positive, my life would be different. I'm a much better person, a lot more confident, and a lot more comfortable about being gay.

Two other San Diego participants made decisions about their work which they may not have done if they were not HIV positive. Just before being interviewed for this study, one of the two had just completed a paralegal course which included an internship at the U.S. Attorney's Office in San Diego. Rather than pursue a paralegal career, he decided to try self-employment, starting a computer printing business from his home. At about the same time as he decided to be self-employed, this participant also asked a roommate who had been very difficult to move out, and he placed his grandmother whom he had been caring for in his home into a nursing home.

The other participant had lived in Los Angeles and had been quite successful buying and selling antiques. He had the opportunity to become more involved with the business on a more international scale but decided to stay in San Diego where he had lived for about a year:

I have made decisions based on being HIV positive, but they might not have a future. The gallery that I was involved in was going to go international, and I could have made a great deal of money. I decided that I liked to live where I like, with a good climate, and I like San Diego much better than L.A. so I made the decision to move here.

Similar to the San Diego participants, those in Tijuana talked of making changes in the basic habits of daily living, improving their diet, getting more rest and exercise. By far, improvements in their diet were the number one change. Several participants decreased or avoided meat, ate more fruits and vegetables, avoided greasy foods, took vitamins, and drank natural water. In addition to trying to sleep more regularly and for longer amounts of times, several participants mentioned that they had decreased or stopped going to late-night parties and abusing alcohol and drugs.

Most of the Tijuana participants spoke of emotional, social, and spiritual changes since becoming aware of being HIV positive. Several moved from their hometowns or villages to Tijuana so that they would have better access to up-to-date treatments and information. Some became more active socially, participating in support groups and the AIDS Organization of Tijuana. Some stopped having sex completely, and some started using condoms. Several mentioned becoming more spiritual and religious, being more aware of what was happening to them and more aware of the needs of others.

Both of the women participants stated that they took better care of themselves, tried to be more patient, and tried not to react to every situation since becoming aware of being HIV infected. Both also made efforts to spend more time with their children. One of the women stated, "I try to spend more time with my children and let them be more independent because before I used to do everything for them. Not anymore."

Seven of the ten San Diego participants emphasized that they spent a great deal of time and effort trying to learn as much as possible about HIV disease. They talked to HIV positive individuals, health care providers, and others; read and researched medical and scientific journals and books, newsletters, newspapers, etc to learn about the disease, new drugs, therapies, community services and resources.

A San Diego participant who never read and knew very little about HIV before being diagnosed said:

I cut articles out of the newspaper about AIDS and stuff like that. I have a box that is at least twelve inches deep that is filled with every bit of medical information that I've found in papers and offices and everything since this all started for me. Just so I can mostly understand for myself because for me before this happened if

you had AIDS you died. And now all of a sudden I'm finding out that it's not an automatic death sentence, even though it will happen more often than not. There are lots of things that you can do to take care of yourself and to still be happy in your life.

The San Diego participant who was married and who received a great deal of help from his wife felt that they knew as much if not more than some physicians and many hospital staff who cared for him:

We got the knowledge we needed. We taught ourselves; we went out and learned. We had people teaching us. I was reading AIDS Treatment News and Project Inform and I had questions (for a physician), simple questions about why haven't we tried this, or is this something I should be interested in. And he would give me no, none of his time. You know, paying \$60 per visit, I want fifteen minutes. I don't think that's too much to ask for. And a lot of physicians are not used to that. They're not used to having their patients as well informed or nearly as well informed as they are. I think they're shooting in the dark as much as anyone else is. Just hope that their shot's a little better.

Another of the San Diego participants stated that a regular part of his routine was "staying well educated". "I want to make an informed choice."

I realized back in 1986, maybe it's my salesmanship being in retail, what I need to sell myself on was my own health. How do I achieve a state of better health, being told that I have a terminal illness and that I may not live three years? My reaction was I want to know the nature of the beast I'm fighting.

The Tijuana participants constantly sought information from any source that was available. Those who crossed the border or who had access to the Internet had a distinct advantage to those who could not.

As discussed previously, seven of the ten San Diego participants were involved in clinical trials to either supplement current therapy or to obtain the best antiretroviral and prophylactic medications available, as well as laboratory monitoring and medical exams. As one of the participants states, "I'm willing to experiment. I really don't think in my state of this disease that I really have too much to lose. Try it, and if it works, it works. And if it doesn't, it doesn't."

Another participant was involved in a clinical trial in which alpha interferon was being tested as an immune enhancing medication. This participant used the clinical trial to supplement the care he was receiving at a Ryan White clinic. The study required that he give himself a subcutaneous injection three times a week with flu-like symptoms lingering 24 to 48 after the injections. He remained in the study for a year in hopes of benefits for himself and others:



I'd been feeling tired a lot but I was determined to go through the study and, if anything else, maybe someone else could benefit from the results. This was very important to me.

One of the San Diego participants who was not involved in a clinical trial stated that he tended to be "very conservative" about what treatments he decided upon:

There are a lot of new things out there that I'm excited about, yet, I'm hesitant. There are so many men that I know that will jump to every new therapy and they die. I don't think that they die because they took that kind of posture but I wonder to myself what kind of a chemical soup they were starting to put into their body, and maybe that has something to do with their disease progression. And so, when I read an article or I read a paper or an abstract about a drug or about a substance, I want to see what the amount of enrollment is, what the split of patients is, what the side effects were, what the toxicity levels were, what the drop out rates were, why were they dropping out, etc. I'm sure that most people with their health care don't get that involved.

The Tijuana participants were involved in clinical trials in order to obtain basic HIV treatments and evaluations. They were willing to take the experimental substances being studied in these trials, and to spend the time and effort because there were no other options available, especially for those who could not cross the border.

Several San Diego participants mentioned that they felt it was important to take charge of their own HIV health care and to not be totally dependent on what their doctor said. They felt this way, in part, because they were not always sure how knowledgeable health care providers were and how well the system worked for them. One participant stated:

I'm my health care provider practitioner, and I work with Dr. X; we work together... When I became HIV, I must have known to say to my inner self, 'let's find out about this so we can fight it rather than draw the party line and let the doctors be the information and me be the dutiful patient'...

Another participant had similar thoughts:

Like my doctor said I tend to be my own doctor. I talk to the doctor. We discuss everything. They tell me what I should do and I tell them what I will do... I know more about my body. I'm a believer that your doctor is not there to cure you or find things wrong with you. The doctor is there so you find out what is wrong with yourself. And he helps you take care of it. I don't depend on my doctor to keep me healthy... I know enough about medicines like rifabutin. I read about it, studied about it. I asked my doctor about it and he didn't know very much - I knew more about it than he did.

One of the San Diego participants, who was diagnosed with two AIDS-defining conditions, felt it was important for his survival that he take part in what was decided and done to him medically:

One thing I have found, in order to survive with this disease you really have to take charge of your own health. You just can't listen to your doctor and take two pills and to home and that's it. You really have to become very knowledgeable... That's what I think is so important with people, particularly in the later stages of HIV. They need to know treatments are out there, what's working, what isn't working, what people are trying, and what they're not trying.

This same participant felt that the health care providers in his HMO were not as concerned or as careful as he was about his condition and his care. He had to struggle with the doctors at the HMO to change his antiretroviral medications from AZT to DDI when he began to feel weak, fatigued and lost weight. After making the change of medications, he grew stronger and gained back the weight.

He also vigorously requested a certain prophylactic medication for cryptococcus meningitis once his CD4 cells reached a certain value because of information he had read. He refused to let the HMO insert a Hickman intravenous catheter into his subclavian vein for daily ganciclovir infusions. He demanded and eventually received an IV access system that was placed under the skin much like a pacemaker so that he could shower and swim and have decreased chances for insertion site infection and a better quality of life.

This same San Diego participant also routinely logged all labs drawn, dates, and results because it seemed that the HMO lab repeatedly lost specimens or results. As he stated, "I just didn't feel confident that the doctors or even the home health people were even looking at the damned things."

Several of the Tijuana participants talked about the need to be cautious about eating foods outside of the home, either from vendors on the street or at restaurants. Another mentioned taking measures to avoid contact with opportunistic infections, "Now that I can contract any opportunistic diseases, I have to be more careful when I travel in public taxis, since there are people sick with the flu and coughing."

Many of the Tijuana participants who feared rejection and discrimination from others were very careful of whom they informed of their status. The participant who felt his wife and infant son were discriminated against at the government hospital did not want to take any actions publicly or legally. He felt that by doing so, he would make himself and family vulnerable to exposure and scandal.

### Staying Alive - For the Cure and Living Better

Being HIV infected and either asymptomatic or ill with AIDS-defining conditions, all participants in this study faced limited therapeutic options. Those participants in Tijuana who could not cross the U.S.- Mexico border experienced even more limited access to HIV treatment and information than their San Diego counterparts.

There is no cure for HIV, with the usual course of the disease being terminal after several years of gradually declining health. Various antiretroviral and immune-enhancing agents have been developed, and new drugs are constantly being investigated. However, there is no drug, combination of drugs, or vaccine yet developed that eradicates or arrests the HIV virus in humans.

Within the environment of limited therapeutic resources and new drug investigation, many San Diego participants spoke of "staying alive" and "hoping a cure" for the infection could be found. "Staying alive" was the overriding concern and major goal that the San Diego participants, despite varying personal or social circumstances, worked to achieve:

I want to live. This is such a passion for me. There is so much that I haven't experienced yet. It's almost like willing myself to stay alive- excuse me but I'm not done, and I'll not let go, and you cannot make me, no matter what.

Another San Diego participant expressed a desire to stay alive, to hope for a cure. He had learned he was infected with HIV when he became acutely ill with PCP and MAI. As a result, he was unable to work and became virtually homeless. He lived out of his truck except when he could arrange stays with friends or his ex-wife:

I work every day at trying to stay alive happily. If people will do the best that they can whether to not get infected or to live with being infected, there's nothing else you can do beyond that. It's out of our hands. We can only hope and pray for a cure, which I myself don't look at as being a realistic solution to my personal sickness.

Taking a more proactive stance towards staying alive, a San Diego participant who had been positive for 8 years, was a recovering drug addict and alcoholic, and in fairly good health stated:

I don't want to live with AIDS, but I always come back to the reality for me. The better educated I am, and the more aware I am of cutting-edge technology, the better chances I have for survival. And the bottom line is survival.

Another long term survivor of 11 years, who was also a recovering drug addict and alcoholic and in excellent

health, actively worked to stay healthy and alive:

I went to a seminar regarding the virus within you and instead of hating it you should learn to live with it, and everything like that I went through, and I changed about it. But a lot of it is that I do believe that you have to accept it. So today, I'm totally aware. I've done a lot of learning of my body and keep up to date for what is happening. I'm fine with the virus as long as it stays the way I am now. It's not bothering me now. But I'm on alert, and I talk to him everyday to stay the way it has behaved until now, and we will work together. I believe that if I made it this far, and I know that a lot of things have been coming along, and I keep an optimistic outlook, I believe that you stay healthy, one day at a time, and I think that I have a really good chance to make it and reach the year 2000 with the new drugs coming out.

Although the Tijuana participants certainly were trying to stay alive as long as possible with HIV infection, they more often expressed the desire to "live better" ("de vivir mejor"). This desire was so for participants who could or could not cross the border to the United States.

A participant who could not cross the border and who utilized the U.S.-sponsored clinical drug trial to obtain antiretroviral medications stated:

When I start the treatment, I felt very happy. I was sure I was always going to take the treatment and live better. I just finished with the treatment (the end of the drug trial), and I feel insecure, insecure of me and my future. The treatment gave me a little assurance and strength.

A Tijuana participant who did cross the border and received HIV medications and information in the United States, talked about living more positively now that he is infected:

I feel that I've made a lot of progress by being more positive towards this disease. Everything changes for you. You enjoy everything, every day that goes by. I try to help people that need help in the same way that I needed help in the beginning. I've received a lot of help, and because of this, I'm feeling better.

Another participant who had lost his job as a bank teller because of a pre-employment HIV positive test commented:

The benefit of being HIV positive is that now I'm more self-aware of everything that surrounds me. Now I try to live a quality life. I try to select my friends very well, the people I hang around with, the places that go for entertainment, what I read. Everything I do, I try to do it with quality. Now I'm closer to religion. I try to help my fellow men, and all the people that are close to me. I learned not to resent anyone, not to be envious, to live a good life. My spirituality has grown and increased even more. Having this disease that doesn't have an immediate cure, I have to believe in something.

A Tijuana participant who was a medical student and who also lost a part-time job because of a positive HIV test stated:

To live with HIV is to live a better life ("vivir mejor") and to give my best to others. I'm trying to have more time here in this life - to be more alive every day. I want to beat this disease because one



day a vaccine might be discovered and I'll get cured.

One of the two women participants in Tijuana who had six children and a husband dying of AIDS related her experience:

I try to live better than before. I eat better, I go to bed earlier. I try to spend more time with my children and let them be more independent because before I used to do everything for them. They say the more fear one has the more the disease develops. Therefore the more calm and serene one is, it is better. It is healthier than to keep on thinking in a negative way. On the contrary, one has to think positively.

#### Summary

Amidst varying personal and societal circumstances, the participants in this study from San Diego, California and Tijuana, Mexico were engaged in the chronic illness work of living with HIV. There were many similarities between the two groups, and there were some distinguishing differences in their attempts to **Stay Alive - For the Cure** and to **Live Better, "de vivir mejor"**, with HIV.

All of the participants were similar in age, most being in their thirties. The San Diego participants as a group had been infected longer, with a mean time of infection of 6 years compared to 3 years, and had more advanced disease progression, 6 of 10 with AIDS as compared to 1 of 11.

All twenty-one participants were receiving antiretroviral therapy. Asymptomatic participants from both groups received antiretroviral therapy as part of the study treatment regimen for various clinical drug trials.

More of the Tijuana participants, 91% (n=10) versus 60% (n=6), were employed either full or part-time. Despite the numbers of employed, the majority of participants from both groups lived within limited financial means.

Psychological responses to being HIV infected were similar across all participants. Initial reactions of shock and denial, followed by feelings of fear, anger, depression were commonly mentioned.

San Diego participants had access to a much more extensive HIV care system of health care providers, social support services, information, and clinical drug trials than did the participants in Tijuana. Four of the eleven Tijuana participants were able to cross the U.S./Mexican border. These legal emigrants were eligible for federally-funded HIV health care and local support services in San Diego. The remaining seven Tijuana participants were limited to the limited resources of the Mexican government health care system.

A majority of participants from both groups, 70% (n=7) from San Diego and 100% (n=11) from Tijuana, utilized participation in clinical drug trials as either an essential means of access to newly developed and promising antiretroviral and prophylactic medications or as a supplement to primary HIV care they were already receiving. San Diego participants and the Tijuana participants who were legal immigrants could select or "shop" from several drug trials at various sites in San Diego.

Most participants from both groups mentioned some exposure to stigma, discrimination, or rejection from friends, family, and others in response to their HIV status. Several participants from both groups used aliases when seeking health care, enrollment in clinical trials, or social services.

Discrimination for the Tijuana participants was a much harsher reality than for many of the San Diego participants. Four of the Tijuana participants were tested for HIV during pre-employment physicals without their knowledge or permission. Two of the four were fired when, without their permission or knowledge, the test results were reported to

their employers by the laboratory or physician who performed the tests.

All twenty-one participants were engaged in various activities to take care of self. These activities included: HIV-related treatment activities, making changes in their lives, being willing to experiment in drug trials, taking charge of their health care, and being cautious.

More of the San Diego participants were actively involved in making choices and decisions with their physicians about treatment regimens and plans. By being well informed, the San Diego participants were better prepared to present treatment options and to dialogue with their physicians about the best course of action at any stage of disease progression.

The Tijuana participants did not have the luxury of the knowledge sources or treatment options that their San Diego counterparts had. Rather than taking charge of their health care and making decisions, the Tijuana participants gratefully followed the advice of trusted primary HIV care physicians in Tijuana and were more cautious in a variety of ways to protect themselves.

San Diego participants were striving to stay alive in hopes that a cure could be discovered in time to save them. Tijuana participants were also trying to stay healthy for as long as possible. But without adequate treatment resources and with the threat of loss of health, employment, friends, and societal acceptance, living a better life and helping others who were infected seemed as important.

## Chapter 5

### Discussion

The purpose of this research was to study the experience of individuals who are infected with HIV or are diagnosed with AIDS as they live with and manage the disease. In more specific terms, this study sought information about individuals living with HIV in terms of the problems they encountered, the differing conditions which influenced their lives, the actions or strategies they used to deal with HIV/AIDS, and the consequences that resulted from the actions/strategies.

Findings from this study will add to the increasing amount of knowledge about how HIV infected individuals live with the disease as a chronic illness. In addition, this study provides a comparison of how participants from binational groups, San Diego, California and Tijuana, Mexico which are geographically so close but culturally and socially so far apart, live with HIV.

### Conclusions

Participants were engaged in the work of living with HIV amidst a complex and sometimes harsh context and

surrounding conditions. The prevailing context for participants in this study was the HIV care system, with conditions of societal stigma and social support. The HIV care system included the various means by which HIV individuals sought treatment, care and knowledge from primary health care providers, social services, clinical drug trials, and information sources. The effects of societal stigma were felt directly in terms of discrimination and rejection or were feared and guarded against. Social support was provided by families, friends, other HIV infected individuals, health care personnel, AIDS organizations, counselors, 12-Step recovery programs, and community agencies.

Problems identified in other studies of HIV infected individuals existed for the participants in this study. Financial concerns were for many both a "burden and occupying preoccupation" as described by Strauss (1975) or some of the "most urgent" needs as identified by Baigis-Smith, et al. (1995).

Many of the nursing dependency needs, prolonged disease/disability, activity intolerance, diarrhea, grieving, powerlessness, and depression, described in a

study by Corless, Halloran, and Belyea (1994) were evident in several of the San Diego individuals with AIDS. One of the San Diego individuals newly diagnosed with AIDS after an episode with PCP reacted by becoming much more preoccupied with fear of dying once he had "crossed the line" of having AIDS. His reaction was similar to findings from a study by Ragsdale and Morrow (1990) which indicated that quality of life was more significantly affected when patients became symptomatic and when they were nearer to death.

Participants from San Diego and Tijuana mentioned psychological symptoms of fear, anxiety, depression, sadness which were similarly experienced by other individuals living with severe, life-threatening conditions (Fitzpatrick, et al., 1984; Fullilove, 1989; Toombs, 1992). Losses associated with chronic illness (Toombs, 1992) were also experienced by participants in this study. Loss of control; wholeness of bodily integrity; connection with work and relationships; independence; the familiar world; and a personal sense of indestructibility were described by participants.

The women participants in Tijuana were not unlike other HIV infected women who were studied by Anastasio, et



al.(1995) and Rose (1993). Concerns about the womens' own health were complicated by concerns about the care of their children.

Exposure to stigma in terms of societal hostility, suspicion, fear, and discrimination was very similar for participants in this study as to what has been described by Goffman (1963) and others (Herek, 1990; Siminoff, et al., 1991; Walkey, et al., 1990). The Tijuana participants, especially, encountered severe societal discrimination and rejection.

Participants in this study were engaged in work similar to that of individuals with other serious chronic illness (Corbin and Strauss, 1988). According to Corbin and Strauss (1988), managing chronic illness and accommodating to the various changes in the body, self-image, relationships, and lifestyle requires work. Work involves a continuous juggling of time, space, energy, money, jobs, activities, and identities to adapt to the problems of the illness, to maintain balance, and to carry on in everyday life.

The activities that participants in this study used to deal with problems and to take care of themselves were similar to actions taken by long-term survivors and

individuals with advanced-stage AIDS as described in studies by Barroso (1997) and Wilson, Hutchinson, and Holzemer (1997). Participants in all three studies pursued health-promoting behaviors; followed treatment regimens; became knowledgeable about HIV disease and therapeutic options; were willing to participate in clinical trials; made personal and lifestyle changes; actively participated in the selection of medications or other therapies; and dealt with stigma.

Wilson, Hutchinson, and Holzemer (1997) found that individuals dealt with stigma by choosing not to reveal, to partially reveal, or to openly reveal their HIV status. Those authors (Wilson, et al., 1997) also found that Hispanics tended not to disclose their HIV status and to remain silent for fear of rejection from friends, family, or the church.

Similar findings about dealing with stigma were evident in this study. Many participants seemed to make decisions on a case-by-case basis about who could be trusted for disclosure and who could not. Several of the Tijuana participants informed selected family members. Most from Tijuana commented that they would not reveal their HIV

status to co-workers or to friends who were not HIV infected because of fear of loss of employment and rejection.

In addition to the dealing with the effects of societal stigma, participants in this study coped with the myriad psychological symptoms of fear, anger, depression, etc., in similar ways as do many other individuals who live with serious, life-threatening illnesses. Denial was used by participants from San Diego and Tijuana and has been described as a common response of individuals with "potentially lethal illnesses" (Fitzpatrick, et al., 1984).

Many participants, especially in San Diego, tried to "control the uncontrollable by detailed knowledge"; questioned health care providers; refused certain treatments; proposed alternatives; or submitted to untried procedures, as reported by Fitzpatrick, et al., 1984 of others with serious life-threatening illnesses.

Fitzpatrick, et al. (1984) found that urban, gay males commonly organized formal networks to deal with the social, economic, scientific problems and demands of HIV disease. These groups provided a supportive environment for exchange of information, expression of feelings, and a decreased sense of isolation.

The usefulness of support groups and social services organized and sustained to a large extent by the gay HIV infected community in San Diego was validated by participants in this study on both sides of the border. The married couple and a heterosexual male from San Diego stated that the gay community was their main source of HIV-related information and community support.

Interestingly, the heterosexual couple from San Diego responded similarly to management of symptoms of the disease as did homosexual couples reported in a study by Rose (1996). Both types of couples used "mutual protection" and working independently, interdependently, and dependently to prevent losses or problems they could control and to let go of problems or situations they could not control.

Several findings from this study were unique from data and findings reported in other nursing studies of individuals living with HIV. A majority of San Diego and Tijuana participants enrolled in clinical drug trials as either a supplemental or essential source for HIV health care. Those participants, who used drug trials as a supplement to their primary HIV health care, sought access to experimental drugs as new therapies were constantly being

changed and developed. Participants used clinical drug trials as an essential source of care because of fear of loss of health insurance or because of no health insurance coverage.

San Diego and Tijuana participants who were legal immigrants had access to a variety of HIV clinical drug trials at multiple university medical center and community sites. These participants were able to "shop" for and select trials that best suited their treatment needs. The Tijuana participants who could not cross the border were dependent for access to promising new drug therapies on the decisions by research units and pharmaceutical sponsors to conduct clinical trials in Mexico.

Differences in HIV treatment options, relationships with physicians, information sources, and societal discrimination between the San Diego and Tijuana groups were striking. Tijuana participants had less of everything compared to San Diego participants: few or no HIV drugs and trained health care providers; limited information about the disease and treatments; lack of social services and support groups to share information and experiences; and loss of confidentiality and privacy with HIV testing. The Tijuana

participants who were fortunate to be able to cross the international border legally could only access Ryan White-funded HIV care which had limited availability of drugs, supplies, and services compared to other U.S. health care providers.

Participants from San Diego were actively involved with physicians and other health care providers in planning and making decisions about treatment options and regimens. Some San Diego participants felt they should direct their own health care because they felt better informed than their physicians about HIV infection and treatment.

Tijuana participants had difficulty finding physicians or other health care providers in Mexico who would care for them with HIV disease. When these participants found a physician at the special HIV clinic in Tijuana, they were profoundly grateful for his care, trusted his knowledge and judgment, and did not challenge his plans of care or decisions.

Discrimination in Tijuana because of HIV/AIDS was widespread and directly affected all eleven of the participants in some way. Employment, health care, and interpersonal relationships were impacted either directly by

the discrimination and rejection of others or indirectly by the fear of participants that something would happen.

Some of the Tijuana participants were denied employment because, without their knowledge or permission, their HIV positive status was revealed to employers. Many participants felt that the government-sponsored healthcare for HIV individuals was "negligent and incompetent" because health care agencies and providers either rejected or totally isolated all HIV individuals. Fear of exposure and being fired at work or "abandoned" by friends was common.

Several Tijuana participants provided false names for enrollment into clinical trials to prevent employers or the government health care system from discovering their HIV status. Tijuana residents also used false names and addresses to gain entry into Ryan White-funded clinics in San Diego.

San Diego participants also encountered rejection from friends and family, as well as discrimination from others in society, such as federal social security clerks or health care personnel in hospitals. To avoid being discovered as HIV positive by employers and insurers, at least two of the San Diego participants did not use employer-provided health

care coverage but chose instead to use Ryan White-funded health care or treatment in clinical drug trials.

The participants from San Diego attempted to "stay alive" and "healthy" until a cure for HIV disease was discovered. Tijuana participants also tried to survive for as long as possible and to "live better" ("de vivir mejor"). Trying to "live better" ("de vivir mejor") was expressed by the Tijuana participants in the context of severe societal discrimination against HIV/AIDS, with the potential of multiple losses of: relationships with families and friends, employment, health care, as well as the loss of their lives.

#### Recommendations for Future Study

More studies of women living with HIV should be a priority. As increasing numbers of women become infected with HIV, the possibility for transmission to and infection of their children also exists. There is a need for more knowledge and understanding of the specific problems that women encounter; the conditions that influence them; and the actions and strategies they use to deal with the disease so that proper health care treatment and assistance can be provided.



Continued investigation of HIV infected individuals in Mexico or other Latin American countries could add to the findings of this study or provide new and different information. Specific studies of Hispanics living in the U.S. would be interesting as a comparison with the experience of the Tijuana participants living with HIV.

Research of HIV individuals during the various stages of disease progression, asymptomatic, symptomatic, and AIDS, could more clearly delineate the specific problems, influences, and responses of individuals during different periods of the HIV illness experience. A long term study of the trajectory of HIV infection in terms of illness work (Corbin & Strauss, 1988) and during various phases, periods of stability and instability, comebacks, and deterioration could be compared and contrasted with the courses and phases of other chronic illnesses.

#### Implications for Nursing Practice

This grounded theory study of binational groups from San Diego, California and Tijuana, Mexico provides information about how HIV infected individuals from two different cultures deal with and manage the disease under varying conditions. The findings from this study can

further the understanding of nurses and other health care providers who work with HIV infected individuals from either cultural group within inpatient, outpatient, community, or home care settings.

HIV/AIDS is now considered a serious chronic illness which requires adaptation, health care, and assistance for infected individuals similar to patients with diabetes, hemophilia, severe cardiac, pulmonary, renal, neurological, and other such diseases. The problems for individuals with HIV disease need to be identified; plans of care and treatment options need to be discussed and organized; and on-going evaluation and research must continue in the same manner as for patients with other life-threatening chronic diseases.

Individuals with HIV infection and AIDS diagnoses are living for longer periods of time with the possibility of improved quality of life. Knowledge of the disease course, best treatment regimens, needs, problems, and conditions of infected individuals from diverse socioeconomic and cultural backgrounds is important for nurses and other providers to understand. With this knowledge, providers can assist individuals with the work of living with HIV so they can

"stay healthy", "live better", and survive for as long as possible.

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## APPENDIX B

### Sample Informed Consents (English and Spanish Language)

**HIV/AIDS CARE CONSENT FORM  
 CONSENT TO ACT AS A RESEARCH INTERVIEWEE**

I have been asked by Christina Joy to be interviewed for a research study about how people who are HIV positive or who have AIDS take care of themselves. She is studying this so that she can learn more about what it is like for people to try and stay healthy and to handle the health care problems of AIDS.

I understand that the interview will take about 1 hour, will be tape-recorded, and will be done in a place convenient for me. I am also aware that Ms. Joy may ask to do a second interview at a later point in the study. I understand that at any time I may quit the study, and if I decide not to participate, my care at the clinic or involvement in other studies will not be jeopardized. I understand that I may ask questions before I sign this consent form and later I can call Ms. Joy at 291-2437 about any questions I have concerning the study.

I understand that the interviews will be identified by codes and locked up in order to protect confidentiality.

I realize that there are few or slight risks to myself other than becoming tired or uncomfortable with some of the questions. And I understand that I may benefit from the interviews by having questions answered or by talking about what is happening to me. Others who provide HIV/AIDS health care and are trying to improve it may also benefit from what is learned from this study.

I have received a copy of this form. There is no agreement, written or verbal, beyond that expressed in this form.

I, the undersigned, understand the above explanations and on that basis, I give consent to my voluntary participation in this research.

----- <b>Signature of Subject</b>	----- <b>Date</b>
----- <b>Location</b>	----- <b>Date</b>
----- <b>Signature of Principle/Researcher</b>	----- <b>Date</b>
----- <b>Signature of Witness</b>	----- <b>Date</b>



CONSENTIMIENTO PARA ACTUAR COMO ENTREVISTADO PARA LA INVESTIGACION

Se me ha pedido por Christina Joy ser entrevistado para un estudio de investigación de como, personas con VIH+ o que tienen SIDA, cuidan de su persona. Ella estudia esto para aprender más sobre lo que significa para estas personas tratar de mantenerse saludables, y resolver los problemas del cuidado de la salud creados por el SIDA.

Yo entiendo que la entrevista tomará aproximadamente una hora, la cual será grabada en una cinta y se llevará a cabo en un lugar conveniente para mí. También entiendo que la Sra. Joy me puede pedir una segunda entrevista en un futuro durante el estudio. Entiendo que en cualquier momento yo puedo dejar el estudio. Si decido no participar, mi cuidado en la clínica, y/o involucración en mi tratamiento, arreglos de sustento u otros estudios, y/o condición legal no se pondrán en peligro. Entiendo que puedo hacer preguntas antes de firmar este consentimiento y que posteriormente puedo llamar al la Sra. Joy al 286-4643 sobre cualquier pregunta que tenga con respecto al estudio.

Yo entiendo que las entrevistas serán identificadas a través de claves y serán guardadas para proteger la confidencialidad.

Yo comprendo que son pocos o ligeros los riesgos que esto me represente, fuera de sentirme cansado o sentirme incómodo con algunas de las preguntas. Y entiendo que me puedo beneficiar de las entrevistas por contestar las preguntas o por comunicar lo que me está sucediendo. Otras personas que proveen cuidados médicos relacionados al VIH/SIDA y tratan de mejorarlo pueden también beneficiarse de lo que se aprenda de este estudio.

He recibido una copia de este consentimiento. No hay un acuerdo escrito o verbal más allá del manifestado en este consentimiento.

Yo, el suscrito, entiendo la explicación arriba mencionada y sobre esta base, doy consentimiento a mi participación voluntaria en esta investigación.

\_\_\_\_\_  
Firma del Individuo

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Lugar

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Firma del Investigador Principal

\_\_\_\_\_  
Fecha

\_\_\_\_\_  
Firma del Testigo

\_\_\_\_\_  
Fecha

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## APPENDIX C

### List of Interview Questions

1. Demographic information: age, HIV status, race, type of medical insurance, type of living arrangements, employment status.
2. What is it like for you to live knowing that you are HIV positive (or diagnosed with AIDS)?
3. What do you have to do differently now that you are HIV positive, either physically or emotionally?
4. What kind of problems do you have now that you know that you are HIV positive?
5. What would help make things better for you?
6. What would help you to make things easier for yourself in terms of living with HIV?