

PATIENTS' PERCEPTIONS OF A DEDICATED AIDS UNIT:  
THE HOSPITAL AS HOME

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To the Dean for Graduate Studies and Research:

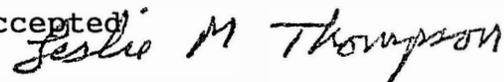
I am submitting herewith a dissertation written by Susan C. Taylor-Hooper entitled "Patients' Perceptions of a Dedicated AIDS Unit: The Hospital as Home". I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

  
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and recommend its acceptance.

  
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## DEDICATION

This dissertation is dedicated to my family who have encouraged and supported me throughout my professional and academic endeavors.

## ACKNOWLEDGMENTS

Special acknowledgments to Diane Ragsdale, RN, Ed.D., and to Joseph A. Kotarba, Ph.D for their guidance and patience in helping me master the qualitative research process.

PATIENTS' PERCEPTIONS OF A DEDICATED AIDS UNIT:  
THE HOSPITAL AS HOME

Susan C. Taylor-Hooper

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ABSTRACT

An ethnographic, qualitative research design was used in this study to determine hospitalized PWAs' perceptions of a dedicated AIDS unit.

The setting for the study was a 508 bed, for-profit, private, community based hospital. The hospital was located in an area accessible to a large percentage of the city's gay population. The hospital had a dedicated 60 bed AIDS unit called the Special Diseases Unit (SDU).

The population for this study consisted of adult males hospitalized with a diagnosis of AIDS. The sample consisted of 15 respondents admitted to the SDU chosen through judgemental sampling. Patients who were well enough to converse were approached by the nursing staff to determine their willingness to be a participant in the study. Participants were sought until thematic categories were exhausted.

The instruments used in the study included a demographic data questionnaire and a semistructured interview form. Respondents were interviewed in their hospital rooms utilizing a semi-structured interview guide. Data analysis was guided by the grounded theory method.

Data were categorized and theory generated based on themes related to the perceptions of the SDU using the constant comparative method of joint coding and analysis. Each incident in the data was coded into as many categories of analysis as possible, as categories or data emerged that fit an existing category. This method was used until all data categories were saturated.

Analysis of data was conducted through the construction of various typologies derived from the research questions. The typologies included the following: organizational philosophy, environment, rules and services; and interactional commitment, honesty, comfort, sensitivity, informality and familiarity. Subcategories of these key findings were then described to further explain the elements of unit culture which impacted patients' hospital stay.

In general, patients described the SDU as homelike. The organizational and interactional features created the familial nature of the SDU. The dedicated AIDS unit enhanced the participants' hospital experience.

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## CHAPTER I

### INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) is a highly lethal, transmittable disease which results from the human immunodeficiency virus (HIV) (Wolcott, Fawzy, and Pasnau, 1985). AIDS meets the criteria of a modern day plague. The incidence, numbering 17.9 reported cases per 100,000 population in 1991, has continued to climb to 18.3 for 1992 (CDC, Dec.1993). This continuing increase in AIDS cases is a grim reminder of its epidemic proportions. The mortality rate for AIDS approaches 80% within 2 years of diagnosis (Gee & Morgan, 1988). Treatments and a cure for the disease remain under scientific investigation. With an estimated 10 million persons infected worldwide, the number of individuals who develop AIDS will continue to increase, even if vaccines and effective therapeutic drugs are developed (Hopp & Rogers, 1989). The significance of the impact of AIDS-related illnesses on the healthcare system of the United States has yet to be fully realized. Epidemiologists and researchers predict that AIDS will continue to have an impact on our lives for many years to come (Gee & Morgan, 1988).

There have been 6,999 confirmed cases of AIDS reported in the Houston Metropolitan Statistical Area as of December, 1992 (CDC, 1993). By 1995, over 27,000 cases are expected to be diagnosed (City of Houston Health and

for future health and social service is imperative (City of Houston Health and Human Services Department, 1991).

Hospitals especially need to plan for comprehensive health care for the increasing number of AIDS-related admissions. Patients who are admitted to the hospital are in one of the most vulnerable states of their lives. This vulnerability is particularly true of patients who are being admitted to hospitals in life-threatening or terminal disease states.

AIDS is a chronic illness which often requires frequent hospitalizations. To care for chronically ill patients, medical knowledge must be supplemented with psychological and sociological knowledge (Strauss, 1975). This holistic approach requires information pertaining to how patients handle their disease, regimens and symptoms, and how their responses ultimately affect the progress of their disease state. The latter are complex entities which should be studied to identify implications for individuals or groups of persons who have chronic diseases.

Part of these responses involve activities to improve quality of life. Strauss (1975) stated that the chief business of chronically ill persons is to live as normally as possible despite their symptoms and adaptation to the disease. How normal their life can be made depends upon: social arrangements, intrusiveness of symptoms, regimens, knowledge of others with the disease and of its fatal potential.

A slow trajectory of disease often gives patients the opportunity to come to terms with their own mortality.

Awareness and understanding may be developed early enough to confront dying. Nurses may be drawn into this process. Nurses who interact with patients during hospitalization may influence how these patients come to terms with their illness and their own mortality (Hopp and Rodgers, 1989).

The concept of quality of life has been used to indicate the impact of health care on the total well being of the patient. Quality of life becomes important in chronic disease. Health care decisions are based on the extent to which persons perceive that quality of life can be promoted (Oleson, 1990). Quality of life has not been adequately explored in persons with chronic disease states including persons with AIDS (PWAs). Therefore, additional research is needed to explore the concept of quality of life. As the concept is further clarified and operationalized, nursing interventions may be devised, implemented and tested for effectiveness in enhancing quality of life (Oleson, 1990).

In describing quality of life, it is important to include the specific events, issues, processes, and associated phenomena (Strauss, 1975). Conceptual clarification of these perceptions is necessary to facilitate appropriate nursing care. Given the growth and incidence of AIDS and the different methods required to treat AIDS, research on the quality of life is necessitated. Because of advances in technology and treatment, AIDS patients are living longer. This phenomenon is of particular interest to the researcher, as a Senior Vice President of Nursing in a hospital which

cares for AIDS patients. Aspects of this job entail developing policies which guide nursing care and set standards for nursing practice. Adherence to these policies will ultimately affect quality of life.

#### Problem of Study

The problem of this study was to identify how persons with AIDS (PWAs) perceive quality of life on a dedicated AIDS unit. The study presents a conceptualization of their perceptions of interactions with nursing personnel, as a way of viewing quality of life.

#### Rationale for Study

As PWAs live longer, the frequency of hospitalizations for treatment of the disease increases. The outlook for some PWAs may seem bleak. Each hospitalization may represent the terminal phase of their lives. Many AIDS patients do, however, "bounce back;" they do go home from the hospital. Therefore, health care workers should plan for long term goals versus preparation for death. Without this planning, many patients will not receive the physical, occupational, and emotional therapy that is essential for quality of life for PWAs (Hopp and Rodgers, 1989). The AIDS epidemic has highlighted many of the strengths and weaknesses of the health care system. Among the most important insights gained has been the fundamental role that nurses must play in any effective system of AIDS care (Gee & Morgan, 1988). Historically, nurses have been personally concerned with the care of the whole person--

body, mind, and spirit. Parameters of care have been expanded with immunodeficiencies such as occur in AIDS. Nurses now face PWAs who have critical, life-threatening situations. Life events become so complex that they are more elusive and less amenable to a mechanistic view of health care (Belcher, Dettmore & Holzemer, 1989).

Nursing care of PWAs poses a tremendous challenge because of the severity of the syndrome and the associated complications. Complex educational, socioeconomic, psychosocial, and spiritual needs of PWAs add further challenges. The focus of nursing care for PWAs should be assisting them to "feel better" because "getting better" is currently, for most, an unattainable goal (Belcher, Dettmore, Holzemer, 1989). Designing nursing care protocols which improve quality of life is a method to assist PWAs in achieving this goal. Nursing interventions should reflect and incorporate personal uniqueness so that PWAs can be helped to live their lives fully and as they wish (Belcher, 1990).

Nurse administrators play a significant role in the design and implementation of nursing practice. Various research methods are being explored as ways to expand management science in general and nursing administration in particular. Quantitative methods are no longer the only accepted methods to investigate organizational questions. Qualitative methods offer opportunities to uncover meaning and expand knowledge of human experiences and interpersonal processes (Parse, 1989). This qualitative study was designed to identify how nurses impact quality of life when

PWAs are hospitalized. Nurse administrators can use these findings to enhance case management and design ways to provide cost-effective, quality patient care. There is a lack of information regarding quality of life, and the findings of this study will be important to nursing administrators in AIDS policy development which will, in turn, impact patient care.

### Conceptual Framework

The purpose of this study was to further develop themes which would contribute to the development of a conceptual framework of quality of life as perceived by hospitalized AIDS patients. A study on quality of life of PWAs in a similar setting by Ragsdale, Kotarba, Morrow (1992) indicated that hospital experiences can be looked at from the patient perspective.

To date, no conceptual or theoretical framework for persons with AIDS has been tested. The Archway of Progression of Life With AIDS (APLWA), developed by Ragsdale (1990), is a beginning framework for nurses to use a focal point for interventions designed to improve the quality of life of PWAs (Figure 1). This framework will be further developed based on the findings of this study. In the Archway of Progression, the title reflects the journey or the path of life which begins with conception/birth and ends with death/life thereafter. Central to the figure is a series of bridges. These bridges graphically represent the changes, growth patterns and other life occurrences which are collectively termed



life events. The arch in the figure illustrates the life span, which starts with life and ends in a unknown time spectrum. The devastating impact of AIDS is illustrated by the disruptive force of the break in the bridges (Ragsdale, 1990). This study indicates that the hospital experience can metaphorically close up the break in the bridges and allow the PWAs life to progress after hospitalized.

The only published quantitative study on quality of life in HIV disease (Ragsdale and Morrow 1990) reported that HIV infection had the greatest disruption in psychosocial aspects of life. The study investigated whether quality of life differed according to HIV staging. Significant differences were found. Due to the lack of established research in the field of PWAs' quality of life, a grounded theory approach will be utilized for this qualitative study (Glaser and Strauss 1967). The results of qualitative inquiry may provide the theoretical framework or identify concepts, hypotheses, or theory to be tested in subsequent research. In addition, the results may identify new paradigms or directions of inquiry (Morse, 1991). This study will utilize a qualitative approach to develop a conceptual analysis of quality of life as perceived by PWAs hospitalized on a dedicated AIDS unit.

#### Assumptions

1. Quality of life is a multidimensional construct (Strauss, 1975).

2. Quality of life is an all-inclusive construct of life and living (Szalai, 1980).
3. Quality of life can be explored on the basis of subjective data. (Kotarba, 1983).

### Research Questions

This research is a grounded theory study utilizing an ethnographic approach; therefore, research questions as opposed to hypotheses are appropriate. The following research questions indicate the general direction of the research.

1. How do PWAs' perceive their hospital experience?
2. What are patients' perceptions of a dedicated AIDS unit?
3. How do PWAs perceive nursing personnel?
4. What are the interactions that occur between patients and nurses?
5. How does hospitalization affect the PWAs' quality of life?

### Definition of Terms

The major terms for this research are:

quality of life, dedicated AIDS unit, PWAs, rules, and nursing personnel. Conceptual and operational definitions for the key terms follow:

1. Quality of Life: Quality of life has been described as privately known and privately evaluated aspects of life, happiness, satisfaction, contentment, fulfillment, and the ability to cope (Andrews & Withey, 1976; Beckmann & Ditlev,

1987), a persons' sense of well being, satisfaction or dissatisfaction with life, or happiness or unhappiness (Dalkey and Rourke, 1973; Dubos, 1976). It has also been expressed in terms of distance between a person's position and goals. Satisfaction refers to the achievement of a goal or to the sense of approaching it, living life to its fullest (Miller, 1983; Sartorius, 1987). For this study, quality of life will be subjective and defined by the participants in the study.

2. Dedicated AIDS Unit: A dedicated AIDS unit is a hospital patient care unit which has been reserved expressly for patients who are hospitalized with AIDS. For this study, the dedicated AIDS unit will be the Special Diseases unit of the selected hospital setting.

3. Persons with AIDS (PWAs): PWAs are individuals who have been diagnosed with acquired immunodeficiency syndrome (AIDS). Diagnosis of AIDS requires evidence, usually signs and symptoms of specific HIV-caused host diseases, which meet the CDC criteria (Hopp and Rodgers, 1989). For the purposes of this study, PWAs will include those persons who have been informed by their physician that they have AIDS and are hospitalized for the treatment of symptoms associated with this syndrome.

4. Hospitalized Persons with AIDS (PWAs): A hospitalized PWA is a person who is hospitalized for the treatment of AIDS-related symptoms or medical conditions. For the purposes of this study, hospitalized PWAs will be patients who are admitted to the dedicated AIDS unit of the study setting.

5. Rules: Webster (1989) defines rules as "a prescribed guide for conduct or action, an accepted procedure, custom, or habit". In this study, rules will be those formal and informal customs and procedures used as PWAs are hospitalized within the defined setting.

6. Nursing Personnel: Nursing personnel are those personnel who are assigned to work in the nursing department. These personnel may include registered nurses, licensed vocational nurses and nursing assistants. For the purposes of this study, all of the preceding categories of nursing personnel will apply.

#### Limitations

The limitations of this study include:

1. The researcher may influence the participants themselves or the interaction of the participants through presence in the setting.
2. The researcher will observe and interpret interactions within the context of personal values and beliefs. Data may be interpreted differently by another investigator with different values and beliefs.
3. The research may be biased by the "halo effect", the tendency to identify all participant traits in the direction of the general impression the researcher has of the individual, rather than in terms particular traits identified by the individual (Wiggins, 1973).
4. The research data may be skewed by the "Hawthorne

effect", a phenomena which occurs when participants know they are subjects in a research study and, as a result, alter their normal behavior (Berg, 1989).

#### Summary

AIDS is a disease with a high mortality rate and is increasing in incidence and prevalence. It is within the realm of nursing to assist PWAs to adapt psychologically to the AIDS chronic disease process. This study will identify concepts and themes from which a conceptual framework will emerge. This framework can be used in health care policy and treatment decisions to positively affect the perceived quality of life of hospitalized PWAs.

## CHAPTER II

### REVIEW OF LITERATURE

Since the first cases of Acquired Immunodeficiency Syndrome (AIDS) were reported to the Center for Disease Control (CDC) on June 5, 1981, AIDS has exhausted every sector of the health care arena. As a clinical entity, it has frustrated and baffled researchers and physicians alike who have been unable to offer persons with Human Immunodeficiency Virus (HIV)/AIDS a curative treatment or vaccine. As a sociological entity, it has touched on every segment of the legal, governmental, insurance and psycho-social communities as policy makers and others struggle to provide care for HIV infected persons (Hinz, 1991). In addition, AIDS has presented a new challenge for nursing leaders as they develop strategies to address the complex needs of those affected with HIV.

This review of current literature will address the epidemiological, physiological, psychosocial, ethical and nursing considerations in HIV/AIDS care. In addition, quality of life will be reviewed in respect to care of the cancer patient, the chronically ill patient and PWAs as documented through qualitative and quantitative research.

#### Introduction

The first case of AIDS was diagnosed in 1981, with five cases of *Pneumocystis carinii* pneumonia (PCP) reported

in Los Angeles in June and 26 cases of Kaposi Sarcoma (KS) reported in New York and California in July of 1981 (Masur, Michelis and Greene, 1981). According to the surveillance information collected by the Centers for Disease Control (CDC), as of December 1993, there have been 253,448 diagnosed cases of AIDS reported in the United States. Approximately 160,372 people have died of AIDS (CDC, 1993), and attendant costs have stretched into the billions of dollars (Alexandre and Vignola, 1991).

However, the number of reported cases of AIDS reflects only a small portion of the HIV-infected population--approximately 10% (CDC, 1993). AIDS is now the leading cause of death for men aged 25 to 35, with 57% of reported AIDS cases in the United States having resulted in death (CDC, 1993). A breakdown of adult/adolescent AIDS cases by risk factors indicates that: 57% are from male to male contact; 23% are intravenous drug abusers; 1% are hemophilia/coagulation disorder individuals; 6% are men who have sex with men and inject drugs; 7% are contracted by male or female contact with a high risk person; 7% are through heterosexual contact; 2% are contracted through transfusion of contaminated blood products; and 4% are contracted from undetermined sources (CDC, 1993). It has been estimated that by 1993, there will be between 390,000 to 480,000 new AIDS cases diagnosed each year with from 285,000 to 340,000 total deaths attributed to AIDS (CDC, 1993). The World Health Organization estimates that between eight to ten million adults and one million children worldwide will be infected with HIV, with 90%

residing in developing countries (Hinz, 1991).

HIV has been cultured from blood, semen, vaginal secretions, cerebrospinal fluid, synovial fluid, pleural fluid, peritoneal fluid, pericardial fluid and amniotic fluid. The modes of transmission identified to date are: sexual activity with an HIV-infected person, blood-to-blood contamination and transplacental, perinatal and postnatal transmission (Larson and Ropka, 1991). Infection was first identified among homosexual and bisexual men, the group that still represents the highest proportion of infected individuals in the United States. Seroprevalence surveys reveal infection rates among homosexual and bisexual men of 20 to 50 percent (Curran et al., 1988). However, reductions in the practice of high risk behaviors, such as unprotected anal intercourse and multiple sexual partners, have been reported among homosexual and bisexual men (Allen and Curran, 1988; Carne, et al., 1987). Infection rates associated with HIV-contaminated blood products are also declining because of increased use of blood screen testing (Curran et al., 1988). HIV infection rates are increasing among intravenous drug usage and minority groups (CDC, 1993).

HIV infection can be determined with a high degree of sensitivity and specificity when tests reactive for HIV antibody are used in series: enzyme-linked immunosorbent assay (ELISA) or immunofluorescence assay followed by a confirmatory Western blot (Larson and Ropka, 1991). Major strides have been made in therapeutic interventions to reduce HIV-related symptoms and treat opportunist

infections. A variety of pharmacological agents such as immunomodulating agents, antivirals, cytokines and vaccines are in various stages of development and testing (DeVita, Hellman, Rosenberg, 1992).

Although some researchers appear optimistic about the feasibility of an AIDS vaccine, the path remaining to an effective vaccine is laden with obstacles. It is unlikely an effective vaccine will be identified by the year 2000 (AIDS Alert, 1991).

#### Physiology of AIDS

The HIV is a member of the retrovirus family. It infects human T-cells, particularly the CD4 lymphocytes, which are essential to normal functioning of the immune system. In the lymphocyte, the virus replicates and escapes through holes produced in the cell membrane, thus invading the infected cell. The subsequent deletion of these cells results in an immune deficiency, causing the infected individual to be susceptible to infection with opportunistic organisms and development of malignancies that would normally be harmless (Gallo, 1987).

Following HIV infection, the period required for the immune system to produce antibodies against HIV is from 2-12 weeks. The antibodies produced have life-long existence but do not inactivate HIV. The incubation period from the HIV infection to the diagnosis of AIDS is 7-10 years (DeVita, Hellman, Rosenberg, 1992).

Several major classification schemes of HIV have been developed to describe the spectrum of HIV infection, which range from asymptomatic infection to a mild mononucleosis-

like syndrome to AIDS. In the early phases of the HIV infection, the person is HIV+ and is asymptomatic or a "carrier" (CDC, 1986, Morbidity and Mortality Weekly Report, 1986). These individuals have a positive antibody test but no disease process. The next classification of the disease is AIDS-related complex (ARC). These individuals have a positive antibody test and non-specific clinical manifestations including: lymphadenopathy, night sweats, night fever, persistent diarrhea, persistent cough, malaise, and fatigue. The final classification is AIDS. This stage is marked by a positive antibody test; clinical manifestations as seen in ARC; and diagnosis of one of the following identifiers: opportunistic infections (OI); malignancies; chronic HIV wasting syndrome; and HIV dementia complex (Redfield, Wright and Tramont, 1986).

Neuropsychiatric complications of HIV infection complicate psychosocial issues. It appears that a common cause of neuropsychiatric dysfunction may be direct infection of the central nervous system (CNS) with HIV, which results in a subacute encephalitis. The most common manifestations of this encephalitis are dementia and delirium (Gabuzda and Hirsh, 1987; Grant, Atkinson, Hesselink, 1987; Holland and Tross, 1987; Perry and Markowitz, 1986). Early signs of HIV infection may sometimes be neurologic manifested by apathy, impaired memory, and cognitive impairment. Subtle signs of dementia may first present as an insidious depression characterized by forgetfulness, poor concentration, loss of interest in work, loss of libido, apathetic blunted affect, psychomotor

retardation, and withdrawal. Later, CNS symptoms may include confusion, seizures, myoclonus, mutism, dementia, and coma (Holland and Tross, 1987).

### Psychosocial Issues

#### Related to AIDS

AIDS is a life-threatening illness that raises complex psychosocial issues. The impact of AIDS on individual and family life has, at the same time, precipitated a fundamental reconsideration of society's responsibilities with regard to human rights, and its role in upholding and protecting them. In doing so, the disease has also focused attention on the value of quality of life in health care. This focus, in turn, has contributed to a renewed awareness of the importance of psychosocial support in health care and treatment (Carballo and Bayer, 1990). Mann (1990) addresses the uniqueness of the challenges facing the international public health community and refers to the transformation that must take place in the collective thinking about AIDS management. An implicit denial of the role played by psychosocial and cultural factors, which has served to undermine the potential success of otherwise sound health initiatives, needs to be replaced by rigorous research in these domains.

#### Discrimination

Misinformation and ignorance continue to make discrimination a daily problem for AIDS-infected people. In countries where data on the problem are available, it is

clear that discrimination against people with, or suspected of having, HIV continues to occur in health care services, in places of education and employment, and in legal decisions (Govoni, 1988). Tindall and Tillett (1990) describe discrimination in many forms: in isolation within and of families, and in discrimination by public and social institutions. Regrettably, many of the fears that lend themselves to discrimination are still present in the health care community (Carballo and Bayer, 1990).

Eakin and Taylor (1990) described the anxiety that accompanies accidental exposure to HIV among health care workers. This anxiety potentially limits the way in which health care staff are able to respond to patients and attempt to meet their day-to-day needs. Fear of discrimination has also affected the attitudes of some healthcare workers. There are reports of staff being more concerned about "social contamination" than any possible physical risks in their day-to-day work. The fear of being stigmatized by co-workers and others, the fear of homophobic reactions and an uneasiness with the sexual nature of the problem continues to affect many workers (Carballo and Bayer, 1990).

#### Life-Span

An issue specific to persons diagnosed with AIDS is their youth. Twenty percent of reported cases have occurred in 20-29 year-old persons, forty six percent in the 30-39 year-old age group and fifteen percent in the 40-45 year-old age group (CDC, 1993). These persons are in what we may refer to as the prime of life (Govoni, 1988).

Erickson (1959) described the developmental tasks of these years as the reconciliation of intimacy versus isolation (ages 18-25) and generativity versus stagnation (ages 21 to 45). During these years the adult is establishing intimate relationships and is concerned with creativity. At this developmental stage (when AIDS strikes most gay men), illness or dying is out of the natural order of life. Young adults are not developmentally prepared to confront their mortality. The result is frustration as the person attempts to reconcile what might have been with what is (Pattison, 1977).

Another issue related to the youth of AIDS patients is the possible lack of financial resources or security. The young PWA may lack health, life, or disability insurance. Disruption of educational and career goals is also complicated by the ambiguous and unpredictable disease course (Ostrow, 1990).

### Dealing with Death

The PWA experiences many physical, mental, and sexual losses along with the greatest loss of all--the anticipated loss of life. There are also numerous losses experienced by the PWA related to both the terminal nature of the illness and the stigma it carries. Friends and lovers may have been lost to AIDS. Some have lost a staggering number of friends. If friends are not lost to the disease, they may be lost out of fear, denial, or internalized homophobia (Ostrow, 1990). The number of losses experienced, especially for those who have lost large numbers of friends

to AIDS, results in what Kastenbaum (1986) originally described as occurring in later life, "bereavement overload". This overload can affect the lover who may also have experienced the loss of numerous friends and is anticipating the loss of the patient. The frequent loss or dramatic change in sexual intimacy because of physical illness, impotence, and concern over contagion alters the relationship (Govoni, 1988).

A diagnosis of AIDS brings the personal and social issues of "coming out" to the forefront. Since HIV/AIDS is a sexually-transmitted disease, disclosure of one's diagnosis often entails disclosure of one's homosexuality (Gee and Morgan, 1988). For some gay men, the risk of acquiring HIV infection results in new perspectives of relationships and sexual expressions. The capacity to use sexual expression to cope with emotions such as depression and anxiety is affected. Relationships that were once open may close, resulting in increasing demands on the primary relationship (Morin, et al. 1987). These potential changes will entail mourning the loss of the familiar in order to proceed to acquiring new behaviors.

The neuropsychiatric complications of HIV infection result in groups of symptoms frequently experienced by people with AIDS and result in anxiety and depression (Govoni, 1988). The anxiety associated with AIDS can be attributed to what Tindall and Tillet (1990) describe as the being's awareness of its non-being, in other words, existential anxiety experienced when confronted with one's own mortality. The anxiety related to AIDS is complicated

by the unpredictable course of the illness. Because of the inability to predict the present or future, the PWA has difficulty setting and maintaining a career.

Additionally, maintaining professional, family, and life goals becomes problematic. The reaction of others to the knowledge of the PWA's homosexuality or diagnosis is also a factor. The number and magnitude of uncertainties lead to a sense of lack of control that compounds the anxiety (Ostrow, 1990).

Depressive symptoms may also result from the psychosocial issues facing the PWA. These symptoms can result from the numerous losses associated with AIDS, the grieving process, the dying process, neurological complications, and previous depression that becomes exacerbated by AIDS. Perry and Markowitz (1986) describe the depression of many people with AIDS as not simply a normal grief response to a fatal illness. The response is a pathological process characterized by alienation, irrational guilt, decreased self-esteem and suicidal ideation.

Guilt is a common symptom experienced by PWAs. The guilt is often irrational and related to behavior prior to the existence and diagnosis of HIV. Guilt over surviving while other gay men are dying of AIDS is common (Govoni, 1988). In order to adaptively cope and live with a life-threatening illness, PWAs must mourn the numerous losses encountered.

Glaser and Strauss (1965) in speaking about the dying situation used the term "awareness context". This term

refers to who knows what about the probabilities of death for the dying patient. The "awareness context" occurs when each interacting person knows of the patient's defined status along with recognition of the others' awareness of their own definitions. It is this context within which these people interact while being cognizant of death and dying.

Nurses' definitions of the patient's illness status-- that is, their expectations--affect their behavior toward the patient. Nurses who care for gay clients with AIDS are confronted with mortality and sexuality. This confrontation requires that nurses examine their values and responses to these factors. This self-appraisal assists nurses in approaching the patient without a judgmental attitude. Knowledge of, and sensitivity to, the psychosocial issues specific to gay men with AIDS is necessary to adequately make a nursing assessment and implement nursing interventions (Gee and Morgan, 1988).

While adaptive mechanisms have developed at both an individual and institutional level, there is a growing need for the development of comprehensive psychosocial health care strategies which, in enhancing the work of health care staff, would also improve the opportunities for patient care.

#### Ethical Considerations

AIDS has unique aspects, but in a remarkable range of areas it confronts the health care personnel with challenges and policy dilemmas common to issues that policy

makers and the health care system have been addressing for some time. These issues may come together differently in AIDS, but it would be a grave error to neglect previous lessons of relevance. Relevant areas include service innovations in terminal care for cancer. In state-of-the-art cancer care, patients usually reach the terminal phase of life in clinical cancer centers where significant efforts are typically made to control symptoms and extend life (Mechanic and Aiken, 1989).

#### Hospital Care

Hospital care for PWAs may differ in fundamental ways from the approach taken with terminal cancer patients because the opportunistic infections that often cause death among AIDS patients can be treated well into the terminal phases. AIDS patients seek continued state-of-the-art treatment even when their debilitated general condition requires the symptomatic and supportive care offered by hospice programs (Mechanic and Aiken, 1989).

#### Medical Insurance

AIDS and ARC accounted for approximately four percent of the private life and health insurance industry's total claims paid in 1989, with that amount increasing steadily over the past several years (Aids Alert, 1991). Costs projections for new AIDS cases vary, as do the cost-of-care estimates. However, one consistent trend is the advancements in medical treatments for AIDS victims to improve their life expectancy, which is increasing the lifetime cost of the disease. The cost of direct medical care for the approximately 54,000 new AIDS cases diagnosed

in 1990 is estimated to total \$3.5 billion over the patients' lifetimes (Alexandre and Vignola, 1991).

#### Health Care Resources

AIDS will continue to be a clinical focal point for healthcare institutions. The general consensus is that AIDS will be restricted by private and governmental reimbursement, the geography of the disease and the probable leveling off of new cases during the next 10 years (Kleinig, 1989). With no cure on the horizon and nothing but preventive measures to slow the speed, this virulent disease will draw on the resources of most hospitals in the next decade. The depth and dimensions of hospital programs will depend on the number of patients treated and their location.

There is much discussion regarding the advantages, both emotionally and practically, of separating AIDS patients in the inpatient setting. According to Hinz (1991), existing delivery systems are too fragmented for the care of the PWA. Delivering efficient care for PWAs is a major plus of segregating patients. The role of healthcare workers extends not only to individuals but also to the maintenance of certain communal structures through which individuality is nurtured and preserved (Hinz, 1991).

#### Nursing Considerations

Nurses plays a major role in responding to the health care needs of individuals with HIV infection because nurses are primary care providers to thousands of patients with AIDS. Nurses face multiple decisions about the type of

comprehensive nursing care and support systems needed by these individuals (Gee and Morgan, 1988). As a PWA's disease progresses, nurses are called upon to provide counseling to family members of patients with AIDS as well as to make recommendations to meet physical and psychosocial needs. Compassion and commitment to a cause, as well as technical skill, are the important attributes of staff caring for AIDS patients (Larson and Ropka, 1991). AIDS draws on the administrative and psychosocial network of a hospital as much or more than any other disease. Because these patients move in and out of the system with a chronic condition that is subject to intense acute flareups, an efficient nursing model must focus on continuity between inpatient and outpatient care (Hinz, 1991).

Individuals who are infected with HIV face more than the threat of death as they encounter diminishing physical and social resources, stigma, social isolation, psychological distress, serial opportunistic infections, and uncertainty as a way of life (Saunders, 1989). Gonda and Ruark (1984) state that the key to realistic hope for AIDS patients is shifting the object of hope to a shorter time frame, for example hoping for relatively symptom-free days. A major challenge for nurses is to facilitate and support patients and their supportive others as they strive to maintain hope as circumstances change. Hope is a multidimensional force, and effective nursing strategies involve matching the nursing strategy to the dimension of hope that concerns the patient. An awareness of the

cultural values, lifestyles and psychosocial problems of AIDS patients will promote effective nursing care (Phillips, 1989).

### Organizational Culture

Over the last six to eight years, the concept of culture has been linked to the study of organizations. A wave of scientific literature on organizational culture has been published. In organizational theory, the cultural perspective is partly recognized because of its anthropological claim of uniqueness. "Uniqueness" in organizational culture studies is an assumption shared by researchers implying that organizations in principle are independent cultural configurations. Organizations develop and maintain unique systems of values, beliefs, norms and meaning of their own (Pedersen and Sorensen, 1989). As in traditional anthropological social entities, organizations create systems of maintaining that influence the myriad of behavior, routines and practices recognized as a distinct way of organizational life (Gregory, 1983).

It is the search for the underlying cultural systems in organizations which has resulted in many more or less operational definitions of culture, developed by researchers with very different views on what culture is and its implications (Pedersen and Sorensen, 1989). Deal and Kennedy (1982) define culture as a stable collection of values, symbols, heroes, rituals and stories that operate beneath the surface, executing powerful influence in the behavior in the work place. Peters and Waterman (1982) see culture as a system of shared values that manifests itself

through different cultural artifacts. Molin (1987) defines culture as a set of norms, routines, and myths, by tradition specific to the organization, handed down from generation to generation that make certain types of explanations and actions appear to be self-evident and natural. Gregory (1983) sees culture conceptualized as a system of meaning and defines culture as learned ways of coping with experience. Schein (1984), on the other hand, defines culture as a listing of cultural artifacts, experiences, systems of shared meanings, values, or norms. These elements are implicitly included in his definition:

Invented, discovered, or developed by a given group as it learns to cope with its problems of external adaptation and internal integration that has worked well enough to be considered valid, and therefore, to be taught to new members as the correct way to perceive, think and feel in relation to those problems (p.32).

Organizational culture is, therefore, an integrating mechanism, the social or normative glue that holds together a potentially diverse group of organizational members (Meyerson and Martin, 1977).

Proponents of the corporate culture paradigm are well-known authors such as Deal and Kennedy (1982), Peters and Waterman (1982), Athos and Pascale (1982), and Ouchi (1981). The espoused values of top-management and consensus and integration flow from the configuration of sound shared values among organizational members which coincide with management goals (Pedersen and Sorensen, 1989). These corporate culture portrayals are characterized by the perception that management-centric position and culture are regarded as key variables to

increased economic performance. Culture is a strong socializer because it conveys a sense of identity for organizational members and facilitates the generation of commitment to something larger than the self (Smircich, 1983) and thereby imparts meaning and demands involvement and behavioral consistency (Pettigrew, 1979).

Schein (1985) explicitly states:

The term culture should be reserved for the deeper level of basic assumptions and beliefs that are shared by members of an organization, that operate unconsciously, and are defined in a basic 'taken for granted' fashion of an organization's view of itself and its environment. These assumptions and beliefs are learned responses to a group's problems of survival in its external environment and its problems of internal integration. They come to be taken for granted because they solve those problems repeatedly and reliably (p.12).

Concern with workplace culture is not new. The concept was first described in business and organizational studies. In 1939, Chester Barnard noted that informal organization was essential to the successful functioning of formal organizations. Codes of conduct, as he referred to them, arose and ensured commitment as well as identified coherence and a sense of community. Most persons entering an unfamiliar work setting know the feeling of being an outsider; one sometimes feels as though one had just arrived in a foreign country. Real wisdom in such situations means recognizing that the unspoken is more powerful than what can be conveyed through speaking. One gradually gains a sense of the feel, the smell, the personality of a workplace, a way of working, or a kind of work--though it may be difficult to translate all of this into words that an outsider could grasp (Louis, 1985).

Researchers who propose that organizations produce cultures usually define culture as the social or normative glue that holds an organization together (Baker, 1978; Siehl and Martin, 1982). Culture consists of values and beliefs that some groups of organization members come to share (Louis, 1985). These values can be expressed through a number of different means, including a special language or jargon (Edelman, 1977); organizational stories and scripts (Wilkins, 1983; Martin, 1990); rituals and ceremonies (Gephart, 1978; Deal and Kennedy, 1982); physical (Peters and Waterman, 1982) and organizational practices such as recruiting, training, and reward systems (Siehl, 1985).

Scott, 1981, described three types of organizational systems: rational, where organizations are instruments designed to attain specified goals; natural, where organizations are collectives; and open, meaning not simply that organizations engage in interchanges with the environment, but that their interchange is an essential factor underlying system viability. Christensen (1988) stated that probably the most useful way to view organizational culture is to see it as the underlying assumptions and shared meaning and values that individuals and groups assign to their social environments. These basic assumptions, values, concepts, and beliefs are frequently discovered, developed, or invented as people learn to cope with problems both from within and without the organization. These shared notions usually work well enough to be considered valid and to be taken for granted

to the extent that they may drop out of active awareness and become almost unconscious, and are thus passed on to new members as "the right way" or simply the way we do things around here". There usually are, of course, multiple cultures within a single organization (Wilkins, 1983; Schein, 1983).

Christensen (1988) stated that organizations are made up of people, not "culture", but it is the assumptions and values that some people appear to share or have in common in a particular setting that we often refer to as "culture", tying the people in an organization together and giving them common purpose.

Most organizations consist of multiple subcultures, and even countercultures or factions that may hold very different or completing views on the nature of situations within the organization (Christensen, 1988). Culture emerges to solve problems posed by situations that people encounter in organizational settings; others see it as the ways in which people cope with experience. Some people talk of it as social "glue" (Frost, et al., 1985).

#### Culture and Health Care

In 1990, Leininger stated that culture has been the critical and conspicuously missing dimension in the study and practice of ethical and moral dimensions of human care. Culture as the totality of learned and transmitted beliefs, values, and life experiences of particular human groups is essential to generate and establish credible ethical and moral care knowledge and to guide nursing decisions and

actions.

Conceptual approaches to the environment have been identified in the fields of business and organizational behavior (Simms, Price and Ervin, 1985). Most of these approaches are geared to the environment external to the organization. The organizational universe model represents one approach that does include both the internal and the external environment. This model provides a basis for looking through the whole to those structures and processes that need to be monitored before change can be managed effectively. This model arbitrarily separates the internal environment into tangible and intangible aspects.

In 1978 Leininger stated that nursing theory must take into account the creative discovery of individuals', families', and groups' caring behaviors, values, and beliefs based on their cultural lifeways in order to provide effective, satisfying and culturally congruent nursing care. If nursing practices fail to recognize cultural aspects of human needs, there will be signs of less efficacious nursing care practices and dissatisfaction with nursing services.

Leininger (1978) developed her theory of cultural care diversity and universality upon the belief that people of different cultures can inform and best determine most of the kind of care they desire or need from professional caregivers. Because culture is the patterned lifeway of people that influences decisions and actions, the theory is directed toward nurses to grasp the world of the client and to use their view points, knowledge, and practices as basis

for making culturally congruent professional actions and decisions.

In 1990, Leininger defined four major concepts relevant to her theory of cultural care diversity and universality: culture, cultural care, cultural care diversity and cultural care universality. These four concepts will be presented as defined by Leininger.

#### Culture

Culture refers to the learned, shared and transmitted values, beliefs, norms and lifeway practices of a particular group that guides thinking, decisions, actions and patterned ways.

#### Cultural Care

Cultural care refers to the cognitively known values, beliefs, and patterned expressions that assist, support or enable another individual or group to maintain well-being, improve a human condition or lifeway or face death and disabilities.

#### Cultural Care Diversity

Cultural care diversity refers to the variability of meanings, patterns, values or symbols of care that are culturally derived for health (well being) or to improve a human condition, lifeway or to face death.

#### Cultural Care Universality

Cultural care universality refers to common, similar or uniform meanings, patterns, values or symbols of care that are culturally derived for health (well being) or to improve a human condition, lifeway or to face death.

Leininger (1978) believes the goal of the care theory

is to provide culturally congruent care. She believes nurses must work toward explicating care uses and meaning so that a cultures care, values, beliefs, and lifeways provide accurate and reliable bases for planning and effectively implementing culture-specific care.

#### Unit Culture and the Care of PWAs

Most organizations consist of multiple subcultures, and even countercultures or factions that may hold very different or competing views on the nature of situations within the organization (Christensen, 1988). AIDS, because of its medical complexities and associated social and ethical problems, does not easily fit into the system of medical care that has evolved during the past several decades (Volberding, 1989).

In 1992, Ragsdale, Kotarba and Morrow described the quality of life on the Special Diseases Unit (SDU) at the study hospital. They conceptualized quality of life as patients' ability to successfully control or manage events taking place around them. Their definition contrasts with the traditional thinking on quality of life. This definition describes quality of life as a variable, and therefore measurable feature of an individual patient. Ragsdale, et al. described quality of life as a feature of the patient's ability to devise a practical and effective style of managing events, such as interactions with physicians and risks of disclosure of potentially discreditable lifestyles. An ethnographic analysis by Ragsdale, et al. (1992b) exploring the various ways that

PWAs manage their illness in order to improve quality of life found PWAs' perceptions of all work-related activities as very important to life in the hospital. They perceived nurses as confederates who were involved in many of the work activities. Quality of life was enhanced when PWAs were able to conduct activities they felt were important and when the health care team supported their work.

The most recent analysis of everyday life on the SDU (Kotarba, Ragsdale, Morrow, 1992) described the more general culture staff and patients establish and maintain in order to manage the unique and often unpredictable events involved with HIV/AIDS. They described the culture as unit culture because of the significant ways it differs from the general organizational culture pervasive in the rest of the hospital. They identified eight cultural domains in the unit that serve to organize everyday life and work: (1) managing the unit ecology through the integration of hospital and home atmospheres, (2) facilitating the unit philosophy relating to the team approach to care, (3) accomplishing extraordinary organizational procedures, (4) accomplishing innovative medical and pharmacological procedures, (5) providing patients with personal space and autonomy, (6) involving significant others in patient care and unit activities, (7) managing alternative healing modalities through cautioned acceptance, and (8) the ritualistic management of death. Their findings illustrate a more general cultural development, "organizational pastiche", a concept originally developed to account for the culture and work

present in an AIDS hospice (Hurt,1992):

Organizational pastiche refers to the everyday, structured work that occurs at the intersection of otherwise disparate ideas, views, logics, goals, experiences, lifestyles and feelings. In the modern world, the assembly of pieces, that on the surface appear not to fit, would automatically lead to organizational distress. Yet, in the postmodern world, the mixing and melding of these pieces is not only 'okay', but is also functional. The functionality of hospice lies in the abilities of its members to address otherwise absurd, distressful, unexplainable and unpredictable AIDS related phenomena (pgs.78-79).

#### Summary

HIV infection is currently incurable. In the absence of an effective vaccine and curative treatment, prevention of HIV transmission is the major focus for controlling the epidemic. Additionally, those individuals who are infected present a myriad of complex health care problems and issues. Research related to the behavior aspects of infection and care delivery issues is beginning to show promise, but much more must be done. The AIDS health care system has responded poorly to long-term care needs and is marked by overspecialization, fragmentation, cost escalation, service gaps, and poor coordination (Mechanic and Aiken, 1989). Because HIV infection remains incurable, the development of measures to minimize symptoms and maximize the function capacities of infected individuals is an important goal (Larson and Ropka, 1991). This chapter has presented a review of the literature in relation to care of hospitalized PWAs. AIDS epidemiology, physiology, psychosocial issues, ethical considerations and nursing care were discussed. Finally, organizational and unit culture were discussed and studies specific to the study

site dedicated AIDS unit were reviewed.

The AIDS crisis offers an opportunity to improve the quality of care. It offers a potential challenge to reorganize inpatient hospital care in a more balanced and comprehensive way, to readdress the imbalance between curing and caring services, and to revitalize nursing roles and services to meet future needs.

## CHAPTER III

### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

Ethnography was the research method used to conduct this study. Ethnography is a method of data collection in which the researcher describes a culture by way of collecting, describing, and analyzing the ways in which human beings categorize the meaning of their world (Glaser and Strauss, 1967). Ethnography is designed to help the researcher learn how people interpret experience and mold behavior within the context of their culturally constituted environment. What people do, say they do, and say they want to do provide information to the researcher (Spradley, 1979, Morse, 1991). Zigarmi and Zigarmi (1980) refer to ethnographers as virtually anyone who enters the natural setting in order to conduct field research. The value of ethnography is that data collection occurs in the settings where the behavior in question actually takes place. From this vantage point, researchers can examine various phenomena as they observe participants and record these observations as accounts (Glaser and Strauss, 1967).

Ethnography, as a research approach, can be used by policymakers and health care professionals to obtain needed information beyond data quantitatively measured (Marshall and Rossman, 1989). The benefits of this type of research include: the ability to study problems in cases where

experimental research would be unethical, assistance in a search for more global and wide-range portrayal of problems, and the identification of unanticipated outcomes of policies or interventions. This approach results in a study with quality, depth and richness in the research findings, which results in valuable explanations of processes (Marshall and Rossman, 1989).

Ethnography provides an increasing range of possibilities for understanding the behavior and problem-solving among both providers and recipients of care. Nursing theory is dependent upon the generation of primitive concepts or constructs from the ideas permeating interaction among human beings. The tools of ethnography provide a way of capturing these human meanings in a language system useful for health providers (Morse, 1991). These human meanings in practical knowledge can be readily adapted to nursing administration policy development related to the care of PWAs.

#### Setting

The setting for this study was a 508 bed, for-profit, private, community based hospital, referred to as "Metropolitan Hospital", in a location accessible to a large percentage of the city's gay population. The hospital provides routine and acute inpatient and outpatient medical-surgical services. Within the gay community, Metropolitan Hospital is referred to as the "AIDS Hospital" because of the 60 bed Special Disease Unit (SDU) dedicated to the care of patients with HIV/AIDS. The

60 beds are located on two floors and generally house 20% of the overall hospital census.

This unit consists of 60 beds located on two floors designated exclusively to the care of patients with HIV disease. Each floor consists of three 12 bed circular nursing "pods". The patient rooms are designed in a circular fashion around the nursing station. This design allows visualization of all patient rooms from the nurses desk. All rooms are designated as private rooms, allowing a maximum of 12 patients per pod. On the 8th floor, two patient rooms have been joined and converted into a patient/family lounge. One pod on the 9th floor has been designated for offices. These offices include 6 research offices for HIV drug protocols.

The SDU originated in 1986 at the request of several physicians who had been admitting HIV+ patients to different areas of the hospital since 1980. Of interest is that one of the physicians claims to have made the first AIDS diagnosis in this large metropolitan area.

Metropolitan Hospital has specialized clinical and ancillary services established to care for the wide range of clinical manifestations of HIV/AIDS. The SDU has a nurse manager, social worker, and nursing staff who work full time on the unit. The nursing staff on the SDU report to a nurse manager. This manager reports to the Medical-Surgical Clinical Nursing Director who in turn reports to the Sr. Vice President of Patient Care. The Sr. Vice President of Patient Care is responsible for all nursing care provided within the hospital. She reports to the

hospital's Chief Executive Officer.

A clinical research program is in place to develop drug protocols for the treatment of HIV/AIDS. Results of the research have included the publication of 38 abstracts at the International AIDS Conferences, 1991-1993. Nurses and physicians have had the opportunity to share their findings with other experts in HIV /AIDS care through the International AIDS Conference and other public and professional forums.

Employees of Metropolitan Hospital interact with a variety of community-based agencies. Two members of senior management have board appointments to the AIDS Alliance and serve as consultants to several community-based AIDS-related organizations.

Nurses who choose to work on the SDU receive an additional hourly salary. This differential was initiated as a recruiting tool to eliminate hiring temporary personnel or "pulling" nurses from other floors. During the study period there was a permanent nursing staff who had been employed on the SDU between several months to 6 years.

The nursing staff represents many distinct cultural and ethnic backgrounds, influencing the culture of the AIDS patient care units. Approximately fifty percent of the nurses are white males with a majority describing themselves as gay. The female nurses represent more closely the ethnic mix of the study city, with many describing themselves as either bisexual or gay. In addition, it is known that a few of the nurses are HIV

positive and/or have family members or significant others who either have AIDS or have died from complications of the disease.

The nurse to patient ratio on the unit is 1:5, a ratio usually reserved for intermediate care units in hospitals. This ratio is required to support the intensive medical care needed by the PWAs. Each patient has at least one IV access with an average of 75% more medications administered than on one of Metropolitan Hospital's medical/surgical nursing units.

#### Population and Sample

The population for this study was adult males hospitalized with a diagnosis of AIDS. The sample consisted of 15 participants admitted to the SDU chosen through convenience sampling. Patients who were well enough to converse were approached by the nursing staff to determine their willingness to be a participant in the study. Theoretical sampling was used, and participants were sought until selected categories of quality of life experiences were exhausted.

#### Protection of Human Subjects

This study has met the criteria for the protection of human subjects. Approval was obtained from Texas Woman's University Human Subjects Review Committee prior to conducting this study since this study is part of a larger Texas Woman's University study (Appendix A). Agency approval was also obtained from Metropolitan Hospital

(Appendix B).

Participants received a written and an oral description of the study and a consent form for audiotaping to sign prior to the initiation of the interview process (Appendices C and D). Time was allowed for the participants to ask questions or to discuss their concerns prior to the interview. The respondents were informed that a possible risk to participating in the study was that they may experience some anxiety or have questions during the interview process. To alleviate any possible anxiety, the interview was conducted in a private setting, the participant's hospital room. The investigator remained in the room after the interview if the participants wished to discuss any concerns related to the study. The participants were also informed that they could interrupt the interview at any time, either to rest or to terminate the interview.

Another possible risk of this study was the improper release of data. Confidentiality was assured by numbering the demographic forms and the audiotapes. Names did not appear on any of the data forms or audiotapes. The list of these numbers were kept in a locked file, with only the investigator having access to this file. Both the audiotapes and list were destroyed upon completion of the study. Neither the patient, the hospital, the physicians, the nurses nor any other persons caring for the participants are identified anywhere in the study.

### Instrument

The instruments used in this study included a demographic data questionnaire and a semi-structured interview form (Appendices E and F). The interviewer attempted to obtain the respondents' natural terminology and conceptualization of quality of life and of the roles played by others in their daily management of quality of life.

Observations and interviews are the fundamental data collection methods utilized in qualitative research (Glaser and Strauss, 1967; Marshall and Rossman, 1989; McCracken, 1988; Strauss and Corbin, 1990). Observation entails the systematic description of events, behaviors, and artifacts in the setting chosen for the study. Immersion in the setting allows the researcher to hear, see, and begin to experience reality as the participants do (Marshall and Rossman, 1989).

Observations were based upon the presence of the nursing administrator on the unit which was accepted as routine and, therefore, unobtrusive. This acceptance allowed the researcher's personal experience to contribute to instrument design in the following ways: as a source of research questions; as a criterion for gauging validity of data from other sources; and as an adjunct in processing the data in practical terms translatable to other nursing administrators.

The interview is a method of data collection that may be described as an interaction involving the interviewer and the participant, the purpose of which is to obtain

valid and reliable information (Marshall and Rossman, 1989). In-depth interviewing is a data collection technique described as "a conversation with a purpose" (Kahn and Cannell, 1957). This type of interview is more like a conversation than a formal, structured interview. For this study, the researcher explored a few general topics to uncover the participants' perspectives but noted how the participants framed and structured their responses. The participant's perspective unfolded according to the participant's view, not as the researcher viewed it (Marshall and Rossman, 1989).

#### Validity and Reliability

No experiment can be perfectly controlled, and no measuring instrument can be perfectly calibrated. All measurement, therefore, is to some degree suspect (Morse, 1991). The key notion in reliability and validity is the concept of "error." Error that occurs anywhere during the research process compromises the outcome of the study and limits the usability of the data. The greater the degree of error, the less truthful the results (Morse, 1991). Knowing what conclusions to draw when findings differ across studies depends upon evaluation of the validity and reliability of observations (Spradley, 1979).

A measurement procedure is said to have instrumental validity if it can be shown that observations match those generated by an alternative procedure that is itself accepted as valid (Kirk and Miller, 1986). Constant error affects the validity of the measurement or the ability to

arrive at true differences between and among subjects (Morse, 1991). The two most stable and problematic sources of constant error are: social desirability in which research subjects respond with what they believe is the preferred social response whether or not it is true; and acquiescent response set in which subjects consistently agree or disagree with the questions (Selltitz, Wrightsman and Cook, 1976). To avoid this type of error in this study, research questions were constructed in such a way as to avoid a correct response. This form of questioning should avoid socially desirable and acquiescent response set errors (Agar, 1980, Spradley, 1979, Spradley and McCurdy, 1972).

Qualitative studies are designed to describe and explain phenomena and are, therefore, not focused on obtaining external validity or generalizability (Morse, 1991). Internal validity is an issue in experimental design. Qualitative research, by its very nature, is not experimental research and does not require manipulation of the independent variable. Therefore, internal validity is not a goal for qualitative research (Morse, 1991). Glaser and Strauss (1967) address the issue of "representativeness" in discussion of validity in theoretical sampling. For this study, the researcher deliberately selected a sample of participants who are theoretically representative of the culture and role needed for the study.

Pragmatic validity, comparative data to assist the researcher to make judgments according to some standard,

can also be a problem in qualitative research (Morse, 1991). The strength of participant observation is pragmatic validation. Concurrent pragmatic validation can be achieved in qualitative research by the use of multiple data collection methods and procedures for the same content over time (Morse, 1991). For this study, information obtained through interviews was verified through repetition. The information obtained from one experienced informant was verified by asking another informant about the same content. Reliability depends essentially on explicitly described observational procedures (Kirk and Miller, 1986). Reliability is the consistency, stability and repeatability of the informant's accounts as well as the investigators ability to collect and record information accurately (Selltiz, et al., 1976). The tests of reliability are: 1) stability over time tested through repeating observations of the same events to look for similar occurrences or by asking informants identical questions for the same content to establish the consistency of the answers; 2) internal consistency judged by the logical or explanatory rationale of ideas about the same topic within a single interview session; and 3) equivalence tested by asking different kinds of questions within the single interview or questionnaire in order to establish the equivalence of the data elicited regardless of the form of question (Morse, 1991).

For this study, the reliability of the data from a particular informant was assessed by the use of identical as well as alternative forms of questions, by transcribing

field notes during the interview, by tape recording the interview for an alternative form of data recording other than investigator memory. Equivalency was developed by working with staff informants. The researcher was asked questions about observations by the staff to determine discrepancies between what is observed and what is explained. Conclusions or inferences that were drawn were also verified by the staff informants and researcher's personal experience. With multiple methods of data collection and verification of data with informants, the validity of the final report should be adequate (Morse, 1991).

#### Data Collection

Participants were interviewed in their hospital rooms utilizing a semi-structured interview guide. Semi-structured interviews are defined as those interviews which are organized along areas of particular interest, while still allowing considerable flexibility in scope and depth (Polit and Hungler, 1987). Early interviews are likely to be more unstructured, with increasing structure developing as analysis of participants' stories begins (Miles and Huberman, 1984). The interviewer audiotaped the interviews and took brief field notes during the interview period. Each interview was done on a "one-time" basis, but the interviewer offered the participant the opportunity to contact the researcher if they would like to add additional information to the interview data.

As the study proceeded, the interviews became more focused as the researcher explored areas of special

interest, began to test preliminary findings, and began to look for areas of commonality and difference in respondents' stories (Strauss and Corbin, 1990). Interviews early in the study were guided largely by the perspectives of the respondents, while later in the study, questions were suggested from preliminary findings generated to that point in the project. In addition, the researcher moved back and forth in the same interview from a very unstructured approach, to see if "new" elements appeared, to direct questions that tested the working hypothesis (Morse, 1991).

#### Treatment of Data

Data analysis was guided by the grounded theory method (Glaser and Strauss, 1967). This method involved a continuous, inductive analysis of data. Data were categorized and theory generated based on the concepts/themes related to the participant's quality of life. Glaser and Strauss (1967) described the constant comparative method of joint coding and analysis in generating theory by using explicit coding and analytic procedures. This method generates and plausibly suggests many categories, properties, and hypotheses about general problems. Glaser and Strauss (1967) described in four stages the constant comparative method. These stages consist of: comparing incidents applicable to each category, integrating categories and their properties, delimiting the theory, and writing the theory. As described, this method of generating theory is a

continuously growing process--with each stage after a time transformed into the next--with earlier stages remaining in operation simultaneously through the analysis and providing continuous development to each successive stage until the analysis is terminated (Glaser and Strauss, 1967).

The constant comparative method, unlike analytic induction, requires saturation of data. This method does not include all available data, nor are data restricted to one kind of clearly defined case (Glaser and Strauss, 1967). This method of generating theory is a continuously growing process. Each stage after a time is transformed into the next with earlier stages remaining in operation simultaneously through the analysis with each providing continuous development to the successive state until the analysis is terminated (Glaser and Strauss, 1967).

Each incident in the data was coded into as many categories of analysis as possible, as categories or data emerged that fit an existing category. As the coding continued, there was a change from comparison in incident to incident to comparison of each incident with properties of the category that resulted from initial comparisons. Theory began to develop as different categories and their properties tended to become integrated through constant comparisons that force the researcher to make some related theoretical sense of each comparison (Miles and Huberman, 1984). As the theory developed, delimitation occurs at two levels: the theory and the categories. The researcher started to achieve two major requirements of theory: parsimony of variables, and formulation and scope in the

applicability of the theory to a wide range of situations while keeping a close correspondence of theory and data. The second level of a theory is the reduction in the original list of categories for coding. The original list of categories was reduced according to the present boundaries of the theory. At the same time the coding and analysis of incidents became more select and focused. Finally, the list of categories becomes theoretically saturated (Glaser and Strauss, 1967, Strauss and Corbin, 1990). Theoretical saturation means: no new or relevant data seem to emerge regarding a category; the category development is dense, insofar as all of the paradigm elements are accounted for, along with variation and process; and the relationships between categories are well established and validated (Strauss and Corbin, 1990).

Analysis of data was conducted through the construction of various typologies derived from the research question.

The typologies included the following: organizational philosophy, environment, rules and services; and interactional commitment, honesty, comfort, sensitivity, informality, and familiarity.

#### Summary

This ethnographic study based upon a grounded theory approach, was conducted in a 508 bed for-profit, community based hospital setting. The population of patients consisted of adult males admitted to the SDU with a diagnosis of AIDS. A demographic data questionnaire and a

semi-structured interview was used as the instrument to obtain respondents' conceptualizations of hospitalization as a PWA. The participants were interviewed in their rooms, and all interviews were audiotaped. The subsequent data derived from the interviews were analyzed utilizing the grounded theory method of constant comparative methods (Glaser and Strauss, 1967). The data were collected until theoretical saturation was achieved.

## CHAPTER IV

### ANALYSIS OF DATA

In this study, an ethnographic, grounded theory approach was used to describe everyday life for patients hospitalized with acquired immunodeficiency syndrome (AIDS) on a dedicated nursing unit. This study was undertaken to contribute to the body of knowledge relating to how hospital nursing units can be made most conducive to the care of patients with human immunodeficiency virus (HIV) and AIDS.

The logic of grounded theory was used in interpreting the data from this study (Glaser and Strauss, 1967; Strauss and Corbin, 1990). Using an inductive approach, the data were collected and placed into categories which represented core concepts. The analysis began as soon as the first piece of data was collected through an "interrelated process" (Strauss and Corbin, 1990). Through this process, the analysis of the data was dynamic and changed with the introduction of new or additional data. The initial data were used to create and organize categories, clarify what each category was in relation to other categories, and then develop theoretical links between the categories (Chenitz and Swanson, 1986, Glaser and Strauss, 1965,). These links then led to the development of a process and the generation of explanatory categories. The final process in the

category description involved the saturation of categories, the identification of a core explanatory category or concept, and identification of themes.

The description of the sample, the findings organized by the core concepts, the emerging theory, and a summary of the findings are presented in this chapter. Data were illustrated by the presentation of key variables, with examples of the variables presented through verbatim quotes from the respondents. Emerging themes were identified from the respondents' interviews. Constant comparative analysis provided a format for generating the core concepts and the emerging themes.

#### Description of Sample

The theoretical sample for this study consisted of adult males hospitalized with a diagnosis of AIDS admitted to the Special Diseases Unit (SDU), a unit dedicated to the care of patients with HIV/AIDS, located in "Metropolitan Hospital". Fifteen male participants were interviewed during an eight month period from September 1991 to May 1992. The sampling was terminated when all categories were saturated and no new themes emerged from the data. The respondents ranged in age from 28 to 48 years, with the mean age of 38.2 years. One (6.6%) respondent was Portuguese, one was Hispanic (6.6%), two (13.3%) were black, the remaining eleven (73.3%) were caucasian. Two (13.3%) respondents stated they were heterosexual intravenous drug abusers (IVDU), and thirteen (86.6%) described themselves as being gay (Table A). Five of the

respondents (33.3%) were on permanent disability support from their work at the time of hospitalization, while the remaining majority (66.6%) of the respondents were employed. All respondents had at least a high school education. One respondent (6.6%) had a doctoral degree, five (33.3%) had from two to four years of college, while eight (53.3%) held undergraduate college degrees (Table B). Fourteen respondents (93.3%) stated their primary relationships were with either significant others, family or friends. Seven (46.4%) stated they had significant others who were participating in their care at the time of hospitalization. Hospitalizations for HIV related illness varied from a low of 1 to a high of 15. Reasons for hospitalizations were varied (Table C).

## Findings

### UNIT CULTURE

The concept of unit culture quickly emerged through data analysis. Kotarba, Ragsdale, and Morrow (1992) described the unit culture of the SDU at Metropolitan Hospital as how nursing staff and patients establish and maintain order to make sense of and manage the unique and often unpredictable events involved with HIV/AIDS. In contrast, this study describes unit culture in terms of hospitalized PWA's perceptions of their experiences as patients on the SDU at Metropolitan Hospital. Patients view things in unique ways that often differ from the views of nurses. For example, nurses do not see the hospital as home, patients do. This perception of hospital as home is

Table A

## PARTICIPANT DEMOGRAPHICS

<u>Name*</u>	<u>Gender</u>	<u>Age</u>	<u>Ethnicity</u>
Vince	M	33	Black
Peter	M	32	Caucasian
Greg	M	34	Portuguese
Joshua	M	40	Caucasian
Carl	M	46	Caucasian
James	M	33	Hispanic
John	M	37	Caucasian
Al	M	43	Caucasian
Charles	M	35	Caucasian
Tommie	M	34	Black
Ray	M	49	Caucasian
Ed	M	44	Caucasian
Rich	M	46	Caucasian
Pat	M	40	Caucasian
Chuck	M	28	Caucasian

Mean Age

38

\* Not actual names

Table B

## PARTICIPANT EDUCATION AND EMPLOYMENT

<u>Name</u>	<u>Employment</u>	<u>Education</u>
Vince	Office Manager*	Jr. College
Peter	Bank Manager*	BS
Greg	Environmentalist	BS
Joshua	Medical Office Manager	Jr. College
Carl	Chemical Manufacturer	2 yrs. College
James	Collection Teller	2 yrs. College
John	Librarian*	BA
Al	Engineer*	BS
Charles	Health Care Worker	BS
Tommie	Unemployed	High School
Ray	IRS Worker	2 yr. College
Ed	Purchasing Manager	BS
Rich	Professor	Ph.D.
Pat	Health Care Worker*	BS
Chuck	Systems Analyst	BA

\* On disability at the time of current hospitalization

Table C

## PARTICIPANT HOSPITALIZATIONS

<u>Name</u>	<u>Total Hosp.</u>	<u>Study Hosp.</u>	<u>Days Hosp.</u>	<u>Diagnosis</u>
Vince	6	4	14	Anemia, Chronic Sinusitis
Peter	6	4	9	Bact. Sinopumony Disease
Greg	7	4	14	CMV Appendicitis, Sinusitis
Joshua	7	7	93	CMV Retinitis, Pancreatitis
Carl	4	4	54	PCP, CMV, Hepatits
James	2	1	4	Bact. Pneumonia
John	7	7	2	MAIC
Al	4	4	9	GI Problems
Charles	7	5	12	PCP, CMV
Tommie	3	2	47	TB, Sinusitis
Ray	15	15	7	SOB, Pneumonia
Ed	2	2	5	Pneumonia, Temperature
Rich	3	3	3	Hickman, Pneumothorax
Pat	1	1	3	PCP
Chuck	15	15	30	Pneumonia
	<u>Mean</u>			
	4.9	5.2	22.5	

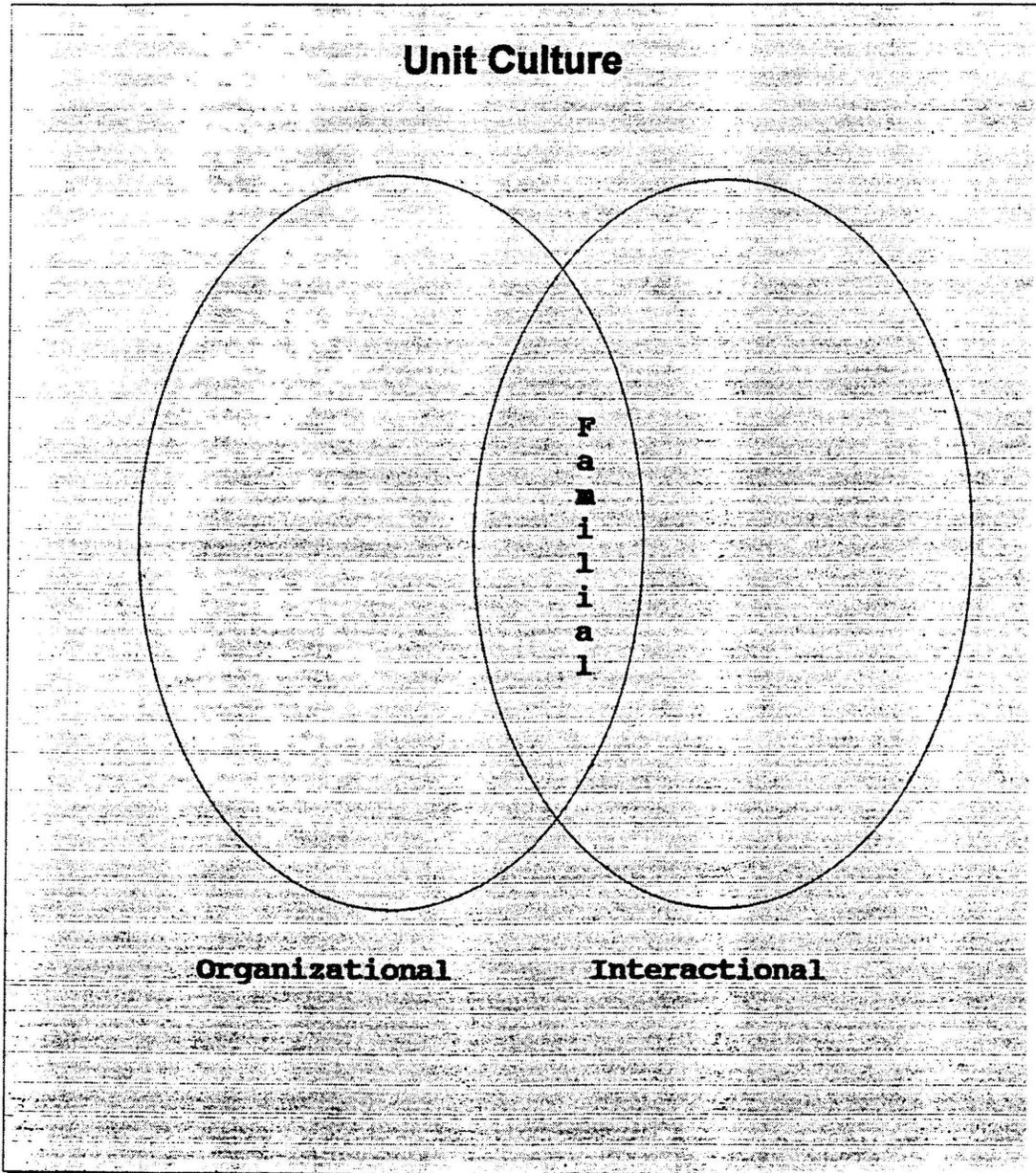
supported and at times contrasts with Kotarba, Ragsdale and Morrow's (1992) description of unit culture as perceived by physicians and nurses. How patients view unit culture is not necessarily apparent to physicians and nurses. Therefore, this study is necessary to add to the existing data related to unit culture.

Unit culture, as described in this study, is reflective of Metropolitan Hospital's SDU and serves to depict its unique features. Patients perceive two major features of the SDU culture, organization and interaction which establish their overall perception of the hospital as home (Figure 2). The data received from the patient interviews were categorized, and core concepts and themes were identified. Through the process of constant comparative analysis, these themes were organized into two major categories of features; organizational and interactional. These features are further divided into subcategories which are derived from respondent quotes. The overview of these categories is presented in the Inventory of Features (Table D).

#### ORGANIZATIONAL FEATURES

The organizational features of the SDU are defined as those features which are established by hospital policy and in this study are defined by patients in four general categories: (1) philosophy; (2) environment; (3) rules; and (4) services. These categories are patients' perceptions

Figure 2  
Hospital as Home



## Table D

## INVENTORY OF FEATURES

In general, PWAs described the dedicated AIDS unit as homelike. Organization and interaction were the two key features of the unit culture.

The organizational features included:

- Philosophy
- Environment
- Rules
- Services

The interactional features included:

- Commitment
- Honesty
- Comfort
- Sensitivity
- Informality
- Familial

of how they feel the hospital administrators try to manage the SDU. These categories are not mutually exclusive, however, they will be presented as such to facilitate discussion purposes.

## ORGANIZATIONAL FEATURES

### Philosophy

Hospital philosophy is defined as the overriding framework for hospital policies, practices and beliefs. In addition to the general hospital philosophy, administrators maintain a specific set of goals for the SDU. From these goals the SDU philosophy is derived. Patients defined the philosophy of Metropolitan Hospital as the hospital's efforts to construct a homelike environment on the SDU. From the respondents conversational interviews, six different features of organizational philosophy were identified. These features were categorized under organizational philosophy. The themes which emerged from the data are: "Known AIDS reputation in the community;" "they know how to treat AIDS;" "the nurses want to be here;" autonomous "unit management;" "the same nurse every day;" and individualism.

#### "Known AIDS reputation in the community"

The first feature of Metropolitan's philosophy is the hospital's effort to construct and maintain a reputation as the "AIDS hospital" in the community. AIDS patients in the SDU maintain a folklore about the SDU unit at Metropolitan. The folklore consists of the following history of the SDU:

In the early 1980's three physicians transferred their AIDS patients to Metropolitan Hospital after the highly publicized closing of the first hospital dedicated to AIDS care in the United States. These physicians were willing to declare their dedication to the care of PWA's and to admit their patients to the SDU. Over time, tradition this has created a community perception of Metropolitan as an "AIDS hospital".

Folklore is easily maintained and perpetuated by the close proximity of Metropolitan hospital to the gay community. This community is politically active, concerned about discrimination, and fights actively to insist that AIDS patients receive good medical care. The early folklore includes the fact that AIDS patients either had nowhere to go, were excluded from some hospitals, or were main-streamed with other patients when admitted to other hospitals. At Metropolitan, the dedicated AIDS physicians, close proximity to a large population of gay males, and a reputation of good care has disseminated through the gay community of friends and acquaintances to support its reputation as the "AIDS hospital".

Patients assess the quality of health care, among other ways, as how it compares to other hospitals. Vince, for example, commented on how Metropolitan's treatment of AIDS patients was different than other hospitals in the community. Vince bases his positive assessment of Metropolitan compared to his experience at other hospitals:

Just the way they treat you. Not just like medicine or whatever, just their decorum with you. I mean there are just so many different ways that they treat you so

differently than normal hospitals that aren't dealing with a lot of AIDS patients. But they see so many AIDS patients. That's all they see, they've learned how to.

"They know how to treat AIDS here"

The second feature of philosophy was the patient's perception that the hospital represented expertise in AIDS care. This perception is based on how patients rate Metropolitan as a result of their knowledge of the experiences other PWAs have had while hospitalized on the SDU. For example, the physicians who care for PWAs are often chosen to direct clinical trials of HIV/AIDS medications and treatment protocols. These clinical trials make medications available to patients that are not available to the general population of PWAs. Patients use this fact to support their claim that the Metropolitan physicians are experts in the care of AIDS. They feel they can reap benefits from the early stages of experimental studies and participate in treatments which represent the state of the art in AIDS care. "Vince" indicated how the expertise at Metropolitan will, in fact, heal him:

I don't know, I mean this is an AIDS hospital, they know how to treat AIDS... You know when I feel I'm coming down with something, I can't wait to get here because I know I'll get the best care. I don't look at it as coming here and dying, but getting well.

Vince concluded that his stay at Metropolitan involved getting well as opposed to dying. Patients understand that physicians and staff at Metropolitan do not treat AIDS as a fatal disease, but as a chronic illness warranting extraordinary care to improve patient's quality of life. However, some patients noted that they were aware of the

experimental drugs which the physicians used as part of their progressive care. Jason stated that he felt his role as a patient was to be a "guinea pig." He stated he knew he would be receiving experimental drugs when he came to Metropolitan Hospital, but he felt he had no choice but to participate in the research protocols if he wanted to have a chance to survive.

"The nurses want to be here"

Nurses as well as physicians support the appearance of clinical expertise. Patients feel, though, that nurse expertise is largely the result of their dedication to the SDU. They are aware that nurses agree to be assigned to the SDU knowing that they will be working exclusively with PWAs. Patients, therefore, perceive that the quality of the nurse's work is enhanced because they believe they really want to work on the SDU. "James" noted that he believed the nurses on the SDU had personal reasons for choosing to work with hospitalized PWAs:

They've (nurses) known a lot of people who have had AIDS. They're tied to people who have passed on. They feel a special need to give a little bit more and that's what they want to be involved in. I think they're special people.

In reality, nurses do volunteer to work on the unit. Each nurse receives a specialty pay differential for hours of work, reinforcing the nurses' understanding that there is personal risk involved in caring for AIDS patients. Patients perceive the nurse's decision to assume the role of AIDS caregiver as "dedication". James commented that he felt the nurses were doing what they wanted to do:

The nurses are exceptional. As you're probably aware, all of the nurses that work on the AIDS floors are volunteers, so they're actually doing something that they want to do. Which, when someone is doing that, they always do a better job. And, the care that you get from them is really exceptional.

#### Autonomous "unit management"

Patients perceive that the SDU nursing management gives the nurses flexibility in managing their day-to-day work. They believe the nurses decide which patients they will care for each day. In fact, the SDU nurses do have a significant voice in their daily assignment as the decision is made among the nurses. The parameters which nurses use to guide their assignments are largely determined by hospital policy, based on regulatory guidelines from Medicare and the Joint Commission on Accreditation of Hospital Organizations (JCAHO).

Nurses routinely change their patient care assignments to allow breaks from an exceptionally difficult patient, to provide continuity of care with a very ill patient or to care specifically for a patient with whom they feel they have cultivated a personal relationship. "Rich" described his positive reaction to a nurse's decision to work to continue caring for him:

Yesterday Rick came by and he had already been assigned to a different unit for today's work and he went to his supervisor and said he wanted to stay here because he'd gotten to know the patients and it made it a little easier not only for them but him. That meant a lot to me. If that's their procedure and he's here today, I was delighted when he walked in the door. Because he's very conscientious and pretty easy to be around and I thought it was neat that it meant enough to whoever made that decision that they would put him back here. I feel like that was pretty neat that he could make a request like that and it would actually be listened to.

### "The same nurse everyday"

Patients perceive that having the same nurse everyday is desirable. They believe the continuity which comes from having the same nurse gives them the opportunity to develop a relationship with the nurse over time. Nurses do attempt to care for the same patients on a day-to-day basis. The continuity of assignments makes it easier for the nurses to be abreast of the patient's plan of care and allows time to develop a style of communication that is comfortable for both patient and nurse. However, if part-time or temporary nurses are used, nursing management assesses the temporary staff's level of expertise with AIDS patients, and then makes assignments based on patient safety and clinical acuity. "Carl's" comments reinforced the importance of continuity in patient care:

One of the things I started noticing this time is that you're getting the same nurse almost everyday except when they're off. When I was here before you'd have one nurse one day, one nurse the next day. You get more of relationship built up with the nurse if they come everyday.

### Individualism

The perception that hospital management allows the nurses to be individuals is important to the patients on the SDU. Metropolitan has a nursing dress code policy that states that the nurses must wear a specific uniform color and outlines how that uniform can be accessorized. However, the nurses on the SDU individualize their dress in areas not covered by the policy. For example, male nurses may wear earrings to work. Unusual hair colors and styles are not uncommon. These subtle variations from policy are generally

ignored as long as there are no complaints from the general hospital staff. In fact, hospital staff do not complain about the individual demeanor of nurses on the SDU as they see them as a part of the culture of the unit. This permissive individualism gives the patients the perception that hospital management "encourages the nurses to be individuals".

### Environment

The environment of Metropolitan Hospital is defined by patients as the physical features of the SDU, established by hospital management. They believe that hospital administration specifically designed the SDU with these environmental features in mind. Patients identified six features of the SDU environment that were significant related to their hospitalization: "Dedicated AIDS floors", "circular 'pod' nursing units", "homelike decor in patient's rooms", "family oriented waiting areas", "nurses visible from the patient rooms", "and private rooms."

#### "Dedicated AIDS floors"

The first feature of the environment which patients identified as significant at Metropolitan Hospital was the dedicated AIDS floors. At the request of the hospital's AIDS physicians, two hospital floors were dedicated to the care of HIV/AIDS in 1988. Only patients with a diagnosis of AIDS or HIV are admitted by hospital policy to these floors. This policy is significant to patients, as they perceive that their care is specialized on these floors. "John"

commented on the emotional support he received from the dedicated AIDS unit:

You don't have to deal with patients who are not HIV positive being scared to be around you or share a room with you or something like that. I think it's a big plus and it gives you some support because you know you're not the only one with HIV and you can walk around and see if you know any names on the doors and go visit them you know. We'll get through this together, you know, that kind of thing.

"James" commented how comfortable the dedicated AIDS unit concept made him feel during his hospitalization:

Coming here you know these are floors that are designated for people with AIDS and everybody knows on these two floors that you are an AIDS patient which is no big deal to me. I don't mind telling people I have AIDS. But to a general population, let's not put that big A on my forehead and have people afraid of me--it's very important.

"The circular 'pod' nursing units"

Patients perceive that having the nurses in close proximity gives them a sense of security. Each SDU floor has three distinct round nursing units or "pods" with 10-12 patient rooms. The nursing stations are in the center of each pod, surrounded by a semi-circle of pie-shaped patient rooms. Each room is within 10 feet of the nursing station. The pod design gives patients a sense of diversion and comfort and was noted to be desirable by a majority of the study patients. "Al" stated how the nursing pod design gave him a sense of security:

I think the set up is great with the clover-leaf figure with the nurses station just right outside the door. I really appreciate that as far as the structure of the thing goes. For one thing, it's just a diversion. I can at least see them (the nurses) when I open the door and see some kind of activity instead of the wall on the other side of the hallway. And the fact that they're close enough in case there's some kind of emergency they should be able to get to the room quicker from where they are, I think. Because all

they've go to do is step across that aisle.

"John" commented on how the SDU design was more desirable than other more traditional nursing units:

It makes a big difference to me because I feel I'm getting much better service and much faster service than in a hospital where the nurses station and all the rooms go down a long hall. I think the nurses respond faster because they don't have so far to go and, well face it, just to walk out to the middle of the room to come in to a room is a lot easier for the nurses than if somebody beeps them way down at the last room at the end of the hall. Even if they're conscientious, it just takes longer to get there. I think all hospitals should be built on this pod theory.

"Homelike decor in patient rooms"

Hospital administration has taken great care to create the environmental atmosphere that the patients recognize on the SDU. The circular nursing unit is an architectural feature of all Metropolitan nursing units. The purpose of a recent hospital renovation was to make the patient rooms more homelike. The room decor includes bedroom furniture decor, large TV's, and wood cabinets designed to hold all items which could be objectionable to patients and visitors (oxygen, suction, needle boxes, and gloves). The hospital administrators at Metropolitan were especially sensitive about the presence of needles and gloves which would remind patients of issues involving contagion. The SDU decor, installed at the direction of hospital administration, was intended to make the PWAs extended hospitalizations as comfortable as possible. Patients perceive the hospital has taken extraordinary measures to make the SDU comfortable for them. Vince commented on how the hospital decor helped him to deal with the long, frequent hospitalizations:

I think I've spent 6 months out of the year here. It's

like a second home to me because I've accepted what's going on and this will probably be part of the rest of my life. It's uplifting. . .The furniture makes it feel more like a hotel suite than a hospital room and the big TV helps alot.

#### "Family-oriented waiting areas"

Another feature of the environment which was identified by patients as important to the hospital environment, was the availability of family-oriented waiting areas that have the appearance of a living room versus a standard hospital waiting area. The patients appreciate this amenity as it allows them to have a homelike environment for their use. These waiting areas were specifically planned by the hospital administration during the SDU renovation. The administrators recognized the need for additional rooms dedicated exclusively for patients to use for: family gatherings, meeting with friends, and for special events, such as birthdays and holidays. Other hospital waiting areas are described as being "cold and impersonal." The SDU waiting areas were intended to create a sense of privacy for PWAs and their families.

#### "Nurses visible from the patient rooms"

As discussed earlier, the circular design of the SDU allows patients to see the nursing staff from their hospital beds. Patients report that this feature assures them of immediate access to nursing care in an emergency. Additionally, nurses of the SDU encourage patients to leave their doors open so that they can see them at all times. Patients with HIV are often very ill. If they were admitted to other hospitals, it is likely they would be admitted to a

more intensive nursing care unit, such as an ICU. The nursing station's proximity to the patients allows both nurses and patients to monitor each other's activities in critical care situations.

"Carl" commented on the sense of security he gained by the accessibility and visibility of the nursing staff:

You can see the nurses at all times just about. They're out there, and you know they're out there, and they're within three steps of you. You can see if they're not out there, they must be in other rooms or something. You know they're not just sitting there saying 'Well, he's not going to get sick tonight', or something. You wonder at other places.

"Private rooms"

Private hospital rooms are perceived as being a very important feature of the hospital environment to the PWA. Private rooms allow patients to maintain their privacy and a sense of dignity. Most hospital rooms are semi-private and have a minimum of two beds. Metropolitan hospital administrators determined that it was important for the SDU to have private rooms because of the frequent, extended hospitalizations PWAs experience. This fact is important to hospital administration, as good customer feedback brings more patients. PWAs simply feel more comfortable in a private room.

"Ed" indicated that he liked the private hospital room because he valued his privacy:

I'm a very private person. I don't like big groups of people and crowds and all that. I prefer private rooms. Every once in a while you'll hear, somebody will tell a joke and they'll all laugh. Well, you kind of need that every once in a while, but as far as general conversations and stuff, no.

"Peter" liked private rooms because it saved him the

embarrassment of being sick in public:

I don't like being sick in front of other people. I feel fine getting sick here by myself with nobody sitting in the next bed and I don't mind getting sick in front of the nurses. But, a stranger, no. I just prefer private rooms.

### Rules

Patients understand that nurses organize their work day around a particular set of rules established by management. Patients view rules as parameters within which nurses perform their work. The rules identified on the SDU by patients include: "Unlimited visiting hours;" "I can go anywhere I like;" protocols; safety precautions; "in charge of the routine;" "know when to do what" and maintain control. Patients, in general, do not believe there are formal rules on the SDU. James's experience taught him that there was no need for formal rules. He felt there were no formal rules of conduct because the SDU functioned well without them:

(Rules?) Well, I guess there are, but its much more free. They gave me a little pamphlet when I came into the hospital, but it was just on the hospital itself. I haven't read every page of it so if there are any rules of conduct for this or any other floor, I'm not aware of them. I like to look at rules as there to be used when they have to be but not 'this is the way we're going to run this floor, and by God don't step out of bounds'. That's kind of the feeling I get. I'm sure that if I did something out there that was a danger to any other patient, they'd be there real quick, but they don't just stay on your back.

"Unlimited visiting hours"

It is the patients' belief that the SDU has unlimited visiting hours which allows them to control their own visitors. Each patient room on the SDU has a single patient

bed and a twin pull out bed where a guest can sleep or nap. The official hospital visitation policy allows patients to have one visitor stay in private rooms indefinitely. Nurses regulate visitors more carefully after established visiting hours (9pm), when the hospital entrances are monitored by security. This feature is an important safety precaution for hospitals in large metropolitan cities. If a visitor presents, the security officer calls the SDU to gain permission for the visitor to be allowed to proceed to the unit. In general, the nurses allow visitors unless the patient is very ill. Although visitation is regulated, the patients perceive that "anybody I want can come and visit anytime," allowing them to individualize the visiting policy to their personal needs. The notion of unlimited visitation is another aspect of the SDU folklore.

"I can go anywhere I like"

Patients like the freedom of movement that they are allowed when hospitalized on the SDU at Metropolitan. They believe that patients are able to go anywhere they like, as long as the nurses know their location. In reality, the nurses on the SDU maintain responsibility for the patients they are assigned, regardless of their location, unless their care is turned over to another healthcare team member. Nurses at Metropolitan have an elaborate system of keeping track of their patients. Patients who go for a walk in the hospital, or to the cafeteria, can be contacted by the overhead paging system. Nurses may ask other nurses who are at lunch to keep an eye on their patients who have gone to

the cafeteria. The nurses use their judgement in determining if patients can leave the unit. They take into consideration the patient's physical condition and the ability of visitors who are accompanying them to assist if a problem should arise.

Not only can patients leave the unit and be monitored, but in some instances the nurses will deliver on-site care. "Ray" commented on his perception that patients can move about the hospital with the nurses' permission:

This one instance, the eye doctor was coming to see me and I was downstairs in the cafeteria eating and they paged me over the loud speaker to hurry and get back up here because the doctor was coming to see me about my eyes. You can go out walking or go outside, but you really have to let them know where you are at all times. You just can't get up and walk. You really have to let them know at all times in case something happens.

James summarized how he managed his freedom to move about the hospital while allowing the nurses to manage his care:

I've been known to get on the elevator and go to the lobby and sit around and watch the people come and go. They (the nurses) don't mind as long as I tell them. In fact they come down to the lobby. It's embarrassing. I'm sitting in the lobby talking with friends or family members and there comes my nurse with shots and bag replacements. I'm in the hospital and they'll follow me anywhere.

## Protocols

Patients believe there are rules which exist that instruct the nurses to administer medication according to strict protocols. In truth, the nurses use their discretion to determine what is safe or of benefit to the patient within the parameters given by the patient's physician. If

they perceive that a patient is experiencing extreme pain, especially as their disease advances, they will administer the maximum dosage of medication at the earliest frequency allowed. Nurses or physician's may make a conscious decision to limit analgesics. If one nurse is opposed to a patient's drug dependency, he or she may alter the dosage, route and or frequency of the medication. This restriction is accomplished by the nurse administering one of the numerous analgesic orders which are usually written by the patient's physician. Patients, in general, do not realize that the nurses may make decisions regarding how their medications are administered.

"Peter", a patient with a history of narcotic dependency, reported his perception of how the nurses managed his medications:

You can't ever ask the nurses to get anything early, everything has a schedule. When your pain medications have worn off and you're not at the four hour limit, they say 'no'. But that's their job and I understand that.

In reality, nurses may choose to have patients wait for their medication to the maximum extent which the physician order allows.

#### Safety Precautions

Patients feel that nurses generally take precautions to protect themselves from HIV infection. These precautions include wearing gloves and using protective coverings when there is a possibility of contact with body fluids.

Sometimes patients actively assume the role of protecting the nurses. Rich noted his response to a nurse who was

wearing protective equipment more than necessary:

The last time I was in here a young lady who was new to working in an AIDS environment, kept wearing gloves and what surprised me so much is that it didn't bother me. I want the staff to protect themselves. I figure it's dangerous enough without taking extra precautions, because I don't want to have an accident occur that might be on my behalf. I think that lady was just fine but somebody needed to deal with her and tell her. They came in and asked me about her and some of the staff was really outraged by her doing that and she was moved from the AIDS area to another area of the hospital. She wasn't fired thank goodness. But it didn't bother me, it bothered the other nurses and everybody else more.

Carl sternly insisted that a nurse be more careful when he noticed the nurse's practice of coming into contact with body fluids without wearing appropriate protective devices:

Some people use gloves, some don't when drawing blood. But other than that, I always insist that they put gloves on because I don't want to be responsible for them pricking themselves or something like that.

"Paperwork"

Patients are concerned about the amount of "paperwork" which the nurses have to do during their shift. Patients realize that paperwork is an important part of a nurse's job, however, they do not know how it relates to their individual care. In reality, the open design of the SDU allows patients to see the extensive amount of paperwork nurses perform. Carl felt that nurses complete paperwork to protect themselves legally:

I always feel like they're busy. I know they have so much paperwork to do. They have to document and redocument. Document everything you do because they're liable to come and get you.

"In charge of the routine"

Patients perceive that the nurses control their routine while in the hospital. Nurses manage their daily work by developing a routine time for certain procedures which they must

perform. At first, patients believe that all activities are tightly structured. Over time, patients begin to understand that not all activities are scheduled and that variances are possible. Patients then may attempt to alter the schedule of certain activities, for example, their bath time. Tony perceived that the nurses were in control of the patient activities:

You just watch. I've kind of got it down now. At 4:30 they take blood from me in the morning. Everything's on schedule, morning pills, afternoon pills. I started to see a pattern.

In contrast, Greg seemed unaware of any schedule: "you never know when it's (medications, tests, procedures) going to happen-- it just sort of does."

"Know when to do what"

Patients on the SDU feel they have significant input in the decisions regarding their healthcare. As previously indicated, this attitude is a result of patients being highly informed of their condition and treatment options. The organization, through the nurses, responds to patients' choices regarding their health care by allowing them input into their treatment decisions. The nurses are described as "going out of their way to let you know what is happening and how it's going to affect you." Chuck's statements revealed how important it was that the nurses take his needs into consideration before they initiate an invasive task: "I haven't had anyone come in here and start doing something without my permission."

"Maintain control"

It is important that patients maintain a sense of autonomy while hospitalized. Their ability to do so varies with their

state of wellness on a day to day basis. At times they may feel like they cannot make decisions about their care. Nurses recognize when it is important to allow patients more autonomy or when they may need to help the patient make decisions. Peter reported that as long as he was feeling strong, he wanted to make decisions regarding his care:

With regards to any major medical decision, I'm learning that I make the decisions really. I've always thought that they controlled the environment. Not really. They give me options or they say this is the only way we can do it, do you want it done or not. They don't come out quite explicitly as that but that's the outcome of the conversation. I feel like I'm in control and I'm the boss. It's real important. In fact, just this morning I was thinking that. I was laying there resting and thought I really am the one that's running this show. I'm sure there's other people who don't feel like that, as they get sicker, but I've been feeling better today. I was really feeling depressed yesterday. I feel like if I have some major control I feel better.

## Services

Services refer to the formal services provided by Metropolitan Hospital. The SDU receives the same support services as the other general care units at Metropolitan Hospital, however, patients perceive hospital services are specialized to the SDU. Support staff (ie. respiratory therapy, dietary, physical therapy, pharmacy) perform the same functions for the SDU patients as they do for other patients in the hospital. Patients believe that they receive extraordinary service for two reasons: 1) they have never been admitted to units in Metropolitan other than the SDU, and 2) they believe the SDU is a specialized unit, therefore the services are also specialized. Patients also perceive they have access to services that respond to their personal needs: "Expert technical care;" "Patient support;" "scheduling tests;" "access to physicians;"

procurers; "information resources;" "prompt service;" "what the patient wants the patient gets." One negative aspect of hospital services was perceived: "you sit and sit and sit."

#### "Expert technicians"

Patients believe that it is important for the nursing staff to be "professional" and "experts in technical care." Patients describe clinical expertise in different terms than nurses. Patients describe good nurses as those who are prompt, have good communication skills and make them feel comfortable and safe. In reality, nursing education is focused on training nurses in three types of expertise; interpersonal skills, clinical skills, and decision making skills. Although patients may not be aware of the nurse's clinical knowledge, they base their assessment of a "good nurse" on how promptly and confidently the nurse responds to their psychosocial and physiological needs. Peter bases his high assessment of the SDU nursing staff on his prior experience with other hospitals:

I won't go to any other hospital. One of the main reasons is the nursing staff. You barely hit the beeper and they're here for you. All your medication is taken care of, they talk to you, they encourage you when you're down, just if you needed anything they'd give it to you. If I just hit that little beeper they'll take care of me. And, they're nice people and dedicated, and they're professional. A couple of times I've had seizures or attacks and they're right there and were taking care of everything. They have a knowledge of medication, hooking up IVs . . . I've been in other situations where they couldn't get an IV started, couldn't take blood samples, so that's what I mean by them being professional.

In his description of a "professional" nurse, Peter does not separate clinical skills from interpersonal skills. In practice, however, nurses often refer to each other as "good nurses" based

only on one or two of areas of expertise. For example, a nurse may describe a colleague as a "great critical care nurse," but one that "could never work on a general care unit because they couldn't relate to patients or their families." This example indicates that nurses may be judged to be "good" in different ways by patients and their nursing peers.

Other patients felt that there were nurses with whom they did not feel as comfortable. "Charles" commented on his concern when he was assigned to agency nursing staff:

I've had some problems with agency nurses. You can tell when they come in they're different. Well, they don't understand that we're almost experts. Sometime their procedures aren't you know, like wiping the caps off and things like that. They aren't as meticulous about it. They skip stuff.

"Patient support"

Some patients felt that the hospital services did not meet all their needs. Some patients wanted more services available to them, others did not see the need. For example, the SDU has an art class weekly. Some patients attended the class and commented that it was a wonderful diversion for them; others thought it was a waste of hospital resources. The SDU also had a counselor service available for group therapy, but it was discontinued because many patients did not like to discuss their problems in group settings. James described his need for more individual therapy by trained psychology staff:

I need somebody, I need more one-on-one therapy. It would be something I feel I needed at least twice a week. Someone who could come in and have a little therapy session--an hour or half-hour is sufficient. Where you have somebody from the psychology staff come in and find out what's going on with you and reach in and talk to you.

### "Scheduled tests"

Patients, in general, perceive it is important for the nurses to be in charge of their hospital routine. Patients often are not aware of what their physician has written as orders or has planned for their hospitalization. The physician may tell a patient that a battery of tests has been ordered for him, but the patient may not be aware of what the tests are or when they will be performed. One of the roles the patients believe the nurses play in their care is getting them the right treatments in a timely manner. They also trust that the nurses will inform them of the specific changes in their care and be able to explain why the change has occurred. Ray reiterated his reliance on the nurses to keep him informed of alternations in his plan of care:

I expect them to know what's going on with me. If I say 'What am I scheduled for today?', they're going to know that I'm scheduled for this or that. Or 'what is this stuff you're hanging up here on the rack to put into my body and why am I taking that?' and so far they've always had the answer.

### "Access to physicians"

Patients perceive that while hospitalized, their communication link to their physician is through the nursing staff. Physicians, in general, see the patients once a day and make determinations about their care. At other times, patients must rely on the nurses to obtain access to their physician. When a patient has a request, or experiences a change in status, the nurses usually call the physician. Patients understand that they might request that a physician be notified regarding a question or concern about their care, however, they are also aware that the nurses use their own judgement to determine whether the physician will actually be called. If the nurse

chooses not to call the physician, the patient knows he may not have access to medications, treatments, or answers to questions which he may feel important. This gate-keeping role gives the patients the perception that a "chain of command" exists between them, the nurses and their physician. Greg described his perception of the nurse as an integral part of the triad of care between him and his physician:

In relationship with the doctor, I see the nurses as key. That's how the nurses work with the doctors. It's important. You've got to have that ability. Because if they don't, it just causes me to suffer.

#### Procurers

Patients understand the nurses not only provide access to the physician, but that the nurses are also procurers. Through their communication with the physicians, the nurses have the ability to make requests for the patients. If the nurses believe that the patient has a legitimate request or need, the nurse will communicate that to the physician for the patient. Al stated the importance he placed on the nurses being able to obtain orders for him from his physician:

They understand that I'm able to communicate through them and they understand what I really need and they are able to either supply it or if they can't, get a hold of the doctor so that they can get permission to supply it. I was having a severe anxiety attack one day, and I had no drugs to take care of that. So, I asked the nurse if she could call the doctor and either get me some Zanax or Ativan. She got a hold of the physician and got permission to get me Ativan which right away took care of my anxiety attack.

Patients also recognize that the nurses can be used in obtaining things for them when their physician is unavailable. Tommie made the following comments of how the nurse assisted him when his primary physician was off for the weekend:

Yesterday was Saturday and it seems there's a little bit of a let off on Saturdays around here. I was wanting to know what the prognosis was--how much longer I would be on this chest tube and my doctor had a weekend off and his substitute didn't even know I had a chest x-ray. I got that impression that it was sort of normal--that they don't read your charts that closely. They just want to make sure they can get you through the weekend okay. If there's any little problem that they can deal with. I got upset after he left because that meant the soonest would be Monday. I got a little concerned about it and I expressed it to the nurse. She ran down Dr. Smith who had come here to see his patients and see me and then I got all my questions answered. So, once I got my questions answered, I was perfectly happy.

#### "Information resources"

The nurses provide an important service to the patients by giving them information regarding their care. In fact, patients expect nurses to know the purpose and side effects of medication, and to share their knowledge with them. On the SDU, nurses go one step further in sharing information with patients. For example, they may give patients the results of tests prior to the physician having an opportunity to do so. This practice contrasts with those in other patient care areas at Metropolitan. PWAs, in general, have a greater understanding of their disease and the treatments involved than other patients might have. In addition, the SDU physicians trust the nurses to use their judgement and share information with patients judiciously.

Carl recounted his experience with the nurses sharing traditional information relating to medications:

If it's a new drug, they'll look it up in the PDR and say it's for this and the reactions you ought to expect from it is this or that. I ask them about all these antibiotics that they hang all the time and they always explain it to me even if they've done it three or four times before.

Ed commented on how the nurses were willing to obtain information for him regarding the outcome of one of his tests:

I told my nurse that I needed to know the outcome of a test. The other nurse, Mark, yesterday, even looked it up on the

computer while I was standing there and told me what it said. That meant a lot to me. Once I realized I could use the nurses, it did help. I was just grateful that somebody who knew about the case came to see me--it meant a lot. Almost anytime I have a question, it gets answered.

"On the ball"

One of the important features of service patients noted on the SDU was the nursing staff's promptness. One patients commented how the nurses seemed to "really be on the ball." This promptness was very important to patients as they rely on the nurses for access to many of the hospital services. One patient commented that "they come back when the time is up, immediately." PWAs may become ill very quickly. It is important for them to feel like they can have a rapid response to their requests. When they have instant attention to their requests, the patients are left with an overall sense of security regarding their safety while hospitalized.

"What the patient wants, the patient gets"

Patients perceive they have almost unlimited access to some services on the SDU. In reality, hospital administrators have intentionally designed certain SDU services differently. Because nutrition is such an important part of care for PWAs, the dietary department provides the SDU with services which are not available to other parts of the general hospital. One feature of the dietary service is a menu system which allows "write-ins." This feature allows patients to "write in" almost an unlimited number of food items which would be prepared and customized to the patients dietary requirements. This service makes patients believe that "what the patient wants, the patient gets." In other hospitals, the patients report having a set menu which

rotates for a predetermined length of time, usually two to three weeks. In Metropolitan Hospital, the general patient care units have a 21 day rotating menu service. Patients on these floors can write in menu items which have been identified as the "special of the day" as indicated by a small clip-on menu. The SDU patients also have the opportunity to use the clip-on menu specials but learn over time that they may write in menu items. This service is not marketed to the SDU patients but the word of mouth between patients spreads quickly. James commented on the availability of what he considered extraordinary service from the dietary department:

They really allow you to order what you want to eat. Sometimes I don't feel like eating, and other times, I get really hungry. When I have an appetite, I need to eat all of the calories I can get my hands on. Tonight I'm going to write on my menu I want broiled strip steak, tomorrow if I feel like eating I might write that I want broiled scallops, and linguine in clam sauce.

"You sit and sit and sit"

One of the negative features identified by the patients was that the hospital experience could be physically uncomfortable. This concern was especially true of situations where the PWAs had to leave the SDU for treatments or when the unit routines interfered with their care. Adequate numbers of staff was identified as the major problem in many of the cases cited by the respondents. James commented on how the inadequate numbers of staff caused him discomfort:

The only thing they need is 10 times as many transporters as they have. It gets a little irritating sometimes when you're sitting out in a hallway with a cold draft with pneumonia. You know I had a CAT scan and I drank that wonderful gooky stuff and I sat out in the hall so long I had to redrink that barium. Well that didn't make me happy at all. It seems to be, if there's an irritant here, it's that. You just go down and sit, and sit, and sit. An then you sit and sit and sit waiting to come back up.

Carl mentioned how the insufficient number of staff available during the nursing report made it difficult for him to get what he needed:

When they change shifts, they call that giving report, and when they give report, everything ceases for 1/2 to an hour. I said what the hell, is this a hospital or a gas station? Are they going to do all of the numbers on the pump before they let the new people come in and buy gasoline. I feel there should be some sort of way to change shifts where the patient isn't affected.

#### INTERACTIONAL FEATURES

The second group of features used to foster feelings of hospital as home were interactional. The interactional features of the SDU at Metropolitan Hospital are those which are identified by the patients as being important in their relationship with the nursing staff. The interactional features described by the patients are: 1) commitment; 2) honesty; 3) comfort; 4) sensitivity; 5) informality; and 6) familiarity.

#### Commitment

Commitment refers to the patients' perceptions that staff and patients shape their actions based not only on their professional role but also on their personal commitment to their work. Patients believe that staff are committed to them as people, not just patients. The key features identified by the patients which demonstrate commitment were: "Homecoming cheerleaders;" "how they talk;" "everyone seems to take a moment;" "and the women of the war;" and "just here to get a paycheck."

### "Homecoming cheerleaders"

Patients perceive the nurses as "homecoming cheerleaders." This perception is based on the nurses "unfailing support" for patients over the course of their disease. Because AIDS results in chronic disorders which require frequent hospitalizations, the nurses see patients repeatedly over the trajectory of their disease. This repeated contact gives the nurses the opportunity to play a significant role in providing emotional support to the patients. Vince stated: "They encourage you when you are down, if you needed anything, they would give it to you." The nurses on the SDU were noted to seek out patients other than those they were assigned to or who were located on other floors. Peter remarked how the nurses found out he was hospitalized and came to see him while he was on another floor:

These nurses are just ecstatic, especially to see someone doing as well because they know how hard it is to get up on your feet with this disease. Each time I go to the hospital and get out, it's harder... There's about six nurses that I know real well who come to visit whether they're on that floor or not while I'm in the hospital... The word got out that I was here and some from the 8th floor came down to visit and I haven't been here in five months and they still remembered me and were concerned about me.

It is not unusual for nurses to remember patients and develop a relationship with them after repeat admissions. However, the SDU patients identified that the nurses actually "seek them out." This feature differentiates the SDU nurses behavior from nurses on other units and in other hospitals the PWAs had experienced.

### "How they talk"

Patients, in general, formed their opinions about how compassionate the nurses were based on "how they talk." The

nurses' communication style imparted a concern for the patient over and above the patients' general condition. This communication style gave the patients the impression that the nurses cared for them "not only as a patient but as a person."

Vince perceived that the nurses talked to him in a way that demonstrated that they knew what he was experiencing as a PWA:

Coming here, these people take care of you when you're really down and out. When they ask you how you feel, they are really asking you how you feel compared to somebody who hasn't dealt with anything like this. They know how hard it is to pick yourself up and keep walking. It makes a big difference.

"Everyone seems to take a moment"

Patients at Metropolitan expressed their pleasure at how frequently the nurses stopped "just to chat." While hospitalized, the patients frequently mentioned their isolation from society and other PWAs hospitalized on the same unit. Some of the respondents had family members or significant others who visited frequently, however, those who had experienced long hospitalizations appreciated the time the nurses made to stop and talk with them. Often the topic of conversation had little or nothing to do with the patient's disease or hospitalization. These conversations were noted to be the most pleasing to the patients as they gave them a break from their daily hospital routine. Vince was impressed that his conversation with the nurses surpassed the interaction that he had with his family or friends: "Sometime I get more interaction in the hospital than when I'm out."

Peter gave an example of how one nurse went out of her way to do something special for him:

I have a terrible sweet tooth and it happens in the middle of the night. One nurse in particular, she was busy yet would still call down to the cafeteria and get my chocolate

chip cookies. Then I came back in and she went ahead and brought me a whole thing of chocolate chip cookies she had baked at home.

"The women of the war"

Working in a hospital setting can sometimes be traumatic for the health care staff as well as the patients. James stated: "I got to understand the women of the war--They are going through some trauma of their own." This quote exemplifies some sharing of angst between the nursing staff and the patients. The patients probably solicit this type of interaction to a degree. It appears that nurses are personally rewarded by their interactions with the patients, fulfilling some need within the nurse. It was commonly known by the PWAs that several of the SDU nurses were either HIV positive or had experienced illness and death from AIDS with significant others, friends or family members. It was openly discussed by the patients and the staff that a nurse's brother had died on the unit from AIDS after many long hospitalizations. They were aware that the SDU staff allowed the nurse to care for her brother whenever possible. This practice was well accepted in the SDU but would be seen as unusual or inappropriate in other areas of the hospital.

Carl commented on how the nurses must be resilient in dealing with all the grief associated with caring for patients with an ultimately terminal disease:

I don't know what it is. They've got guts. Building a relationship with somebody and then seeing them go. I don't know how you'd describe it until you saw them in action. It's something that might go unrecognized some other place, some other system.

"Just here to get a paycheck"

Patients are very aware of nurses who are not committed to

caring for them. They are especially sensitive to nurses who are not a part of the regular SDU staff. Ray noted how the non-caring attitude of one of the staff affected his care:

I've had nurses where just some time they just seemed like they were here to get a paycheck. They don't care. I remember one night when I had a high fever and it just felt like it took forever for them to bring me something to bring the fever down. It went higher and it was taking too long. I had a nurse in here that night that just didn't care-- stayed on the telephone all the time.

### Honesty

Honesty refers to the patients' perception that staff will share the truth about their illness whether it would be painful to them or not. Most patients indicated that they wanted to know the truth about what they were facing in their illness. Features of honesty were: "Tell me if this little change is important;" "tell the truth;" and "know what I have to deal with."

"Tell me if this little change is important"

One feature of honesty identified by the patients was when the nurse indicates to the patient the severity of a change in their condition. The patients are interested in knowing answers to their questions, such as: Is the change short term or a more serious change? Do you (the nurse) conceptualize the change as little or big? For example, patients stated that "they wanted people to talk to them." They remarked that they did not understand all the technicalities and subtleties of the disease and what each change meant to the outcome of their current hospitalization. Greg expressed his desire to know what was happening to him:

I don't understand all this stuff. I don't know what's important and what's not. I rely on the medical staff and the nurses to figure that part out. You tell me if this

little change is important or if it's just a side effect.

"Tell the truth"

Not only do patients want to know what is going to happen to them in regards to their care, but they also want the nurses to "tell the truth, tell me what you know." Patients expressed their desire for the nurses to actually share information with them beyond the technical details to how the planned activity was going to effect them physically and psychologically, eg. Is it going to hurt? How long will I be uncomfortable? Will I get any medication to help the pain? In general, the patients wanted the nurses to share this information with them unsolicited, as several commented that they would not have known what to ask the nurses because they did not understand what was happening to them. Rich relayed an incident which indicated to him the importance of nurses sharing what they knew he was going to experience following his spontaneous pneumothorax:

My lung collapsed and Mike, one of the nurses, came in to try to thoroughly explain to me what was going on. But even with all his efforts, I didn't realize what was coming up-- how painful the procedure was going to be. Just tell me what you know, tell me the truth, even if it's hard for you to tell me what it is. I felt like it was a little bit hard for Mike yesterday even though he did tell me. Always tell me the truth and I can deal with it. I think communication--letting me know what they're planning on doing when they come in the room, is important, and they seem to do that pretty good.

Chuck commented on his need for details regarding procedures and test that were planned for him:

They (nurses) are real informative about tests and things. The other day the nurse said 'you've got a rough day ahead'. I didn't want to hear that but it was the truth, so I needed to. I've been through some very unpleasant tests that some of the people I work with, the doctors and the nurses, because of their knowledge, kept my mind much more at ease than I might have been.

Because the patients rely on the nurses for information, encountering a nurse who does not communicate well can be very disconcerting. Carl made reference to nurses who were not as approachable for information, and how he found that unacceptable:

Some nurses aren't as approachable--they don't seem as open. I don't know what it is that defines that but, when you ask the first question to somebody and they say 'It's doctor's orders' or 'Take this because the doctor ordered it', so you start to say I'm not getting any information out of this person so why bother asking.

"Know what I have to deal with"

Some patients felt they had a responsibility to know what is happening to their bodies and what the treatments mean to them. Several PWAs commented on how they felt they had a duty to ask what was happening to stay informed about their care.

Ed reflected on his role in maintaining a knowledge base about his disease:

It's hard for me to imagine somebody not wanting to know all the stuff they pump through you. It's just a matter of knowing. Once I know what I have to deal with, I can usually, generally deal with it.

### Comfort

Comfort was described as the patient's overall sense that nurses have intimate concern for them personally, over and above their defined professional role. The features of comfort identified include: Comfort measures; "pal up to you;" and "keep my mind at ease." "Protect myself" is a negative feature which some patients experience when the nursing staff try to comfort them.

### Comfort measures

Patients look to the nurses to make them feel comfortable.

Comfort measures were defined as those nursing activities that were focused on providing psychological care to the patient. Al described his experiences with the nurses going out of their way to make sure the patients are comfortable:

Their job is to see that we are comfortable and as an example, last time I was in the hospital, for some reason my feet all dried out and one of the nurses noticed that at 2:30 in the afternoon and he was done working at 3:00. He said 'we'll get somebody to take care of your feet for you'. Well, he couldn't find anybody. When his shift was done, he came in here and massaged lotion into my feet for a half hour on his own time before he went home. Now, that's exceptional.

"Pal up to you"

Normally, nurses do not comfort patients by touching them, other than a tap on the arm for comfort or a pat on the hand. Nurses are very aware that patients have a right to their "personal space" and that some patients are uncomfortable with the nurses needing to touch them to administer medications or treatments. In fact, nurses are aware that unwelcome touching can be interpreted as battery by patients.

In general, however, PWAs welcome the nurses touching them, especially to hug them and sit next to them on their beds. Peter believed the physical attention he got from the nurses was very important: "You know, I enjoy the affection. They'll give you a hug and stuff."

"Keep my mind at ease"

Patients look to the nurses to provide psychological support that they might normally get from their family or friends. The extended stays of many of the PWAs allows them time to develop

long term relationships with members of the nursing staff. The PWAs begin to rely on the nurses to help them stay encouraged and to talk with them about their problems. James stated:

"sometimes I just need someone to tell me everything will be OK". Vince referred to the satisfaction he got from talking to the nurses when he felt depressed:

Lots of comfort, besides medicine and stuff. A lot of comfort. They know how to tell when you're depressed or sad or you know. They'll take the time out if they have the time you need to spend a little time with you to make you feel at least a little better.

"Protect myself"

Some patients perceive the need to protect themselves from the hospital environment and remain separate from it. They are not comfortable with the familial nature of the hospital and want to keep everyone at arm's length. These patients may not be comfortable with the closeness which a family environment exudes. The touching, intimate conversation and informal structure of the unit may create stress for these individuals, rather than imparting a feeling of comfort. James noted how he was not comfortable with people imposing on his personal space:

I can't talk with a lot of people. I just have to hold everybody at arm's length. I was the boss for so long that I can't open up to people because they may use me or take advantage of me so I've always had this built-in thing especially when it come to medical personnel. I've got to keep them at arms length, because if they really got to know the real me, they could possibly use it against me or take advantage of it or take advantage of friendships away from the job and I might have ended up firing them or doing something like that.

### Sensitive

The sensitive features of interaction are the patients' desire that nurses are really in tune with their deepest feelings, anxieties, hopes and fears. The features identified by

the patients relating to the nursing staffs' sensitivity include: Intuitive; discretion; "touching;" and "knowing that my life is precarious."

#### Intuitive

PWAs expect the nursing staff to use their intuition in determining what type of intervention the patients need and when. Several PWAs commented that the nurses seemed to be more aware of their needs than they were themselves. Pat noted a time when the nurse was particularly insightful about his needs and what a profound effect it had on him:

One of the most significant things happened to me yesterday. I told you that I had just realized that I have full blown AIDS, not just HIV based on the diagnosis from this admission. Well, I was very depressed about that fact and I was just lying in my room with a wash cloth over my eyes for a long time. This nurse, who is really great, came and said she wanted to check to make sure that the call light was working since I hadn't called. A little later, she came back in and asked me if I needed anything. What I realized later was that she knew how upset I was and was giving me the opportunity to talk without pushing me. When I realized that, I felt like this was one of the most significant things that had ever happened to me in my whole life. That someone, this nurse, was that tuned in to what was going on with me. I think that is absolutely incredible. I've not been in the hospital much, but I never expected to be treated with so much caring and dignity.

John recounted an experience where the staff were not being sensitive to his moods and his requirements for intervention regarding his depression:

I was in here over Christmas and I was miserable at the time. I was getting depressed and more and more depressed and it seemed like all these, I know these people mean well, but all these people, volunteers, strangers that I didn't know kept popping into the room and wishing me a Merry Christmas like I was a long lost pal or something. That was a little annoying, it was okay once or twice but after two weeks of it you go wait a minute here.

### Discretion

Patients feel comfortable sharing information with the nursing staff on the SDU, but do not feel comfortable with the nurses sharing personal information with other staff or other patients. In discussing their personal issues with the staff, PWAs expect the same type of confidentiality they would have if they were in a psychologist-patient relationship. Ray described his expectations of the nurses to be discrete with information they obtain from him or through their observations during his care:

(I want) somebody that's discrete. Your condition, my shower habits, or what I had to do aren't anybody's business but mine. I don't think they should say anything, whatever I have a temperature or anything to anybody without asking my permission.

### Touching

Patients and nurses generally do not have physical contact unless it is involved in a treatment or a procedure. In general, PWAs like to have physical contact with the nurses in incidences when it is not related to a technical procedure. The PWAs expect the nurses to be in touch with their needs for tactile stimulation and respond to this need without the patient asking. John described how the nurses could be intuitive and anticipate his needs to be touched:

I like the ones that are relatively outgoing and are more tactile than some of the other ones are. It's just nice to have contact. Maybe they might see my shoulders tensed up around my ears and they'll come in and rub on my back for awhile and help me calm down, you know things like that.

### "Know that my life is precarious"

In the course of their disease, certain changes in their

care become landmarks for the PWAs. Because they are knowledgeable about AIDS, the requirements of more aggressive treatments makes patients aware that their disease is progressing, and they are faced with their mortality. Carl commented that he wanted the nurses to "Just know that I know this may be my last visit." Rich gave an example of how he felt when he realized he was going to have to receive blood and have a Hickman catheter placed:

I had to have two units of blood and that was a big thing to me. I thought 'Oh, my God, I'm one step further along the AIDS route.' I'm truly taking new roads and it upsets me when I think I'm getting sicker. And then the next day I had to get a Hickman, which is a big thing for AIDS victims. I had been fretting and worrying about the Hickman for three years because I'm a body builder... When I see these little things happening, like the first time, I have to deal with them and recognize that my life is precarious and I'm in danger of losing my life. These little things are significant to me.

### Informality

The informal feature of interaction is the perception by the PWA that nurses can relate to them as a friend, a buddy or family member. This interaction is very significant because the PWAs see that the nurses can accept them as a person, not just a patient or "the guy in room 219." However, some patients are uncomfortable with informal discussions. The informal features include: "Laid-back;" "talk about anything;" and a negative feature of informal interaction, "don't go over the line."

#### "Laid-back"

PWAs enjoy talking to the nurses about topics other than health care. It is important to them that the nurses take time to talk informally. Al commented on how he appreciated the time the nurse took to divert his attention when they were

administering a medication:

They take time with the patients. They chat with the patients, they joke with them... Just joke around. We talked about a flower show on TV today and one of the nurses was giving me a shot of Demerol and there were some beautiful irises and he has an iris garden and we were talking about the iris garden he has. Just whatever pops into your head at any given moment.

Peter remembered an incident where a nurse took time to sit down and share an experience in her personal life:

I hadn't been here in 5 or 6 months and my first night here Nancy walked in and asked how I was doing and she wasn't even on duty. She sat down and talked about her trip to Africa and I'm going to South America. We talked about things we're doing in our lives not just sickness or illness.

"Talk about anything"

Patients stated that talking about topics which were unrelated to health care helped them to maintain their "perspective." As many patients are hospitalized for long periods of time, their only contact with the outside world may be the discussions they have with the nurses. Therefore, it is important to the PWAs that the nurses feel free to talk about a wide variety of topics. Ed described how his communication with the nurses on varied topics helped him keep oriented to the outside world:

A lot of times I like to know where they're from and where they got their education and if there's a current event going on and we see it on the TV and we discuss it. Just a lot of stuff like that--and you get to know somebody better. But I really like other things to be discussed. It helps your perspective of the world be maintained because your world can become the room and I know that. Like today, I went for a walk for the first time and we were just going around the pod and I said 'My God, there's a real world out here.' I had just gotten so much into my little room, that I was losing my perspective.

Carl remarked how important casual conversation with the nurses was to his psychological well-being:

I went out and sat and talked with the nurses last night at about 4:30 in the morning. I don't remember what we talked about last night. It had nothing to do with medical stuff. I think it's a very important part of healing. In fact they encourage it.

"Don't go over the line"

A negative feature of informal interaction identified by one patient was the nurse who used exceptional psychological or emotional overtones in communication. James stated that he has experienced nurses who chose topics of communication which were not acceptable and seemed to serve the nurse's needs, not his own:

The thing that really bothers me is when they start talking religion to me and letting my heart go to Jesus and things like that and letting go first, it's like they're telling me to die, to just let loose and die. Those things upset me. They bother me and I think religion at this point is nothing that I want to interact with the nursing staff about. If I want that help I'll seek out counsel from the clergy. They're nice people--they mean well. But if it gets too far over the line then I will do something. But that's one of the main concerns that I've had is nurses trying to outpour, educate you within their religious beliefs and so forth. Religion and nursing--that's two different aspects altogether. Heal the body--let somebody else heal the soul.

Familial

The familial feature of interaction is the patient's perception that they are really part of the nurse's family, and experience a sense of home when they are hospitalized on the SDU. The patients identified the following familial features of the unit: "They're part of the family;" and "it's like a second home to me."

"They're part of the family"

Some patient see the nursing staff as members of their family, not just health care providers. As many PWAs have been

estranged from their families and may not have had time to deal with their illness, the nurses may be the first people with whom they begin to share their feelings. This may provide an opportunity for the nurses to become like family to the patients. Peter commented on what an important role the nurses played in his life:

That's all I had were the nurses. I asked them what can I expect, is it going to be painful, is it going to hurt, and they put me at ease as to what it was going to be. When I had the bone marrow done, which is horrible, the nurses-- there were two or three of them with me--one was holding my hand and the other was just here helping. There was another night where we were pretty sure my lung had collapsed. I just looked at the nurse and she looked at me and I said 'This is it, it's bad man.' She picked me up and almost literally carried me into the room, three other nurses came running and it was late at night. I think they were trying to switch shifts and they had tons of work and they left it all behind to come take care of me and fix things up. Like I said, it's worth three hours driving to come here than go anywhere else.

Ed's comments note what an important role the nurses play in the lives of many PWAs:

There's unfortunately, a lot of HIV people, with families that have turned their backs on them. They don't have a lot of people to turn to. I think in that case, the doctors and nurses would become super important in that person's mental attitude as far as what's going on. That's the only place they have to go.

"It's like a second home to me"

PWAs know that when they are ill enough to be admitted to the hospital, there is a chance that they may never return home. Therefore, they take every opportunity to make their stay in the hospital feel comfortable. Vince remarked how important the SDU was in his life in the current state of his disease. "It's like a second home to me because I've accepted what's going on, this will probably be part of the rest of my life."

## OTHER HOSPITALS

Other hospitals are described by patients as frightening and cold, giving them the impression that they are not welcome guests. One feature of other hospitals that appears to be very different from the study hospital was the general comfort level of the hospital and the staff with caring for HIV+ patients.

James commented on the difference he noticed in the culture of other hospitals and the SDU:

The way they do their AIDS patients, they almost don't treat you as human, let me put it that way. They don't give you real dishes--everything's plastic and styrofoam. There are four people to a room. The time I was there, I was the only IV patient that was in the room. I feel I can relate to them better than with a person who doesn't have it. Really, people are just stereotyped. You tell them that you're HIV+, it seems like their attitude just changes, you know. That's why I feel like I can communicate better with a person that has HIV instead of somebody who doesn't have it. I've seen in the past, people, friends, I tell them I'm HIV+ and they just turn their back. I don't know if they're scared or whatever the deal is but I've seen it happen too many times.

Another feature of other hospitals was the difference in the environment, and how patients perceived that affected their care:

When I first got sick I went to a hospital in California. They were mixing me in with the general staff or the general patients and they would put these isolation things outside your room with a big yellow card and the big isolation things and everybody would have to wear masks and gloves and you were like the leper in the room and you were the one ear marked. People didn't want to come in your room. I'd be throwing up and they wouldn't want to come around to empty my bucket, empty my bedpan. They were afraid to come near me and it was horrible, the treatment I received.

Patients also perceived that other hospitals did not understand how to apply universal safety precautions to AIDS patients. One patient commented on his experience of visiting a friend in another hospital: "you had to wear mask, gloves,

everything...wash your hands in betadine before you left and it makes both of you feel dirty." This comment was in direct opposition to how patients perceived the culture of the SDU at Metropolitan.

#### Summary of Findings

Patients in general, describe the SDU as homelike. This perception is developed over time as they become more accustomed to their disease and accept and expect the support they can receive from the SDU staff. The organizational and interactional features of the hospital in combination work to create the familial nature of the unit. Vince's comment regarding the specialized care he feels he receives on the unit indicates the hospital has designed the SDU in a way which meets his needs better than "on the outside":

They're a lot more understanding here than the people on the outside that are not so understanding because they don't know what to do, what to give, or what the person needs or what he's asking for. This is like a second home to me because I've accepted what's going on and this will probably be part of the rest of my life.

It is apparent that the hospital plays an increasingly important role in the life of PWAs as their disease progresses. AIDS is currently a terminal disease, which has significant social and economic implications and additionally forces many individuals to declare sexual preferences or at-risk behaviors. These significant life stressors may cause PWAs to seek physiological and psychological comforts from a dedicated AIDS unit and staff in addition to the support they may receive from friends or family members.

Metropolitan Hospital, by dedicating a unit to the care of PWAs, has designed and supported a unit culture which, in the

perception of the study participants, enhanced their quality of life while hospitalized. Some of the environmental features of the unit, for example the family-oriented waiting areas and private rooms, were designed by the hospital administration specifically for the SDU. Other environmental features, such as the circular "pod" nursing units, are features of the hospital in general. These features also contribute significantly to the perception of quality of life of the PWAs.

The interactional features identified by the respondents were almost exclusively related to their interaction with the SDU nursing staff. It may be extrapolated from the findings of this study that those nurses who chose to care for PWAs have the interactional style which meets the unique needs of this patient population. Respondents who had the opportunity to see or experience care in other hospitals did not, in general, have the same type of interactions or experience the same environmental features as the SDU.

In summary, by dedicating the SDU as an "AIDS unit," this study indicates that Metropolitan hospital may have created a unit culture which gives PWAs the perception of enhanced quality of life in a "hospital as home" environment.

## CHAPTER V

### SUMMARY OF THE STUDY

The rapid increase in the number of patients with acquired immunodeficiency syndrome (AIDS) has presented a significant challenge to nurses and other health care professionals. Nurses and hospital administrators alike are challenged to develop a full scope of patient care services which meet both the physical and psychosocial needs of persons with AIDS (PWAs).

This qualitative study was conducted to explore how PWAs experience hospitalization on a dedicated AIDS unit. The research was intended to provide information that nursing administrators can use to enhance quality of patient care for PWAs, their families and their loved ones during periods of hospitalization.

An ethnographic, qualitative research design was used in this study to determine how PWAs perceive hospitalization on a dedicated AIDS unit. The research questions used to provide the general direction of the research were: 1) How do PWA's percieve the hospital? 2) What are patients' perceptions of a dedicated AIDS unit? (3) How do PWAs perceive nursing personnel? and (4) What are the interactions that occur between patients and nurses?

The setting for the study was a 508 bed, for-profit,

private, community based hospital, referred to as "Metropolitan Hospital." The hospital was located in an area accessible to a large percentage of the city's gay population. Metropolitan Hospital was referred to as the "AIDS Hospital" within the gay community because of its 60 bed dedicated AIDS unit called the Special Diseases Unit (SDU).

The population for this study was adult males hospitalized with a diagnosis of AIDS. The sample consisted of 15 participants admitted to the SDU. Patients who were well enough to converse were approached by the nursing staff to determine their willingness to be a participant in the study. Theoretical sampling was used and respondents were sought until selected categories of quality of life experiences were exhausted.

The instruments used in the study included a demographic data questionnaire and a semistructured interview form. Respondents were interviewed in their hospital rooms utilizing a semi-structured interview guide. Data analysis was guided by the grounded theory method (Glaser and Strauss, 1967). Data were categorized and theory generated based on themes related to the participants' quality of life using the constant comparative method of joint coding and analysis. Each incident in the data was coded into as many categories of analysis as possible as categories or data emerged that fit an existing category. This method was used until all data categories were saturated.

Analysis of data was conducted through the

construction of various typologies derived from the research questions. The typologies included the following: organizational philosophy, environment, rules and services; and interactional commitment, honesty, comfort, sensitivity, informality and familiarity. Subcategories of these key findings were then described to further explain the elements of unit culture which impacted patients' perceived quality of life (Appendix G).

In general, patients describe the SDU as homelike. The organizational and interactional features combined to create the familial nature of the unit. By dedicating an AIDS unit, Metropolitan Hospital has supported a unit culture which enhanced the study participants' quality of life while hospitalized.

#### Discussion of Findings

Health care for AIDS patients differs from other types of patients. Possible reasons for to this are: AIDS patients are dying, they have been rejected by many aspects of society, there is a high personal cost, and they see themselves as experts in their disease process. Volenburg (1989) stated that patients with AIDS are frequently young with few accumulated financial resources. Because of medical problems or discrimination, they may lose their jobs, homes, families, and friends. Therefore, the hospital experience of PWAs may be very significant to their overall quality of life. PWAs in this study described the hospital as "homelike" and regarded selected nursing staff as "family".

In the findings of this study patients perceived that a dedicated AIDS unit was as important to their hospitalization. Fahs, et al. (1992) conducted a study at a hospital which provides care to patients both in general medical/surgical beds and in an AIDS cluster unit. Their findings indicated that after controlling for severity of illness, length of stay, charges and inpatient mortality rate, the two hospital settings did not differ. However, their study did not measure patient satisfaction nor quality of life. Even though this study did not measure the variables identified in the Fahs study, hospitalized PWAs reported their satisfaction with both the environmental and the interactional features of a dedicated AIDS unit.

In a study by van Servellen, Lewis, Leake, and Schweitzer (1991), occupation had some influence on patient satisfaction. This influence was particularly notable when unemployed patients reported rather low satisfaction in comparison to patients holding clerical or sales positions. In the sample used in this study, only one (6%) of the participants was unemployed, five (33%) were on disability from their employer with full insurance coverage, and seven (46%) were employed with health insurance. All of the employed participants held professional level positions. The van Servellen, et al. study findings were not consistent with the findings of this study, as all participants stated their satisfaction with the SDU, regardless of occupation.

## ORGANIZATIONAL FEATURES

The two key features, organization and interaction are outlined with comparative studies to further explain the findings. In this study, patients noted several distinct ways in which they felt the SDU met their needs as hospitalized patients. One of the key features, organization, was categorized into four general categories: philosophy, environment, rules and services.

Hospital philosophy was described by the participants as the overriding framework for hospital policies, practices and beliefs. One feature of philosophy identified was the theme of "known AIDS reputation in the community". Because of the perceived specialty care they and other PWAs receive on a dedicated AIDS unit, PWAs self-selected the study hospital. This finding has been supported by research that found patients direct themselves to specialty hospitals, primarily those related to potentially terminal disease processes ie. oncology hospitals (van Servellen, et al., 1991).

PWAs took comfort in knowing that the nursing staff chose to work with their particular disease process and that the staff "know how to treat AIDS". This finding is consistent with the Belcher, Dettmore, and Holzemer (1989) statement that HIV/AIDS is viewed as a social stigma; therefore, maintaining a high degree of comfort with their treatment facility and the nursing staff is critically important to PWAs. In this study, patients perceived that the hospital represented expertise in AIDS care.

The hospital environment was perceived as an important organizational element. The dedicated AIDS unit, the pod architectural configuration, the homelike decor, family-oriented waiting areas and private rooms where the nurses could be easily visualized by the patients were identified as being significant aspects of the SDU.

Several relevant studies have been done which support the SDU environmental findings of this study. Kotarba, Ragsdale and Morrow (1992) described the ways everyday life in the SDU differed from that in other, more traditional hospital units. They defined eight key cultural domains that served to organize everyday life and work and signified the contrast between the SDU and other, more traditional, hospital units. The elements of environment in this study correlate with a domain of unit culture identified by Kotarba, et al. "managing the unit ecology through the integration of hospital and home atmospheres". Managing the unit ecology through the integration of hospital and home atmospheres establishes an aura of intimacy, warmth, emotional support and familiarity through the manipulation of the physical as well as the symbolic environments of the unit. This finding was consistent with the environmental features identified by the participants in this study.

PWAs perceived that being hospitalized on a dedicated AIDS unit improved their quality of life because they felt comfortable with the care they were receiving. In the van Servellen, et al. (1991) study, similar findings were reported. They found that patient satisfaction with

nursing care was a function of delivery method, and that AIDS and oncology patients on dedicated units expressed greater satisfaction with their care than medical, oncology or AIDS patients on integrated units.

PWAs recognized the role that "homelike decor" played in their perception of quality of life. Kotarba et al. (1992) noted that organizationally, a warm environment is helpful in attracting patients and ensuring repeat visits. This environment is useful in masking the awesome reality of the purpose of the unit. Ujhely (1968) suggested that one of the roles of nurses is to "make the patient's room bearable to him." The attempt by the study hospital administration and nursing staff to achieve a home-like environment was perceived as contributing to the PWAs' overall quality of life.

The circular design of the unit, private rooms, and nurses visible from the patients' beds were all significant to the hospital environment. However, there is no research currently available on how these features affect the quality of life of PWAs or other dedicated units.

PWAs understood that nurses organize their work day around a particular set of rules which were established by management. Skipper and Leonard (1965) reported that the functions of the hospital are carried out through its social structure ie., a network of role relationships in which the diverse activities of the organization are allocated and coordinated into a system. In the process of performing its functions, the hospital develops its own culture, that is, its own system of shared values, beliefs

and orientations. This common pattern sets standards of conduct for behavior within the organization and has its own unique effects on action not only for the staff, but also for patients. Similarly, the SDU rules which govern the day-to-day unit activities were identified as an important part of everyday life. The flexible visiting hours, knowledge of hospital protocols, understanding of the differing roles of the nurse and the patient, and the nurse's ability to "know when to do what" to patients who were trying to "maintain control" were all cited as key features of the unit rules and rituals.

The hospital services provided to PWAs on the SDU were another organizational feature. Expert technical care, patient support, access to physicians, information resources and prompt services were important aspects of the unit services. These findings were substantiated by the Kotarba, et al., study (1992) in which they reported that the specialized services on the SDU added value by adapting otherwise bureaucratic procedures to the specific needs of PWAs. Hospitalized PWAs noted that the nurses and physicians worked as a team to provide expert care, support, and access to the hospital resources.

#### INTERACTIONAL FEATURES

The second set of key features of the SDU identified as having a positive effect on PWAs' quality of life were interactional in nature. The participants described interactional features as being important in their relationship with the nursing staff. Skipper and Leonard

(1965) indicated that patients should be treated as persons rather than as cases. Warm, cordial nurse-patient relationships were appropriate; but close, personal emotional relationships were not. In this study, patients preferred that the nurses have personal relationships with them and described the desired interactional features of the nurses as: commitment, honesty, comfort, sensitivity, informality and familial. Kotarba, et al. (1992) noted that a warm and intimate environment is conducive to the nature of relationships on a dedicated AIDS unit. Nurses enjoyed if not sought the role of confidant with PWAs. In the SDU, nurses typically cared for patients for many weeks and sometimes months, resulting in a situation where some patients actually indicated that their "favorite nurses" were the most important people in their lives.

The commitment of the nurses was described by PWAs in how they talk, the time they take with each patient, their personal commitment to the disease itself, and how nurses who are not as committed are perceived by the patients. Frost, et al. (1985) noted that workers bring outside issues to work with them. Therefore, the commitment of the nursing staff to their work as AIDS caregivers was significant to the PWAs. Kotarba et al. (1992) noted that SDU nurses typically come from and have prior training in such nursing specialties as intensive care and emergency care. These specialties are not structured to promote personal relationships with patients and can lead to a feeling of alienation. Nurses who come from these specialties and desire closer interpersonal relationships

with their patients may find them through their work with PWAs. This finding is relevant because PWAs must feel that the nursing staff is dedicated to them as persons, not just "the patient in room 8", as they expect the nursing staff to support them emotionally and physically.

The other interactional features--honesty, comfort, sensitivity and informality - all relate to the higher level of socialization PWAs desire while hospitalized. Kotarba, et al. (1992) identified a domain of unit culture which provided patients personal space and autonomy, allowing control over self-identity in an otherwise public clinical setting. They noted that openness and appreciation has a clinical and interpersonal relevance and requires the nurses to communicate with a level of honesty and sensitivity which appreciates the patient's lifestyle choices and identity. Hurt (1992) found that the thread that links otherwise disparate pieces of a PWA's life are relational in nature. The system of relationships which she described among staff members and residents of an AIDS hospice was based on a primitive basis, primarily the mutuality of fears, hopes, likes, dislikes, stories and lives. The link provided by these relationships transcended the awesome realities of the HIV virus, conflicting lifestyles, conflicting moralities, and basic differences. The findings of these studies are similar to the findings in the present study.

The sensitive feature of interaction was the patients' desire that nurses are really in tune with their deepest feelings, anxieties, hopes and fears. "Touching"

was found to be an important part of the nurse-patient relationship. This finding is supported by research done by Krieger (1979) and Heidt (1990) which indicated that in many instances nurses "touching" their patients offered a therapeutic relationship that engendered hope in the patient, provided a sense of trust, and gave patients a sense of control in planning their own health care.

Sandstrom (1990) examined how PWAs construct and negotiate the meaning of their illness. Findings revealed that in an effort to counteract the dilemmas evoked by the problematic emotional and social reactions they face with AIDS, the PWAs engage in various types of identity management, including defensive strategies that allow them to avoid potentially threatening interactions. These forms of embracement enable PWAs to affirm an identity and integrate this identity with other value aspects of self. The data suggested that PWAs are increasingly likely to engage in embracement of these activities with the nursing staff as their illness progresses. These findings are similar to this study. Patients' interaction with the nursing staff was of such great significance that they sought to integrate their AIDS-related identity into the SDU environment.

Ragsdale, Kotarba and Morrow (1991) explored quality of life by interviewing PWAs during periods of hospitalization. Quality of life was described as the patients' perceptions of the effectiveness of a chosen management style in addressing the problems presented by the illness. Six management styles were identified as

being used by the respondents to improve their quality of life. Research by Ragsdale, et al. (1991) strongly suggests that nurses can positively impact the PWA's quality of life and enhance the a sense of control over self during hospitalization. A study by van Servellen, Padilla, Brecht and Knoll (1993) noted that certain aspects of hopefulness may buffer the effect of PWAs' stressful life events. Furthermore, interventions aimed at increasing a sense of being in control and feeling good about one's life (in the face of a changing clinical picture where numbers of complications and hospitalizations are inevitable) may help these patients cope with disruptions in their lives. They found that the ability to sustain internal feelings of control may be a stress-resistance resource of equal or greater importance than social support. These studies suggest that nurses, by supporting PWAs respective management style, can improve quality of life.

Peplar and Lynch (1991) found that when dying patients are young adults or have a contagious disease, nursing staff may feel acutely uncomfortable, and the patients may become isolated and alone. They noted that nurses who work on palliative care units develop special interactive skills that are generally acknowledged but not clearly defined or understood. The most frequent behavior noted when nurse-patient verbal interactions were analyzed was that of nurses offering control. In their study, nurses and patients took control with approximately the same frequency, and by far the least frequent situation was that

of the patient offering control to the nurse. Weitz (1989) found that PWAs respond to the uncertainties of their illness by attempting to assert as much control as possible over their lives, through such divergent strategies as seeking or avoiding knowledge about their illness. These studies parallel the findings of this study in which patients wanted to retain as much control as possible. The fact that nurses who work with PWAs have special interactive skills (Weitz, 1989) is corroborated by the participants of this study who reported less positive experiences on integrated patient care units or other hospital settings.

Peplar and Lynch (1991) found that nurses with higher AIDS-related knowledge levels were perceived as having more positive attitudes towards caring for PWAs. This finding may support why the participants in this study perceived the nurses as dedicated to the care of PWAs. Belcher, Dettmore and Holzemer (1989) found that nurses who listened to PWAs without judgement were the most beneficial. Their study supported the findings of this study in which PWAs described a desire for the nursing staff to allow them autonomy while providing honest, sensitive communication which was informal and familial. One participant described how he did not want the nurses to be judgmental by stating that (a nurse should not) "go over the line" and discuss the patients lifestyle or personal choices.

The familial nature of the SDU was the feature which described the PWAs' experience of the hospital as home. Ujhely (1968) noted that whatever the duration of the

hospitalization and whatever the outcome of the health crisis, patients will rarely consider the general hospital setting to be a substitute for home. The participants in this study considered the nursing staff as part of their family and felt more at home and accepted while hospitalized. This finding conflicts with Ujhely's statement.

Frost, et al. (1985) stated that the search for a community is a fundamental part of human experience. Kotarba, et al. (1992) noted that staff members, specifically nurses, commonly perceive themselves as family for the patients thus providing a type of community. Nurses, both male and female, were expected to develop intimate and familial relationships with patients. The patients reported that the majority of the nursing staff were willing to do so. Their findings corroborate those of this study as the PWAs described the SDU as "homelike" and the nursing staff as their "family".

Kendall, et al. (1989) explored AIDS patients' "state of well being" to generate an understanding of the concept "doing well". Five themes emerged from the data: autonomy/mastery over the disease; existential/spiritual journey towards understanding; self-acceptance; staying active and involved; and positive thinking. These themes suggested several similarities to this study that would support their recommendations for the nursing care of PWAs. These are: (1) develop relevant nursing-assessment strategies; (2) encourage as much autonomy and freedom of choice as possible; (3) be aligned and sensitive to the

patients' spiritual and existential needs; (4) encourage honest optimism and positive interactions; and (5) conduct additional research on other possible care strategies.

In general, this study indicates that PWAs liked the ambiance of a dedicated AIDS unit, particularly nurse-patient relationships. These perceptions were present regardless of presence or absence of drug use or sexual orientation. Breault and Polifroni (1991) found that nurses perceived and treated AIDS patients differently who were intravenous drug users and those who were homosexuals. Their findings differ from this study in that the patients who were gay or intravenous drug abusers did not perceive a difference in positive nurse-patient interactions. In the van Servellen, et al. (1991) study, a relationship was noted between race and satisfaction, with whites expressing consistently greater satisfaction than non-whites with all aspects of nursing care. This finding was not consistent with this study, as all participants related satisfaction with their care; however, the non-white portion of the sample was small (n=5) and may not be representative of the study population.

#### Conclusions and Implications

The following statements outline the conclusions and implications derived from this study:

1. PWAs perceive dedicated AIDS units as homelike. They feel comfortable with the environmental and interactional features of the unit. Therefore, hospital administrators should attempt to support the features which were

identified as important.

2. Having the same nurses over an extended period of time enhances the quality of life of hospitalized PWAs.

Consistent nursing staff assignments facilitate relationships between patients and their nurses.

Therefore, all efforts should be made by nursing administration to maintain consistent nursing assignments and minimize the use of agency or part-time nursing staff. For example, nursing assignments could be computerized so that patients could automatically be reassigned to their nurse when readmitted to the hospital.

3. The presence of home-like decor in patient rooms is important to PWAs. Since these patients often experience frequent, prolonged hospitalizations, all efforts should be made to have the hospital room decor resemble a home-like environment. This might include hospital policies which allow patients to bring in certain items from home.

4. Waiting areas which are oriented to families and provide a place for PWAs outside of the patient rooms are important. This amenity allows patients to have a living room atmosphere in contrast to the bedroom atmosphere of their rooms. Hospital administration should designate rooms for this purpose when planning dedicated AIDS units.

5. Patients prefer that their rooms be located close to the nursing station where they can visualize the nursing staff. Hospital administrators do not ordinarily have the luxury of participating in the architectural design of patient care units. However, if possible, patient care units should be designed so the patients are in close

proximity to the nursing staff. This design provides a sense of comfort and security to the patient.

6. PWAs liked the privacy of a private hospital room. Although most hospitals would not be in a position to provide private rooms, there are strategies for increasing privacy. Nurses admitting patient should provide as much privacy as possible if private rooms are not available. This feature may be accomplished through the use of curtains or furnishing which act as room dividers.

7. Hospitalized PWAs like knowing that their friends and family can visit them any time. Visiting hours should be flexible and provide an opportunity for the patient to have a significant other or family member stay in the room overnight. Arrangements should be made for the nursing staff to have the autonomy to vary the policy to meet the needs of the individual patient. A collaborative effort between the nursing staff and the patient to determine individualized visiting hours would enhance autonomy and a sense of control.

8. PWAs value their independence while hospitalized. It is important for them to know that they can leave the nursing unit to go to the cafeteria or outside if their physical condition allows. Unit policies should allow ambulatory patients to leave the unit with the permission of the nursing staff as long as they can be located and monitored.

9. PWAs expect the nursing staff to act as information resources by providing access to physicians, procuring information and telling them if changes are important.

Nursing policies should be developed for dedicated AIDS units with clear guidelines on what type of medical information nurses can share with their patients.

10. PWAs expect prompt service while hospitalized because they experience frequent, prolonged hospitalizations and are often acutely ill. Prolonged waiting for response to a patient call or for procedures can be physically uncomfortable. Nurses, transporters, and ancillary staff should be oriented to the needs of PWAs and special emphasis should be placed on systems which ensure services comparable to those provided to critical care units.

11. Most nurses working in hospitals would be willing to care for PWAs even if they are not assigned to dedicated units. However, PWAs feel most comfortable with nurses whom they perceive as being committed to their care. Therefore, special considerations should be used when interviewing and hiring nurses. Nurses who request caring for PWAs and are comfortable with close interpersonal relationships with patients should be given priority employment status on dedicated AIDS units.

12. AIDS is different from other diseases. Unlike some other chronic illnesses, AIDS is terminal. In addition, the lifestyle factors of AIDS differ from the lifestyle factors of many other chronic diseases. Knowledge of, and sensitivity to, the psychosocial issues specific to gay men with AIDS is necessary to adequately make a nursing assessment and implement nursing interventions. Thus, nurses who have never cared for a PWA may have difficulty in relating their past experiences with other chronic-

disease patients to the care of PWAs. Because caring for PWAs may be a new experience, nursing education should be provided by hospitals to assist nurses in understanding the special attributes of AIDS care.

13. Comfort measures, including touching, holding hands and hugging, are important to PWAs. Nurses should be oriented to these needs and information should be provided to nurses on what patients perceive as appropriate touching in this setting. Nurses need to ask individual patients if they want this type of physical contact with the nursing staff.

14. Many PWAs perceive themselves as "experts" in their disease. Nurses should be informed that patients believe they are knowledgeable about their disease and therefore may expect very specific information while hospitalized.

15. In general, close interpersonal relationships contribute to PWAs' quality of life; however, nurses must determine if this type of relationship is the desire of the individual patient. For example, discussions of religion, alternative treatment modalities and discussions regarding how the disease was transmitted may be inappropriate for some patients. Each nurse should be encouraged to ask the patients what topics they would like to discuss.

#### Recommendations for Further Study

Based on the findings of this study, the following research studies are recommended to expand the findings with the goal of improving the care of PWAs:

1. Units in which AIDS patient care is integrated with

other types of patients (ie. medical, oncology) should be further examined to determine if there is a difference in patient satisfaction from dedicated units. It is safe to assume that no one special care unit approach is like another because the specific hospital and staff may alter the program significantly. Each institution is distinguished by a distinct style and an emotional atmosphere peculiar to its tradition, staff and patients. Therefore, additional studies of dedicated and integrated units will provide additional information regarding how different hospital settings affects PWAs' quality of life.

2. Environmental factors should be investigated that address the impact of unit design including the designation of private versus semi-private room assignments. The outcome of this research may impact how units should be designed to enhance hospitalized PWAs' quality of life.

3. Research which expands the information regarding the difference in quality of life between PWAs who are assigned to a full-time nurses versus part-time or agency personnel is necessary. Patients in this study preferred interactions with full-time nursing staff. It would be beneficial to determine if this finding can be generalized to other dedicated AIDS unit settings.

4. Since touching by nurses was important to the PWAs, further studies are warranted to identify what types of touching is valued and how that touch is accomplished. This information would be important to the education of nurses caring for PWAs.

5. Studies need to be conducted which investigate whether

other AIDS or non-AIDS patient groups perceive the nursing staff as family or experience a sense of home while hospitalized. These studies should also be conducted in non-hospital settings such as rehabilitation facilities, nursing homes and hospices. PWAs in this study returned to Metropolitan Hospital for their repeat hospitalizations because of the satisfaction with the environment and the nursing staff interactions. If this finding is true of other health care settings, it would assist administrators in improving their patient census and would provide a marketing tool to increase hospital admissions.

6. The study hospital was located in a primarily white, upper middle-class neighborhood and may not be representative of the locale of SDUs in other institutions. Therefore, this study should be conducted in other dedicated AIDS units to determine if the findings of this study are particular to the local population represented by the SDU.

7. Other PWA patient populations need to be studied to expand the findings of this study. Women, children, intravenous drug abusers and heterosexual males have not been well represented by the participants in this study. This recommendation is particularly significant because of the increase in the incidence of AIDS in these demographic groups. Hospital experiences may differ in these groups.

Since care of the sick remains a basic nursing responsibility, a relatively new priority concerns the care of PWAs and enhancement of their quality of life. Perceptions of hospitalization are crucial factors in

health care policy and treatment decision making. Additional research is needed to further explore hospitalization as it is experienced by various populations of PWAs. As the concept is further clarified and operationalized, nursing interventions may be devised, implemented, and tested for their effectiveness in enhancing quality of life while hospitalized. This knowledge can then be used to guide nurses in the care of hospitalized PWAs. Further information regarding patients' perception of hospitalization would serve to improve nursing care, case management and resource allocation in caring for persons diagnosed with AIDS.

## REFERENCES

- Agar, M. (1980). The professional stranger: An informal introduction to ethnography. New York: Academic Press.
- Alexandre, M., Vignola, M. (1991). AIDS in the 1990's. Changing implications for health care providers and HMO's. Solomon Brothers Stock Research, Feb. 8, 1-11.
- Allen, F., Curran, J (1988). Prevention of AIDS and HIV infection: Needs and priorities for epidemiologic research. American Journal of Public Health, 8, 381-386.
- Andrews, F., & Withey, S. (1976). Social Indicators of Well-Being: Americans' perceptions of life quality. New York: Plenum Press.
- Athos, A., Pascale, R. (1982). The Art of Japanese Management: Applications for American Executives. New York: Warner.
- Baker, R. (1978). The study of folklore in American colleges and universities. Journal of American Folklore, 9, 792-807.
- Barnard, C. (1939). The Functions of the Executive. Cambridge, MA: Harvard University Press.
- Beckman, J., Ditlev, G. (1987). Quality of life and empirical research. In Aaronson, N., Beckman, H. (eds.), The Quality of Life of Cancer Patients, (pp.37-40). New York: Raven Press.
- Belcher, A. (1990). Nursing aspects of quality of life enhancement in cancer patients. Oncology, 4, (5), 197-199.
- Belcher, A., Dettmore, D., Holzemer, S., (1989). Spirituality and sense of well-being in persons with AIDS. Holistic Nursing Practice, 3, (4), 16-25.
- Berg, B. (1989). Qualitative research methods for social sciences. Needham Heights, Mass: Simon and Schuster.
- Breault, A., Polifroni, E. (1991). Caring for people with AIDS: Nurses' attitudes and feelings. Journal of Advanced Nursing, 17, 21-27.
- Carballo, M., Bayer, R. (1990). Social, cultural and political aspects of AIDS. AIDS 1990, 4, (supp. 1), S243-S245.

- Centers for Disease Control (1993). U.S. AIDS cases reported through December 1992. U.S. Public Health Services, Atlanta, GA.
- Centers for Disease Control (Dec.,1990). HIV/AIDS Surveillance. Atlanta, GA.
- Centers for Disease Control (1986). Classification system for human T-lymphotropic virus type III/lymphadenopathy-association virus infections. Annals of Internal Medicine, 105, 234-237.
- Centers for Disease Control (1981). Kaposi sarcoma, pneumocystis pneumonia among homosexual men--N.Y.C. and California. Morbidity and Mortality Weekly Reports, 30, 305-308.
- Chenitz, W., Swanson, J. (1986). From Practice to Grounded Theory. Menlo Park, CA: Addison-Wesley.
- Christensen, D. (1988). Mirror, mission and management: Reflections on folklore and culture in a healthcare organization. In Jones, M., Moore, M., Snyder, R. (eds.) Inside Organizations: Understanding the Human Dimension. Newbury Park: Sage Publications.
- City of Houston, Health and Human Services Department. Aids Surveillance Update, September 1990.
- Could obstacles delay availability of AIDS vaccine? (1991, Sept.) AIDS Alert, p. 177.
- Curran, J., Jaffe, H, Hardy, A., Morgan, W., Selik, R., Dondero T., (1988). Epidemiology of HIV infection and AIDS in the United States. Science, 239, 610-616.
- Dalkey, N., & Rourke, D. (1973). The delphi procedure and rating quality of life factors. In the Quality of life Concept. Washington, DC: Environmental Protection Agency.
- Deal, T., Kennedy, A. (1982). Corporate Cultures. Reading, MA: Addison-Wesley.
- DeVita, V. Hellman, S., Rosenberg, S.(1992). AIDS: Etiology, Diagnosis, Treatment and Prevention. Philadelphia: J. B. Lippincott.
- Dubos, R. (1976, July). The state of health and the quality of life. Western Journal of Medicine, 125, 8-9.
- Eakin, J., Taylor, K. (1990). The psychosocial impact of AIDS on health workers. AIDS 1990, 4, (supp. 1), S257-S262.
- Edelman, M. (1977). Political Language. New York: Academic Press.

- Erickson, H. (1959). Growth and crisis of the healthy personality. Psychological Issues, 1, (1), 40-47.
- Fahs, M., Fulop, G., Strain, J., Sacks, H., Muller, C., Cleary, P., Schmeidler, J., Turner, B. (1992). The inpatient AIDS unit: A preliminary empirical investigation of access, economic, and outcome issues. American Journal of Public Health, 82, (4), 575-578.
- Frost, P., Moore, L., Louis, M., Lundberg, C., Martin, J. (1985). An allegorical view of organizational culture. In Frost, P., Moore, L., Louis, M., Lundberg, C., Martin, J. (eds.). Organizational Culture. Beverly Hills: Sage Publications.
- Gabuzda, D., Hirsh, M. (1987). Neurologic manifestation of infection with human immunodeficiency virus. Annals of Internal Medicine, 107, (3), 332-336.
- Gallo, R. (1987). The AIDS virus. Scientific American, 256, 47-56.
- Gee, G., Morgan, T. (1988). AIDS: Concepts in Nursing Practice. Baltimore: Williams and Wilkins.
- Gephart, R. (1978). Status degradation and organizational succession. Administrative Science Quarterly, 23, 553-581.
- Glaser, B., Strauss, A. (1967). The Discovery of Grounded Theory. Chicago: Aldine.
- Glaser, B., Strauss, A. (1965). Awareness of Dying. New York: Aldine.
- Gonda, T., Ruark, J. (1984). Dying Dignifies: The Health Professional's Guide to Care. Menlo Park, CA: Addison-Wesley.
- Govoni, L. (1988). Psychosocial issues of AIDS in the nursing care of homosexual men and their significant others. Nursing Clinics of North America, 23, (4), 749-765.
- Grant, I., Atkinson, J., Hesselink, I. et al. (1987). Evidence for early central nervous system involvement in the acquired immunodeficiency syndrome (AIDS) and other human immunodeficiency virus (HIV) infections. Annals of Internal Medicine, 108, (6), 678-684.
- Gregory, K. (1983). Native view paradigms: Multiple cultures and culture conflicts in organizations. Administrative Science Quarterly, 28, (3), 88-95.
- Heidt, P. (1990). Openness: A qualitative analysis of nurses' and patients' experiences of therapeutic touch. IMAGE: Journal of Nursing Scholarship, 22, (3), 180-190.

- Hinz, C. (1991, August). Slim profits, moral issues characterize AIDS care. Health Care Strategic Management, 18-22.
- Holland, J., Tross, S. (1987). Psychosocial consideration in the therapy of epidemic Kaposi's sarcoma. Seminars in Oncology, 14, (supp. 3): 2, 411-418.
- Hopp, J., Rogers, E., (1989). AIDS and the allied health professions. Philadelphia: F. A. Davis.
- Hurt, D. (1992). An Ethnography of AIDS Hospice. Masters Thesis. Department of Sociology, University of Houston.
- Kahn, R., Cannel, C. (1957). The Dynamics of Interviewing. New York: John Wiley.
- Kastenbaum, R. (1986). Death and bereavement in later life. in A. Kutcscher (ed.) Death and Bereavement. Springfield, IL: Charles C. Thomas.
- Kendall, J., Gloersen, B, Gray, P., McConnell, S., Turner, J., West, J. (1989). Doing well with AIDS: Three case illustrations. Archives of Psychiatric Nursing, 3, (3), 159-165.
- Kirk, J., Miller, M. (1986). Reliability and Validity in Qualitative Research. Newbury Park: Sage.
- Kleinig, J. (1989). The ethical challenge of AIDS to traditional liberal values. AIDS and Public Policy Journal, 5, (1), 42-44.
- Kotarba, J. (1983). Chronic Pain: Its Social Dimiensions. Beverly Hills: Sage.
- Kotarba, J., Ragsdale, D., Morrow, J. (1994). Everyday culture in a dedicated HIV/AIDS unit. Journal of Health and Social Behavior. (In press.)
- Kotarba, J., Ragsdale, D., Morrow, J., (1991). Quality of life of hospitalized AIDS patients. Unpublished manuscript.
- Krieger, D. (1979). Therapeutic touch: How to use your hands to help and heal. New Jersey: Prentice-Hall.
- Larson, E., Ropka, M. (1991). An update on nursing research and HIV infection. Image: Journal of Nursing Scholarship, 23, (1), 4-11.
- Leininger, M., ed. (1990). Ethical and Moral Dimensions of Care. Detroit: Wayne State University Press.
- Leininger, M. (1985). Qualitative Research Methods in Nursing. Orlando: Grune and Stratton.

- Leininger, M. (1978). Transcultural nursing: Concepts, theories, and practices. New York: John Wiley and Sons.
- Louis, M. (1985). Perspectives on organizational culture. In Frost, P., Moore, L., Louis, M., Lundberg, C., Martin, J. (eds.). Beverly Hills: Sage Publications.
- Mann, J. (1990). Global AIDS: revolution, paradigm and solidarity. AIDS 1990, 4, (supp. 1), S247-S250.
- Marshall, C., Rossman, G. (1989). Designing Qualitative Research, Newbury Park: Sage Publications.
- Martin, D. (1990). Effects of ethical dilemmas on stress felt by nurses providing care to AIDS patients. Critical Care Nursing Quarterly, 12, 53-62.
- Masur, H., Michelis, M. Greene, J., et al. (1981). An outbreak of community-acquired Pneumocystis carinii pneumonia: Initial manifestations of cellular immune dysfunction. New England Journal of Medicine, 305, 1431.
- McCracken, G. (1988). The Long Interview. Newbury Park: Sage.
- Mechanic, D, Aiken, L. (1989, fall). Lessons from the past: Responding to the AIDS crisis. Health Affairs, 16-31.
- Merriam-Webster Dictionary. (1989). Springfield, MA: Merriam-Webster, Inc.
- Meyerson, D., Martin, J. (1977). Cultural change: An integration of three different views. Journal of Management Studies, 4, (6), 23-27.
- Miles, M., Huberman, A. (1984). Qualitative Data Analysis. Newbury Park: Sage.
- Miller, J. F. (1983). Coping with Chronic Illness: Overcoming Powerlessness. Philadelphia: Lippincott.
- Molin, J. (1987). Beyond Structure and Rationality. Copenhagen: Akademisk Forlag.
- Morbidity and Mortality Weekly Report (1990). Report 39, no. 7.
- Morin, S., Malyon, A., Epstein, D, et al. (1987). Meeting psychological needs in the AIDS crisis. In Moffat, B. Spiegel, J., Parrish, S. et al. (eds). AIDS: A Self-Care Manual. Santa Monica, CA: IBS Press.
- Morse, J. ed. (1991). Qualitative Nursing Research. Newbury Park: Sage Publications.

- Oleson, M. (1990). Subjectively perceived quality of life. IMAGE, 22, (3), 187-189.
- Ostrow, D. (1990). Behavioral Aspects of AIDS. New York: Plenum Medical Books.
- Ouchi, W. (1981). Theory Z: How American Business Can Meet the Japanese Challenge. New York: Addison-Wesley.
- Parse, R. (1989). The phenomenological research method: Its value for management science. In A. Henry, C. Arndt, M. Vincenti, A. Marriner-Toomey (eds.), Dimensions of Nursing Administration. Boston: Blackwell Scientific Publications.
- Pattison, E. (1977). The Experience of Dying. Englewood Cliffs, NJ: Prentice Hall.
- Pedersen, J., Sorensen, J. (1989). Organizational Culture Theory and Practice. Brookfield: Avery.
- Pepler, C., Lynch, A. (1991). Relational messages of control in nurse-patient interactions with terminally ill patients with AIDS and cancer. Journal of Palliative Care, 7, (1), 18-29.
- Perry, S., Markowitz, J. (1986). Psychiatric interventions for AIDS-spectrum disorders. Psychiatry, 37,(10), 345-349.
- Peters, T., Waterman, R. (1982). In Search of Excellence. New York: Harper & Row.
- Pettigrew, A. (1979). On studying organizational cultures. Administrative Science Quarterly, 24, (4).
- Pfeffer, J. (1981). Management as symbolic action: The creation and maintenance of organizational paradigms. In Cummings, L., and Staw, B. (eds.) Research in Organizational Behavior, vol.3. Greenwich, CT: JAI Press.
- Phillips J. (1989). Sustaining our hope. In Meisenhelder, J., LaChariet (eds): Comfort in Caring: Nursing the Person With HIV Infection. Glenview, IL: Scott & Foresman.
- Polit, D., Hungler, B. (1987). Nursing research: Strategies for a natural sociology (3rd ed.). Philadelphia: J. B. Lippincott.
- Ragsdale, D. (1990). Archway of progression of life with AIDS. Unpublished conceptual model.
- Ragsdale, D. (1990b). Quality of life of persons with AIDS. Unpublished grant proposal.

- Ragsdale, D., Kotarba, J., Morrow, J. (1992). Work-related activities to improve quality of life in HIV disease. Journal of the Association of Nurses in AIDS Care, 3, (1), 39-44.
- Ragsdale, D., Kotarba, J., Morrow, J. (1992). Quality of life of hospitalized persons with AIDS. IMAGE, 24, (4), 259-265.
- Ragsdale, D., Morrow, J. (1990). Quality of life as a function of HIV classification. Nursing Research, 6, (39), 355-359.
- Redfield, R., Wright, D., Tramont, E. (1986). The Walter Reed Staging classification of HTLV-III/LAV infection. New England Journal of Medicine, 314, 131-132.
- Sandstrom, K. (1990). Confronting deadly disease: The drama of identity construction among gay men with AIDS. Journal of Contemporary Ethnography, 19, (3), 271-274.
- Sartorius, N. (1987). Cross-cultural comparisons of data about quality of life: A sample of issues. In N. M. Aaronson & J. Beckmann (eds.). The Quality of Life of Cancer Patients (pp.19-24). New York: Raven Press.
- Saunders, J., 1989. Psychosocial and cultural issues in HIV infection. Seminars in Oncology Nursing, 5, (4), 284-288.
- Schein, E. (1985). Organizational Culture and Leadership: A Dynamic View. San Francisco: Jossey-Bass.
- Scott, W. R. (1981). Organizations: Rational, Natural and open systems. Englewood Cliffs, N.J.: Simon & Shuster.
- Selltiz, C., Wrightsman, L., Cook, S. (1976). Research methods in social relations. (3rd ed.). New York: Holt, Reinhart & Winston.
- Siehl, C., Martin, J. (1982). The management of culture: the need for consistency and redundancy among cultural components. Presented at the annual meeting of the Academy of Management, Boston.
- Siehl, C. (1985). After the founder: An opportunity to manage culture. In Frost, P., Moore, L. Louis, M., Lundberg, C., Martin, J. (eds.) Organizational Culture. Beverly Hills: Sage.
- Simms, L., Price, S., Ervin, N. (1985). The Professional Practice of Nursing Administration. New York: John Wiley & Sons.
- Skipper, J., Leonard, R. (1965). Social interaction and patient care. Philadelphia: J.B. Lippincott.

- Smircich, L. (1983). Concepts of culture and organizational analysis. Administrative Science Quarterly, 28, (3), 34-39.
- Spradley, J. (1979). The ethnographic interview. New York: Holt, Rinehart and Winston.
- Spradley, J., McCurdy, D. (1972). The cultural experience: Ethnography in complex society. Chicago: Science Research Associates.
- Strauss, A. (1975). Chronic Illness and the Quality of Life. St. Louis: C. V. Mosby.
- Strauss, A., Corbin, J. (1990). Basics of Qualitative Research. Newbury Park: Sage Publications.
- Szalai, A. (1980). The meaning of comparative research on the quality of life, In Szalai, A., Andrews, F. (eds.) The quality of life: Comparative studies. Beverly Hills: Sage Publications.
- Tindall, B, Tillet, G. (1990). HIV-related discrimination. AIDS 1990, 4, (supp. 1), S251-S256.
- Ujhely, G. (1968). Determinants of the nurse-patient relationship. New York: Springer Publishing Co.
- van Servellen, G. Padilla, Brecht, M. Knoll, L. (1993). Journal of the Association of Nurses in AIDS Care, 4, (1), 11-22.
- van Servellen, G., Lewis, C., Leake, B., Schweitzer, S. (1991). Patient satisfaction on AIDS and oncology special care units and integrated units: A pilot study. JANAC, 2, (3), 29-40.
- Volberding, P. (1989). Supporting the health care team in caring for patients with AIDS. JAMA, 261, (5), 747-748.
- Weitz, R. (1989). Uncertainty and the lives of persons with AIDS. Journal of Health and Social Behavior, 30, 270-281.
- Wiggins, J. (1988). Personality and prediction: Principles of personality assessment. Malabar, FL: Robert Krieger.
- Wilkins, A. (1983). The culture audit: A tool for understanding organizations. Organizational Dynamics, 3, 24-38.
- Wolcott, D., Fawzy, F., Pasnau, R. (1985). Acquired immunodeficiency syndrome (AIDS) and consultation-liaison psychiatry. General Hospital Psychiatry, 10, 280-293.
- Zigarmi, D., Zigarmi, P. (1980). The psychological stresses of ethnographic research. Education and Urban Society, 12, (3), 291-322.

## APPENDICES

APPENDIX A

Human Subjects Review Approval



**HSRC APPROVAL FORM**

Name of Investigator(s): Diane Ragsdale

Social Security Number(s): 157031757

Address: 4725 Stillbrooke  
Houston, TX 77035

Dear: Dr. Ragsdale

Your study entitled: Quality of Life as Perceived by AIDS Patients

*(The applicants must complete the top portion of this form)*

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

           Add to informed consent form: "I understand that the return of my questionnaire constitutes my informed consent to act as a subject in this research".

           The filing of signatures of subjects with the Human Subjects Review Committee is not required.

           Other: see attached sheet.

           No special provisions apply.

Sincerely,

  
William R. Gould, Ph.D.  
Chairman, HSRC - Houston Center

4-20-90

Date

APPENDIX B

Agency Approval



AGENCY PERMISSION FOR CONDUCTING STUDY

THE Park Plaza Hospital

GRANTS TO Diane Ragsdale, RN, EdD  
the privilege of its facilities in order to study the following problem.

Quality of Life as Perceived by Hospitalized AIDS Patients

The conditions mutually agreed upon are as follows:

1. The agency (~~may~~) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (~~may~~) (may not) be identified in the final report.
3. The agency (wants) (~~does not want~~) a conference with the student when the report is completed.
4. The agency is (willing) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other #1 & #2 - Written permission to be sought at time of release.

Date 5/29/90

[Signature]  
Signature of Agency Personnel

Date 5/29/90

[Signature]  
Signature of Applicant

APPENDIX C

Description of Study

You are being asked to participate in a study conducted in the Nursing Department of Texas Woman's University. This study is designed to explore the meaning of quality of life and how nurses' actions impact on your quality of life while you are hospitalized. It is necessary to identify these areas so that nurses, physicians and other health care personnel will know how to give the best possible care to hospitalized persons with AIDS (PWASs).

If you agree to participate, you will be asked questions relating to your quality of life with HIV infection. Your answers to these questions will be audiotaped so that they may be transcribed for analysis. This interview will take approximately one hour.

Your interview will be conducted by a trained research assistant. A possible risk is that you may experience some anxiety or have questions during the interview. To alleviate any possible anxiety, the entire interview will be conducted in this room with the door closed. Adequate time will be allowed for you to ask questions or to discuss any concerns. You will be free to interrupt the interview at any time, either to rest or to terminate the interview. If you wish any rest period, the interview will be stopped until you wish to continue. The research assistant will remain in the room after the interview is completed to answer questions or to discuss any other concerns. Additionally, if you have any questions, please call Susan Taylor at 527-5011 during business hours. She will be happy to answer your questions.

The indirect benefit from participating in this study is that this information will be used to identify what aspects of life are important to PWA's. This information can then be used as the basis for planning the type of care that is most relevant to PWA's. An additional indirect benefit will be the identification of actions by nurses which have an impact of quality of life. We are conducting no similar study at this time in which you could participate. You are free to participate or not to participate., The choice is yours. If you choose to join the study, you may withdraw from the study at any time without penalty. Your health care will not be affected in any way if you do or do not participate. There will be no penalty or loss of benefits.

Another possible risk to you is the improper release of your name. Confidentiality will be assured. Only a number will be place on each form and audiotape. This is necessary to keep your data separate. No names will appear on any data forms or audiotapes. Neither you, your physician(s), your nurses, nor any other person caring for you will be identified anywhere in this research study. The name and location of this hospital will remain confidential as this information will not be included in this research study.

No injury is anticipated as a result of your participation in this study. However, Texas Woman's University is not able to offer financial compensation nor to absorb the costs of medical treatment. First aid care will be provided as necessary.

Thank you for your time and interest,

---

Susan Taylor, RN, MS  
Doctoral Student  
College of Nursing  
Texas Woman's University

APPENDIX D

Consent to Audiotape

## Consent Form

I hereby authorize Susan Taylor, or one of her research associates to ask me some questions about myself and my feelings or perceptions of quality of life with HIV infection. I was informed that my answers to these questions will be audiotaped. It is my understanding that this interview will take about one hour.

I understand that the entire interview will be conducted in this room with the door closed. I also understand that a possible risk to me is that I may experience some anxiety during the interview. I know that if I experience some anxiety or have questions during the interview, that adequate time will be allowed for me to ask these questions or to discuss any concerns. I am free to interrupt the interview at any time, either to rest or to terminate the interview. If I wish any rest period, the interview will be stopped until I wish to continue. I understand that the research assistant will remain in the room after the interview is completed to answer questions or to discuss any other concerns. Additionally, if I have any questions, I may call Susan Taylor at 527-5011 during business hours..

I understand that the indirect benefit from participating in this study is that this information can be used to identify what aspects of life are important to PWAs. This information can then be used as the basis for planning the type of care that is most relevant to PWAs.

I was informed that the researchers are conducting no similar study at this time in which I could participate. I understand that I am free to participate or not to participate. This choice is mine. If I choose to join the study, I may withdraw from the study at any time without penalty. My health care will not be affected in any way if I do or do not participate. There will be no penalty or loss of benefits.

I understand that another possible risk to me is the improper release of my name. I was informed that confidentiality will be assured. Only a number will be placed on my data forms and audiotape. I know that this is necessary to keep my data separate. I further understand that my name will not appear on any data forms, or audiotapes. Neither myself, my physician(s), my nurses, nor any other person caring for me will be identified in anywhere in this research study. The name and location of this hospital will also remain confidential.

I understand that no injury is anticipated as a result of my participation in this study. However, Texas Woman's University is not able to offer financial compensation nor to absorb the costs of medical treatment. First aid care will be provided as necessary.

An offer to answer all my questions regarding this study has been made. If alternative procedures are more advantageous to me, they have been explained. A description of possible discomfort or risks reasonable expected have been discussed with me.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Date

APPENDIX E

Demographic Data Questionnaire

**DEMOGRAPHIC DATA FORM**

RESPONDENT I.D.:

Biographical data:

- 1) gender:
  - 2) age:
  - 3) residence:
  - 4) work:
  - 5) leisure:
  - 6) primary relationship(s):
  - 7) education:
  - 8) ethnicity:
  - 9) belief system(s):
-

APPENDIX F

Semi-Structured Interview Form

The following research questions are examples of probable interview questions:

1. Describe the nursing staff in general.  
What are they like, and how do you know?
2. What do the nurses do to and for you? How do you talk to these nurses?
3. What kinds of things do you want to talk to your nurse(s) about? Do you share lifestyles or confidential information?
4. Give me examples of times when you asked the nurse(s) for something and you were refused.
5. How do you negotiate with the nurses? Give an example.
6. Ever try to manipulate the nurses? What strategies do you use in this manipulation?
7. How intimate do you allow yourself to be with the nurse(s)? Do you disclose your fears, and if so, how? Under what circumstances?
8. Do you use the nurse(s) as ombudsmen? Do you complain to nurses about anyone else besides other nurses, eg. physicians, family, other staff?
9. What protocols or procedures that the nurses perform make you feel comfortable? Which make you uncomfortable?
10. What are the rules on this unit? How do you know?
11. Describe what the ideal nurse(s) would be like and how this/these persons would relate to you.