Factors that Influence Health-Related Quality of Life and Satisfaction with Care among Adults at a Community-Based AIDS Service Organization

A DISsertation

Submitted to the Faculty of the

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2002
The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables that influence health-related quality of life and satisfaction with care. The theoretical frameworks that guided this study were the Wilson and Cleary’s (1995) health-related quality of life conceptual model of patient outcomes and Ware’s (1978) taxonomy of patient satisfaction.

The research design consisted of a nonexperimental, descriptive and correlational study that was designed to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization. The focus of this research was to examine the influence among socio-demographic variables on health-related quality of life and satisfaction with care. Factors were examined retrospectively and data were gathered at one point in time. A convenient sample of 81 subjects that consisted of adults who (a) were 18 years of age or older, (b) had documented positive ELISA and western blot tests for HIV-1 or 2 virus, (c) read and spoke English, (d) had a Karnofsky score of 80 or higher, and (e) had attended a minimum of four primary health care appointments. Data were collected using the HIV Overview of Problems-Evaluation System (HOPES) and DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ).
The results of this study indicate that health-related quality of life and satisfaction with care were positive among adults receiving care at a community-based AIDS service organization. ANOVA revealed that differences in health-related quality of life scores were statistically significant between regional clinics, that patients at clinic B reported the highest health-related quality of life scores, and that satisfaction with care was the highest among subjects who had a nurse practitioner as a health care provider. There was a statistically significant negative correlation between health-related quality of life and Karnofsky scores. Satisfaction with care had two statistically significant negative correlations: (a) gender and (b) treatment with HIV medications. Socio-demographic variables did not determine the perception of health-related quality of life and satisfaction with care among the adults who were participants in this study.
This dissertation by Robert Thomas Dodge fulfills the dissertation requirement for the doctoral degree in nursing approved by Sister Mary Jean Flaherty, PhD, RN, FAAN, as Director, and by Sister Rosemary Donley, PhD, RN, C-ANP, FAAN, and John Alexander Bartlett, MD, as readers.

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CHAPTER I
THE PROBLEM

Introduction

Now, entering the third decade of existence, human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS), prevalent since 1981, are the United States of America's (USA) leading public health epidemic. The HIV virus is the organism that causes the body to lose its natural defenses against diseases. The body eventually becomes weak and open to attack by several types of infections and diseases that the body is unable to resist. When the body can no longer resist certain infections and the immune system is severely compromised (CD4 cell count < 200/mm$^3$ or CD4 % < 14), a person is diagnosed with AIDS. AIDS is the final stage of a serious health condition caused by the HIV virus.

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS recorded that 3 million people worldwide died of AIDS in 2001, while an estimated 5.6 million adults and children became newly infected with HIV. By the end of 2001, 40 million people are estimated to be living with HIV/AIDS worldwide (CDC, 2002). The National Intelligence Council estimated that nearly 40 million people were infected with HIV in 1999. By the year 2020, AIDS will likely be the primary infectious disease killer in the world. The National Intelligence Council reported in the spring of 2000 that AIDS is not only a threat to public health around the world, but also a threat to the global economy and security (CDC, 2001a; Gellman, 2000). On April 30, 2000, the Clinton administration formally designated AIDS as a threat to the United States' national security.
because it could topple foreign governments, touch off ethnic wars, and undo decades of work in building free-market democracies abroad. This is all due to the global spread of AIDS that has reached catastrophic dimensions particularly in developing countries (Gellman, 2000).

The Centers for Disease Control and Prevention (CDC, 1999) report that AIDS is the fifth leading cause of death among 25-44 years olds in the United States. AIDS is the leading cause of death of African-American men between the ages of 25-44, and the third leading cause of death of African-American women between the ages of 25-44 in the United States. The incidence of HIV-infection is rising among heterosexuals, minorities (particularly African-Americans and Latinos), women, and intravenous drug users (IVDUs). According to CDC (1999), African-American and Latina women accounted for 80% of all cases of AIDS; among men, African-Americans and Latinos accounted for 61% of all cases of AIDS. As of June 31, 2001, 793,026 persons with AIDS had been reported in the United States; 457,667 of these had died; 3,542 persons had unknown vital status. The number of persons living with AIDS, 339,000, is the highest ever reported as of December 2000 (CDC, 2002).

The increase in the incidence of HIV-infection is highest in Washington, DC and in the southern states according to the CDC's (2000) HIV/AIDS Surveillance Report. The Washington, DC AIDS rate for men is 299.4 per 100,000 population (the United States rate is 27.2) and for women 102.2 per 100,000 population (the United States rate is 8.4). The cumulative AIDS cases in Washington, DC are 24,029, which makes Washington, DC the fifth highest metropolitan area with reported cases (CDC, 2002). The CDC estimates, that in
1998, approximately 111,054 of the 297,137 individuals with AIDS lived in the southern part of the United States (CDC, 1999).

The incidence of deaths from AIDS has decreased 42% from 1996 to 1997, 20% from 1997 to 1998, and 11% from 1999 to 2000 (CDC, 2002). The decrease in AIDS deaths has been attributed to new effective antiretroviral agents, particularly the protease inhibitors (Pis), which were approved by the Food and Drug Administration (FDA) in late 1995 and early 1996. Also, there has been great advancement in the knowledge of the viral replication and life cycle, which has led to new diagnostic tests. These new tests, the HIV-RNA viral load test and the bDNA, help health care providers monitor replication of the virus and adherence of the patient to the prescribed medical regime.

As the number of individuals living with HIV/AIDS continues to increase yearly, this syndrome is beginning to be recognized as a chronic disease. As survival rate increases, attention is turning to issues of health-related quality of life and satisfaction with care among the individuals seeking medical care for HIV-infection. Formerly, the focus of care was on preventing opportunistic infections and making individuals comfortable during the end stages of AIDS. Now, with the decline in AIDS deaths, the attention has shifted to maintaining health-related quality of life and supporting satisfaction with care.

Health-Related Quality of Life

Health-related quality of life is the patients' evaluation of the effects of a disease and its treatment on well-being (Murdaugh, 1992; Sousa, 1999). Health-related quality of life addresses the issues of how the disease process and management of the disease affect the individual's ability to function in society. Common measures include upholding and maintaining employment, and/or carrying out activities of daily living (ADLs), such as
walking up a flight of stairs, bathing, or dressing. An individual’s health-related quality of life score will be low when the individual experiences too many side effects from medications or has recurrent opportunistic infections. The individual will score low when there is no support from family and friends, when there are concerns about relationships and when there are fears about the possibility of infecting a loved one. For mothers, particularly, there are concerns about caring for their children who may also be infected. Health-related quality of life scores are high when the individual is able to maintain employment, has few or a limited number of side effects or complications from the disease process, and has support from family and friends. The construct of health-related quality of life is gradually becoming accepted as an important outcome measure in assessing medical interventions and in evaluating the organization of health care services for people with HIV/AIDS (Hughes et al., 1997; Weinberger, Oddone, Samsa, & Landsman, 1996).

Satisfaction with Care

Satisfaction with care is the individual’s attitude about the degree to which health services exist and meet the individual’s wants and needs (DiTomasso & Willard, 1991). Satisfaction with care represents the collaboration between patient and health care provider around the common goal of maintaining optimum health-related quality of life. Satisfaction is the patients’ perception of the medical institution’s ability to provide services, such as case management, dental services, mental health and addiction services, and medication assistance.

Community-Based AIDS Service Organizations

Assuring health-related quality of life and satisfaction with care are particularly important to community-based AIDS service organizations. Community-based AIDS
service organizations are private, not-for-profit organizations that provide free or reduced cost, primary health care services to individuals with HIV-infection. The majority of the community-based AIDS service organizations started out as grassroots organizations. Community-based AIDS service organizations now receive Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funding, this support increases the availability of primary health care and support services, reduces utilization of more costly inpatient care, increases access to care for underserved populations, and improves the quality of life of those affected by HIV/AIDS. The Ryan White CARE Act is composed of five different programs (HIV/AIDS Bureau, 1999).

Uninsured and under insured individuals seek medical care at these community-based AIDS service organizations. Individuals with limited or no insurance are not able to afford the cost of medical care or the cost of the medications. The yearly cost of highly active antiretroviral agents (HAART) can range from approximately $12,000 to well over $15,000. Therefore, patients rely on the community-based AIDS service organizations to assist them with obtaining medications and other services like case management and housing.

The demographics of individuals with HIV-infection have changed drastically since the late 1980’s when the majority of the community-based AIDS service organizations were established. In the 1980’s, the HIV-infected population consisted of mostly white men who had sex with men (MSM). Now, in the third decade of the epidemic, the second wave of the HIV/AIDS population consists of minorities, women, heterosexuals, incarcerated persons, and intravenous drug users. However, there has recently been an increase in the infection rate among young adult and adolescent men who have sex with men. This new cadre of
individuals, people in the second wave of HIV/AIDS, have an array of wants and needs that are different from the classic case, white men who have sex with men. These wants and needs include mental health and addiction services, housing, vocational rehabilitation, drug assistance, transportation, and childcare services (Katoff, 1992; Kawata & Andriote, 1988).

The community-based AIDS service organizations need to change with the population and disease demographics to assist with health-related quality of life and satisfaction with care of patients. If the community-based AIDS service organizations are not able to meet or exceed these expected outcomes, unsatisfied patients will seek services elsewhere and the organizations will risk losing Ryan White CARE Act funding due to the decline in patient numbers.

Problem Statement

What factors influence health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization?

Conceptual Framework

Health-Related Quality of Life

Wilson and Cleary's (1995) health-related quality of life conceptual model is a taxonomy of patient outcomes. This model categorizes and measures patient outcomes according to the underlying health concepts they represent and proposes specific causal relationships between different health concepts, thereby integrating biomedical and social science paradigms. Wilson and Cleary's (1995) measures of health exist on a continuum of increasing biological, social, and psychological complexity. The conceptual model of patient outcomes is composed of the following dimensions: (a) biological and physiological factors; (b) symptom status; (c) functional status; (d) general health perceptions; and (e)
overall quality of life. There are two external factors involved in this model: (a) characteristics of the individual, and (b) characteristics of the environment. Refer to Figure 1 for diagram of the conceptual model.

Figure 1. Health-Related Quality of Life: A conceptual model of patient outcomes


The assessment of biological and physiological factors focuses on the function of cells, organs, and organ systems. Examples include: (a) diagnoses such as pulmonary tuberculosis, or small cell lung cancer; (b) laboratory values such as serum hemoglobin or creatinine; and (c) physical findings such as a systolic ejection murmur (Wilson & Cleary, 1995).

Symptom status focuses on the organism as a whole. Symptoms are classified as physical and psychophysical and are defined as the patient’s report of abnormal physical, emotional, or cognitive states (Wilson & Cleary, 1995).
Functional status assesses the ability of the individual to perform particular, defined tasks. Four domains of functional status are measured: (a) physical function; (b) social function; (c) role function; and (d) psychological function (Wilson & Cleary, 1995).

General health perceptions are, by definition, subjective ratings. These perceptions are among the best predictors of use of general medical and mental health services and are strong predictors of mortality (Wilson & Cleary, 1995). Overall quality of life is the respondent’s subjective well being with general measures of how happy and/or satisfied he or she is with life as a whole (Wilson & Cleary, 1995).

Characteristics of the individual are distinguishing traits, qualities, or identities of a human being. Characteristics of the environment are a conglomerate of external conditions that influence the life of human beings or are influenced by their decisions (Sousa, 1999: Wilson & Cleary, 1995).

**Patient Satisfaction**

Ware, Davies-Avery and Stewart’s (1978) taxonomy of patient satisfaction addresses the multidimensional phenomena associated with patient satisfaction. The taxonomy of patient satisfaction provides detailed information of the following dimensions for medicine: art of care, technical quality of care, accessibility/convenience, finances, physical environment, availability, efficacy, and continuity. Greeneich, Long and Miller (1992) applied Ware’s taxonomy of patient satisfaction to nursing practice. They believed that four out of the eight dimensions emerge and are directly related to nursing practice across all clinical settings: art of care, technical quality of care, physical environment, and efficacy. Greeneich and associates (1992) also believed that the four remaining dimensions are related to medical care.
Art of care focuses on the nature of caring shown to the patient. It is the health care provider's behavior and response to the patient's health care needs (Greeneich et al., 1992; Ware et al., 1978). The personality of the health care provider influences the patient's perception about the amount and quality of care that he or she receives. Ware and his associates (1978) believed that behaviors and attributes, that are perceived to be positive, are associated with the art of care as friendliness, patience, and sincerity. Health care providers, who present with positive attributes, will have a positive impact on patients' perception of quality of care.

Technical quality of care or competence encompasses the patient's perception of the health care provider's knowledge and practice standards (Greeneich et al., 1992; Ware et al., 1978). Accessibility and convenience are concepts that health care providers are very familiar with. Accessibility of health care providers is enhanced when patients are provided with phone numbers or pager numbers that enable them to contact their health care provider(s).

Availability of the health care provider is crucial for patients when they are having acute medical problems or issues. Patients want to be seen by a health care provider when they feel that it is important to their health status. The majority of the time, patients want to be seen the day that they experience an acute medical problem or issue. Health care providers need to be flexible with their schedules to accommodate walk-ins or acute medical problems.

Finances apply to the cost effectiveness of a health care provider. Cost effectiveness is associated with increased revenues for the institution and lower expenses for the patient. Health care providers need to manage patients in a holistic model, which can lead to lower
costs. The holistic model allows the health care provider to provide both primary care, preventative health care, and psychosocial interventions. Preventative health care helps patients maintain up-to-date immunizations and participation in health screening procedures (examples: self breast exams, routine pap smears, and colon-rectal cancer screenings). Application of the holistic model can lead to decreased utilization of the emergency department.

Physical environment, the atmosphere and environment of the clinic, sets the tone and mood for the patient's medical appointment. Physical environment includes the general atmosphere of clinical setting, temperature, lighting, and cleanliness (Greeneich et al., 1992; Ware et al., 1978).

Efficacy is probably the main driving force behind patient satisfaction. Efficacy is the health care provider's ability or capability to improve the health status of the patient (Greeneich et al., 1992; Ware et al., 1978). The health care provider's lack of competence, dependence, and limited authority or control in the practice setting can hinder efficacy (Greeneich et al., 1992).

Continuity of care is the final important dimension to patient satisfaction. Patients want to have one health care provider who is familiar with their health management and maintenance. Health care providers need to function as primary care providers who meet this need for continuity of care. Continuity of care occurs when the patient sees the same health care provider at all medical appointments and during hospital stays. The primary care provider remains in contact or is involved in the patient's medical management during hospitalization and upon discharge.
Purpose

The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables (age, education level, and time since HIV diagnosis) that influence health-related quality of life and satisfaction with care among this population.

Research Questions

1. What is the health-related quality of life for adults who receive care at a community-based AIDS service organization?

2. How satisfied with care are adults who receive care at a community-based AIDS service organization?

Hypotheses

Hypothesis 1

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on the health-related quality of life for adults receiving care at a community-based AIDS service organization.

Hypothesis 2

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on satisfaction with care for adults receiving care at a community-based AIDS service organization.
Hypothesis 3

There would be a positive relationship between health-related quality of life and satisfaction with care for adults receiving care at a community-based AIDS service organization.

Definition of Terms

Health-Related Quality of Life

For the purpose of this study, health-related quality of life is theoretically defined as the dimensions of physical functioning, social functioning, role functioning, mental health, and general health perceptions. Measures of health exist on a continuum of increasing biological, social, and psychological complexity (Wilson & Cleary, 1995).

For the purpose of this study, health-related quality of life is operationally defined as the subjects’ overall scores on the HIV Overview of Problems-Evaluation Systems (HOPES) survey (Schag, Ganz, Kahn & Petersen, 1992).

Satisfaction with Care

For the purpose of this study, satisfaction with care is theoretically defined as an individual’s attitude about health services received and the extent to which these services meet individual wants and needs (DiTomasso & Willard, 1991).

For the purpose of this study, satisfaction with care is operationally defined as the subjects’ overall scores on the DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ) (DiTomasso & Willard, 1991).

Adult

For the purpose of this study, adult is theoretically defined as one who is fully developed and matured and who has attained the intellectual capacity and the emotional and
psychological stability characteristic of a mature person. A person who has reached full legal age (Anderson, 1994).

For the purpose of this study, adults are operationally defined as individuals who (a) are 18 years of age or older; (b) have documented positive enzyme-linked immunosorbent assay (ELISA) and western blot tests for HIV-1 or 2 virus in their medical records; (c) read and speak English; (d) have a Karnofsky score of 80 or higher; and (e) have attended a minimum of four primary health care appointments at one of the community-based AIDS service organizations regional clinics.

Karnofsky score is a means to clinically estimate a patient's physical state, performance, and prognosis. The scale is from 100, perfectly well, to 0, dead. It has been used in studying cancer and chronic illness (Thomas, 1997).

Community-Based AIDS Service Organization

For the purpose of this study, a community-based AIDS service organization is theoretically defined as an organization that provides medical or support services, primarily or exclusively, to populations infected with and affected by HIV disease (HIV/AIDS Bureau, 1999).

For the purpose of this study, a community-based AIDS service organization is operationally defined as a private-not-for-profit health care organization located in the Mid-Atlantic metro area. This clinic provides primary medical care and support to HIV-infected adults and receives Ryan White CARE Act funding.

Significance of the Study

The measurement of outcomes such as health-related quality of life and satisfaction with care are key elements that can be used to evaluate therapeutics, clinical management
strategies, the general health of the patient population, organizational performance, and the impact or effect of health care policies. Therefore by incorporating these outcomes measurements in the evaluation of competing therapies and organizational structures, there is a better understanding of the effectiveness of patient care delivery. Based on available resources, researchers, administrators, and clinicians can determine optimal strategies for delivering health-related quality of life and enhancing satisfaction with care at community-based AIDS service organizations (Sousa, 1999). Research conducted at community-based AIDS service organizations could provide valuable data on an understudied population, one that is uninsured, under insured, and representative of minorities and intravenous drug users.

Assumptions of the Study

1. Health-related quality of life could be determined at or after the fourth medical visit among this disease population.

2. Satisfaction with care could be determined at or after the fourth medical visit among this disease population.

3. Patients with HIV-infection would have sufficient knowledge about their disease and medical management at or after the fourth medical visit.

4. Subjects would answer the questionnaires truthfully and to the best of their ability.
The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables (age, educational level, and time since HIV diagnosis) that influence health-related quality of life and satisfaction with care.

To address the purpose of this study, the review of the literature is divided into six sections. The first section focuses on the natural history of HIV/AIDS. The second section addresses the emergence, services, and funding of community-based AIDS service organizations. The third section discusses the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The fourth section describes the Department of Health and Human Services’ (DHHS) guidelines for the use of antiretroviral agents in adults and adolescents. The fifth section focuses on health-related quality of life research in both the general and the HIV/AIDS population. The sixth section addresses satisfaction with care research in both the general and the HIV/AIDS population.

The Natural History of HIV/AIDS

June 05, 2001 marked the 20th anniversary of the first published reports of patients with AIDS in the CDC’s Morbidity and Mortality Weekly Report (MMWR). This section of the review of literature will reflect on the extraordinary and brief natural history of HIV/AIDS.

Acute Infection

The acute infection syndrome generally develops 2 to 4 weeks following initial exposure to HIV, although incubation periods of 6 days to 6 weeks have been reported.
The most common presenting signs and symptoms, seen in the acute infection syndrome, similar to the features typical of infectious mononucleosis-like or flu-like syndromes, are fever (96%), lymphadenopathy (74%), pharyngitis (70%), rash (70%), myalgia and arthralgia (54%), diarrhea (32%), nausea and vomiting (27%), hepatosplenomegaly (14%), weight loss (13%), thrush (12%), and neurological symptoms (12%) (CDC, 2001b; Libman, 1992; Sheppard & Ascher, 1992; Vergis & Mellors, 2000).

Physical examination may be unremarkable or reveal regional or generalized lymphadenopathy, a maculopapular rash, tender hepatomegaly, or evidence of meningeal irritation. Laboratory evaluation may show an elevated erythrocyte sedimentation rate, decreased lymphocyte count, and elevated liver function tests (Libman, 1992).

### Chronic Infection

Progression of HIV-infection is characterized by gradual decline of CD4 cell count, approximately 50 to 75 cells per year, and increasing viremia. The absolute CD4 cell count has traditionally been used as the indicator of immunological disease progression. (Vergis & Mellors, 2000). Patients are usually asymptomatic during this period of chronic infection, especially with a CD4 cell count greater than 500/mm³. Symptoms, that are an exception to this pattern, include mild to moderate lymphadenopathy and exacerbation of dermatological conditions, such as psoriasis or recurrent herpes simplex.

Patients with CD4 cell counts between 500/mm³ and 200/mm³ may develop the following symptoms such as oral candidiasis (thrush), recurrent herpes simplex, varicella zoster (shingles), and pulmonary tuberculosis (Libman, 1992). Patients with these CD4 cell counts are classified as having mild disease.
End-Stage or AIDS

Patients, with a CD4 cell count less than 200/mm$^3$ or CD4 % less than 14, have advanced immunodeficiency and are classified as having AIDS by the 1993 CDC definition (Table 1). End-stage AIDS is classified as a CD4 cell count less than 50/mm$^3$. Currently, the median incubation period from infection to AIDS is estimated to be between 8 to 10 years (Libman, 1992; Royce, Luckmann, Fusaro, & Winkelstein, 1991; Sheppard & Ascher, 1992; Vergis & Mellors, 2000). Certain opportunistic infections including Pneumocystis carinii pneumonia (PCP), Toxoplasmosis of the brain, and Non-Hodgkin's lymphoma are seen during this stage (Refer to Table 2).

Table 1

CDC's 1993 Revised Classification System for HIV-Infection

<table>
<thead>
<tr>
<th>CD4 CELL CATEGORIES</th>
<th>(A) ASYMPTOMATIC, ACUTE HIV</th>
<th>(B) SYMPTOMATIC</th>
<th>(C) AIDS-INDICATOR CONDITIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD4 cell &gt;500/mm$^3$ (1)</td>
<td>A1</td>
<td>B1</td>
<td>C1</td>
</tr>
<tr>
<td>CD4 cell 200-499/mm$^3$ (2)</td>
<td>A2</td>
<td>B2</td>
<td>C2</td>
</tr>
<tr>
<td>CD4 cell &lt;200/mm$^3$ (3)</td>
<td>A3</td>
<td>B3</td>
<td>C3</td>
</tr>
</tbody>
</table>

Table 2

Opportunistic Infections

| Bacterial infections, multiple or recurrent (child <13 years old) |
| Candidiasis of esophagus or bronchopulmonary tract |
| Cervical cancer, invasive |
| Coccidioidomycosis, disseminated |
| Cryptococcosis, extrapulmonary |
| Cryptosporidiosis, chronic |
| Cytomegalovirus infection, disseminated |
| Herpes simplex virus infection, chronic mucocutaneous or visceral |
| HIV encephalopathy |
| HIV wasting syndrome |
| Histoplasmosis, disseminated |
| Isosporiasis, chronic |
| Kaposi’s sarcoma |
| Lymphoma of the brain, primary |
| Lymphoma, undifferentiated non-Hodgkin’s |
| Lymphoid interstitial pneumonitis (child <13 years old) |
| Mycobacterial disease, atypical/disseminated |
| Nocardiosis |
| Pneumocystis carinii pneumonia |
| Pneumonia, recurrent |
| Progressive multifocal leukoencephalopathy |
| Salmonella septicemia, recurrent |
| Strongyloidosis, extraintestinal |
| Toxoplasmosis of the brain |
| Tuberculosis, extrapulmonary and pulmonary |

AIDS incidence increased rapidly through the 1980s, peaked in the early 1990s, and then declined (Figure 2). The peak of new diagnoses was associated with the expansion of the AIDS surveillance case definition in 1993. As of 1996, sharp declines were reported in AIDS incidence and deaths. From 1998 through June 2000, AIDS incidence and deaths leveled off and AIDS prevalence continued to increase (Table 3) (CDC, 2001a).

Figure 2. Estimated Incidence of AIDS, Death, and Prevalence


Table 3

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northeast</td>
<td>19,541 (38.9)</td>
<td></td>
<td>62,102 (30.7)</td>
<td></td>
<td>78,000 (30.3)</td>
<td></td>
<td>81,466 (30.8)</td>
<td></td>
</tr>
<tr>
<td>North Central</td>
<td>3,772 (7.5)</td>
<td></td>
<td>20,416 (10.1)</td>
<td></td>
<td>25,778 (10.0)</td>
<td></td>
<td>25,532 (9.7)</td>
<td></td>
</tr>
<tr>
<td>South</td>
<td>12,933 (25.7)</td>
<td></td>
<td>65,754 (32.5)</td>
<td></td>
<td>89,559 (34.8)</td>
<td></td>
<td>102,576 (38.8)</td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>13,502 (26.9)</td>
<td></td>
<td>46,303 (22.9)</td>
<td></td>
<td>55,586 (21.6)</td>
<td></td>
<td>45,574 (17.2)</td>
<td></td>
</tr>
<tr>
<td>U.S. Territories</td>
<td>524 (1.0)</td>
<td></td>
<td>7,883 (3.9)</td>
<td></td>
<td>8,812 (3.2)</td>
<td></td>
<td>8,829 (3.3)</td>
<td></td>
</tr>
<tr>
<td>Vital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living</td>
<td>2,103 (4.2)</td>
<td></td>
<td>20,572 (10.2)</td>
<td></td>
<td>96,998 (37.7)</td>
<td></td>
<td>203,192 (76.9)</td>
<td></td>
</tr>
<tr>
<td>Deceased</td>
<td>47,993 (95.5)</td>
<td></td>
<td>181,212 (89.5)</td>
<td></td>
<td>159,048 (61.8)</td>
<td></td>
<td>59,807 (3.3)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>50,280</td>
<td></td>
<td>202,520</td>
<td></td>
<td>257,262</td>
<td></td>
<td>264,405</td>
<td></td>
</tr>
</tbody>
</table>


Although the care and treatment of HIV-infection have dramatically improved with the advancements in highly active antiretroviral therapy (HAART), it is clear that AIDS is still a progressively debilitating disease in which an individual will require a diverse range and often intensive set of formal and informal services. HIV-infection is now viewed as a chronic, disabling, yet manageable, condition. Most people with HIV-infection or AIDS hope that medical treatments will improve or at least stabilize their illnesses, and with appropriate assistance, quality of life can be maintained. Assistance is generally provided by family and friends, health care providers, social service agencies, and community-based AIDS service organizations (Katoff, 1992).
Community-Based AIDS Service Organizations

Emergence of Community-Based AIDS Organizations

Community-based AIDS organizations were established in the early 1980s, in part as grassroots organizations, because of the inadequate responses of government and private institutions to meet the needs of HIV-infected individuals. No one was providing support or advocacy for persons with AIDS; no one was addressing neglect or discrimination (Katoff, 1992).

Community-based AIDS organizations were created by volunteers, most of whom were not health care providers, to address what was missing. Concerned gay men, acting as volunteers, began the initial organizations. Clearly, the emergence of these community-based AIDS organizations was an indictment of the institutions that failed to respond to the HIV/AIDS epidemic (Howell, 1991; Katoff, 1992). Community-based AIDS organizations emerged as gay men and lesbians recognized that they had to turn to each other for help in caring for those who were suffering and to define and advocate for what the government and existing institutions should do. These community-based AIDS organizations have provided a means for coping with feelings of danger and rage, for protesting against the HIV/AIDS disease, and for highlighting the inhumanity that was engendered by lack of attention (Katoff, 1992).

According to Kawata and Andriote (1988), because of the variety of needs engendered by AIDS, a broad-based response to the epidemic was warranted. The traditional medical model, with its emphasis on inpatient hospital care, is expensive and fails to address holistically the needs of people with AIDS (PWAs). An alternative model, the community-based response or continuum-of-care model, is implemented in community-
based AIDS organizations. This model builds on earlier community service models of integrated networks of service providers to meet a range of needs of people with AIDS. The continuum-of-care model incorporates other non-acute and psychosocial services offered through community-based providers, and relies, to a large extent, on volunteers.

Services of Community-Based AIDS Organizations

The goal of a continuum-of-care model can only be achieved through the involvement of community-based organizations. A range of community-based services is needed to address the unending stress of illness and disability. People with AIDS can stay in a home-like setting without an intensive level of medical care if supports are available. The intensity of community-based services is related to (a) existing social support, (b) availability of resources, (c) intensity and complexity of needs, (d) knowledge about HIV-infection, health maintenance, and resources, (e) financial resources, and (f) capacity for self-advocacy. The elements of an AIDS care continuum are (a) case management, (b) home care, (c) peer counseling, (d) support groups, (e) therapeutic recreation, (f) entitlement advocacy, (g) legal services, (h) skilled nursing facilities, (i) hospice, (j) housing, and (k) medical/dental services (Katoff, 1992; Kawata & Andriote, 1988).

The goal of care is to provide the individual with the most appropriate and least restrictive setting which supports the highest possible level of functioning. With AIDS, there are complex physical and social problems and, more significantly, the likelihood of precipitous changes in physical and emotional status. Most community-based services attempt to address a limitation or problem that has resulted from illness. The functional limitations that must be assessed can be physical, social, and psychological. A large number of non-AIDS related social problems significantly affect the lives of some individuals with

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HIV-infection and require attention. Substance abuse is certainly the most frequently encountered problem, but people may also need assistance with pre-existing psychiatric problems, inadequate housing, vocational issues, and immigration problems (Katoff, 1992).

Frequent changes in needs and health status must be anticipated and carefully monitored. The health care provider can assist patients and their caregivers in meeting these changes by providing sufficient information for them to gain access to appropriate community-based services.

Funding of Community-Based AIDS Organizations

Initially, funding for community-based AIDS organizations began as fund-raising, organized and managed by volunteers; educational campaigns were then designed and conducted by volunteers, and volunteers also provided support services and advocacy. The use of unpaid employees was the only available option for newly established community-based AIDS organizations (Katoff, 1992). Today twenty years after their inception, fund raising and private donations remain the primary source of financial support for community-based AIDS organizations. Annual fund raising events help raise AIDS awareness and money. Some examples of fund raising events are (a) AIDS walk, (b) AIDS ride, (c) AIDS marathon, and (d) AIDS benefit festivals. Donations are obtained from pharmaceutical industries, corporate donors, and private enterprise.

The Health Resources and Services Administration (HRSA) recognized the potential, positive role of community-based AIDS organizations on the service delivery system for people with AIDS. HRSA implemented a policy of expanding community-based care through a series of service demonstration grants. The HRSA grant solicitation of February 14, 1989 expresses this goal: the AIDS Service Demonstration Program is intended to
support the development and demonstration of community-based systems of care which provide the spectrum of needed services for people with HIV-infection and its complications and provide appropriate alternatives to inpatient care (Howell, 1991).

In developing its AIDS service demonstrations, HRSA hoped that the availability of public funding would stimulate more non-profit community-based organizations to develop a comprehensive out-of-hospital service delivery system for persons with AIDS (Howell, 1991). Congress, in 1990, passed and funded the Ryan White Comprehensive AIDS Resources Emergency Act that would provide the funding and support to community-based AIDS service organizations.

Community-based AIDS service organizations have had a preeminent role in defining unmet needs and required services. These organizations have challenged governmental and health authorities to act more directly to help those who need to be educated or served, to detail gaps and shortfalls in service provisions, and to correct improper treatment of persons with AIDS (Katoff, 1992).

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

Establishment of Ryan White CARE Act

The Ryan White CARE Act is intended to help communities and states increase the availability of primary health care and support services, in order to reduce utilization of more costly inpatient care, increase access to care to an underserved population, and improve the quality of life of those affected by the epidemic (HIV/AIDS Bureau, 1999). The Ryan White CARE Act dollars fund outpatient primary health care, pharmaceuticals, oral health care, mental health counseling, substance abuse treatment, and social support services such as case management and housing assistance. Vulnerable populations, defined in the legislation, include HIV-positive individuals who lack insurance or are underinsured, women, minorities, and adolescents, as well as individuals with co-morbidities such as intravenous drug use, active psychiatric illness, and/or tuberculosis. A nationally representative sample of HIV-positive adults, receiving medical care in the contiguous United States, suggests that 19% of men and 21% of women with HIV disease are uninsured (Ashman et al., 2000).

Ryan White CARE Act Programs

Briefly, the Ryan White CARE Act directs assistance through the following channels (HIV/AIDS Bureau, 1999; Valenti, 2001):

**Title I**
Eligible Metropolitan Areas (EMAs) with the largest numbers of reported cases of AIDS, to meet emergency service needs of people living with HIV disease.

**Title II**
All States, the District of Columbia, Puerto Rico, and eligible United States Territories to improve the quality, availability, and organization of health care and support services for individuals living with HIV disease and their families.

**Title III**
Public and private nonprofit entities to support outpatient, early intervention HIV services for people living with HIV disease (PLWH).
Title IV

Public and private nonprofit entities for projects to coordinate services to, and provide enhanced access to research for children, youth, women, and families with HIV/AIDS.

Part F

Special Projects of National Significance (SPNS) to support the development of innovative models of HIV/AIDS care that are designed to be replicable and have a strong evaluation component; AIDS Education and Training Centers (AETC) to conduct education and training for health care providers; and the HIV/AIDS Dental Reimbursement Program to assist accredited dental schools and postdoctoral dental programs with uncompensated costs incurred in providing oral health treatment to HIV-positive patients.

The Health Resources and Service Administration’s (HRSA) HIV/AIDS Bureau has lead responsibility for the implementation of the Ryan White CARE Act. Within the HIV/AIDS Bureau, the Division of Service Systems (DSS) administers Titles I, II, and the AIDS Drug Assistance Program (ADAP). The Division of Community-Based Programs administers Titles III, IV, and the HIV/AIDS Dental Reimbursement Program. The Division of Training and Technical Assistance (DTTA) administers the AIDS Education and Training Center (AETC) Program and technical assistance activities for the HIV/AIDS Bureau. The HIV/AIDS Bureau’s Office of Science and Epidemiology administers, Part F, the Special Projects of National Significance (SPNS) Program, and manages evaluation studies, data collection, and analysis (HIV/AIDS Bureau, 1999).
### Table 4

Flow of Funds for Ryan White CARE Act

<table>
<thead>
<tr>
<th>Title I</th>
<th>Title II</th>
<th>Title III</th>
<th>Title IV</th>
<th>Part F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Federal Grants for Emergency Relief to Eligible Metropolitan Areas</td>
<td>Federal Grants to States and Territories</td>
<td>Federal Grants for Early Intervention</td>
<td>Federal Grants to Pediatric/Family Programs</td>
<td>SPNS, AETC, and the Dental Reimbursement Program</td>
</tr>
<tr>
<td>Chief Elected Official Designates HIV Services Planning Council</td>
<td>Governor, Administrative Agent (usually the State Health Department)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Governmental Unit (often Health Department)</td>
<td>Consortia (in some States)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community-Based Organizations</td>
<td>Community-Based Organizations and Providers</td>
<td>Community-Based Organizations</td>
<td>Community-Based Organizations</td>
<td>Community-Based Organizations</td>
</tr>
<tr>
<td>Services to people living with HIV disease</td>
<td>Services to people living with HIV disease</td>
<td>Services to people living with HIV disease</td>
<td>Services to women and families living with HIV disease</td>
<td>Services to people living with HIV disease and training for health care professionals</td>
</tr>
</tbody>
</table>

Guidelines for the Use of Antiretroviral Agents

The availability of an increasing number of antiretroviral agents and the rapid evolution of new information has introduced extraordinary complexity into the treatment of HIV-infected persons. Since 1996, The Panel on Clinical Practices, convened by the Department of Health and Human Services (DHHS) and the Henry J. Kaiser Family Foundation, has developed guidelines for the treatment of HIV-infection (CDC, 2001b).

Their report recommends that care should be supervised by an expert, and makes recommendations for laboratory monitoring including plasma HIV-RNA, CD4 cell counts, and HIV drug resistance testing. The report also provides guidelines for antiretroviral therapy, including protocols for changing therapy (Refer to Table 5, p. 29). Special considerations are provided for adolescents and pregnant women. As with treatment of other chronic conditions, therapeutic decisions require a mutual understanding between the patient and the health care provider regarding the benefits and risks of treatment. Antiretroviral regimes are complex, have major side effects, pose difficulty with adherence, and carry serious potential consequences, such as the development of viral resistance due to non-adherence to the drug regime or sub-optimal levels of antiretroviral agents. Patient education and involvement in therapeutic decisions are important for all medical conditions, but are considered especially critical in HIV-infection and its treatment (CDC, 2001b).
Table 5

Indications for the Initiation of Antiretroviral Therapy in the Chronically HIV-1 Infected Patient

<table>
<thead>
<tr>
<th>Clinical Category</th>
<th>CD4 Cell Count</th>
<th>Plasma HIV RNA</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptomatic (AIDS, severe symptoms)</td>
<td>Any Value</td>
<td>Any Value</td>
<td>Treat</td>
</tr>
<tr>
<td>Asymptomatic, AIDS</td>
<td>CD4 cell &lt;200/mm³</td>
<td>Any Value</td>
<td>Treat</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>CD4 cell &gt;200/mm³ but &lt;350/mm³</td>
<td>Any Value</td>
<td>Treatment should generally be offered, though controversy exists.</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>CD4 cell &gt;350/mm³</td>
<td>&gt;30,000 (bDNA) or &gt;55,000 (RT-PCR)</td>
<td>Some experts would recommend initiating therapy, recognizing that the 3-year risk of developing AIDS in untreated patients is &gt;30%. In the absence of very high levels of plasma HIV RNA, others would defer therapy and monitor the CD4 cell count and level of plasma HIV RNA more frequently. Clinical outcomes data after initiating therapy are lacking.</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>CD4 cells &gt;350/mm³</td>
<td>&lt;30,000 (bDNA) or &lt;55,000 (RT-PCR)</td>
<td>Many experts would defer treatment and observe, recognizing that the 3-year risk of developing AIDS in untreated patients is &lt;15%.</td>
</tr>
</tbody>
</table>


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Health-Related Quality of Life

Historical Perspectives of Health-Related Quality of Life

The concept of quality of life has been an important outcome measurement in health care for many decades. The assessment of quality of life was introduced into research studies in the early 1960’s, and the health-related quality of life assessment became popular a decade later (Flanagan, 1982; Zhan, 1992). An early effort to address quality of life was made when the World Health Organization (WHO, 1947), defined health not only as the absence of infirmity and disease but also as a state of physical, mental, and social well-being (Zhan, 1992). Quality of life research has sparked a rebirth of interest among health care researchers since the 1990’s health care reform and managed care movement. Under managed care, health care providers needed to prove that their services were better or superior to their competitors, to obtain contracts. The health care reform and managed care movement also led to the development of health care policies and procedures to guide health care institutions in the way they deliver care. Quality of life is a central concern in evaluative research; improved quality of life is probably the most desirable outcome of all health care policies (Farquhar, 1995).

Assessment of health-related quality of life represents a relatively recent advance in measuring the effectiveness of medical interventions (Hughes, Kaplan, Coons, Draugalis, Johnson & Patterson, 1997). Growing interest in outcomes of health care is evident in the executive branch of government and in the Congress. It has resulted in the creation of a new office within the Public Health Service, the Agency for Health Care Research and Quality (AHRQ). The mission of this agency is to evaluate outcomes of care and to establish clinical guidelines for practice, designed to achieve optimal outcomes (Wachtel, Piette, Mor,
Stein, Fleishman & Carpenter, 1992). The standards of quality of care for particular disease processes, such as in HIV/AIDS, are founded upon the health-related quality of life clinical guidelines set for by the Agency for Health Care Research and Quality. It is these health-related quality of life clinical guidelines that assist community-based AIDS service organizations in the delivery of their medical services.

**Definition of Health-Related Quality of Life**

The definition of health-related quality of life is extremely broad with multiple dimensions. Health-related quality of life is a difficult construct to define and measure because cultural, ethical, religious and personal values influence perceptions of health-related quality of life. The definition is also influenced by the researcher's definition of the dimensions to be measured.

Conceptual clarity is extremely important because differences in meaning can lead to profound differences in outcomes for research, clinical practice, and allocation of health care resources (Ferrans, 1996). The only aspects that are uniformly agreed upon by outcomes researchers are the common dimensions of the term, health-related quality of life. The common dimensions are in some form of physical, mental, and social functioning. Hughes and his colleagues (1997) state that health-related quality of life is a multidimensional construct that generally includes the categories of physical, mental, and social functioning.

There are several researchers who have multiple dimensions that are subsets of physical, mental, and social. Such as, Zhan (1992) who states that there are a variety of terms that equate health-related quality of life with such attributes as life satisfaction, well-being, health, happiness, self esteem, adjustment, value of life, meaning of life and functional status. The key quality of life dimensions are health, function, comfort, emotional...
response and economics (Farquhar, 1995; Gough, Furnival, Schilder & Grove, 1983; Patterson, 1975). The definition of health-related quality of life needs to encompass the idea that health-related quality of life depends on the unique experience of life for each person or population being studied.

Health-Related Quality of Life in Clinical Practice

Wachtel and his colleagues (1992) stated that the primary goal of health care for patients with chronic conditions, such as in HIV/AIDS, is to maximize function and well-being in everyday life. Functional status and well-being are among the essential outcomes of medical care. Outcomes such as symptoms, daily functioning, well-being, and health-related quality of life are relevant in assessing medical care (Wachtel et al., 1992). Ferrans (1996) states that health-related quality of life has become a critically important concept for health care in recent years. Health-related quality of life considerations are significant in decisions to stop life-sustaining treatment and in debates regarding physician-assisted suicide. In clinical practice and clinical trials, health-related quality of life indicators are used to evaluate treatment in terms of human costs and benefits. Health-related quality of life has also been used to make decisions regarding allocation of health care services (Ferrans, 1996).

Zhan (1992) stated that in order to understand the phenomenal world of health-related quality of life in the field of health and illness, some nursing researchers have sought to study a person in context. Meaning, which denotes how a person perceives his or her sense of well-being and life in relation to his or her situation, is an important consideration in the study of the health-related quality of life. Meeberg (1993) notes from a review of literature, four critical attributes of health-related quality of life: (a) a feeling of satisfaction
with one's life in general, (b) the mental capacity to evaluate one's own life as satisfactory or otherwise, (c) an acceptable state of physical, mental, social and emotional health as determined by the individual referred to, and (d) an objective assessment by another that the person's living conditions are adequate and not life threatening.

The measurement of outcomes are key elements that can be used to evaluate therapeutics, clinical management strategies, the general population's health status, organizational performance, and health care policy. By incorporating the measurement of outcomes in the evaluation of competing therapies and organizational structures, researchers, administrators, and clinicians can determine optimal strategies for quality patient care based on available resources (Sousa, 1999).

Current Research in HIV Health-Related Quality of Life

Health-related quality of life research in the area of HIV/AIDS became popular in the early 1990s. Increased life expectancy for HIV-infected patients makes quality of remaining life a critical element (Wachtel et al., 1992). The issue of health-related quality of life continues to be of a growing interest among all health care providers of HIV-infected individuals. During the 1990's, attention to health-related quality of life issues became an essential part of conducting clinical trials on HIV-infected individuals. The Food and Drug Administration required that all pharmaceutical companies incorporate some form of health-related quality of life questionnaires in their Phase II and Phase III clinical trials. Once the Food and Drug Administration made this requirement, there was a significant amount of research in developing a disease specific health-related questionnaire for the HIV/AIDS population.
Many studies have reported information about health-related quality of life in patients with HIV-infection, but these data have generally been gathered from clinical trials or regional samples where women or ethnic minorities were under represented (Bing et al., 2000; Cleary et al., 1993; Hays et al., 2000; Watchel et al., 1992). A study, of 2,295 men who have sex with men, enrolled in the Multi-Center AIDS Cohort Study, reported that the physical health of symptomatic HIV-infected patients was significantly worse than that of the general United States population. The physical health of symptomatic HIV-infected patients was also significantly worse than that of asymptomatic HIV-infected patients (Bing et al., 2000; Hays et al., 2000). Wu and his associates (1991) discovered that the scores of asymptomatic HIV-infected individuals' were higher on most subscales than the age-adjusted scores of a Medical Outcomes Study (MOS) of outpatients with hypertension, diabetes, recent myocardial infarction, or depression. Symptomatic HIV-infected individuals scored closest to hypertensive patients.

Previous studies have found inconsistent associations between demographic variables and health-related quality of life in the HIV/AIDS population. Lower income, public insurance, and older age were associated with significantly worse health-related quality of life in 1,193 patients enrolled in Multi-Center AIDS clinical trials (Bing et al., 2000; Hays et al., 2000). However, the same associations were not seen among 205 patients receiving care for HIV-infection at two Los Angeles public hospitals (Cunningham, Bozzette, Hays, Kanouse, & Shapiro, 1995; Hays et al., 2000). In the United States, African-Americans and Latinos were more likely than whites to report limitations in physical functioning (Fleishman & Crystal, 1998; Hays et al., 2000). O’Keefe and Wood (1996) studied 134 HIV-infected outpatients in South Africa; and reported that patients of
mixed race had poorer physical function than whites or blacks. Similarly in the United States, an AIDS Clinical Trial Group (ACTG) study found that whites had significantly greater physical and social functioning, but lower perceived health than African-Americans and Latinos (Hays et al., 2000; Lenderking, Testa, Katzenstein & Hammer, 1998). Kemppainen's (2001) study of 162 hospitalized patients with AIDS reported that the strongest predictor of decreased quality of life scores was depression. Depression accounted for 23% of the variance, with symptoms of HIV-infection accounting for 9.75% and female gender accounting for an additional 8%. Two measures of patient engagement with nursing care providers contributed a total of 13.44% of the variance in quality of life scores.

It is clear from research and clinical observations, that physical health declines with progression of HIV disease and that an increase in the number of symptoms is associated with poorer health-related quality of life. However, there is still limited understanding of the influence of clinical stage, CD4 cell count, and symptoms on health-related quality of life (Hays et al., 2000). Patients, who were symptomatic or had lower CD4 cell counts, reported lower health-related quality of life scores compared to patients who were asymptomatic and had higher CD4 cell counts (Wu et al., 1991; Wachtel et al., 1992; Schag et al., 1992; Ganz et al., 1993). However, medical and demographic variables explained only 35% of the variability of health-related quality of life ratings in a sample of 318 HIV-infected patients in the Los Angeles and Baltimore areas (Ganz et al., 1993). Table 6 summarizes selected HIV health-related quality of life research.
Table 6

Summary of Selected HIV Health-Related Quality of Life Research

<table>
<thead>
<tr>
<th>Study</th>
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</thead>
</table>
| Wu, Rubin, Mathews, Ware, Brysk, Hardy,   | University of California, San Diego and Los Angeles AIDS Clinical Trials| Test reliability and validity of adding 30-items to the Medical Outcome Study (MOS). | Randomized controlled clinical trials (one point in time measurement). | 117 subjects:  
73 asymptomatic HIV-infected individuals (97% men)  
44 symptomatic with early AIDS individuals (98% men)  
CD4 cell counts 200-800 | Asymptomatic subjects scored higher, reported superior overall health, less pain, and better QoL than the symptomatic subjects. | Nonlongitudinal  
Subjects, mostly men, enrolled in a clinical trial rather than a community-based random sample, and.  
Not able to generalize the findings. |
| Bozzette, Spector, & Richman, 1991         | Units.                                                                 |                                                                      |                                                      |                               |                                                                         |                                                  |
| Wachtel, Piette, Mor, Stein, Fleishman,    | Nine community-based organizations and hospitals.                      | Assess the reliability and validity of the Medical Outcomes Study Short Form (MOS-SF). | Patient interview survey: conducted between November 1988 and April 1989. | 520 subjects with HIV-infection:  
Men (89%)  
Nonwhite (39%)  
IVDUs (34%) | MOS-SF is a reliable measure of QoL.  
Symptoms were the strongest or adjusted indicator of lower QoL. | Nonlongitudinal  
Majority of the subjects were white males.  
Not able to generalize the findings. |
| Carpenter, 1992                            |                                                                       |                                                                      |                                                      |                               |                                                                         |                                                  |

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| Schag, Ganz, Kahn, & Petersen, 1992 | Medical Centers, community physicians, VA Medical Centers, and County hospitals in Los Angeles and Baltimore. | To develop and evaluate the reliability and validity of the HOPES questionnaire. | Cross-sectional surveys and interviews: conducted between November 1990 and March 1992. | 318 subjects:  
Asymptomatic (37%): CD4 cell counts 294-433  
Symptomatic (20%): CD4 cell counts 268-320  
AIDS (25%): CD4 cell counts 155-336  
Males (96%)  
Nonwhite (28%) | HOPES questionnaire is a reliable and valid tool to assess QoL.  
Medical and demographic variables explain 35% of HRQoL. | Nonlongitudinal  
Majority of the subjects were white males.  
Not able to generalize the findings. |
| Ganz, Schag, Kahn, Petersen, & Hirji, 1993 | Medical Centers, community physicians, VA Medical Centers, and County hospitals in Los Angeles and Baltimore. | To develop and evaluate the reliability and validity of the HOPES questionnaire. | Cross-sectional surveys and interviews: conducted between November 1990 and March 1992. | 318 subjects:  
Asymptomatic (37%): CD4 cell counts 294-433  
Symptomatic (20%): CD4 cell counts 268-320  
AIDS (25%): CD4 cell counts 155-336  
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Majority of the subjects were white males.  
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<tr>
<td>Cleary, Fowler, Weissman, Massagli, Wilson, Seage, Gatsonis, &amp; Epstein, 1993</td>
<td>Three academic group practices based at a private teaching hospital; ambulatory care clinic at a public teaching hospital and HMO in the Boston area.</td>
<td>To develop and evaluate the reliability and validity of assessing symptoms and functioning of HIV-infected individuals.</td>
<td>Face to face interview: conducted between February 1989 and February 1990.</td>
<td>189 subjects with AIDS</td>
<td>Fatigue, functional status, and average severity of all symptoms were the best predictors of overall perceived health status. Psychological well-being and perceived health status were the best predictors of overall perceived health status. Psychological well-being and perceived health status were the strongest correlates of life satisfaction.</td>
<td>Instrument excludes several aspects of HRQoL. Small sample size and limited to the Boston area. Not able to generalize the findings.</td>
</tr>
<tr>
<td>Cunningham, Bozette, Hays, Kanouse, &amp; Shapiro, 1995</td>
<td>County hospitals and VA Medical Center in Los Angeles.</td>
<td>To determine the association between access to medical care and QoL.</td>
<td>Cross-sectional study: conducted between September 1991 and June 1993.</td>
<td>205 subjects: Low income and symptomatic CD4 cell counts 20-189</td>
<td>Uninsured subjects reported worse access to medical care and QoL.</td>
<td>Nonlongitudinal All subjects receiving some form of medical care. Not able to generalize the findings.</td>
</tr>
</tbody>
</table>

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<tbody>
<tr>
<td>Lenderking, Tesu, Katzenstein, &amp; Hammer, 1998</td>
<td>Multi-centers involved in the AIDS Clinical Trials Group (ACTG).</td>
<td>To examine the reliability and validity of the General Health Self-assessment questionnaire.</td>
<td>Randomized ACTG 175, four-arm trial:</td>
<td>1,694 subjects with early HIV-infection enrolled in the ACTG 175.</td>
<td>Worse QoL was associated with recent hospitalization and symptomatic status.</td>
<td>Nonlongitudinal All subjects in a clinical trial. Not able to generalize the findings.</td>
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<td>(1) AZT monotherapy</td>
<td>White-men (89.9%)</td>
<td>Prior antiretroviral therapy was associated with higher health perceptions and well-being.</td>
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<td>(2) ddI monotherapy</td>
<td>Black-men (62.4%)</td>
<td>Women showed lower QoL than men on all scales.</td>
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<td>(3) AZT + ddI</td>
<td>Hispanic-men (70.5%)</td>
<td>Ethnicity was related to difference in health perceptions, physical, and psychological functioning.</td>
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<td>(4) AZT + ddC</td>
<td>Men (83.2%)</td>
<td>General Health Self-assessment shows excellent potential as a measure of QoL for HIV-infected individuals in clinical trials.</td>
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<td></td>
<td>Females (16.8%)</td>
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<td></td>
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<td></td>
<td>CD4 cell counts 200-500</td>
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<td></td>
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<td></td>
<td>No history of AIDS-defining illnesses</td>
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<tbody>
<tr>
<td>Fleishman &amp; Crystal, 1998</td>
<td>26 providers in 10 cities across the United States.</td>
<td>To examine the prevalence of limitations in physical functioning and patterns of change in functional status with time in HIV-infected individuals.</td>
<td>Cross-sectional interview: every 3 months during 18-months between March 1991 to August 1992.</td>
<td>1,784 adults with HIV-infection involved in the AIDS Costs and Service Utilization Survey.</td>
<td>Limitation was most prevalent for vigorous activities (55%), and least prevalent for ADLs (12%).</td>
<td>One year period of observation, results may be different if longitudinal. Declines in functioning were related to developing of AIDS. African-Americans and Hispanics more likely to report limitations in physical functioning.</td>
</tr>
</tbody>
</table>

| Bing, Huys, Jacobson, Chen, Gange, & Kass, 2000 | Medical Centers in Baltimore, Chicago, Los Angeles, and Pittsburgh. | To examine the natural history of HIV-infection on QoL. | Longitudinal observational study conducted between April 1984 and October 1994. | 2,295 gay and bisexual men without AIDS. | Asymptomatic subjects had similar perceived mental health but worse perceived physical health than seronegative men. | The sample was a convenience sample of gay and bisexual men who were relatively very well educated, primarily white, and older. Not able to generalize the findings. |

CD4 cell count ranges: 
- >500
- 200-499
- <199
Table 6

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<tbody>
<tr>
<td>Kemppainen, 2001</td>
<td>Seven sites in California and southern Florida.</td>
<td>Identify factors that influence or enhance QoL.</td>
<td>Cross-sectional</td>
<td>A convenient sample of 162 AIDS hospitalized subjects:</td>
<td>Depression accounted for 23% of the variance; symptoms accounted for 9.75%; female gender accounted for an additional 8% for a decreased QoL.</td>
<td>Subjects were acutely ill and hospitalized. Not able to generalize findings.</td>
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<td>Males (65%)</td>
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<td>Females (35%)</td>
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<td>CD4 cell counts 1-582</td>
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<tr>
<td>Hays, Cunningham, Sherbourne, Wilson, Wu, Cleary, McCaffrey, Fleishman, Crystal, Collins, Eggn, Shapiro, &amp; Bozette, 2000</td>
<td>Health care systems in the contiguous USA (excluding military hospitals, prisons, or emergency rooms).</td>
<td>Compare HRQoL of adults with HIV with that of the general population and other chronic conditions; and to determine the associations of demographic variables and disease severity on HRQoL.</td>
<td>Cross-sectional survey conducted between January 5 and February 29, 1996.</td>
<td>Probability sample of 2,864 HIV-infected adults. CD4 cell counts 0-500</td>
<td>Physical functioning about the same for asymptomatic adults as for US population, worse for adults that are symptomatic or have AIDS. AIDS subjects had worse physical functioning than those with other chronic diseases. Emotional well-being was comparable among subjects with various stages of HIV disease, but was significant worse than the general population and for subjects with other chronic diseases except depression. HIV-related symptoms were strongly associated with physical and mental health. Race, sex, insurance status, disease stage, and CD4 count were at most weakly associated with physical and mental</td>
<td>Nonlongitudinal Causal relations are limited. Measured at one time period. Not able to generalize findings.</td>
</tr>
</tbody>
</table>
Satisfaction with Care

Definition of Satisfaction with Care

Patient satisfaction has become an increasingly important variable in all aspects of health care delivery. This was particularly true in the 1990s with health care reform and the managed care movements. Patient satisfaction has become a tool to measure quality of medical care provided by institutions or health care providers. Because the health care market has become competitive, institutions and health care providers want to ensure the highest level of patient satisfaction to maintain and expand their patient base (Abramowitz, Cote, & Berry, 1987).

Patient satisfaction is a multidimensional phenomena because there is no one definition or factor that influences how a patient will perceive his or her health care services. DiTomasso and Willard (1991) state patient satisfaction refers to an individual's attitude about health services received and the extent to which these services meet the person's wants and needs. Patient satisfaction has become a means to evaluate accountability for customer services among the health care professions. Pascoe (1983) characterized patient satisfaction as the emotional and cognitive reaction to a specific health care experience. This reaction is internal, unique to the individual, and manifested by observable behaviors. Patient satisfaction results when there is a match between expected care and care received. Petersen (1988) describes patient satisfaction as the patient's perception of how care was delivered. Thus, patient satisfaction results from a subjective judgment about each individual nursing and or medical interaction. Cleary and McNeil (1998) explain patient satisfaction in terms of patient health values. Understanding the patient health value system may be an important adjunct to the assessment of patient satisfaction.
Patient Satisfaction with Care in Clinical Practice

Studies of patient satisfaction with care in clinical practice have been aimed at determining the effectiveness between nurse practitioners and physicians in primary care. Marsh (1999) stated that patient satisfaction with care in clinical practice is a subjective evaluation of health care providers and services that capture a personal evaluation of care that cannot be known by observing care directly. Expressions of satisfaction or dissatisfaction represent the patient’s judgment on the quality of care received. Patient satisfaction with care is fundamental to quality of care because it provides information on the provider’s success at meeting patient expectations on matters in which the patient is the ultimate authority. Therefore, patient satisfaction with care in clinical practice is often conceptualized as the congruence between the patients’ expectations of health care providers and the perceptions of the actual care received.

Mundinger, et al. (2000) compared outcomes for patients randomly assigned to nurse practitioners or physicians for primary care follow-up and ongoing care after emergency department or urgent care visits. The study described an ambulatory care situation in which patients were randomly assigned to nurse practitioners or physicians. The nurse practitioners had the same authority, responsibilities, productivity, administrative requirements, and patient population as primary care physicians. In this study, there were no significant differences found in patients’ health status or satisfaction ratings following the initial appointments. However, patients with hypertension who were seen by a nurse practitioner showed diastolic values that were significantly lower.

Several other studies have looked at patient satisfaction with nurse practitioners. Larrabee, Ferri, and Hartig (1997) studied nurse practitioners at four primary care clinics in
a government hospital in the south-central United States. The nurse practitioners provided care to nonurgent patients. Overall, patients were satisfied with the nurse practitioners' health care delivery, and written patient complaints decreased by 56% after implementation of nurse practitioners. Ramsay, McKenzie, and Fish (1982) compared 40 patients attending a hypertension clinic staffed by physicians to 40 patients attending a hypertension clinic staffed by nurse practitioners. Overall, there were no significant differences found in patients' overall satisfaction ratings. However, the nurse practitioners showed statistically significant scores in handling obesity and achieving better control of hypertension.

Sullivan (1982) summarized the outcomes of patient satisfaction studies that compared nurse practitioners and physicians. Nurse practitioners continue to show an uncanny ability not only to provide primary care equivalent to that of physicians, but also to offer something special that increases adherence to medications and medical appointments, decreases symptoms, lessens the use of prescription drugs, and decreases the use of hospital days.

Current Research in HIV Patient Satisfaction with Care

The review of the current literature was limited to the HIV patient population that is most studied, white men who have sex with men, because studies that included minorities and intravenous drug users had small sample sizes. Men who have sex with men, who had no insurance or public insurance, were significantly less satisfied with care than patients with private insurance (Stein, Fleishman, Mor, & Dresser, 1993). Stone, Weissman, and Cleary (1995) also identified that patients with lower self perceived health status had lower health-related quality of life scores.
Patient satisfaction has been found to influence adherence to treatment plans, utilization of health services, continuity of care, and presumably, health status (Stein et al., 1993). Patient satisfaction is also of concern because studies have shown that satisfied patients are more likely to comply with treatment regimes and therefore should be more likely to have good outcomes (Larrabee et al., 1997). The issue of adherence to treatment regimes is extremely important to HIV/AIDS patients. Strict adherence to the prescribed, highly active antiretroviral therapy (HAART) is necessary to suppress HIV viral replication and prevent drug resistance. Health care providers, who can provide optimal and effective medical management to HIV-infected individuals, can increase patient's adherence and reduce the complications due to opportunistic infections.

Langner and Hutelmyer (1995) compared patient satisfaction as delivered by nurse practitioners and physicians in an urban medical teaching clinic. Overall, satisfaction with patient care was high. When nurse practitioners were compared with physician providers, however, nurse practitioners fared more favorably in the areas related to clinic waiting time, provider knowledge about the disease, continuity of care, and patient education. Aiken, et al. (1993) conducted a similar study at a university hospital outpatient clinic. Overall, nurse practitioners' patients functioned at comparable levels and used no more health care services than physicians' patients; patients reported 45 % fewer problems with their care; patients were three times as likely to report their health status as only fair or poor; and reported significantly more unpleasant symptoms over a four-week period. Nurse practitioners' patients were in poorer health that the physicians' patients.

Studies have shown that gender, age, education, and race have little relationship to patient satisfaction (Beck et al., 1999; Stein et al., 1993). A few selected studies reported
that minorities and intravenous drug users had lower scores on their satisfaction with care scales (Stein et al., 1993; Stone et al., 1995; Wachtel et al., 1992; Wu, Revicki, Jacobson, & Malitz, 1997). These concepts are extremely crucial when managing individuals with HIV-infection. Patient dissatisfaction has been associated with poor physical health, lack of access to care, poor accessibility of the health care provider, and inadequate knowledge of the health care provider about disease processes. Patient's expectations of the health care provider or institution form the context within which satisfaction and dissatisfaction must be assessed (Oberst, 1984). Table 7 summarizes selected HIV patient satisfaction research.
Table 7

Summary of Selected HIV Patient Satisfaction Research

<table>
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<tr>
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<tr>
<td>Wachtel, Piette, Mor, Stein, Fleishman, &amp; Carpenter, 1992.</td>
<td>Nine community-based organizations and hospitals.</td>
<td>Assess the reliability and validity of the Medical Outcomes Study Short Form (MOS-SF).</td>
<td>Patient interview survey: conducted between November 1988 and April 1989.</td>
<td>520 subjects with HIV-infection: Men (89%)</td>
<td>Global satisfaction with care scores: IVDUs had lower scores than nonusers. Lower educational level was associated with lower scores. Minorities and women had lower scores.</td>
<td>Nonlongitudinal Majority of the subjects were white males. Not able to generalize the findings.</td>
</tr>
<tr>
<td>Aiken, Lake, Semaan, Lehman, O'Hare, Cole, Dunbar, &amp; Frank, 1993</td>
<td>University hospital outpatient clinic.</td>
<td>Exploratory study to examine whether outcomes of care for HIV-infected patients are related to whether the patient's primary provider is a physician or a nurse practitioner</td>
<td>Self-administered questionnaire: conducted in 1991.</td>
<td>87 subjects with HIV-infection: Men (85%)</td>
<td>NP patients functioned at comparable levels and used no more health care services than MD patients. NP patients reported 45% fewer problems with their care. NP patients were three times as likely to report their health status as only fair or poor, and to report significantly more unpleasant symptoms over a four-week period.</td>
<td>Nonlongitudinal NP patients in poorer health than MD patients. Conducted in a single site with limited number of primary providers and uses a convenience sample. Not able to generalize the findings.</td>
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<tr>
<td>Stein, Fleishman, Mor. &amp; Dresser, 1993.</td>
<td>Nine city hospitals and community-based organizations.</td>
<td>To describe the effects of socio-demographic, clinical, and system characteristics on patient satisfaction as an outcome of medical care among symptomatic HIV-infected individuals.</td>
<td>Patient interview survey: conducted between November 1988 and April 1989.</td>
<td>957 subjects enrolled in the AIDS Health Services Program: Men (89%) Nonwhites (39%) IVDUs (34%)</td>
<td>More educated people reported less overall satisfaction. IVDUs were less satisfied with interpersonal relations than nonusers. Uninsured subjects reported less overall satisfaction than insured subjects. Symptom intensity was significantly negatively related to all satisfaction outcomes.</td>
<td>Nonlongitudinal. Majority of the subjects were white males. Not able to generalized the findings.</td>
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<tr>
<td>Langner &amp; Hutelmyer, 1995</td>
<td>Ambulatory Care Services Clinic in a general internal medicine in an urban medical teaching clinic.</td>
<td>A patient satisfaction survey designed to include aspects of care specific to HIV compared between NPs and MDs.</td>
<td>Patient survey conducted between February and May 1994.</td>
<td>Convenient sample of 52 HIV-infected patients: NP patients (29) MD patients (19)</td>
<td>Overall satisfaction with patient care was high. NPs fared more favorably in the areas related to clinic waiting time, provider knowledge about the disease, continuity of care, and patient education.</td>
<td>Nonlongitudinal. Conducted in a single site with limited number of primary providers and uses a convenience sample. Not able to generalize the findings.</td>
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<td>Stone, Weissman, &amp; Cleary, 1995</td>
<td>A public-hospital HIV clinic, an academic group practice, and staff-model HMO in Boston</td>
<td>To examine the relation of patient characteristics and site of care to the perceptions of ambulatory care quality by persons with AIDS</td>
<td>Patient surveys and medical record reviews.</td>
<td>305 subjects received HIV care as of February 1990, and new patients during a subsequent 13 months.</td>
<td>Women, minorities, IVDUs, and Medicaid subjects were found to have significantly lower scores.</td>
<td>Nonlongitudinal Further research is needed to clarify the relative importance of each of these non-physician providers in enhancing patients' care.</td>
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<td>Males (98.2%)</td>
<td>Subjects with a primary nurse reported significantly higher scores.</td>
<td>Large number of the black and IVDU subjects were at a single site (public-hospital), it is possible that general beliefs about public health care may have influenced the subjects' perceptions of the quality of care they received there.</td>
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<tr>
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<td>Whites (64.9%)</td>
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<td>Not able to generalize the findings.</td>
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<td>Blacks 23.6%</td>
<td>Subjects who could not identify a primary physician tended to have less satisfied scores.</td>
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<td>Larrabee, Ferri, &amp; Hartig, 1997.</td>
<td>Four primary care clinics of a government hospital in south-central United States.</td>
<td>To assess patient satisfaction with care provided by four nurse practitioners.</td>
<td>Quantitative, descriptive pilot study.</td>
<td>Convenience sample of 43 subjects. Males (93%); Whites (63%)</td>
<td>Subjects were satisfied with nurse practitioners' care. Written patient complaints decreased 56% after implementation of the nurse practitioner role.</td>
<td>Nonlongitudinal. Small sample size. Not able to generalize the findings.</td>
</tr>
<tr>
<td>Wu, Revicki, Jacobson, &amp; Malitz, 1997.</td>
<td>Six medical centers across the United States.</td>
<td>To evaluate the equivalence between self and interview-administered responses to satisfaction with care in clinical trials.</td>
<td>Patient survey and interview. Conducted between November 1992 and January 1994.</td>
<td>68 subjects enrolled in a randomized double-blinded clinical trial. Males (91%); Whites (75%)</td>
<td>More educated people reported less overall satisfaction. IVDUs were less satisfied with interpersonal relations than nonusers. Uninsured subjects reported less overall satisfaction than insured subjects.</td>
<td>Nonlongitudinal. Subjects consisted of advanced HIV disease and screen for a clinical trial. Majority of subjects were white and fairly well educated. Small sample size.</td>
</tr>
</tbody>
</table>

(table continues)
Table 7

Summary of Selected HIV Patient Satisfaction Research

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Focus</th>
<th>Design</th>
<th>Sample</th>
<th>Results</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beck, Griffith, Fitzpatrick, Mandalia, Carrier, Conlon, Mandel, Ong, Pozniak, Tang, Tomlinson, &amp; Williams, 1999</td>
<td>Three London and Three non-London HIV clinics.</td>
<td>Evaluate the standards of care HIV outpatient services in the National Prospective Monitoring System (NPMS).</td>
<td>Cross-sectional survey: conducted between April to May 1996.</td>
<td>548 subjects: Men (92%), White (88%), Homosexual (76%)</td>
<td>Satisfaction scores were significantly lower for the clinic environment. Satisfaction scores did not differ significantly by gender, age, sexual orientation, ethnic group, employment status, or severity of symptoms.</td>
<td>Nonlongitudinal. Subjects' mostly white-homosexual males. Not able to generalize findings.</td>
</tr>
</tbody>
</table>
Conclusion

There is currently no research found in the extant literature which examines health-related quality of life and satisfaction with care of HIV-infected adults who seek medical care and services at community-based AIDS service organizations. Research conducted at community-based AIDS service organizations would be able to capture a patient population that is uninsured, under insured, and representative of minorities and intravenous drug users. Although the underserved HIV/AIDS patient population is under represented in studies, one would expect that this population would have low quality of life and satisfaction with care outcomes. Level of care in community-based AIDS service organizations has not been studied. Community-based AIDS service organizations receive public funds and are publicly accountable for their standards of medical care and services. Community-based AIDS service organizations rely on measurements of health-related quality of life and patient satisfaction with care outcomes to continue to receive Ryan White CARE Act funding.

There needs to be more research in these areas of health-related quality of life variables along with the organization structure and services provided to HIV-infected individuals, particularly at community-based AIDS service organizations. Also important is more research on the issue of patient satisfaction with care at the community-based AIDS service organizations.
CHAPTER III
METHODODOLOGY

Purpose

The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables (age, educational level, and time since HIV diagnosis) that influence health-related quality of life and satisfaction with care.

Design

This was a nonexperimental, descriptive and correlational study that was designed to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization. The focus of this research was to examine the influence among socio-demographic variables (age, education level, and time since HIV diagnosis) on health-related quality of life and satisfaction with care. Factors were examined retrospectively, and data were gathered at only one point in time.

Research Questions

1. What is the health-related quality of life for adults who receive care at a community-based AIDS service organization?

2. How satisfied with care are adults who receive care at a community-based AIDS service organization?

Hypotheses

Hypothesis 1

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on the health-related quality of life for adults
receiving care at a community-based AIDS service organization.

**Hypothesis 2**

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on satisfaction with care for adults receiving care at a community-based AIDS service organization.

**Hypothesis 3**

There would be a positive relationship between health-related quality of life and satisfaction with care for adults receiving care at a community-based AIDS service organization.

**Setting**

This study was conducted at a community-based AIDS service organization in a Mid-Atlantic metropolitan area that has four regional clinics. This organization (a) receives Ryan White CARE Act funds, (b) has regional clinics approximately 5 to 15 miles distance from each other, (c) serves a patient population with similar demographics, (d) provides similar health-related services, such as medical/dental, case management, testing and counseling, and mental health/substance abuse counseling, (e) shares a common mission statement of a non-profit community-based health organization serving the Mid-Atlantic metropolitan area, (f) is staffed by a diverse group of volunteers and paid staff who provide or facilitate the delivery of high quality, comprehensive, accessible health care and community services, and (g) is especially committed to ending the suffering of all those infected and affected by HIV/AIDS.

Clinic A, the main clinic, is located in the northwest section of the metropolitan area. Patient population consists of 550 females and 1,550 males; age range is between 30-49;
sexual orientation composition is 43.1% men who have sex with men, 44.0% heterosexual, 8.6% intravenous drug users, and 4.3% unknown; mode of payment consists of 64.7% uninsured, 22.0% Medicaid, and 13.3% private insurance; and the racial composition is 75.9% African-American, 15.5% White, 5.5% Latino, and 3.1% other. Thirty-four (42%) subjects from this regional clinic participated in the study.

Clinic B is located east of the river serving the southeast region of metropolitan area. Patient population consists of 169 females and 294 males; age range is between 30-49; sexual orientation composition is 23.7% men who have sex with men, 64.0% heterosexual, 10.0% intravenous drug users, and 2.3% unknown; mode of payment consists of 56.6% uninsured, 36.1% Medicaid, and 7.3% private insurance; and the racial composition is 97.1% African-American, 2.0% White, 0.5% other, and 0.4% Latino. Forty-six (56.8%) subjects from this regional clinic participated in this study.

Clinic C is located in northern metropolitan area of an adjacency state. Patient population consists of 94 females and 205 males; age range is between 30-39; sexual orientation composition is 34.3% men who have sex with men, 47.6% heterosexual, 11.3% intravenous drug users, and 6.8% unknown; mode of payment consists of 75.6% uninsured, 16.8% Medicaid, and 7.6% private insurance; and the racial composition is 54.0% African-American, 23.8% White, 17.7% Latino, and 0.5% other. There were no subjects from this regional clinic due to the investigator was unable to be available during clinic hours at this site.

Clinic D, the newest clinic, opened in the fall of 2000 is located in suburban area of another state. Patient population consists of 55 females and 94 males; age range is 30-39; sexual orientation composition is 24.1% men who have sex with men, 38.4% heterosexual,
32.0% intravenous drug users, and 4.5% unknown; mode of payment consists of 89.5% uninsured, 5.3% Medicaid, and 5.2% private insurance; and the racial composition is 78.9% African-American, 12.8% White, 5.3% other, and 3.0% Latino. One (1.2%) subject from this regional clinic participated in this study.

The patients' demographics at this community-based AIDS service organization reflect the demographics of the HIV/AIDS cases in the Mid-Atlantic metropolitan area according to the latest statistics from the Centers for Disease Control and Prevention. This Mid-Atlantic metropolitan region is ranked as the fifth leading metropolitan area reporting the highest number of cumulative AIDS cases among residents as of June 2001 (CDC, 2002).

Subjects

A convenient sample population of adults who (a) were 18 years of age or older, (b) had a documented positive enzyme-linked immunosorbent assay (ELISA) and western blot tests for HIV-1 or 2 virus in their medical records, (c) read and spoke English, (d) had a Karnofsky score of 80 or higher as recorded in the medical record, and (e) had attended a minimum of four primary health care appointments at one of the community-based AIDS service organization's regional clinics was chosen. Karnofsky score is a means to clinically estimate a patient's physical state, performance, and prognosis. The scale is from 100, perfectly well, to 0, dead. It has been used in studying cancer and chronic illness (Thomas, 1997). The investigator chose a Karnofsky score of 80 or higher to control for limited or absence of physical and psychological problems related to the subjects' HIV-infection. A staff member at each of the community-based AIDS service organization's regional clinics...
referred potential subjects to the investigator during the potential subject's medical appointment.

Cohen's (1988) power analysis for the behavioral sciences was used to determine the sample size of 77 subjects for a regression analysis for a medium effect, a power of .80, at an alpha of .05. The sample size of 77 subjects was a cumulative total of all subjects from the four regional clinics. The sample size was treated as one group; there was no consideration for patients at a particular clinic.

Protection of Human Subjects

The proposed research was approved by the Committee for Protection of Human Subjects at The Catholic University of America and at the community-based AIDS service organization. Refer to appendix A for a copy of the approval letter. All subjects were required to sign an informed consent agreeing to participate in the study. A subject number or code was then assigned to each participant. This code was used to identify potential subjects and their data. There was a minimal risk for subjects in this study. The instruments took approximately 1 hour to complete. Subjects could withdraw from the study without penalty or loss of benefits to health care services. Out of the 91 eligible HIV-infected adults, 89% (n = 81) agreed to participate in the study. Reasons why 11% (n = 10) of the potential subjects did not participate in this study were identified as follows: (a) 7 stated they did not have enough time; (b) 1 stated that he had completed several surveys already for the clinic; (c) 1 left the clinic before he signed the informed consent; and (d) 1 stated that he was not a good reader. Refer to appendix B for a copy of the informed consent.

Actual names and codes of the potential subjects were made available only to the investigator. The master list was kept separate from the data collection instruments in a
locked file at the investigator’s office. The investigator had access to the subjects’ medical records and all information was kept as confidential as legally possible. Permission to review medical records was included in the consent form. The medical records and research records may be subpoenaed by court order or may be inspected by federal regulatory authorities. All research records will be kept in a locked file for a period of five years in the investigator’s office, at which time they will be destroyed.

Instruments

Three instruments were used in this study (a) Demographic Data Form (DDF), (b) HIV Overview of Problems-Evaluation Systems (HOPES), and (c) DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ). The conceptual framework of Wilson and Cleary’s (1995) health-related quality of life conceptual model of patient outcomes undergirds the HIV Overview of Problems-Evaluation Systems (HOPES). The conceptual framework of Ware’s (1978) taxonomy of patient satisfaction undergirds the DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ).

Demographic Data Form (DDF)

The Demographic Data Form is a multi-dimensional socio-demographic survey developed by the investigator. The Demographic Data Form is a 18-item self-administered questionnaire that includes the subject’s age, educational level, number of year’s HIV-infected, financial status and type of health care provider. Refer to appendix C for a copy of the Demographic Data Form.

HIV Overview of Problems-Evaluation Systems (HOPES)

The HIV Overview of Problems-Evaluation Systems (HOPES) survey is a multi-dimensional, HIV/AIDS disease specific, health-related quality of life survey (Ganz et al.,
1993; Schag et al., 1992). The HOPES is a 165-item questionnaire, which uses a 5-point scale ranging from (0) "not at all" to (4) "very much". The survey is self-administered and takes approximately 20-30 minutes to complete. The global score represents the overall health-related quality of life. The five domains of the overall health-related quality of life are (a) physical functioning, (b) psychosocial functioning, (c) significant other, (d) medical interaction, and (e) sexual functioning. There are 35 subscales of daily functions and problems. These subscales address ambulation, pain, weight loss, difficulty working, body image, psychological distress, sexual interest, and chemotherapy problems (Ganz et al., 1993; Schag et al., 1992). The mean global score of less than or equal to 330 was chosen for this study, by the investigator, to indicate significant quality of life. There is no set cut off level or score established by the developers of the HOPES. The investigator chose a mean global score of less than or equal to 330 by calculating the average of the possible high and low scores on the HOPES. A global score below or equal to 330 indicates significant quality of life with limited or absence of medical or psychosocial problems. A global score greater than 330 on the HOPES indicates poorer quality of life and one or more severe medical or psychosocial problems.

The HOPES has a reliability, cronbach's alpha score > 0.70, and adequate levels of construct validity when compared to the Medical Outcomes Study-HIV (MOS-HIV) questionnaire (Ganz et al., 1993; Schag et al., 1992). The Medical Outcomes Study-HIV is one of the most widely used measures for assessing health-related quality of life in HIV-infected patients (Douaihy & Singh, 2001). The Medical Outcomes Study-HIV has been used in numerous AIDS Clinical Trial Groups (ACTG), since the 1990's, when the Food and Drug Administration (FDA) required that health-related quality of life questionnaires be
incorporated in Phase II and Phase III clinical trials. Both the HOPES and the Medical Outcomes Study-HIV questionnaires are disease specific health-related quality of life instruments. The HOPES was used for this study because of its logical consistency with the study variables and its correlation to the Wilson and Cleary's (1995) health-related quality of life conceptual model. Refer to appendix D for a copy of the HOPES questionnaire.

**DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ)**

The DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ) is a multidimensional questionnaire that has 46-items using a 4-point Likert scale ranging from (1) "strongly disagree" to (4) "strongly agree". The questionnaire is self-administered and takes approximately 15-20 minutes to complete. The five domains of the overall patient satisfaction are (a) satisfaction with physician, (b) dissatisfaction with practice management, (c) availability, (d) receptionist behavior, and (e) wait time. The global score represents the overall patient satisfaction. The mean global score of greater than or equal to 117 was chosen for this study, by the investigator, to indicate significant patient satisfaction with care. There is no set cut off level or score established by the developers of the DWPSQ. The investigator chose a mean global score of greater than or equal to 117 by calculating the average of the possible high and low scores on the DWPSQ. A global score greater than or equal to 117 on the DWPSQ indicates significant patient satisfaction with care at a particular institution. A global score less than 117 on the DWPSQ indicates insignificant or poor patient satisfaction with care at a particular institution.

The DWPSQ coefficient alpha reliabilities for the five subscale components are 0.96, 0.93, 0.89, 0.84, and 0.78 respectively (DiTomasso & Willard, 1991; Larrabee, Ferri, & Hartig, 1997). This coefficient alpha provides an estimate of the internal consistency of the
subscales and the homogeneity of the content sampled. It also closely approximates the alternate form, test-retest and split-half reliabilities. All items correlated highly with total scores on the respective components. Factor intercorrelations were all significant ( \( p < 0.001 \)) and in the expected directions. The DWPSQ is considered to have adequate levels of construct and content validity. Content validity refers to the extent to which an instrument adequately represents the universe of the content domain from which items are sampled. Items in the DWPSQ were developed, selected, and followed the standard psychometric protocol (DiTomasso & Willard, 1991; Larrabee et al., 1997). Refer to appendix E for a copy of the DWPSQ survey.

Procedure

The investigator sought approval from the Committee for the Protection of Human Subjects at The Catholic University of America. Once permission was obtained from the Committee for Protection of Human Subjects at The Catholic University of America, approval was sought and received from the community-based AIDS service organization’s Committee for Protection of Human Subjects.

At each of the community-based AIDS service organization’s regional clinics, a staff member was identified as the key person. The staff member identified potential subjects based on the criteria for subject selection. The staff member then scheduled the potential subjects to meet the investigator to discuss the study once a subject expressed interest in the study.

The investigator discussed the study with potential subjects and explained the informed consent form in a private office or an examination room. All subjects signed the
informed consent if they agreed to participate in the study. Each subject then received a
copy of the informed consent after the investigator had signed the document.

Subjects who participated in the study received a self-addressed and stamped
package containing the Demographic Data Form, the HOPES, and the DWPSQ surveys.
The package also contained instructions on how to complete all three surveys and how to
mail the completed surveys back to the investigator in the event that the subjects did not
complete them at that clinic appointment. The expected time for completion of these
questionnaires is about 1 hour.

Data Analysis

1. Internal consistency of the study instruments, the HIV Overview of Problems
   Evaluation Systems (HOPES) and the DiTomasso-Willard Patient Satisfaction Questionnaire
   (DWPSQ), was established using Cronbach's coefficient alpha.

2. Descriptive statistics were used to analyze the demographic data and the scores of
   the HIV Overview of Problems-Evaluation Systems and the DiTomasso-Willard Patient
   Satisfaction Questionnaires.

3. Multiple regression analyses were performed on the independent socio-
   demographic variables (age, educational level, and time since HIV diagnosis) to see which
   variables explained most of the variance for the dependent variables of health-related quality
   of life and satisfaction with care. The variables were entered hierarchically into a SPSS 9.0
   program.

4. The t-test was performed on the quantitative scores of the dependent variables
   health-related quality of life and satisfaction with care.
Limitations

1. The generalization of the results was limited to one community-based AIDS service organization in a Mid-Atlantic metropolitan area. Other constraints are the inability to generalize the results with the general HIV-infected population of the United States or the inability to generalize the health-related quality of life and satisfaction with care of HIV-infected adults at non-community-based AIDS service organizations.

2. The subject population was limited to subjects who were underserved and or uninsured and received care at a community-based AIDS services organization.

3. The surveys were conducted at one point in time.

4. There may be personal circumstances or individual events that had an impact on health-related quality of life and satisfaction with care that were not considered in this study.
CHAPTER IV
DATA ANALYSIS

The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables (age, educational level, and time since HIV diagnosis) that influence health-related quality of life and satisfaction with care.

To address the purpose of this study, data analysis was divided into four sections. These sections are (a) description of the sample, (b) instrument data, (c) answering of the research questions, and (d) hypotheses testing.

Description of the Sample

Over a period of six weeks, 91 eligible HIV-infected adults were identified. Out of the 91 eligible HIV-infected adults, 89% (n = 81) agreed to participate in the study. Reasons for the 11% (n = 10) potential subjects, who did not participate in this study, were identified as follows: (a) 7 stated they did not have enough time; (b) 1 stated that he had completed several surveys for the clinic staff; (c) 1 left the clinic before he signed the informed consent; and (d) 1 stated that he was not a good reader.

Out of the 81 eligible HIV-infected adults who consented to participate, 100% (n = 81) completed the study questionnaires, 94% (n = 76) of the questionnaires were completed in the clinic. The other 6% (n = 5) were completed at home and returned to the investigator at the clinic within a week. All study questionnaires were reviewed with subjects. Missed question items were presented to the subjects to complete. Consequently all (n = 81) questionnaires were complete when the data were entered into the SPSS 9.0 program.
Gender, Race, Age

The subjects identified their gender as: female 39.5% (n = 32), male 56.8% (n = 46), and transgender 3.7% (n = 3). Race of the subjects was: African-American 92.6% (n = 75), White 6.2% (n = 5), and Latino 1.2% (n = 1). Subjects' stated ages ranged from 20 to 65 with a mean of 41 years. Refer to figures 3-5.

Figure 3. Gender

Figure 4. Race
Table 8 provides a comparison of the subjects’ gender to race. Diversity was mostly evident among gender, 39.5% (n = 32) were females; 56.8% (n = 46) were males, seventy-five of the subjects were African-American. However, all of the women in the study were African-American. These demographic statistics are representative of the Mid-Atlantic metropolitan area’s current CDC (2002) HIV/AIDS statistics.

Table 8

<table>
<thead>
<tr>
<th>Gender</th>
<th>Race</th>
<th>Total</th>
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<tbody>
<tr>
<td></td>
<td>African-American</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>32</td>
<td>32</td>
</tr>
<tr>
<td>Male</td>
<td>40 5 1</td>
<td>46</td>
</tr>
<tr>
<td>Transgender</td>
<td>3 5 1</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>75 5 1</td>
<td>81</td>
</tr>
</tbody>
</table>
Socio-economic Status

Educational level ranged from 7 to 19 years of schooling with a mean of 13 years of school. Sixty-nine percent of the women had an educational level of 12\textsuperscript{th} grade or lower compared to twenty-two percent of the males. The women in this study were less educated than the males. Marital status of subjects was as follows: married 13.6\% (n = 11), single 74.1\% (n = 60), and divorced 12.3\% (n = 10). Social support for subjects came from: partner/significant other 21\% (n = 17), family 37\% (n = 30), friends 22.2\% (n = 18), church 13.6\% (n = 11), and other which was identified as the clinic 6.2\% (n = 5). Refer to figures 6-8.

Figure 6. Educational Level

![Histogram of Educational Level](image_url)
**HIV Risk Behaviors and Status**

Risk behaviors of subjects were identified as: heterosexual 53.1% (n = 43), homosexual 33.3% (n = 27), bisexual 4.9% (n = 4), intravenous drug use 7.4% (n = 6), and other, identified as a blood transfusion 1.2% (n = 1). There were gender differences between heterosexual and IVDUs risk behaviors. Eighty-one percent of the females
identified themselves as heterosexual versus thirty-seven percent of the males. Thirteen percent of the females identified themselves as IVDUs versus four percent of the males. Subjects' HIV status was: HIV positive 42% (n = 34) and AIDS 58% (n = 47). Years in which subject were HIV-infected ranged from 1 to 20 with a mean of 6 years. Karnofsky scores, ranging from 80 to 100 with a mean of 93, indicated that the subjects had limited or absence of medical or psychological problems. Refer to figures 9-12.

Figure 9. Risk Behaviors

![Pie chart showing risk behaviors: 53.2% Heterosexual, 33.3% Homosexual, 4.9% Bisexual, 7.4% IVDUs, and 1.2% Other.]
Figure 10. HIV Status

Figure 11. Years HIV-Infected

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Figure 12. Karnofsky Scores

![Karnofsky Scores Graph]

Std. Dev = 5.65  
Mean = 92.6  
N = 81.00

Financial and Insurance Status

Work status was reported as: employed-fulltime, 17.3% (n = 14), employed-parttime, 14.8% (n = 12), unemployed, 35.8% (n = 29), disabled, 28.4% (n = 23), student, 2.5% (n = 2), and other, retired, 1.2% (n = 1). Income was: < $20,000, 75.3% (n = 61), $20,000 to $34,999, 13.6% (n = 11), $35,000 to $49,999, 7.4% (n = 6), $50,000 to $64,999, 2.5% (n = 2), and $65,000 to $79,999, 1.2% (n = 1). The majority of subjects had health insurance: Medicaid, 43.8% (n = 36), AIDS Drug Assistance Program (ADAP), 41.3% (n = 33), private insurance, 8.7% (n = 7), other, identified as Medicare 1.2% (n = 1), and no insurance, 5.0% (n = 4). Refer to tables 9-10 and figure 13.

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Table 9

Work Status

<table>
<thead>
<tr>
<th>Work Status</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed Full-Time</td>
<td>14</td>
<td>17.3</td>
</tr>
<tr>
<td>Employed Part-Time</td>
<td>12</td>
<td>14.8</td>
</tr>
<tr>
<td>Unemployed</td>
<td>29</td>
<td>35.8</td>
</tr>
<tr>
<td>Disabled</td>
<td>23</td>
<td>28.4</td>
</tr>
<tr>
<td>Student</td>
<td>2</td>
<td>2.5</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>81</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Table 10

Income Levels

<table>
<thead>
<tr>
<th>Income Levels</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; $20,000</td>
<td>61</td>
<td>75.3</td>
</tr>
<tr>
<td>$20,000-$34,999</td>
<td>11</td>
<td>13.6</td>
</tr>
<tr>
<td>$35,000-$49,999</td>
<td>6</td>
<td>7.4</td>
</tr>
<tr>
<td>$50,000-$64,999</td>
<td>2</td>
<td>2.5</td>
</tr>
<tr>
<td>$65,000-$79,999</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>81</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Medical Services

Health care providers of subjects were as follows: physician, 28.4% (n = 23), nurse practitioner, 66.7% (n = 54), and physician assistant, 4.9% (n = 4). At the time of this study, the ratio of physicians to nurse practitioners or physician assistants was 1 to 1. Clients were treated in three locations: Clinic A 42% (n = 34), Clinic B 56.8% (n = 46), and Clinic D 1.2% (n = 1). Clients reported that they have sought care at the community-based AIDS service organization from 1 to 14 years with a mean of 3 years. HIV drugs use was reported in 84% (n = 68) of the population. Clients reported therapy with HIV drugs from less than 1 year to greater than 10 years with a mean of 3 years. The number of HIV drugs in the patients' profile ranged from 1 to 6 with a mean of 3.77. Refer to figures 14-19.
Figures 14. Health Care Provider

- Physician: 4.9%
- Physician Assistant: 4.9%
- Nurse Practitioner: 66.7%

Figure 15. Clinic Site

- Clinic A: 42.0%
- Clinic B: 56.8%
- Clinic D: 1.2%

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Figure 16. Years Seeking Services

Figure 17: HIV Medication Use

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Instrument Data

**HIV Overview of Problems-Evaluation System**

Health-related quality of life was measured by using the HIV Overview of Problems-Evaluation System (HOPES). The mean global score of less than or equal to 330 was chosen for this study, by the investigator, to indicate significant quality of life. There is no set cut off level or score established by the developers of the HOPES. The investigator chose a mean global score of less than or equal to 330 by calculating the average of the possible high and low scores on the HOPES. A mean global score greater than 330 indicates insignificant or poor quality of life and one or more severe medical or psychological problems. The global scores for the HIV Overview of Problems-Evaluation System (HOPES) median was 108 with a mean global score of 131.35. This mean global score of 131.35 which is less than 330, is considered to be favorable in terms of indicating significant quality of life with limited or absence of medical or psychological problems. Data from this study resulted in an average alpha of 0.83 for the five subscales: (a) physical functioning, (b) psychosocial functioning, (c) significant other, (d) medical interaction, and (e) sexual functioning.

**DiTomasso-Willard Patient Satisfaction Questionnaire**

Satisfaction with care was measured by using the DiTomasso-Willard Patient Satisfaction Questionnaire. The mean global score of greater than or equal to 117 was chosen for this study, by the investigator, to indicate significant patient satisfaction with care. There is no set cut off level or score established by the developers' of the DWPSQ. The investigator chose a mean global score of greater than or equal to 117 by calculating the average of the possible high and low scores on the DWPSQ. A mean global score less that
indicates insignificant or poor patient satisfaction with care. The global scores for the
DiTomasso-Willard Patient Satisfaction Questionnaire median was 149 with a mean global
score of 144.48. This mean global score, of 144.48 is greater than 117, and considered to be
favorable in terms of indicating significant patient satisfaction with care. Data from this
study on the five domains of the overall patient satisfaction resulted in an alpha of (a)
satisfaction with health care provider (0.95), (b) dissatisfaction with practice management
(0.83), (c) availability of provider (0.86), (d) receptionist behavior (0.89), and (e) wait time
(0.84).

Answering the Research Questions

Research Question 1

What is the health-related quality of life for adults who receive care at a community-

based AIDS service organization? This research question was analyzed by applying
descriptive statistics to the global scores of the HIV Overview of Problems-Evaluation
System (HOPES). Total scores for the HIV Overview of Problems-Evaluation System ranged
from 3 to 556 with a mean global score of 131.35. This mean global score, of 131.35, is
considered favorable and indicative of significant quality of life with limited or absence of
medical or psychological problems. Five of the eighty-one subjects had mean global scores
less than 10; they could represent outliers in this study. These subjects indicated no medical
or psychological limitations. This is possible because the five subjects either had no
complications or limitations from their HIV-infection; they chose all “0 = not at all” and/or
some “1 = a little” on the HOPES instrument to complete the questionnaire quickly; they
wished to satisfy the researcher that they had high health-related quality of life scores.
Health-related quality of life score, acceptable for limited or absent medical or psychological problems and physical limitation, was determined to be less than 330 on the HIV Overview of Problems-Evaluation System questionnaire by the investigator. Forty-six (56.8%) of the subjects achieved acceptable health-related quality of life scores, while thirty-five (43.2%) of the subjects achieved poor health-related quality of life scores. This research question was answered by the data indicating that more than half of the subjects (56.8%) achieved acceptable global scores on the HOPES. Refer to table 11 and figure 20.

Table 11
Health-Related Quality of Life (QoL) Global Scores

<table>
<thead>
<tr>
<th>Global Scores' Ratings</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good QoL</td>
<td>46</td>
<td>56.8</td>
</tr>
<tr>
<td>(Global Score of 330 and less)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor QoL</td>
<td>35</td>
<td>43.2</td>
</tr>
<tr>
<td>(Global Score of 331 and greater)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Research Question 2

How satisfied with care are adults who receive care at a community-based AIDS service organization? This research question was answered by using descriptive statistics to analyze the scores of DiTomasso-Willard Patient Satisfaction Questionnaires. Global scores for the DiTomasso-Willard Patient Satisfaction Questionnaire ranged from 65 to 184 with a mean global score of 144.48. This mean global score, of 144.48, is considered to be favorable and indicative of substantial satisfaction with care.

Satisfaction with care, for this study, was determined to be a DiTomasso-Willard Patient Satisfaction Questionnaire score greater than 117 by the investigator. Subjects satisfied with care were 96.3% (n = 78) and subjects not satisfied with care were 3.7% (n = 3). This research question was answered by these data indicating that overwhelming...
majority of the subjects (96.3%) achieved acceptable global scores on the DWPSQ. Refer to table 12 and figure 21.

Table 12

Satisfied with Care Global Scores’ Ratings

<table>
<thead>
<tr>
<th>Global Scores’ Ratings</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied with Care</td>
<td>78</td>
<td>96.3</td>
</tr>
<tr>
<td>(Global Score of 117 and greater)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsatisfied with Care</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>(Global Score of 116 and less)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Figure 21. Satisfaction with Care Global Scores’ Ratings

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Hypotheses Testing

To answer the hypotheses the researcher tested the following regression model in this study: 

\[ Y = \beta_0 + \beta_1 X_1 + \beta_2 X_2 + \beta_3 X_3 + \varepsilon. \]

- \( Y_1 = \) Health-Related Quality of Life Scores on the HOPES
- \( Y_2 = \) Satisfaction with Care on the DWPSQ
- \( X_1 = \) Age
- \( X_2 = \) Educational Level
- \( X_3 = \) Times Since HIV Diagnosis (Years Infected)

\( \beta_0 = \) The intercept of the line of best fit
\( \beta_1 = \) The slope associated with Age
\( \beta_2 = \) The slope associated with Educational Level
\( \beta_3 = \) The slope associated with Time Since HIV Diagnosis
\( \varepsilon = \) The error term

**Hypothesis 1**

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on the health-related quality of life for adults receiving care at a community-based AIDS service organization. A regression analysis was used to test this hypothesis: regression of health-related quality of life on the socio-demographic variables (age, educational level, and time since HIV diagnosis).

The regression analysis did not support a significant relationship between the social-demographic variables and health-related quality of life. The significant level was set for 0.05 and the regression analysis significant level was determined to be 0.305. This hypothesis was not supported by the data. Refer to table 13.
Table 13

Regression Model for Health-Related Quality of Life

<table>
<thead>
<tr>
<th>Model</th>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of the Estimate</th>
<th>Change Statistics</th>
<th>Sig. F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.214*</td>
<td>.046</td>
<td>.008</td>
<td>99.391</td>
<td>.046</td>
<td>1.228</td>
</tr>
</tbody>
</table>

a. Predictors: (Constant), age, educational level, years infected.

Table 14 is a summary of the analysis of variance portion of the regression analysis that was conducted to study health-related quality of life. The F (1.228, df 3, 77, p = 0.305) was highly non-significant, indicating that the simultaneous test that β₁ = 0, β₂ = 0, and β₃ = 0 is not rejected. The R (0.214) obtained in this analysis is a correlation between the observed and predicted values of the criterion variables (age, educational level, time since HIV diagnosis), on health-related quality of life scores on the HOPES. More meaningfully, the R is the correlation between the observed scores on health-related quality of life and the predicted values on the health-related quality of life in this model (Burns & Grove, 1997; Munro, 1997). The table also displays the adjusted R² (0.046). The sample estimate of R² tends to be an overestimate of the population parameter, thus the adjusted R², designed to compensate for an optimistic bias of R² by adjusting for the number of variables in the model and the sample size, is reported in the table (Burns & Grove, 1997; Munro, 1997).
Table 14

Summary of Regression, Analysis of Variance for Health-Related Quality of Life

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>R²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>36400.39</td>
<td>3</td>
<td>12133.46</td>
<td>1.228</td>
<td>0.046</td>
<td>0.305</td>
</tr>
<tr>
<td>Residual</td>
<td>760657.93</td>
<td>77</td>
<td>9878.67</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>797058.32</td>
<td>80</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 15 is a summary of the estimates of the model coefficients: $\beta_0$, intercept; $\beta_1$, slope associated with Age; $\beta_2$, slope associated with Educational Level; and $\beta_3$, slope associated with Time Since HIV Diagnosis (Years Infected). So using this information the model is: Health-related quality of life = 242.65 (constant) –0.795 (Age) –7.42 (Educational Level) + 2.94 (Years Infected). In an effort to assess the usefulness of each predictor in the model, to quantify the unique contribution of each predictor variable, the beta coefficients were examined. Using standardized beta weights permitted a better comparison of each variable that had different units of measure. The t statistic provided insight into the relative importance of each predictor variable in the model, when the other predictor or predictors are in the model (Burns & Grove, 1997; Munro, 1997). This table demonstrates that Age ($p = 0.564$) does not make a significant contribution when Educational Level and Years Infected are in the model. Educational Level ($p = 0.134$) does not make a significant contribution.
when Age and Years Infected are in the model. Years Infected (p = 0.227) does not make a significant contribution when Age and Educational Level are in the model.

Table 15
Summary of Full-Entry Model of Regression Analysis for Variables for Health-Related Quality of Life

<table>
<thead>
<tr>
<th>Variable</th>
<th>b weights</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.795</td>
<td>1.371</td>
<td>-0.066</td>
<td>-0.580</td>
<td>0.564</td>
</tr>
<tr>
<td>Educational Level</td>
<td>-7.417</td>
<td>4.877</td>
<td>-0.170</td>
<td>-1.521</td>
<td>0.134</td>
</tr>
<tr>
<td>Years Infected</td>
<td>2.939</td>
<td>2.414</td>
<td>0.138</td>
<td>1.218</td>
<td>0.227</td>
</tr>
</tbody>
</table>

Table 16 is a summary of the correlation matrix between health-related quality of life (HOPES Total scores) and the socio-demographic variables (age, educational level, and years infected [time since HIV diagnosis]). There were no statistically significant correlations between health-related quality of life and the socio-demographic variables, since all significant levels were greater than 0.05. There was a possible clinical relevance between health-related quality of life and educational level (r = -0.160, p = 0.076). The negative correlation between health-related quality of life and educational level, indicates that as educational levels increase there is a decrease in health-related quality of life scores on the HOPES. Since there were no statistically significant correlations between health-related
quality of life and the socio-demographic variables (age, educational level, and time since HIV diagnosis), the results of the regression analysis were also non-significant.

Table 16

Correlation Matrix between Health-Related Quality of Life and Socio-Demographic Variables

<table>
<thead>
<tr>
<th>Pearson Correlation</th>
<th>HOPES Total</th>
<th>AGE</th>
<th>Educational Level</th>
<th>Years Infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>HOPES Total</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td>-.036</td>
<td>1.000</td>
<td>-.028</td>
<td>.184</td>
</tr>
<tr>
<td>Educational Level</td>
<td>-.160</td>
<td>-.028</td>
<td>1.000</td>
<td>.055</td>
</tr>
<tr>
<td>Years Infected</td>
<td>.117</td>
<td>.184</td>
<td>.055</td>
<td>1.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sig. (1-tailed)</th>
<th>HOPES Total</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>HOPES Total</td>
<td></td>
<td>.376</td>
<td>.076</td>
<td>.150</td>
</tr>
<tr>
<td>AGE</td>
<td>.376</td>
<td>.</td>
<td>.401</td>
<td>.050</td>
</tr>
<tr>
<td>Educational Level</td>
<td>.076</td>
<td>.401</td>
<td>.</td>
<td>.314</td>
</tr>
<tr>
<td>Years Infected</td>
<td>.150</td>
<td>.050</td>
<td>.314</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N</th>
<th>HOPES Total</th>
<th>AGE</th>
<th>Educational Level</th>
<th>Years Infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>HOPES Total</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>AGE</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>Educational Level</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>Years Infected</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
</tbody>
</table>

Hypothesis 2

The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on satisfaction with care for adults receiving care at a community-based AIDS service organization. A regression analysis was used to test
this hypothesis: regression of satisfaction with care on the socio-demographic variables (age, educational level, and time since HIV diagnosis).

The regression analysis was not significant for social-demographic variables having a direct influence on satisfaction with care. The significant level was set for 0.05 and the regression analysis significant level was determined to be 0.705. This hypothesis was not supported by the data. Refer to table 17.

Table 17
Regression Model for Satisfaction with Care

<table>
<thead>
<tr>
<th>Model</th>
<th>R</th>
<th>R Square</th>
<th>Adjusted R Square</th>
<th>Std. Error of the Estimate</th>
<th>R Square Change</th>
<th>F Change</th>
<th>df1</th>
<th>df2</th>
<th>Sig. F Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.134*</td>
<td>.018</td>
<td>-.020</td>
<td>17.183</td>
<td>.018</td>
<td>.468</td>
<td>3</td>
<td>77</td>
<td>.705</td>
</tr>
</tbody>
</table>

a. Predictors: (Constant), age, educational level, years infected

Table 18 is a summary of the analysis of variance portion of the regression analysis that was conducted using the model for satisfaction with care. The F (0.468, df 3, 77, p = 0.705) was highly non-significant, indicating that the simultaneous test that \( \beta_1 = 0, \beta_2 = 0, \) and \( \beta_3 = 0 \) is not rejected. The R (0.134), obtained in this analysis, is a correlation between the observed and predicted values of the criterion variables (age, educational level, time since HIV diagnosis) and satisfaction with care scores on the DWPSQ. More meaningfully, the R is the correlation between the observed scores on satisfaction with care and the predicted values on the satisfaction with care using this model (Burns & Grove, 1997; Munro, 1997).
The table also displays the adjusted $R^2$ (0.018). The sample estimate of $R^2$ tends to be an overestimate of the population parameter, thus the adjusted $R^2$, designed to compensate for an optimistic bias of $R^2$ by adjusting for the number of variables in the model and the sample size, is reported in the table (Burns & Grove, 1997; Munro, 1997).

Table 18

Summary of Regression, Analysis of Variance for Satisfaction with Care

<table>
<thead>
<tr>
<th>Source</th>
<th>Sum of Square</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>$R^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>414.614</td>
<td>3</td>
<td>138.205</td>
<td>0.468</td>
<td>0.018</td>
<td>0.705</td>
</tr>
<tr>
<td>Residual</td>
<td>22735.608</td>
<td>77</td>
<td>295.268</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>23150.222</td>
<td>80</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 19 is a summary of the estimates of the model coefficients: $\beta_0$, intercept; $\beta_1$, slope associated with Age; $\beta_2$, slope associated with Educational Level; and $\beta_3$, slope associated with Time Since HIV Diagnosis (Years Infected). So using this information the model is: Satisfaction with Care = 147.18 (constant) + 0.034 (Age) -0.075 (Educational Level) - 0.49 (Years Infected). In an effort to assess the usefulness of each predictor in the model and to quantify the unique contribution of each predictor variable, the beta coefficients were examined. Using the standardized beta weights permitted a better comparison of each variable that had different units of measure. The t statistic provided insight into the relative importance of each predictor variable in the model, when the other predictor or predictors are in the model (Burns & Grove, 1997; Munro, 1997). This table demonstrates that Age (p =
0.886) does not make a significant contribution when Educational Level and Years Infected are in the model. Educational Level (p = 0.929) does not make a significant contribution when Age and Years Infected are in the model. Years Infected (p = 0.245) does not make a significant contribution when Age and Educational Level are in the model.

Table 19
Summary of Full-Entry Model of Regression Analysis for Variables for Satisfaction with Care

<table>
<thead>
<tr>
<th>Variable</th>
<th>b weight</th>
<th>SE B</th>
<th>β</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td>3.424E-02</td>
<td>0.237</td>
<td>0.017</td>
<td>0.144</td>
<td>0.886</td>
</tr>
<tr>
<td>Educational Level</td>
<td>-7.547E-02</td>
<td>0.843</td>
<td>-0.010</td>
<td>-0.090</td>
<td>0.929</td>
</tr>
<tr>
<td>Years Infected</td>
<td>-0.489</td>
<td>0.417</td>
<td>-0.135</td>
<td>-1.172</td>
<td>0.245</td>
</tr>
</tbody>
</table>

Table 20 is a summary of the correlation matrix between satisfaction with care (DWPSQ Total scores) and the socio-demographic variables (age, educational level, and years infected [time since HIV diagnosis]). There were no statistically significant correlations between satisfaction with care and the socio-demographic variables, since all significant levels were greater than 0.05. Since there were no statistically significant correlations between satisfaction with care and the socio-demographic variables (age, educational level, and time since HIV diagnosis), the regression analysis is non-significant.
Table 20

Correlations between Satisfaction with Care and Socio-Demographic Variables

<table>
<thead>
<tr>
<th>Pearson Correlation</th>
<th>DWPSQ Total</th>
<th>AGE</th>
<th>Educational Level</th>
<th>Years Infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>DWPSQ Total</td>
<td>1.000</td>
<td>-.008</td>
<td>-.018</td>
<td>-.132</td>
</tr>
<tr>
<td>AGE</td>
<td>-.008</td>
<td>1.000</td>
<td>-.028</td>
<td>.184</td>
</tr>
<tr>
<td>Educational Level</td>
<td>-.018</td>
<td>-.028</td>
<td>1.000</td>
<td>.055</td>
</tr>
<tr>
<td>Years Infected</td>
<td>-.132</td>
<td>.184</td>
<td>.055</td>
<td>1.000</td>
</tr>
</tbody>
</table>

Sig. (1-tailed)

<table>
<thead>
<tr>
<th></th>
<th>DWPSQ Total</th>
<th>AGE</th>
<th>Educational Level</th>
<th>Years Infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>DWPSQ Total</td>
<td></td>
<td>.472</td>
<td>.437</td>
<td>.119</td>
</tr>
<tr>
<td>AGE</td>
<td>.472</td>
<td>.401</td>
<td></td>
<td>.050</td>
</tr>
<tr>
<td>Educational Level</td>
<td>.437</td>
<td>.401</td>
<td></td>
<td>.314</td>
</tr>
<tr>
<td>Years Infected</td>
<td>.119</td>
<td>.050</td>
<td>.314</td>
<td></td>
</tr>
</tbody>
</table>

N

<table>
<thead>
<tr>
<th></th>
<th>DWPSQ Total</th>
<th>AGE</th>
<th>Educational Level</th>
<th>Years Infected</th>
</tr>
</thead>
<tbody>
<tr>
<td>DWPSQ Total</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>AGE</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>Educational Level</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
<tr>
<td>Years Infected</td>
<td>81</td>
<td>81</td>
<td>81</td>
<td>81</td>
</tr>
</tbody>
</table>

Hypothesis 3

There would be a positive relationship between health-related quality of life and satisfaction with care for adults receiving care at a community-based AIDS service organization. Performing a t-test tested this hypothesis on the scores of the HIV Overview of Problems-Evaluation System and DiTomasso-Willard Patient Satisfaction Questionnaire.

The results revealed that there were no positive relationship between health-related quality of life and satisfaction with care. The significant level was 0.262, which is not
statistically significant for less than 0.05. This hypothesis was not supported by the data.

Refer to table 21.

Table 21

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error</th>
<th>Paired Differences</th>
<th>95% Confidence Interval of the Difference</th>
<th>t</th>
<th>df</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>dwps_tot-hopes_tot</td>
<td>13.135</td>
<td>104.656</td>
<td>11.628</td>
<td>-10.0057</td>
<td>36.277</td>
<td>1.130</td>
<td>80</td>
<td>0.262</td>
</tr>
</tbody>
</table>

Summary

The health-related quality of life for adults who receive care at a community-based AIDS service organization was favorable indicating considerable quality of life with limited or absence of medical or psychological problems. The scores on the HOPES were less than 330 on the average, with a mean of 131.35. More than half (56.8%, n= 46) subjects had acceptable health-related quality of life scores, while 43.2% (n = 35) subjects achieved poor health-related quality of life scores. This answered the research question 1: What is the health-related quality of life for adults who receive care at a community-based AIDS service organization?

Adults who received care at a community-based AIDS service organization had overwhelming satisfaction with care. The scores on the DWPSQ were greater than 117, with a mean of 144.48. Seventy-eight (96.3%) subjects were satisfied with care. This response
answered the research question 2: How satisfied with care are adults who receive care at a community-based AIDS service organization?

The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not have a significant influence on health-related quality of life. The regression analysis significant level was determined to be 0.305. There was possible clinical relevance between health-related quality of life and educational level ($r = -0.160$, $p = 0.076$). This finding did not support hypothesis 1: The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on the health-related quality of life for adults receiving care at a community-based AIDS service organization.

The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not have a significant influence on satisfaction with care. The regression analysis significant level was determined to be 0.705. This did not support hypothesis 2: The socio-demographic variables (age, educational level, and time since HIV diagnosis) would have a positive influence on satisfaction with care for adults receiving care at a community-based AIDS service organization.

There were no positive or negative relationships between health-related quality of life and satisfaction with care. The $t$-test significant level was 0.262. This did not support hypothesis 3: There would be a positive relationship between health-related quality of life and satisfaction with care for adults receiving care at a community-based AIDS service organization.
CHAPTER V
FINDINGS, DISCUSSION, AND CONCLUSIONS

Introduction

Health-related quality of life and satisfaction with care are key outcome measurements and are important to patients and health care providers. This is especially true when patients have HIV/AIDS. In the United States, AIDS is the fifth leading cause of death among 25-44 years olds. As of June 31, 2001, 793,026 persons with AIDS had been reported in the United States; 457,667 of these persons had died; 3,542 persons had unknown vital status. The number of persons living with AIDS, 339,000, is the highest ever reported as of December 2000 (CDC, 2002). The majority of quality of life studies dealing with HIV/AIDS have focused on clinical trials and patients in academic health settings. There have been a limited number of studies of satisfaction with care among the HIV/AIDS population.

Assessment of factors that influence the perception of health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization has received minimal attention from researchers. It is also important to note that health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization have not been described or measured.

The Purpose

The purpose of this study was two-fold: (a) to describe health-related quality of life and satisfaction with care among adults at a community-based AIDS service organization, and (b) to identify the socio-demographic variables (age, educational level, and time since HIV diagnosis) that influence health-related quality of life and satisfaction with care.
Research Questions and Hypotheses

This investigation utilized a nonexperimental, descriptive and correlational design to address two major research questions and three hypotheses.

Research Question 1

What is the health-related quality of life for adults who receive care at a community-based AIDS service organization? Health-related quality of life was positive for adults who receive care at a community-based AIDS service organization. Subjects with acceptable health-related quality of life scores were 56.8% (n = 46). Subjects with poor health-related quality of life scores were 43.2% (n = 35).

Research Question 2

How satisfied with care are adults who receive care at a community-based AIDS service organization? Satisfaction with care was positive for adults who receive care at a community-based AIDS service organization. Persons satisfied with care were 96.3% (n = 78) of the study subjects, and subjects not satisfied with care were 3.7% (n = 3) of the group.

Hypothesis 1

The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not have a positive influence on the health-related quality of life for adults receiving care at a community-based AIDS service organization. The regression analysis was not statistically significant for the socio-demographic variables having a direct influence on health-related quality of life. The regression analysis significant level was determined to be 0.305.
Hypothesis 2

The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not have a positive influence on satisfaction with care for adults receiving care at a community-based AIDS service organization. The regression analysis was not statistically significant for the socio-demographic variables having a direct influence on satisfaction with care. The regression analysis significant level was determined to be 0.705.

Hypothesis 3

There was no positive relationship between health-related quality of life and satisfaction with care for adults receiving care at a community-based AIDS service organization. The t-test revealed a non-significant level at 0.262.

Findings

Health-Related Quality of Life

Health-related quality of life had no statistically significant correlation or influence with socio-demographic variables (age, educational level, and time since HIV diagnosis). The multiple regression model results were (p = 0.305). There however, was an interesting finding between health-related quality of life and educational level (r = -0.160, p = 0.076). This result would indicate a negative correlation between health-related quality of life and educational level, even though there was no statistical significance. This suggests that as educational levels increase there is a decrease in health-related quality of life scores on the HOPES. There was also a negative correlation between health-related quality of life and Karnofsky scores (r = -0.265, p = 0.017). This indicated that an increase in health-related quality of life scores, indicating poor health-related quality of life, were associated with lower Karnofsky scores. This finding, while interesting, is not surprising since Karnofsky
scores are a subjective health-related quality of life score. A Karnofsky score is a means to estimate clinically a patient’s physical state, performance, and prognosis. The scale is from 100, perfectly well, to 0, dead. It has been used in studying cancer and chronic illness (Thomas, 1997). A high Karnofsky score indicates that the subject has minimal limited or absent medical or psychological problems and/or physical limitation, which parallel a low score on the HOPES questionnaire. These two non-statistically significant findings warrant further investigation into how the educational levels and Karnofsky scores influence health-related quality of life of HIV-infected patients seeking care at a community-based AIDS service organization.

Previous studies have found inconsistent associations between demographic variables and health-related quality of life. Stone and his associates (1995) identified that patients with lower self perceived health status had lower health-related quality of life. In the Multi-Center AIDS Cohort study (2000), physical health of symptomatic HIV-infected patients was significantly worse than that of other persons with chronic disease states in the United States population. The physical health of symptomatic HIV-infected patients was also significantly worse than that of asymptomatic HIV-infected patients (Bing et al., 2000; Hays et al., 2000). Wu and his associates (1991) discovered that the health-related quality of life scores of asymptomatic HIV-infected individuals were higher on most subscales than the age-adjusted scores of a Medical Outcomes Study (MOS), a health-related quality of life instrument, of outpatients with hypertension, diabetes, recent myocardial infarction, or depression. Also, asymptomatic HIV-infected individuals reported superior overall health and less pain. Where as, symptomatic HIV-infected individuals scored closest to hypertensive patients on the Medical Outcomes Study instrument.
However, in the current literature review, medical and demographic variables (HIV status, age, total CD4 count, current work status, use of pain medications, and income) explained only 35% of the variability of health-related quality of life ratings in a sample of 318 HIV-infected patients in academic medical centers and the VA medical system (Ganz et al., 1993; Schag et al., 1992). Kemppainen’s (2001) study of 162 hospitalized patients with AIDS reported that the strongest predictor of decreased quality of life was depression. Depression accounted for 23% of the variance, with symptoms of HIV-infections accounted for 9.75% and female gender accounted for an additional 8%. Two measures of patient engagement with nursing care providers contributed a total of 13.44% of the variance in quality of life. Lenderking and his associates (1998) discovered that in multi-centers involved in the AIDS Clinical Trials Groups (ACTG) women showed lower quality of life scores than men on all scales of the General Health Self-Assessment questionnaire. Prior antiretroviral therapy was associated with higher health perceptions and well-being. Worse health-related quality of life was associated with a recent hospitalization and symptomatic status.

Cunningham and his associates (1995; 1998) determined that uninsured subjects, in county hospitals and in the VA medical centers, reported the worst access to medical care and poor health-related quality of life scores. Hays and associates (2000) discovered that race, sex, insurance status, disease stage, and CD4 count were most weakly associated with health-related quality of life scores, while HIV-related symptoms were strongly associated with health-related quality of life scores. Further research examining educational levels and Karnofsky scores in relation to health-related quality of life is warranted based on the results from this research study and the current literature.
Satisfaction with Care

Satisfaction with care had no statistically significant correlation or influence with socio-demographic variables (age, educational level, and time since HIV diagnosis). The multiple regression model results were ($p = 0.705$). There were significant negative correlations between satisfaction with care and gender ($r = -0.257$, $p = 0.021$), and treatment with HIV drugs ($r = -0.259$, $p = 0.019$). This indicated that males and transgenders had less satisfaction with care than women, and those subjects, not on HIV drugs, had less satisfaction with care. Refer to table 22 for a cross tabulation summary of gender and race to satisfaction with care.

Table 22

Gender-Race-Satisfaction with Care Cross Tabulation

<table>
<thead>
<tr>
<th>Satisfied with Care</th>
<th>Gender</th>
<th>Race</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Gender</td>
<td>African-American</td>
<td>White</td>
</tr>
<tr>
<td>Satisfied with Care</td>
<td>Female</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>38</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Transgender</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>72</td>
<td>5</td>
</tr>
<tr>
<td>Unsatisfied with</td>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care</td>
<td>Male</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transgender</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
The current literature review reported different findings than those of this study. In Stein and his associates' (1993) study, patients, men who have sex with men and had no private or public insurance, were significantly less satisfied with care than patients with private insurance. Also, symptom intensity from the HIV-infection had a significantly negative relationship to all satisfaction outcomes and that more educated people reported less overall satisfaction with care. Wachtel and associates (1992) along with Stone and associates (1995) found that women with HIV/AIDS were significantly less satisfied with care. A few selected studies reported that minorities and intravenous drug users had lower scores on their satisfaction with care scales (Stein et al., 1993; Stone et al., 1995; Wachtel et al., 1992; Wu et al., 1997). These findings are of interest. Future research examining gender and participation in HIV drug therapy in relation to satisfaction with care are warranted based on the results of this research study.

Health-Related Quality of Life and Satisfaction with Care

There was no positive or negative relationship between health-related quality of life and satisfaction with care. The t-test result was non-significant (p = 0.262). However, there was an interesting finding between health-related quality of life and satisfaction with care (r = -0.206, p = 0.065), a negative correlation between health-related quality of life and satisfaction with care. This suggests that as health-related quality of life scores increased, indicating poor health-related quality of life, there was a decrease in satisfaction with care. Refer to appendix F for Pearson correlation matrix of all socio-demographic variables that have statistical correlation with either health-related quality of life and or satisfaction with care.
Discussion

This section is divided into six sections. The first section presents a discussion of the sample; the second section presents a discussion of the study variables; the third section addresses health-related quality of life; the fourth section describes satisfaction with care; the fifth section addresses the biases of the study; and the sixth section presents its conceptual frameworks.

The Sample

The demography of the subjects, in this research study, correlated or paralleled those of the Center for Disease Control and Prevention’s (CDC) descriptive analysis of HIV/AIDS persons of the Mid-Atlantic region. The subjects of this study were mostly minorities, African-Americans (92.6%) and Latinos (1.2%), with an almost equal distribution of women (39.5%) and men (56.8%). According to CDC (1999) African-American and Latina women accounted for 80% of all cases of women with AIDS; while, African-Americans and Latinos accounted for 61% of all cases of men with AIDS. The Washington, DC AIDS rate is 299.4 per 100,000 population (the United States rate is 27.2) for men, and 102.2 per 100,000 population (the United States rate is 8.4) for women. The cumulative AIDS cases in Washington, DC are 24,029, which makes Washington, DC the fifth highest metropolitan area with reported cases (CDC, 2002).

Risk behaviors of subjects were as follows: heterosexual 53.1% (n = 43), homosexual 33.3% (n = 27), bisexual 4.9% (n = 4), intravenous drug use 7.4% (n = 6), and other, identified as a blood transfusion 1.2% (n = 1). According to CDC (1999), the incidence of HIV-infection is rising among heterosexuals, minorities (particularly African-Americans and Latinos), women, and intravenous drug users (IVDUs). The mean age of
subjects in this study was 41 years. The Centers for Disease Control and Prevention (CDC, 1999) report that AIDS is the fifth leading cause of death among 25-44 years olds in the United States. AIDS is the leading cause of death of African-American men between the ages of 25-44, and the third leading cause of death of African-American women between the ages of 25-44 in the United States.

The gender differences were of interest to the investigator. The most interesting differences between the genders was that women were hundred percent satisfied with their care at this community-based AIDS service organization compared to only ninety-five percent of the men (p = 0.027). This is interesting because studies by Wachtel and associates (1992) and Stone and associates (1995) reported that women with HIV/AIDS were found to have significantly lower satisfaction with care scores. There was a statistical significance (p = 0.021) between the educational levels of women and men in the study. Women had an average educational level of 8th grade compared to the 12th grade of the men. The years of HIV-infected was also statistically significant (p = 0.037), on average, women were infected for 5.3 years while men were infected for 6.2 years. The high number of women participating in this research study was surprising to the investigator. The community-based AIDS service organization, the site for this study, began and has historically been recognized as an organization that provides medical and psychological services primarily to gays, lesbians, and bi-sexuals. The majority of the women in this research study identified themselves as heterosexual (96.8). They indicated that they contracted HIV-infection via unprotected sexual activities (81%) and or intravenous drug users (1.3%).
When comparing the different regional clinics of this community-based AIDS service organization, more women sought medical care at clinic B (72%) rather than clinic A (25%). More men sought medical care at clinic A (56%) rather than clinic B (43%). This finding was statistically significant (p = 0.050). Possible reasons for gender differentiation among regional clinics may reflect that the clinic A, the main and oldest clinic, has traditionally and historically associated with serving the gay, lesbian, and bi-sexual community of the area. Clinic B, the clinic east of the river, meets the medical needs of all residents, regardless of sexual preference.

The Study Variables

Each of the study variables will be discussed in terms of its relationship to health-related quality of life and satisfaction with care, because a more thorough explanation and discussion of the effects of each non-significant variable is warranted. Appendix F represents socio-demographic variables that correlated with health-related quality of life and satisfaction with care.

Age. Age did not contribute to the explained variances in health-related quality of life or satisfaction with care. There was no statistically significant correlation and a non-significant regression analysis. The mean age of the subjects, 41, indicated a fair amount of lived experience. The investigator had hypothesized that since individuals newly infected with HIV, are generally over the age of 40, they would have better views or expectations of quality of life and satisfaction with care. Only one other research study, Beck and associates (1999), reported that satisfaction with care scores did not differ significantly by age. Beck et al.’s (1999) research was conducted on HIV-infected subjects in government-sponsored clinics in the United Kingdom.
**Educational Level.** Educational level did not contribute to the explained variances in health-related quality of life or satisfaction with care. There was no statistically significant correlation and a non-significant regression analysis. The mean educational level of the subjects was 13 years of education. The investigator had hypothesized that less educated individuals would be less skeptical of the medical system and allow the health care providers full control of their medical care, while the more educated individuals would be more skeptical and want more control over their medical care. The mean educational level of the subjects' was higher than the investigator had expected. The educational level possibly could reflect the 12th grade educational of the subjects who identified themselves as men who have sex with men. The investigator was expecting a mean educational level less than the 10th grade because, in his experience, newly HIV-infected individuals, have an educational level of less than 10th grade. Women who participated in the study presented this educational profile. The current literature review indicates ambiguity about educational level and satisfaction with care. Wachtel and associates (1992) reported that subjects with lower educational level were associated with lower satisfaction with care scores. Whereas, Stein et al. (1993) and Wu et al. (1997) discovered that more educated people reported less overall satisfaction with care.

**Time Since HIV Diagnosis.** Time since HIV diagnosis did not contribute to the explained variances in health-related quality of life or satisfaction with care. There was no statistically significant correlation or regression. The average time since HIV diagnosis was 6.4 years for the subjects in this study. The investigator had hypothesized that there would be a difference in health-related quality of life and satisfaction with care because of the individual’s experience and years of HIV-infection. Newly diagnosed individuals would
have psychological issues or concerns that would affect their health-related quality of life and satisfaction with care. The long-term survivor, on the other hand, would have changes in physical appearance and complications from the disease process and medication regimes that would affect his or her health-related quality of life and satisfaction with care. Currently, no research studies have identified time since HIV diagnosis as a variable that influences health-related quality of life and satisfaction with care positively or negatively.

**Health-Related Quality of Life**

The mean global score for the HIV Overview of Problems-Evaluation System was 131.34 with a median of 108. This indicated that, in general, subjects were satisfied with their health-related quality of life and expressed limited or absence of medical and psychological problems. It was determined, by the investigator, that a score less than or equal to 330 on the HIV Overview of Problems-Evaluation System was acceptable. There is no set cut off level or score established by the developers' of the HOPES. So the investigator chose a mean global score of less than or equal to 330 by calculating the average of the possible high and low scores on the HOPES. In fact, the health-related quality of life scores were distributed as follows: (a) good health-related quality of life score (56.8%), and (b) poor health-related quality of life score (43.2%). The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not explain the variances in health-related quality of life.

When looking at the variables that influence health-related quality of life, in the current research, no differences were found between contemporary research findings and the results of this research study. This research found no statistical difference between gender and the health-related quality of life scores. Lenderking et al. (1998) and Kemppainen
(2001) reported that women are more likely to have poorer health-related quality of life scores.

In this research study, where this subject population was composed of minorities (93.8%), there was no negative correlation with health-related quality of life. Whereas, Lenderking et al. (1998), Fleishman et al. (1998), and Hays et al. (2000) identified that minorities, particularly African-Americans and Latinos, reported lower health-related quality of life scores.

An one-way analysis of variance (ANOVA) was conducted to see if there were any significant differences between clinic sites, health care providers and health-related quality of life. The ANOVA results between clinic sites and health-related quality of life were statistically significant ($p = 0.054$). Subjects at clinic B rated their health-related quality of life higher than subjects at the other regional clinics. The reason for the subjects at clinic B rating their health-related quality of life better than subjects at the other regional clinic is due to the primary health care provider at clinic B was an adult nurse practitioner during the time the study was conducted. The ANOVA in the following section, satisfaction with care, supports that subjects that had a nurse practitioner as their primary health care provider had statistically significant more or greater satisfaction with care. However, the ANOVA results between health care providers and health-related quality of life were not statistically significant ($p = 0.741$).

There was an interesting finding, of potential clinical relevance between health-related quality of life and educational levels ($r = -0.16, p = 0.76$). Subjects with higher educational levels would have lower or better health-related quality of life scores, indicating they experienced fewer complications or physical limitations than the less educated subjects.
Based on the investigator's observations and ten years experience working in the HIV/AIDS field, patients with higher education levels are usually men who have sex with men. These men have access to the internet or support groups which allows them to understand the HIV disease process better than the less educated subjects. They are also more aware of new therapies and research in HIV management. Better educated subjects communicate more concerns to the health care provider about HIV disease, such as side effects or complications from highly active antiretroviral therapy. Also the highly educated subject is less willing to release control to the health care provider in making decisions about his health care. These patients come to appointments with a list of concerns or recommendations for the improvement in their HIV management. The higher educated subject is less trusting about their health care and the health care system.

While, the less educated subjects are more willing to release control to health care providers, these subjects, especially less educated minorities, are more skeptical about the health care system. When it comes to HIV/AIDS, minorities are still hesitant to participate in clinical trials or take certain highly active antiretroviral therapy (HAART). The literature explains this behavior by reference to the Tuskegee studies that generalized mistrust in the health care system among minorities and within the African-American community (Clark, 1998; Gamble, 1997; Thomas & Quinn, 1991). This skepticism often is demonstrated in interviews when patients say what they think health care providers want to hear: they are taking the highly active antiretroviral therapy as prescribed and they have no side effects or complications. However, the lower educated subjects, who are not adhering to their prescribed highly active antiretroviral therapy, develop more complications or opportunistic infections. This leads to the lower educated subjects having higher or poorer health-related
quality of life scores than highly educated subjects. The lower educated subjects are also more likely to be active substance users and have mental health issues. This constellation results in more physical and psychological limitations for lower educated subjects.

The only statistically significant correlation was a negative correlation between health-related quality of life and Karnofsky scores ($r = -0.265$, $p = 0.017$). This indicated that as health-related quality of life scores increase there would be a decrease in the Karnofsky scores suggesting more physical and psychological limitations. The Karnofsky score, is a subjective rating, which reflects a clinical estimate of a patient’s physical state, performance, and prognosis. The scale is from 100, perfectly well, to 0, dead. It has been used in studying cancer and chronic illness (Thomas, 1997). At the community-based AIDS service organization where this study was conducted, health care providers assign a Karnofsky score to each patient at each visit. Patients were only eligible to participate in this research study if they had a Karnofsky score of 80 or higher. A Karnofsky score of 80 or higher indicates that the subject has limited or absent medical and/or psychological problems. In this study, the Karnofsky scores ranged from 80 to 100 with a mean of 93. The investigator expected that there would be a higher percentage of subjects with good health-related quality of life scores, rather than the fifty-seven percent ($n = 46$), since the subjects, had on average, mean Karnofsky scores of 93.

Several research studies have shown that individuals, symptomatic from HIV-infection, have lower health-related quality of life scores indicating one or more severe medical or psychological problems on the Medical Outcomes Study-HIV (MOS-HIV) (Bing et al., 2000; Cleary et al., 1993; Hays et al., 2000; Kemppainen, 2000; Lenderking et al.,...
1998; Wachtel et al., 1992; Wu et al., 1991). Table 23 is a cross tabulation summary of Karnofsky scores with health-related quality of life.

Table 23
Karnofsky Scores and Quality of Life Cross Tabulation

<table>
<thead>
<tr>
<th>Karnofsky Scores</th>
<th>Good QoL (HOPES scores 330 or less)</th>
<th>Poor QoL (HOPES score 331 or greater)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>80.00</td>
<td></td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>90.00</td>
<td>28</td>
<td>22</td>
<td>50</td>
</tr>
<tr>
<td>100.00</td>
<td>18</td>
<td>8</td>
<td>26</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>35</td>
<td>81</td>
</tr>
</tbody>
</table>

Satisfaction with Care

The mean score on the DiTomasso-Willard Patient Satisfaction Questionnaire was 144.48 with a median of 149. This indicated that the majority of the subjects were satisfied with their care. Satisfaction with care was determined, by the investigator, to be a DiTomasso-Willard Patient Satisfaction Questionnaire score greater than or equal to 117. There is no set cut off level or score established by the developers of the DWPSQ. So the investigator chose a mean global score of greater than or equal to 117 by calculating the average of the possible high and low scores on the DWPSQ. Subjects satisfied with care comprised 96.3% (n = 78) of the population and subjects not satisfied with care were 3.7% (n = 3). The socio-demographic variables (age, educational level, and time since HIV diagnosis) made no contribution to explaining the variances in satisfaction with care.
An interesting finding from this study was that one hundred percent (n = 32) of the women, and one hundred percent of the minorities, were satisfied with their care. Several research studies have shown that HIV/AIDS women have significantly lower satisfaction with care scores (Stone et al., 1995; Wachtel et al., 1992). Beck et al. (1999) found that gender did not have a significant influence on satisfaction with care in government-sponsored clinics in the United Kingdom. Also, research studies have shown that minorities report less satisfaction with care (Stein et al., 1993; Stone et al., 1995; Wachtel et al., 1992; Wu et al., 1997).

An one-way analysis of variance (ANOVA) was conducted to see if there were any significant differences between clinic sites, health care providers and satisfaction with care. The ANOVA results between clinic sites and satisfaction with care were not statistically significant (p = 0.848). However, the ANOVA results between health care providers and satisfaction with care were statistically significant (p = 0.059). These results indicate that subjects were more satisfied with care when their health care provider was a nurse practitioner. Several research studies have also shown that satisfaction with care is higher among subjects who have nurse practitioners as health care providers (Aiken et al., 1993; Langner & Hutelmyer, 1995; Larrabee et al., 1997).

Satisfaction with care had two negative correlations: (a) gender (r = -0.257, p = 0.021), and (b) treatment with HIV medications (r = -0.259, p = 0.019). The negative correlation between satisfaction with care and gender indicated that females in the study were more likely to have higher satisfaction with care scores than male or transgender participates. Although eighty-one percent (n= 26) of the females in this study were unmarried or divorced, the majority were mothers or grandmothers, raising children that
may also have HIV-infection. They stated that their major goal in life was to stay alive and be healthy long enough to see their children grow up. Access to care, satisfaction with care, and quality of care for this subpopulation were important. This community-based AIDS service organization provides primary care to all its patients. Especially for women, there are special women health clinics that allow women to receive all their gynecological and primary care in one setting.

Subjects who were not on HIV medications had lower satisfaction scores than those on HIV medications. Patients at this community-based AIDS service organization are all offered highly active antiretroviral therapy regardless of gender, race, risk behavior for HIV-infection, or financial status. Unwillingness to start highly active antiretroviral therapy is particularly common in African-Americans who still feel that HIV medications are toxic or will cause death (Clark, 1998; Gamble, 1997; Thomas & Quinn, 1991). This belief is especially evident in discussions about AZT (zidovudine). In this study, 92% (n = 12) of the 13 subjects, not on HIV medications, were African-Americans; 46.2% (n = 6) were female, 46.2% (n = 6) were male, and 7.6% (n = 1) was a transgender. Based on the investigator’s observation, subjects not on HIV medications have more negative feelings about their disease status and express unwillingness to start highly active antiretroviral therapy. These subjects skip medical appointments, only came for medical appointments when they have an acute medical problem, have a generally negative attitude about the health care delivery system, and verbalize complaints more often than the subjects on HIV medications. These subjects are the ones that have not adjusted to or are not coping well with their HIV diagnosis, they have not told any one of their HIV status. They have fears that someone might see them taking their HIV medications.
Subjects, who are not on HIV medications, tend to be active substance abuse users and/or have mental health issues. These subjects do not keep regular medical appointments and are non-adherent to their prescribed medical regimes. Also these subjects are more skeptical and unwilling to release some control over health status or treatment to the health care provider.

Biases

The biases in this study were: (a) the use of a convenience sample, (b) the researcher, an employee of the community-based AIDS service organization was known to the subjects where the study was undertaken, and (c) the design did not control for other co-morbidities.

Subjects were recruited into the study by the staff nurses at each regional clinic who thought that the patient would be a good candidate based on the entry criteria. They were recruited into the study at the time of their routine medical appointment. No subjects were recruited during an urgent medical appointment. In the study, subjects had a mean Karnofsky score of 92.6, indicating that they had limited or absence of medical and/or psychological problems. High entry scores of the participants may have influenced favorable scores on the HIV Overview of Problems-Evaluation Systems (HOPES) and DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ) for this study.

The subjects either knew the researcher was a health care provider or was an employee of the community-based AIDS service organization. This may have influenced the subjects to score well on the HIV Overview of Problems-Evaluation System and DiTomasso-Willard Patient Satisfaction Questionnaires. Subjects might have wanted to please the researcher because they feared that their scores would be reported to subjects’
individual health care provider(s) or to the administration of the community-based AIDS service organization.

The Karnofsky score of 80 or higher was used to control for symptomatology of HIV-infection such as fatigue or fever. But, such co-morbidities as hypertension, diabetes, and mental illness, especially depression, were not factored into the research design. Co-morbidities, especially the presence of other chronic illness, might have had a negative influence on the subjects' health-related quality of life scores. Co-morbidities were not factored into the research design because subjects were being surveyed only at one time period, and because the investigator was interested in studying the influence of HIV-infection on health-related quality of life and satisfaction with care.

Conceptual Frameworks

Health-Related Quality of Life

This study used Wilson & Cleary's (1995) health-related quality of life conceptual model, a taxonomy of patient outcomes. The conceptual model of patient outcomes is composed of the following dimensions: (a) biological and physiological factors; (b) symptom status; (c) functional status; (d) general health perceptions; and (e) overall quality of life. There are also two external factors involved in this model: (a) characteristics of the individual, and (b) characteristics of the environment. This framework was selected because of its compatibility with the HIV Overview of Problems-Evaluation System (HOPES) instrument, and because it provides insight into particular socio-demographic variables that might influence health-related quality of life.

Characteristics of the individuals are distinguishing traits, qualities, or identities of the subjects. Characteristics of the environment are a conglomerate of external conditions...
that influence life of the subjects or are influenced by their decision to seek and adhere to their medical regimes (Sousa, 1999; Wilson & Cleary, 1995). The framework seemed appropriate because the investigator sought to determine the factors associated with positive or negative health-related quality of life experiences at a community-based AIDS service organization, and to see what organizational structures are conducive to providing optimal care and to meeting the needs of their patients.

The study examined specific characteristics of the individual to determine the influence of health-related quality of life, socio-demographic variables as age, educational level, and time since HIV diagnosis. These socio-demographic variables did not demonstrate a positive or a negative influence on health-related quality of life. There was an interesting, but not a significant relationship between health-related quality of life and educational level. After conducting a Pearson correlational matrix between health-related quality of life and all the socio-demographic variables, it was determined that there was a negative correlation between health-related quality of life and Karnofsky scores.

As patients continue to live longer with HIV-infections, new complications emerge from highly active antiretroviral treatment (HAART), and new treatment strategies are employed. Factors that influence health-related quality of life will become extremely important to patients, nurses and health care providers. The Wilson & Cleary (1995) health-related quality of life conceptual model can be used to guide nurses and health care providers in determining what factors of the HIV disease process and/or characteristics of the individual and environment influence health-related quality of life. Even though this research study did not find a positive or negative influence between the socio-demographic variables of age, educational level, and time since HIV-infection, and health-related quality

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of life, there were some interesting findings that resulted from this research study that need further investigating. The use of the Wilson & Cleary (1995) health-related quality of life conceptual model in future studies is relevant to examine the influence of biological/physiological factors, symptom status, functional status, and characteristics of the individual and environment are warrant in the HIV/AIDS population.

**Satisfaction with Care**

This study used the Ware's (1978) taxonomy of patient satisfaction. This multidimensional taxonomy of patient satisfaction provides detailed information of: the art of care, technical quality of care, accessibility/convenience, finances, physical environment, availability, efficacy, and continuity. The taxonomy was selected for this research study because of its compatibility with the DiTomasso-Willard Patient Satisfaction Questionnaire as a study instrument and to provide an insight into particular socio-demographic variables that could influence satisfaction with care. The investigator expected that the use of the model would yield a better understanding of factors that influence satisfaction with care by exploring the socio-demographic variables of underserved, urban subjects, newly infected with HIV. The goals were to investigate what influences subjects to continue to seek care at a community-based AIDS service organization, and what organizational structures of a community-based AIDS service organization are conducive to providing optimal care.

This study examined all dimensions of the Ware's (1978) taxonomy of patient satisfaction except the finance of the community-based AIDS service organization. In this model, finance considers the cost effectiveness of a health care provider in association with increase revenues for the institution and lower expenses for the patient. Finance was not examined because the setting was a community-based AIDS service organization that is able...
to provide medical services to patients at no cost because it receives its revenues from Ryan White Comprehensive AIDS Resources Emergency (CARE) act's titles I-III and Part F. The socio-demographic variables (age, educational level, and time since HIV diagnosis) did not have a positive or negative influence on satisfaction with care in this study. After conducting a Pearson correlational matrix between satisfaction with care and all the socio-demographic variables, it was determined that there was a negative correlation between satisfaction with care, gender and being treated with HIV drugs.

The Ware's (1978) taxonomy of patient satisfaction can be used to guide nurses and health care providers in determining what factors of the HIV disease process or characteristics of the individual influence satisfaction with care. Even though this research study did not find a positive or negative influence between the socio-demographic variables (age, educational level, and time since HIV-infection) and satisfaction with care, there were some interesting findings that need further investigating using the Ware’s (1978) taxonomy of patient satisfaction. Satisfaction with care or patient satisfaction questionnaires currently remain popular means of evaluating the accountability of health care professions. Understanding the patient health value system may be an important adjunct to the assessment of patient satisfaction (DiTornasso & Willard, 1991; Cleary & McNeil, 1998).

Summary

Measurement of outcomes such as health-related quality of life and satisfaction with care are key elements used to evaluate therapeutics, clinical management strategies, the general health of the patient population, organizational performance, and the impact or effect of health care policies on care delivery. Incorporating these outcomes measurements in the evaluation of competing therapies and organizational structures, yields better
understanding of the effectiveness of patient care delivery. Researchers, administrators, and clinicians at community-based AIDS service organizations can use these methodologies to determine optimal strategies for enhancing health-related quality of life and delivering satisfaction with care based on available resources (Sousa, 1999).

Conclusions

Adults receiving care at a community-based AIDS service organization who participated in this study indicated that their health-related quality of life and satisfaction with care were improved due to the care they received. These results indicate that a community-based AIDS service organization that receives Ryan White Comprehensive AIDS Resources Emergency (CARE) funding is capable of improving health-related quality of life and providing quality health care in individuals with HIV-infection. The continuation funding by the Ryan White CARE act, particularly for the underserved and/or uninsured HIV-infected individuals, is beneficial to community-based AIDS service organizations in providing optimal standard of care to their patients. One-way analysis of variances (ANOVA) revealed that health-related quality of life was statistically significant between regional clinics, clinic B ranked the highest, and that satisfaction with care was the highest among subjects who had a nurse practitioner as a health care provider. There was a statistically significant negative correlation between health-related quality of life and Karnofsky scores. Satisfaction with care had two statistically significant negative correlations: (a) gender and (b) treatment with HIV medications. However, socio-demographic variables (age, educational level, and time since HIV diagnosis) did not determine the perception of health-related quality of life and satisfaction with care among the adults who were participants in this study.
Although this study failed to demonstrate any statistical relationship between the socio-demographic variables of age, educational level, and time since HIV diagnosis, the investigator thinks that nursing and health care providers need to address and understand socio-demographic variables that influence health-related quality of life and satisfaction with care for patients, particular women, with HIV/AIDS. Nursing and health care interventions should be focused on articulating variables that influence health-related quality of life and satisfaction with care. Also, nurse practitioners should continue to be utilized as health care providers for individuals with HIV-infection.

The investigator believes that nursing and health care interventions should include: (a) incorporating family/social support members into the patient’s medical regime and decision making, (b) providing adherence lectures, (c) offering peer support groups, and (d) establishing medical regimes that are compatible with the individual’s life style, particularly in the case of HIV-infected women who are care givers themselves. Since there was an interesting finding, which was not statistically significant, between health-related quality of life and satisfaction with care further research is warranted. Further research should be aimed at identifying other influential variables, with the ultimate goal of developing interventions to aid patients in their effort to manage living with HIV/AIDS.

Recommendations

1. Conduct the study in a similar population using a longitudinal design to validate relationships among health-related quality of life and satisfaction with care over time, controlling for co-morbidities.

2. Conduct the study comparing populations in regional community-based AIDS service organizations, public health settings, and academic settings.
3. Conduct a qualitative study of the health-related quality of life and satisfaction with care of HIV-infected women and elderly persons with HIV-infection, who receive care at a community-based AIDS service organization.

4. Investigate the relationships and influences of patients' attitudes and beliefs toward health-related quality of life and satisfaction with care beyond those of socio-demographic variables of age, educational level, and time since HIV diagnosis.
References


Appendix A

Approval Letter
December 5, 2001

Mr. Robert T. Dodge
School of Nursing

Dear Mr. Dodge:

Your research project titled "Factors that Influence Health-Related Quality of Life and Satisfaction with Care among Adults at a Community-Based AIDS Service Organization," was certified by the Committee for the Protection of Human Subjects (CPHS) as meeting the requirements of the Federal regulations governing protection of human subjects.

CPHS will maintain a copy of your submission on file. You are obligated to follow the research protocol and procedures for obtaining informed consent as you have specified. If you wish to initiate any changes in the research protocol or the informed consent procedure, you should submit this request to CPHS in writing.

This approval will remain active for a period of one year from the date of this letter. If the project continues beyond one year, please resubmit your materials for renewal in a timely fashion so that your research may continue uninterrupted.

All researchers are required to complete training in the protection of human subjects. A way to do this is to visit the NIH training link at: http://obstm.nih.gov.ccl. An alternative is to pick up a tutorial from the Office of Sponsored Programs and Research Services, 213 McMahon Hall.

Good luck with your research.

James W. Mayo, Ph.D.
Secretary
Committee for the Protection of Human Subjects

cc: Sr. Mary Jean Flaherty
Appendix B

Informed Consent
INFORMED CONSENT FORM

NAME OF STUDY: Factors that Influence Health-Related Quality of Life and Satisfaction with Care among Adults at a Community-Based AIDS Service Organization.

INVESTIGATOR: Robert Dodge, MSN, RN, ANP

SUPERVISOR: Professor Sr. Mary Jean Flaherty, Ph.D., RN, FAAN
- Telephone:

QUESTIONS: Robert Dodge, MSN, RN, ANP
- Telephone:
- E-mail:

I. DESCRIPTION AND PURPOSE OF THE STUDY: I understand that I am being asked to participate in this research study. I understand that the purpose of this study is to find out the factors that affect HIV-infected adult patients' health-related quality of life and satisfaction with care at a community-based AIDS service organization. The results of this study may help in the evaluation of services currently being given to HIV-infected people at a community-based AIDS service organization. This study if being done at a community-based AIDS service organization in order to collect information on those groups typically not included in studies of this nature: people who are uninsured, under-insured, and representative of minorities. I understand that this study is being carried out to fulfill partial requirements for a doctoral dissertation in nursing for Robert Dodge, MSN, RN, ANP at The Catholic University of America.

II. DESCRIPTION OF PROCEDURES: A mutually agreed upon time and place will be scheduled. I understand that the investigator will provide a packet of questionnaires including a consent form, the Demographic Data Form, the HIV Overview Problems-Evaluation System a quality of life questionnaire, and the DiTomasso-Willard Patient Satisfaction Questionnaire, to me. The completion of these questionnaires will take about 1 hour. I understand this will be the duration of this study. I also understand that Robert Dodge, MSN, RN, ANP may review my medical records for verification of my health status.

III. FORESEEABLE RISKS OR DISCOMFORTS: I understand that participation in this study is voluntary and will not affect my care. I understand that some items on the questionnaires may cause anxiety. If I express anxiety I can request to stop the completion of the questionnaires and contact Robert Dodge, MSN, RN, ANP who will provide me with
some support. I will be referred to my health care provider or case worker if additional resources are necessary. I understand that I may discontinue my participation at any time for any reason and it will not affect my continuing care.

IV. BENEFIT TO SUBJECTS: Although my participation may not benefit me directly, I understand that my participation in this study has the potential of assisting in the verification and evaluation of health-related quality of life and satisfaction with care of HIV-infected adults at community-based AIDS service organizations. I understand there is no monetary compensation for my participation in this study.

V. CONFIDENTIALITY OF SUBJECT IDENTITY/RESEARCH RECORDS: I understand that no questionnaires will identify me by name. I understand that my privacy will be secured by the use of coding of all the questionnaires and securing them in a locked place in Robert Dodge’s office. I understand that all information provided by me in relation to this study is guaranteed confidential to the extent that it is legally possible. I understand that my research records may be subpoenaed by court order or may be inspected by federal regulatory authorities.

VI. STORAGE OF STUDY TOOLS: I understand that all study materials will be secured under lock and key for five years in Robert Dodge’s office, at which time they will be destroyed. Identifying data, such as my name and informed consent form, will be kept separate from the questionnaires. Only the investigator will have access to these questionnaires and the informed consent forms.

VII. TERMINATION OF PARTICIPATION: I understand that my participation in this study is entirely voluntary. I understand that I may refuse to participate and can withdraw my consent at any time during the study without penalty or loss of benefits to which I may be entitled. I understand that my health care services at this community-based AIDS service organization will not be affected by my decision to participate or withdraw from this study.

I have had an opportunity to ask any questions about the study and/or my participation in the study with Robert Dodge, MSN, RN, ANP and these questions have been answered to my satisfaction. If I have any other questions about this study, I understand that I can call him at [redacted]

I understand that I will receive a signed copy of this informed consent form to keep.

I have agreed to participate in this study.

Subject’s Signature ___________________________ Investigator’s Signature ___________________________ Witness’s Signature ___________________________
Any complaints or comments about your participation in this research projects should be directed to the Secretary, Committee for the Protection of Human Subjects, Office of Sponsored Programs and Research Services, The Catholic University of America, Washington, D.C. 20064; Telephone [redacted].
Appendix C

Demographic Data Form

(DDF)
Demographic Data Form:

Patient ID #: __________

This questionnaire is designed to describe the patients who receive care in this clinic. Your information, along with those of other patients, will be used to try to improve the care you are now receiving.

Please circle or fill in the response that best describes you. 
THERE IS NO RIGHT OR WRONG ANSWER. THIS IS NOT A TEST.

Thank you very much for your time and your help.

1) Gender:

1. Female
2. Male
3. Transgender

2) Age: __________

3) Race:

1. African-American
2. White
3. Latino/a
4. Other __________

4) Education Level: __________

5) Marital Status:

1. Married
2. Single
3. Divorced
4. Widowed
Demographic Data Form:

Patient ID #: __________

6) Social Support:
   1. Partner/Significant Other
   2. Family
   3. Friends
   4. Church
   5. Other __________

7) Risk Behavior For HIV:
   1. Heterosexual
   2. Men Who Have Sex with Men
   3. Bisexual
   4. Intravenous Drug Use
   5. Other __________

8) HIV Status:
   1. HIV positive
   2. AIDS

9) Number of Years Since HIV Diagnosis? ________
Demographic Data Form:

Patient ID #: __________

10) Medical Finances:
   1. Medicaid
   2. ADAP
   3. Private Insurance
   4. None
   5. Other ______

11) Household Income:
   1. Less than $20,000
   2. $20,000-$34,999
   3. $35,000-$49,999
   4. $50,000-$64,999
   5. $65,000-79,999
   6. $80,000 or more

12) Work Status:
   1. Employed-Full Time
   2. Employed-Part Time
   3. Unemployed
   4. Disabled
   5. Student
   6. Other ________
Demographic Data Form:

Patient ID #: __________

13) Primary Health Care Provider:
   1. Physician
   2. Nurse Practitioner
   3. Physician Assistant

14) Which clinic do you seek your health care at?
   1. Elizabeth Taylor Medical Center
   2. Max Robinson Center
   3. Whitman-Walker Northern Virginia Clinic
   4. Suburban Maryland of Whitman-Walker

15) Length of time seeking care at this clinic? ____________

16) Are you currently taking any HIV/AIDS drugs?
   1. Yes
   2. No
Demographic Data Form:

Patient ID #: __________

17) How long have you been taking HIV/AIDS drugs?
   1. Less than 1 year
   2. 1 year to 2 years
   3. 2 years to 4 years
   4. 4 years to 6 years
   5. 6 years to 8 years
   6. 8 years to 10 years
   7. Greater than 10 years __________

18) How many HIV/AIDS drugs do you currently take?
   1. None
   2. 1 drug
   3. 2 drugs
   4. 3 drugs
   5. 4 drugs
   6. 5 or more drugs
Appendix D

HIV Overview of Problems-Evaluation System (HOPES)

and

Approval Letter
HIV Overview of Problems-Evaluation System (HOPES) For Research

Developed

by

C. Anne Coscarelli Schag, Ph.D.,

Richard L. Heinrich, M.D.

and

Patricia A. Ganz, M.D.

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HIV Overview of Problems-Evaluation System
For Research

Patient ID#:__________________________________________________________

Date:______________________________________________________________

Instructions

Below is a list of Problem Statements that describe situations and experiences of individuals
who have HIV-infection. Read each statement and circle the number that best describes
HOW MUCH EACH STATEMENT APPLIES TO YOU during the PAST MONTH,
INCLUDING TODAY. Some sections will not apply to you. Please skip these sections
and proceed to the next one as directed.

Example

How much does it apply to you? 0= Not at all
1= A little
2= A fair amount
3= Much
4= Very much

1. I have difficulty walking
0 1 2 3 4

2. I find that food tastes bad
0 1 2 3 4

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### HOPES

<table>
<thead>
<tr>
<th>How much does it apply to you?</th>
<th>0 = Not at all</th>
<th>1 = A little</th>
<th>2 = A fair amount</th>
<th>3 = Much</th>
<th>4 = Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have difficulty bending or lifting</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty walking and/or moving around</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty doing physical activities such as running and playing sports</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not have the energy I used to</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty driving</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty doing household chores</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty bathing, brushing my teeth, or grooming myself</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty preparing meals</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am not interested in recreational activities like I used to be</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not engage in the recreational activities that I used to</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not have enough enjoyable activities to fill the day</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty planning activities because of the HIV infection or its treatments</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot gain weight</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am continuing to lose weight</td>
<td>0 1 2 3 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HOPES

15. I find food unappealing.................................................................0 1 2 3 4

16. I find that food tastes bad..............................................................0 1 2 3 4
17. I find it difficult to swallow............................................................0 1 2 3 4

18. I find that HIV infection or its treatments keep me from working.................................................................0 1 2 3 4

19. I find that HIV infection or its treatments interfere with my ability to work.................................................................0 1 2 3 4

20. I frequently have pain.................................................................0 1 2 3 4

21. I have pain that is not controlled by pain medication....................0 1 2 3 4
22. I have pain that is controlled by pain medication................................0 1 2 3 4

23. I find that my clothes do not look good on me................................0 1 2 3 4
24. I find that my clothes do not fit......................................................0 1 2 3 4

25. I have difficulty finding clothes to fit.................................................0 1 2 3 4

26. I find that the medical team withholds information from me about the disease.................................................................0 1 2 3 4

27. I find that medical staff is disrespectful or discourteous....................0 1 2 3 4

28. I find that doctors don't provide enough information....................0 1 2 3 4
29. I find that nurses don't provide enough information.....................0 1 2 3 4

30. I have difficulty asking doctors questions.........................................0 1 2 3 4
31. I have difficulty asking nurses questions........................................0 1 2 3 4

32. I have difficulty expressing my feelings to the doctors and nurses........0 1 2 3 4

33. I have difficulty telling my doctor about new symptoms.................0 1 2 3 4

34. I have difficulty understanding what the doctors tell me about the disease or its treatments.................................................................0 1 2 3 4
HOPES

Patient ID #: __________

35. I have difficulty understanding what the nurses tell me about the disease or its treatments.................................................................0 1 2 3 4
36. I would like to have more control over what the doctors do to me......0 1 2 3 4
37. I would like to have more control over what the nurses do to me......0 1 2 3 4
38. I am concerned about my physical appearance........................................0 1 2 3 4
39. I am embarrassed to show my body to others because of my illness......0 1 2 3 4
40. I am uncomfortable with the changes in my body............................0 1 2 3 4
41. I feel badly about myself since having the HIV infection...............0 1 2 3 4
42. I feel a sense of guilt associated with the HIV infection...................0 1 2 3 4
43. I frequently feel anxious.................................................................0 1 2 3 4
44. I frequently feel depressed..............................................................0 1 2 3 4
45. I frequently feel angry....................................................................0 1 2 3 4
46. I frequently feel upset....................................................................0 1 2 3 4
47. I frequently feel overwhelmed by my emotions and feelings about the HIV infection.................................................................0 1 2 3 4
48. I feel emotionally distressed by the loss of others with HIV infection...0 1 2 3 4
49. I have difficulty sleeping.................................................................0 1 2 3 4
50. I have difficulty concentrating..........................................................0 1 2 3 4
51. I have difficulty remembering things..................................................0 1 2 3 4
52. I have difficulty thinking clearly..........................................................0 1 2 3 4
53. I feel socially isolated due to the HIV infection..................................0 1 2 3 4
54. I have difficulty telling my friends or relatives to come over less often.................................................................0 1 2 3 4
55. I have difficulty telling my friends or relatives to leave when I do not feel well.................................................................0 1 2 3 4
<table>
<thead>
<tr>
<th>Question</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>56. I have difficulty asking my friends or relatives to do something fun with me.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>57. I feel that I can not tell everyone I know about the HIV infection.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>58. I do not know what to say to my friends or relatives.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>59. I have difficulty asking friends or relatives to do things for me.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>60. I have difficulty telling my friends or relatives about the HIV infection.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>61. I have difficulty asking my friends or relatives to come over more often.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>62. I find that my friends or relatives tell me I'm looking well when I'm not.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>63. I find that my friends or relatives withhold information from me.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>64. I find that my friends or relatives avoid talking with me about the HIV infection.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>65. I find that my friends or relatives avoid touching me.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>66. I find that my friends or relatives do not visit often enough.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>67. I find that my friends or relatives do not call often enough.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>68. I find that my friends or relatives are uncomfortable when they visit me.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>69. I find that friends, or relatives, have difficulty talking with me about my illness.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>70. I feel uncomfortable when I see other patients.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>71. I become nervous when I have to go to the hospital.</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>72. I become nervous when I am waiting to see the doctor.</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>
73. I become nervous when I am waiting to find out the results of tests........0 1 2 3 4
74. I become nervous when I am having diagnostic tests..........................0 1 2 3 4
75. I become nervous when I get my blood drawn......................................0 1 2 3 4
76. I worry about whether my treatments are working..............................0 1 2 3 4
77. I worry about whether the HIV infection is progressing......................0 1 2 3 4
78. I worry about transmitting the HIV infection to others.......................0 1 2 3 4
79. I worry about not being able to care for myself..................................0 1 2 3 4
80. I worry about being alone as the HIV infection progresses....................0 1 2 3 4
81. I worry about how my friends or family will manage if I die.................0 1 2 3 4
82. I sometimes don't show up for my doctor's appointment......................0 1 2 3 4
83. I sometimes don't show up for my treatments......................................0 1 2 3 4
84. I sometimes don't take my medication as prescribed............................0 1 2 3 4
85. I sometimes don't follow my doctor's instructions...............................0 1 2 3 4
86. I have financial problems.....................................................................0 1 2 3 4
87. I find it difficult to make financial arrangements, wills, or living wills.0 1 2 3 4
88. I have difficulty finding a place to live..............................................0 1 2 3 4
89. I have difficulty paying for my medication.........................................0 1 2 3 4
90. I have difficulty getting dental or other medical care........................0 1 2 3 4
91. I have difficulty getting personal services (haircuts, manicures, laundry, etc.)0 1 2 3 4
92. I have insurance problems..................................................................0 1 2 3 4
93. I have difficulty with transportation to and from my medical appointments and/or other places. ..........................................................0 1 2 3 4

94. I am gaining too much weight.................................................................0 1 2 3 4

95. I cough a lot ............................................................................................0 1 2 3 4

96. I find some diagnostic procedures extremely painful..........................0 1 2 3 4

97. I have fevers and/or sweats.......................................................................0 1 2 3 4

98. I have times when I do not have control of my bowels or have frequent diarrhea..............................................................0 1 2 3 4

99. I have times when I do not have control of my bladder.......................0 1 2 3 4

100. I have frequent episodes of constipation..............................................0 1 2 3 4

101. I have shortness of breath with my everyday activities..........................0 1 2 3 4

102. I have increasing problems with my vision..........................................0 1 2 3 4

103. I have rashes or sores in my mouth.........................................................0 1 2 3 4

Are you working or have you been employed during the last month? Yes No

If No, skip to next section

104. I have difficulty talking to my boss about the HIV infection...............0 1 2 3 4

105. I have difficulty talking to the people who work with me about the HIV infection..........................................................0 1 2 3 4

106. I have difficulty telling my employer that I cannot do something because of my HIV infection..............................................0 1 2 3 4

107. I have difficulty asking for time off from work for medical care........0 1 2 3 4
HOPES

Patient ID #: ________

108. I am worried about being fired.........................................................0 1 2 3 4

Did you look for work during the past month? Yes No

If No, Skip to next section.

109. I have difficulty finding a new job since I have had HIV infection......0 1 2 3 4

110. I find that employers are reluctant to hire people with HIV infection.........................................................0 1 2 3 4

Have you attempted any sexual activity since your diagnosis of HIV infection? Yes No

If No, Skip to next section.

111. I find that the frequency of sexual activity has decreased.................0 1 2 3 4

112. I have difficulty becoming sexually aroused.................................0 1 2 3 4

113 a. I have difficulty getting or maintaining an erection (Males)........0 1 2 3 4

b. I have difficulty getting lubricated (Females).................................0 1 2 3 4

114. I have pain or discomfort with sexual activity..............................0 1 2 3 4

115. I have difficulty reaching orgasm..................................................0 1 2 3 4

Do you have a lover(s), are you married or are you in a significant relationship? Yes No

If No, Skip to next section.

116. My partner(s) and I have difficulty talking about our feelings.........0 1 2 3 4
HOPES

117. My partner(s) and I have difficulty talking about our fears.................0 1 2 3 4

118. My partner(s) and I have difficulty talking about what will happen after my death...........................................................................................................0 1 2 3 4

119. My partner(s) and I have difficulty talking about our future....................0 1 2 3 4

120. My partner(s) and I have difficulty talking about the HIV infection and what might happen..........................................................0 1 2 3 4

121. My partner(s) and I have difficulty talking about wills and financial arrangements......................................................................................0 1 2 3 4

122. I do not feel like embracing, kissing, or caressing my partner(s)............0 1 2 3 4

123. My partner(s) does not feel like embracing, kissing or caressing me.............................................................................................................0 1 2 3 4

124. I am not interested in touching my partner(s).........................................0 1 2 3 4

125. My partner(s) is not interested in touching me........................................0 1 2 3 4

126. My partner(s) and I are not getting along as well as we usually do.........................0 1 2 3 4

127. My partner(s) and I are upset with each other more often than usual.............................................................................................................0 1 2 3 4

128. My partner(s) and I have so much time together that we get on each other's nerves......................................................................................0 1 2 3 4

129. My partner(s) and I are more distant than usual........................................0 1 2 3 4

130. My partner(s) won't let me do activities that I am capable of doing.........................0 1 2 3 4

131. My partner(s) spends too much time taking care of me........................0 1 2 3 4

132. My partner(s) does not take care of me enough........................................0 1 2 3 4

133. I have difficulty asking my partner(s) to take care of me.......................0 1 2 3 4
134. I worry that my partner(s) will leave me as a result of the HIV infection.

Are you single and/or not in a significant relationship? Yes No
If No, Skip to next section.

135. I have difficulty initiating new relationships.

136. I have difficulty telling new acquaintances about the HIV infection or its treatments.

137. I am afraid to initiate a sexual relationship with someone because I might infect them with HIV.

Has your sexual activity/interest decreased since your diagnosis of HIV infection? Yes No
If No, Skip to next section

138. I am less active/interested in sex because I am afraid of infecting others.

139. I am less active/interested in sex because I feel less sexually attractive.

140. I am less active/interested in sex because my partner(s) fears being infected.

141. I am less active/interested in sex because I do not have enough energy.

142. I am less active/interested in sex because I might get new infections.
Have you had chemotherapy treatments for Kaposi's Sarcoma (KS), Lymphoma or other cancer in the last month?  
Yes  
No  
If No, Skip to next section.

143. I become nervous when I get chemotherapy

144. I become nauseated during and/or before chemotherapy

145. I vomit during and/or before chemotherapy

146. I feel sick when I think about my chemotherapy

147. I feel nauseated after I receive chemotherapy

148. I vomit after chemotherapy

149. I feel tired after my chemotherapy

150. I have other side effects after chemotherapy

151. I have lost my hair and/or it is growing back slowly because of chemotherapy

Have you had radiation therapy treatments for Kaposi's Sarcoma (KS), Lymphoma or other cancer in the last month?  
Yes  
No  
If No, Skip to next section.

152. I feel fatigued after my radiation treatments

153. I get nervous when I get radiation treatments

154. I feel nauseous or vomit after my radiation treatments
Have you had antiretroviral therapy (e.g. AZT, DDI, etc.) in the last month?  

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<th>Scale</th>
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</tr>
<tr>
<td>156. I feel nauseous or have other stomach discomforts from antiretroviral therapy</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>157. I have stomach pain from antiretroviral therapy</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>158. I have abnormal blood tests from antiretroviral therapy</td>
<td>0 1 2 3 4</td>
</tr>
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<td>159. I have muscular or body aches from antiretroviral therapy</td>
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</tr>
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<td>160. I have headaches from antiretroviral therapy</td>
<td>0 1 2 3 4</td>
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<tr>
<td>161. I feel agitated or confused from antiretroviral therapy</td>
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<td>162. I have other side effects from antiretroviral therapy</td>
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Do you have children?  

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<th>Scale</th>
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</thead>
<tbody>
<tr>
<td>163. I have difficulty taking care of the children and/or the grandchildren</td>
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<tr>
<td>164. I have difficulty helping my children cope with my illness</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>165. I have difficulty helping my children talk about my illness</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

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Please list any additional problems related to your HIV infection or treatment-related problems that may not have been addressed:

A. 

B. 

C. 

D. 

E. 

Patient ID #: _________
February 29, 2000

Dear Dr. Patricia Ganz,

I am writing to you today to obtain a copy of the instrument titled HOPES. I am a doctoral student at The Catholic University of America School of Nursing. My dissertation proposal is the health-related outcomes and satisfaction of adult HIV-infected individuals at an outpatient clinic. I would like to review the HOPES instrument to see if it would be an appropriate instrument for my dissertation. I would be looking at patients that attend a community based HIV clinic in the Washington, DC area.

If there are any questions or concerns please feel free to contact me. Thank you for your time and cooperation.

Sincerely,

Robert Dodge, RN, MSN, ANP
Adult Nurse Practitioner
January 4, 1999

Dear Colleague:

Thank you very much for your letter regarding use of the HOPES. The HOPES is copyrighted and is available to users under a specific agreement. Because it is still in development, there is no charge for its use, but we do request information on how you have used the instrument and access to the data that you collect. I will enclose a copy of the user’s agreement and will be happy to forward a copy of the instrument after I receive the information from you.

Sincerely,

Patricia A. Ganz, M.D.
Professor, Schools of Medicine and Public Health
Overview of Problems-Evaluation System (HOPEs)

USER AGREEMENT

1. The HOPEs is a copyrighted instrument that is owned by CARES Consultants. [Redacted]

2. Since the HOPEs is still in a developmental phase, it is available for use without fee under certain specific conditions. If you are interested in using the HOPEs, please see the conditions listed below and provide the information necessary along with a signed copy of this user agreement.

3. The HOPEs shall not be modified, abridged, condensed, translated, adapted, recast or transformed in any manner or form including but not limited to any minor or significant change in wording or organization.

4. The USER shall not reproduce the HOPEs or materials provided by CARES Consultants except for the limited purpose of generating sufficient copies for its own uses as granted by this agreement. The USER shall not distribute copies of the HOPEs or other materials to third parties by sale, rental, lease, lending or any other means.

5. The USER shall not take any action which would destroy or diminish CARES Consultants rights in the HOPEs copyright or trademark. The USER shall not use the HOPEs copyright/trademark or any mark or names confusingly similar thereto, for any purpose not authorized in writing by CARES Consultants. The USER otherwise agree to cooperate with CARES Consultants in preserving the goodwill in the HOPEs trademark/copyright.

6. The USER shall provide CARES Consultants or its representative with a written summary of the project in which the HOPEs shall be used. This summary will include the purpose, research questions to be addressed, number of administrations over what time periods, number of patients, and expected date of completion. Estimated publications to be generated using the HOPEs will be identified by number and topic area.

7. The USER shall agree to provide CARES Consultants or its representative with the data collected with the HOPEs so that normative data can be obtained and used for further psychometric
and descriptive purposes. The data shall be sent on IBM
compatible diskette in a database program. All raw data from each
item shall be included along with descriptive information and a
codebook for how the data is organized. Demographic and medical
data must be provided including the following:

Date of HOPES Completion (month, day, year),
Age (in years),
Gender (1 male, 2 female),
Marital Status (1 single, 2 married, 3 separated, 4 Divorced,
5 Widowed),
Education (6-20 representing years completed),
Ethnicity (1 white, 2 African American, 3 Hispanic, 4 Asian,
5 Native American & Other),
Date of HIV diagnosis (month, day, year),
Risk Factor for HIV infection (Homosexual contact,
heterosexual contact, Bisexual contact, IV drug
use, Transfusion, Other: 1 yes 2 no),
Current Status of HIV infection (1 Asymptomatic, 2 ARC, AIDS,
AIDS with cancer)
Antiretroviral therapy (1 yes, date, 2 no tried by couldn’t
tolerate, 3 no, 4 planned, not started yet),
Karnofsky Performance Status (0-100 in deciles).

Additional information may be provided and specified as an
addendum to this agreement.

8. The USER may publish data related to the specific goals of
project as indicated in the summary provided by the USER and will
not publish on other topics without first obtaining permission in
writing from CARES Consultants. The USER will acknowledge the
developers of the HOPES and indicate that all correspondence
regarding the use of the HOPES will be directed to CARES
Consultants including name, address, telephone and FAX # as
indicated above. The HOPES will be acknowledged as a copyrighted
instrument that was obtained through special agreement with CARES
Consultants.

9. A separate USER agreement must be obtained before using the
HOPES in any project as specified above. The agreement obtained
apply to only one project and subsequent projects must receive
approval and a separate agreement filed with CARES Consultants or
their representative.

10. Dr. Patricia Gans has been given the authority to grant
approval for the use of the HOPES provided this agreement is
signed and all conditions agreed to and carried out. Dr. Patricia
Gans will act as a representative of CARES Consultants, although
Dr. Gans has no financial involvement with CARES Consultants. Her
interest is from an academic interest in the area of quality of
life and HIV infection. Dr. Gans may specify that approval of the
HOPES USER AGREEMENT

HOPES may be contingent upon collaboration and co-authorship. If this condition is in effect it will be marked below.

11. This USER agreement may be revoked by CARES Consultants if conditions are breached. Should the HOPES become available for fee, future projects will require payment, although current projects approved may be completed without any charges incurred.

12. Signature CARES Consultants and Representative:

C. Anne Coscarelli Schag, Ph.D. Patricia A. Gans, M.D.

13. USER Information:

Name: Robert Dodge, RN, INS, AU
Affiliation: Whitman Walker Clinic, Inc.
Address: [Redacted]
Telephone: [Redacted]
Fax: [Redacted]

14. Summary of Project attached to validate agreement: Yes No

15. Translation of HOPES Needed? Yes No

If Yes, Must attach signed TRANSLATION AGREEMENT

16. Co-authorship Required: Yes No

Specify Conditions: [Redacted]

17. Signature indicates that the USER understands the conditions of agreement and agrees to abide by the conditions set forth.

USER Signature: [Redacted] Date: 03/09/00
Appendix E

DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ)

and

Approval Letter
Patient Satisfaction Survey

Patient ID #: ________

This questionnaire is designed to find out what kind of things patients like and dislike about the care they receive in this clinic. Your opinions, along with those of other patients, will be used to try to improve the care you are now receiving.

Please circle the response which best describes how you feel about each statement according to whether you Strongly Disagree (SD), Disagree (D), Agree (A), or Strongly Agree (SA). THERE ARE NO RIGHT OR WRONG ANSWERS. THIS IS NOT A TEST.

Thank you very much for your time and your help.

Circle the response that comes closest to your own opinion.

Code:  SA- Strongly Agree (4)
A- Agree (3)
D- Disagree (2)
SD- Strongly Disagree (1)

1. The receptionist(s) here have respect for patients.
   1- SD  2- D  3- A  4- SA

2. My health care provider spends enough time explaining my medical condition(s) to me.
   1- SD  2- D  3- A  4- SA

3. My health care provider really knows his/her stuff.
   1- SD  2- D  3- A  4- SA

4. My health care provider truly understands me as a person.
   1- SD  2- D  3- A  4- SA
Patient ID #: _________

5. My health care provider gives me the best quality of care.
   1- SD  2- D  3- A  4- SA

6. I would recommend my health care provider to my friends.
   1- SD  2- D  3- A  4- SA

7. During an office visit, the receptionist(s) makes me feel welcome.
   1- SD  2- D  3- A  4- SA

8. The receptionist(s) have a pleasant attitude at this clinic.
   1- SD  2- D  3- A  4- SA

9. The nurse(s) treat me politely.
   1- SD  2- D  3- A  4- SA

10. I can trust what my health care provider tells me.
    1- SD  2- D  3- A  4- SA

11. My health care provider confuses me with technical terms.
    1- SD  2- D  3- A  4- SA

12. My health care provider is available when I need him/her.
    1- SD  2- D  3- A  4- SA
Patient ID #: __________

13. I am confident that my health care provider really knows what he/she is doing.
   1- SD  2- D  3- A  4- SA

14. It is easy to get an appointment at the clinic.
   1- SD  2- D  3- A  4- SA

15. My health care provider is warm and friendly.
   1- SD  2- D  3- A  4- SA

16. I spend too much time in the waiting room before I am taken to the exam room.
   1- SD  2- D  3- A  4- SA

17. My health care provider really follows through.
   1- SD  2- D  3- A  4- SA

18. I can never seem to get to speak to my health care provider.
   1- SD  2- D  3- A  4- SA

19. My health care provider accepts me as an individual.
   1- SD  2- D  3- A  4- SA

20. I get rushed through my office visits at this clinic.
   1- SD  2- D  3- A  4- SA
Patient ID #: __________

21. I can usually get an appointment at times that is convenient to me.
   1- SD  2- D  3- A  4- SA

22. My health care provider is well trained and knowledgeable.
   1- SD  2- D  3- A  4- SA

23. My health care provider encourages me to ask questions.
   1- SD  2- D  3- A  4- SA

24. I can depend on my health care provider.
   1- SD  2- D  3- A  4- SA

25. I wait too long in the exam room before my health care provider comes in to see me.
   1- SD  2- D  3- A  4- SA

26. My health care provider acts as though he/she is doing me a favor by treating me.
   1- SD  2- D  3- A  4- SA

27. My health care provider is really on the ball.
   1- SD  2- D  3- A  4- SA
Patient Satisfaction Survey

Patient ID #: __________

28. I can talk to my health care provider about important personal matters.
   1- SD   2- D   3- A   4- SA

29. If you want to meet someone nice, talk to my health care provider.
   1- SD   2- D   3- A   4- SA

30. My health care provider meets my needs.
   1- SD   2- D   3- A   4- SA

31. It is easy to get an appointment when I need one.
   1- SD   2- D   3- A   4- SA

32. My health care provider wastes time talking about things that don’t really matter to me.
   1- SD   2- D   3- A   4- SA

33. The nurse(s) seem to care about my well-being.
   1- SD   2- D   3- A   4- SA

34. My health care provider treats the “whole” person.
   1- SD   2- D   3- A   4- SA
Patient Satisfaction Survey

Patient ID #: __________

35. If something was bothering me emotionally, I could speak to my health care provider about it.
   1- SD  2- D  3- A  4- SA

36. I see the same health care provider most of the time.
   1- SD  2- D  3- A  4- SA

37. I receive a wide range of services here at the clinic.
   1- SD  2- D  3- A  4- SA

38. My health care provider respects my time.
   1- SD  2- D  3- A  4- SA

39. I am satisfied with the quality of the medical care I receive.
   1- SD  2- D  3- A  4- SA

40. It takes a long time to get waited on at this clinic.
   1- SD  2- D  3- A  4- SA

41. I have to tell my story several times before getting an appointment.
   1- SD  2- D  3- A  4- SA

42. Checking in or out at the front desk is too time consuming.
   1- SD  2- D  3- A  4- SA

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Patient ID #: __________

43. My health care provider conveys a true sense of understanding to me.
   1- SD  2- D  3- A  4- SA

44. Everything seems so confusing at this clinic.
   1- SD  2- D  3- A  4- SA

45. My health care provider listens carefully to what I have to say.
   1-SD  2-D  3-A  4-SA

46. When I am sick I can get an appointment pretty quickly.
   1- SD  2- D  3- A  4- SA

Thank you again for your time and your help with this patient satisfaction survey.

DiTomasso & Willard, 1991
October 31, 2000

Dr. Robert A. DiTomasso
Tatem-Brown Family Practice Center

Dear Dr. DiTomasso,

I am a doctoral student at The Catholic University of America School of Nursing in Washington, DC. I am writing to you today to request permission and receive a copy of the DiTomasso-Willard Patient Satisfaction Questionnaire (DWPSQ). My doctoral dissertation is entitled Health-Related Quality of Life and Satisfaction of Care of Adults at a Community Based AIDS Service Organizations. I would like to use your questionnaire to measure the satisfaction of care portion of my dissertation proposal.

Please feel free to contact me if there are any questions or concerns on this matter. Thank you for your time and cooperation on this matter.

Sincerely,

Robert Dodge, RN, MSN, ANP, CS, CNS, ACRN
Adult Nurse Practitioner
Medical Coordinator
Mr. Dodge,

Regarding your request to use my modified DiTomasso-Williard patient satisfaction survey for your dissertation. Please use this as my written permission to use the above mentioned survey for your dissertation.

Sincerely,

[Signature]

Jeannie Fern FNP
Appendix F

Pearson Correlation Matrix
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*Correlation is significant at the 0.05 level (2-tailed).