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Predictors of Patient's Perceptions of Nurse Behaviors: Scale Development and Validation with HIV Infected Patients

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ABSTRACT

The purpose of this two phase study was to develop and empirically test a scale for the measurement of AIDS patient behavior toward nurses. Phase I was concerned with the development of scale items, and scale construction. The psychometric testing of the scale was completed during Phase II.

A representative sample of 118 hospitalized and recently hospitalized AIDS patients who participated in the first phase of the study included women, minorities, and subjects from all HIV/AIDS risk factor groups. The critical incident technique, a factual approach to gathering data on behavior, was used to identify the behavioral responses of AIDS patients. Scale items were generated, based on those responses, and an initial draft of the scale was developed.

During Phase II, the scale was completed by a second sample of 162 hospitalized, and recently hospitalized AIDS patients. During this second phase, the study was expanded to include multiple sites in high AIDS prevalence areas of California and Southern Florida, including 5 federally funded hospitals and two community agencies.

Rather than a single, anticipated scale, a principal components factor analysis indicated two separate and independent scales, the Anger scale and the Participation scale. Items for each scale fit logically together and related closely to the behavioral response categories generated through the critical incident interviews. Each scale demonstrated high reliability at 0.82. Each scale demonstrated a promising pattern of convergent and discriminant validity. The positive correlation between the Participation scale and a similar measure, the Patient Reactions Assessment (PRA) was highly significant. The correlation between the Anger scale and the PRA was also significant. Discriminant validity of each scale was supported by the absence of a significant correlation with a dissimilar scale, the Beck Depression Inventory. The analysis also identified interesting patterns of correlation with the Living with HIV, a scale on quality of life issues.

Demographic data, severity of illness variables, scores from the PRA, and also three HIV/AIDS related measures were entered into a stepwise regression analysis with the Participation scale as the dependent variable. Analysis indicated that 42% of the variance was explained by the predictor variables, with a PRA subscale accounting for 31.4% of the variance, and a Living with HIV subscale accounting for 5%. A separate regression analysis of the Anger scale indicated that 29.5% of the variance was explained by the predictor variables, with the scores on a PRA subscale contributing 16%, ethnicity contributing 2.4%, and 3.5% contributed by scores on the Living with HIV subscale.

The brevity of these scales make them highly suitable for research with acutely ill patients. Knowledge of patient reports can prove useful for planning future education and research, and also for evaluating the outcomes of nursing care.

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William L. Holzemer

William L. Holzemer, RN, Ph.D., FAAN
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Jeanne K. Kemppainen, RN, PhD

Dedication

To my husband and best friend, Dale
for the love and support I could always count on;
you inspired my inherited Finnish “sisu” which
gave me the energy and determination to persevere.

To my family,
Jon and Susan, Karl, and Paul
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CHAPTER ONE

THE STUDY PROBLEM

Background to the Problem

The most serious infectious disease in modern times, acquired immune deficiency syndrome (AIDS), was first recognized in 1981. Investigators at the UCLA Medical Center diagnosed five cases of Pneumocystis carinii pneumonia, an uncommon, virulent form of pneumonia in the United States. Several months later, researchers in New York City, San Francisco, and Los Angeles reported twenty-five cases of Kaposi's sarcoma, an unusual and extremely rare tumor. Each of the patients exhibited a severe immune system deficiency of unknown cause. The mysterious syndrome was eventually identified as AIDS (Kelly & St. Lawrence, 1991). The syndrome which affected only several dozen persons in 1981 has now reached pandemic proportions; persons in all of the major countries of the world have been affected (Guss, 1994).

During the 1980's, HIV/AIDS emerged as a leading cause of death in the United States and in 1993, HIV became the most common cause of deaths in persons aged 25-44 (MMWR, 1996). Latest survey information indicates that there are currently an estimated 700,000 persons living with HIV/AIDS with 41,000 new infections reported yearly (Holmberg, 1996). There are also significant shifts are taking place as the patterns of the epidemic change. Overall, rates of HIV/AIDS are beginning to decline but important and worrisome subepidemics are occurring. Young and minority gay and bisexual men have rates of HIV/AIDS two and three times higher than those of older white males. An additional concern involves the rapidly increasing infection rates in young, minority, indigent heterosexual women who use crack or cocaine and trade sex for drugs. Infection rates continue to increase for women, racial and ethnic minorities, adolescents, intravenous drug users, and persons infected through heterosexual contact (MMWR, 1996; MMWR 1996). While earliest reported cases were reported primarily among homosexual and bisexual men in large metropolitan cities, the present epidemic "is clearly being driven by infections among injection drug users, their sex partners, and their offspring" (Holmberg, 1996, p. 649). The current "ruralization" of HIV creates the newest concern as the epidemic moves out of the larger metropolitan areas and into more rural areas; especially in the Southern regions of the United States (Graham et al., 1995; Holmberg, 1996; Sowell, 1996).

AIDS is caused by a retrovirus, called the human immunodeficiency virus (HIV); this blood-born disease has sexual, parenteral, and perinatal modes of transmission (Guss, 1994). Persons who contract the HIV virus develop a syndrome which is characterized by progressive and usually irreversible deterioration of the human immune system (Ungvarsky, 1994). The disease progresses through a stage of initial infection followed by an asymptomatic period. As the disease progresses, however, opportunistic pathogens produce a wide range of AIDS defining illnesses (Corey & Coombs, 1993) and the person begins to experience a prolonged period of physical decline. Changes in mental status are frequently experienced, especially in the later stages of disease progression. Persons with AIDS become vulnerable to additional central nervous system opportunistic diseases, infections, tumors, and vascular complications which result in severe impairment of cognition, motor function, memory and learning (Flaskerud, 1992; Dunbar, Perdices, Grunseit, & Cooper, 1992; Swanson, et al., 1990).

Recent advances in medical treatment are shifting the patterns of disease progression; HIV positive patients are now living longer with fewer symptoms, and patients with AIDS are surviving longer after receiving their diagnosis (Moore, Hidalgo, Sugland & Chaisson, 1991). As the numbers of patients living with HIV/AIDS continue to grow, more and more will seek specialized treatment from health care professionals in all health care settings. Their treatment poses new and difficult challenges for health care workers.

Statement of the Problem

The literature shows that both nurses and patients are frequently dissatisfied with their clinical encounters in AIDS health care settings. While many patients with HIV/AIDS have had positive experiences with health care workers, including nurses, many report negative reactions including lack of interest, inadequate care, problems getting medications, and fears of contagion (Gaskins & Brown, 1992; McCain & Gramling, 1992). Patients also report feeling stigmatized and rejected by health care workers (Bennett, 1990).

Despite a decade of advancement in knowledge about HIV/AIDS, the literature documents the enormous impact of HIV/AIDS on nursing. AIDS patients require twice the average patient care hours allotted for medical-surgical patients (Nagelkerk, 1994); nurses who care for patients with HIV/AIDS often experience physical fatigue and exhaustion. Time consuming and highly complex physical care issues are compounded by difficult behavioral problems associated with AIDS related central nervous system changes. In addition, patients with HIV/AIDS require extensive emotional support. The stresses caused by "battle fatigue" may result in physical problems, fatigue, decreased job performance, decreased ability to focus on assigned tasks, or excessive use of drugs and alcohol (Brewington, 1994).

Many professional articles document the enormous stress experienced by nurses who care for AIDS patients (Turner, 1993; Catalan et. al, 1996; Tierney 1996). The most frequently cited stresses include, fear of contagion, homophobia, repeated exposure to death and dying, and feelings of guilt and grief (Silverman, 1993). Negative attitudes toward AIDS patients are widespread, especially toward homosexuals and injection drug users (Breault & Polifroni, 1992).

Literature suggests that nurses who provide continuous care for AIDS patients are prone to emotional exhaustion and burnout (Van Servellen & Leake, 1993; Bennett, 1990), and may experience periods of sudden outbursts, irritability, or withdrawal (Brewington, 1994). They also express anger over the personality and the demanding and unappreciative behaviors of some AIDS patients. Some nurses cope by avoiding AIDS patients or by limiting their interactions with them; they report that they provide only the necessary care and leave quickly. In an effort to protect themselves from these challenging patients, nurses also distance themselves emotionally. Other nurses use active coping behaviors by granting a sense of meaning to their work (Reutter & Northcott, 1993).

Even though the known rate of viral transmission is low, nurses report feeling anxious about contracting the HIV virus. Their perceptions about contagion are affected by previous experience in AIDS patient care, levels of knowledge about the transmissibility of the virus, educational levels, their ability to choose an AIDS patient care assignment, or by an assignment to complete nursing tasks that involve direct exposure to blood and body fluids (Munodawafa, Bower, & Webb, 1993).

Some of the most significant social and economic factors associated with nurses' stress are related to the broader organization which provides care to patients with HIV/AIDS, including style of care delivery, resources, staffing patterns, and workload. In addition, "the increasing needs for health care combined with shrinking resources, struggling health care institutions, and an inadequate system places immense stress on health care professionals who are frequently caught in the middle between enormous patient physical and psychological needs and the limited care they can offer (Macks & Abrams, 1992, p. 292).

A large number of empirical studies focus on nurses' perceptions and their behavioral response to AIDS patients. Few studies, however, focus on the reactions of patients in AIDS health care settings to health care workers, including nurses. Specifically, there has been little work which captures the range of patient behavioral responses to nursing action in HIV/AIDS treatment settings.

Purpose of the Study

The purpose of this research study is to develop a practical, brief instrument (Predictors of Patients' Perceptions of Nurse Behaviors) which measures the behavioral responses of patients with HIV/AIDS to nurses behaviors. The instrument which will be developed could be used by patients with HIV/AIDS to report their responses to professional caregiver behavior and attitudes.

The specific objectives of the study are:

1. To identify the behavioral responses of hospitalized patients with HIV/AIDS to nursing attitudes and behaviors.
2. To develop a research instrument which measures the behavioral responses of patients with HIV/AIDS to the behaviors of nurses.
3. To evaluate the research instrument through preliminary psychometric testing of reliability and validity.

Significance of the Study

As the number of patients with HIV/AIDS continues to increase during the decade of the 90's, more and more nurses in all areas of clinical practice will find themselves "on the front lines" of AIDS patient care. There is an urgent need to describe and understand quality nursing care for these patients (Holzemer, 1992). The significance of this problem is most urgent, especially since hospitalized patients with HIV/AIDS who are weak and debilitated must depend greatly on nursing care.

Despite vast amounts of literature which catalogue and describe stress responses of nurses to patients with HIV/AIDS, little is known about nurse-patient interactions in AIDS care settings. There are many unanswered questions about the nature of the nurse-patient relationships in AIDS care, or the outcomes of interactions. The attitudes and behaviors of health care workers have been recognized as a critical factor in the quality of care given to patients with HIV/AIDS. The interaction which occurs between and patient and a nurse in an AIDS health care setting plays an important part in the outcome of care. It is essential to identify and consider patient's own reports during periods of hospitalization since that response may reflect the quality of care received.

A practical, brief instrument which measures patient response to nursing behaviors would provide nurses with an opportunity to examine the effects that their own practice has on patients (Ervin, 1994). A research instrument which focuses on the patient's behavioral response would be a valuable tool for nurse practitioners, educators, administrators interested in measuring quality assurance, and researchers. Findings which demonstrate outcomes of nursing care are essential in a time of increasing patient acuity, shorter length of stays, and an increasing emphasis on quality of care.

Clearly, a number of measures have been developed which can be used to evaluate the perceived quality of patient-provider interactions including the Medical Interview Satisfaction Scale (Wolf, Putnam, James & Styles, 1978) and the Trust in Physician Scale (Anderson & Dedrick, 1990). The Patient Reactions Assessment (Galassi, Schanberg, & Ware, 1992) was designed to measure both the what the provider is perceived to contribute in terms of knowledge and information, but also the patient's perceived ability to contribute to the interaction. In addition, numerous patient satisfaction scales have been developed (Rubin, Ware, Nelson, & Muriko, 1990; Nelson, Ware, & Batalden, 1990; Rubin, Ware, & Hayes, 1990; Stein, 1993). The majority of these measures are designed to provide useful information on the numerous dimensions of hospital care; they do not specifically address the patient's behavioral responses to patient-provider interactions. The development of a scale which is sensitive to the outcomes of nursing behaviors and attitudes would add significantly to 1) the evaluation of nursing practice in AIDS care settings, and 2) provide outcome data for nursing research studies focusing on the quality of care. A study which develops and tests a valid and reliable outcome measure will provide urgently needed direction for nursing education, clinical practice, and research.

CHAPTER TWO

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Introduction

This chapter reviews related literature including 1) the nursing response to HIV/AIDS, 2) patient response to HIV/AIDS, and 3) patient responses to health care providers in HIV/AIDS care settings.. A discussion of the theoretical framework which guided this study will also be presented.

Nursing Response to HIV/AIDS

The stigmatization of persons suffering with certain physical or emotional diseases has occurred throughout history. Persons with contagious diseases such as tuberculosis, leprosy, plague, or syphilis have been shunned and their diseases have been associated with fear of contamination and death. According to health care workers, however, "AIDS isn't just another communicable disease!" It is the most feared and horrifying disease, one that is associated with shame, degradation, intense suffering, one that leads to a "hard death" (Sontag, 1989). In addition, "the disease not only kills young people in the prime of life,...it is also damaging the bond between the caregiver and the patient with AIDS as well" (Rogers, 1988). The fact that knowledge of a patient's HIV status is often concealed, makes nurses regard each patient as "a potential enemy who may do them harm." As Rogers laments, "the age old contact between physician or nurse and a patient is coming apart. Replacing the samaritanism of medicine has become a guarded, almost adversarial mindset" (Rogers, 1988).

As "key players" in the AIDS epidemic, nurses have the primary responsibility for providing direct, "hands on" care to patients with HIV/AIDS. A rapidly increasing number of studies report on the response of nurses toward these highly vulnerable patients. The findings presented in this chapter are based on an extensive review of the literature; the literature includes studies conducted by nurses, physicians, and psychologists between 1984 and 1997. These studies provide supportive data on the major impact of the HIV/AIDS epidemic on nurses.

Knowledge, Attitude and Beliefs Surveys

Most evident in the literature are the large number of surveys of nurses' knowledge, attitudes, and beliefs about patients with HIV/AIDS. A total of 62 surveys were found and reviewed.

Fear of contagion emerged as a predominant theme in the initial survey conducted by Reed, Wise, and Mann in 1984. Eighty percent of the 267 nursing staff members who worked in a large metropolitan hospital reported that they were fearful of "catching AIDS." Despite a decade of progress in the treatment of HIV disease, and a vast increase in knowledge, most current surveys report little change (Wang, 1997).

Fear of contracting AIDS was found to be the most pervasive theme in the surveys on nurses' attitudes and beliefs about HIV/AIDS (Kerr & Horrocks, 1990; Rae, Brown, & Calder, 1992; Wallach 1989, Wiley, Health, Ackline, Earl & Barnard, 1990). Fear of exposing friends and family members to the virus was found to be a second prevalent theme in the literature (Blumenfield et al., 1987; Haughey, Wu, & Kuhn, 1992; Lashinger, Goldenberg, & Dal Bello, 1995). Although the earliest surveys reported significant levels of homophobia in nurses (Douglas, Kalman, & Kalman, 1985; Kelly et al., 1988), more recent surveys reflect a consistent difference in nurses' attitudes. Several of the surveys indicated negative attitudes toward intravenous drug users and prostitutes (Curry, 1990; Melby, Moore, & Murray, 1993). In general, these surveys identified patterns of attitudinal negativity on the part of nurses, and also patterns of withdrawal from highly dependent AIDS patients. Many of the nurses who participated in these surveys reported avoiding AIDS patient contact, and also a reluctance to carry out necessary patient care procedures.

The current literature includes several studies which moved beyond the level of the descriptive survey. Laschinger and Goldenberg (1993), for example, used a correlational design, based on the Ajzen-Fishbein theory of reasoned action, to examine the links between nurses' attitudes and their behavioral intent to avoid AIDS patient care. One hundred forty one nurses in a large teaching hospital in urban, central Canada were included in this study. Nurses' attitudes and subjective norms were found to be significant predictors for their intent to care for patients with HIV/AIDS. A replication of this study, by the same investigators, with a second sample of 145 community health nurses produced similar findings (1995).

Studies by Jemmott, Jemmott, and Cruz-Collins (1992) and Jemmott, Freleicher, and Jemmott (1992) were also based on correlational designs. These investigators found that nurses' negative attitudes toward HIV/AIDS risk groups correlated positively with their intent to avoid providing care and with their perceived level of occupational risk. The findings in these studies were consistent with the themes of avoidance, frequently reported in the attitudinal surveys.

Only two qualitative studies of nurses' attitudes and beliefs about AIDS patients were found in the extensive literature review. These studies examined the meaning of the AIDS caregiving experience to the nurse. Reutter and Northcott (1993) used a grounded theory methodology to explore how nurses coped with risks of contagion while caring for patients with AIDS. In this study, the investigators found that nurses coped with situations that were potentially threatening by granting a sense of meaning to their work. They reappraised the experience of caring for AIDS patients by redefining the patient as a person who shared similarities, and who deserved care (p. 1382). The investigators reported that this changed perception and allowed nurses to develop more satisfying relationships with patients and to feel that their work was enjoyable.

Breault and Polifroni (1992) based their qualitative study on the framework of Cognitive Dissonance theory. The authors interviewed 16 nurses employed in 3 acute care hospitals. Six themes emerged which represented the thoughts and feelings of nurses: fear, anger, sympathy, self-enhancement, fatigue, and helplessness. Although the study identified negative feelings and emotions, the theme of "self-enhancement" was related to the rewards that come with patient care.

Nurses Willingness to Provide HIV/AIDS Patient Care

A prevalent theme in the literature relates to nurses' willingness, or intent, to provide HIV/AIDS patient care. The unwillingness, or reluctance of many nurses to care for these patients has been reported in several studies (Bond et al., 1990; Kelly et al., 1988). In one early study of nurses' willingness, Gordon and her colleagues (1987) found that nurses (n=505) were least willing to work in dedicated AIDS units.

Numerous instruments were developed to measure the construct of nurses' willingness. Most were developed for only one use, and have not been adequately tested (Harrison, Fusilier, & Worley, 1994). In addition, the majority of the studies on nurses' willingness to care for patients with HIV/AIDS are limited by the more general nature of the instruments used in the measurement of this construct. Few of these studies included the use of instruments which were sensitive to nursing issues, or which focused on nurse-patient interactions in acute HIV/AIDS care settings.

Kemppainen and her colleagues (1994) attempted to address this by developing a measure of willingness, the Nurses Willingness Questionnaire (NWQ), which would connect this construct to a more specific nursing focus. The NWQ was validated with a sample of 581 registered nurses from 5 Veteran's Hospitals across the United States (Dubbert, Kemppainen, & White-Taylor, 1994). The instrument, with a high reported reliability (.97), contains a vignette with an acutely ill hospitalized AIDS patient; nurses are asked to rate their willingness to complete 13 nursing care tasks for the patient described in the vignette. The findings in a study of nurses' willingness to care for AIDS patients, based on data from the NWQ, indicated that nurses with the highest levels of experience in AIDS patient care, in the highest AIDS prevalence areas, were less willing to perform nursing care tasks associated with intense AIDS patient care. Nurses with lower levels of experience reported that they were significantly more willing to complete the tasks associate with AIDS patient care (Kemppainen et al., 1992).

A cross-sectional survey of 311 public health nurses in North Carolina by Tessaro and Highriter (1994) investigated the relationship between nurses' willingness to care for AIDS patients, perceived concern from the patient's family, and the professional work experience of the nurse. The theory of Reasoned Action guided this study. A measure of willingness was developed specifically for this study with high reported reliability (.86). Significant predictors for nurses' willingness included fewer years in nursing, previous care for patients with HIV/AIDS, and being personally acquainted with a patient with HIV/AIDS.

A recent survey by Berkowitz & Nuttall (1995) examined willingness to perform AIDS patient care in a sample of 517 pediatric nurses from 20 states and Puerto Rico The investigators in this study also designed a measure for testing nurses' willingness to care for HIV infected children. Minimal results of the psychometric testing, however, were reported. In this study, nurses with the greatest levels of experience in caring for HIV/AIDS infected children were significantly more willing to care for these patients. The findings in this study contrast with the results reported by Kemppainen and colleagues. The investigators concluded that nurses who care for pediatric patients are not presented with the difficult and challenging issues of adult HIV/AIDS patients.

Sherman (1996) examined the relationship between nurses' willingness to care for AIDS patients and the correlates of spirituality, perceived social support, and death anxiety in a sample of 220 registered nurses in the New York metropolitan area. Willingness was positively correlated with spiritual and social support, and negatively correlated with death anxiety. A concern voiced by the investigator related to narrow range of subject responses in this study and the resulting pattern of weak statistical correlations. The nursing theory of Martha Rogers provided a theoretical framework for this study.

Occupational Stress and Burnout

Studies which evaluated the effects of AIDS caregiving stress on health care workers are also beginning to appear in the literature. Although study findings presented in the literature vary, the studies show that nurses who care for AIDS patients are vulnerable to high levels of occupational stress and burnout. Forty eight percent of the 237 hospital staff members (physicians and nurses) surveyed by Pleck et al. (1988) reported high levels of stress related to AIDS patient care. AIDS-stress was significantly associated with AIDS-phobia, being an LPN or nursing assistant, and low AIDS patient contact. Nashman, Hoare, and Heddeshimer (1990) attempted to identify specific sources of stress in 126 AIDS healthcare workers. Stressors associated with AIDS patient care included: 1) fear of contagion, 2) being forced to cope with repeated death, and 3) AIDS stigma. Eighty one percent of the individuals surveyed indicated that they "experienced greater levels of stress when caring for AIDS patients than when caring for patients with equally serious diseases" (p.25). In contrast, the study showed that health care workers experienced significant levels of job satisfaction when they were able to provide comfort and support to AIDS patients.

Klonoff and Ewers (1990) asked 528 registered nurses to rate levels of occupational stress associated with a variety of AIDS patient care tasks. Three themes emerged: 1) general anxiety about the patients, 2) fears related to dealing with invasive procedures, and 3) stressors from outside the hospital, including concern from family and friends.

Two recent studies specifically addressed the issues of burnout in AIDS care providers. Van Servellen and Leake (1993) examined levels of burnout in 237 nurses who worked in 18 high stress units in 7 hospitals, including general medical units, oncology special care units, medical ICUs, and AIDS special care units (SCU). In general, nurses on all units reported similar levels of work stress on the Maslach Burnout Inventory. The nurses who worked in the AIDS special care units however, showed a trend toward higher levels of emotional exhaustion than nurses in other units. The authors suggested that follow-up studies on the effects of job tension and workload would be warranted.

Bennett (1991) compared levels of burnout in 32 Oncology nurses and 32 AIDS care nurses in two large public hospitals in Australia. In this study, oncology nurses reported a greater frequency of burnout; AIDS care nurses, on the other hand, showed a greater intensity of burnout. Older nurses reported the lowest levels of burnout.

In a recent study, Catalan and his colleagues (1996) compared psychological stress and work related burnout in a sample of 111 nurses and physicians working with AIDS patients and Cancer patients. More than one third of the respondents in this study reported significant levels of psychological distress, with 1/5 of the subjects reporting significant levels of burnout, as measured by the Maslach Burnout Inventory. There were no difference between the AIDS care or oncology staff. AIDS nurses and physicians, however, reported significantly lower levels of personal accomplishment. The findings in this study contrast with the earlier mentioned findings by Bennett (1991) and Van Servellen (1993), who found differences between AIDS care nurses and oncology nurses in relation to emotional exhaustion.

HIV Nursing Workload and Retention

There are some beginning studies which reflect the impact of HIV/AIDS on nursing workload, and also problems which surround recruitment and retention of nurses in AIDS special care units.

Although anecdotal reports address high levels of fatigue and exhaustion, little research has directly examined time requirements for nursing care of AIDS patients. Only two research studies reported data on the time required in caring for patients with AIDS. Swan, Benjamin, and Brown (1992) examined hours of nursing care required for patients with AIDS in a hospital based skilled nursing facility. Patients with AIDS required over an hour (6.5 vs 5.4) more direct nursing care daily than other patients. The study was limited, however, by a small sample size. Van Servellen and her colleagues (1991) reported data on the average and actual nursing care hours required for AIDS patients in special care units. The overall study was designed to provide descriptive data on the quality and cost of nursing care in AIDS special care units. The standard hours of care ranged from 6.8 to 8.3; actual time ranged from 6.6 to 9.6 nursing care hours per patient day (p. 25).

A study by Nagelkerk (1994) described the major problems that nursing administrators faced in Florida in trying to recruit and retain nurses to AIDS special care units. Even with special pay incentives, and educational opportunities, the majority of the administrators were unable to recruit adequate numbers of nursing staff. The administrators agreed that providing physical care for AIDS patients is exhausting and time consuming. Only one study provided data on nursing turnover in the units that provided AIDS patient care. Fahs et al. (1992) examined different dimensions of care between an AIDS cluster bed unit and a general inpatient unit. Nursing staff turnover, although high (45%), was comparable to rates on other units, including geriatrics (44%) and gynecology (45%).

Summary of Findings on Nursing Response to HIV/AIDS

In summary, a growing body of literature provides strong, supportive evidence for the profound impact that the HIV/AIDS epidemic has had on nursing practice. The vast number of studies which appear in the literature direct their focus toward an examination of nurses' knowledge, attitudes and beliefs about AIDS patient care; the findings in these studies are predominantly negative (Bennett, 1995; Horseman & Sheeran, 1995). Few studies examine ways in which nurses cope with the difficult challenges presented by these patients, or present data on the outcomes of HIV/AIDS patient care.

The majority of the studies which appear in the literature remain at the level of descriptive surveys, or exploratory research. Many studies lack valid and reliable instruments; others base their findings on instruments which are not sensitive to issues or circumstances unique to nursing care. Several of the more recently published studies, based on correlational designs, move the literature forward, and beyond the level of the descriptive survey. Few of the studies reported in the literature, however, are guided by theoretical frameworks. While the majority of the studies use convenience samples of nurses in large, urban hospitals, several of the more recent studies include nurses in community care settings.

Although the numbers of women, minorities, and injection drug users are currently increasing at an alarming rate, few studies exist which examine the responses of nurses toward these patient groups. There is also an absence of studies which contrast the responses of nurses to HIV/AIDS in urban and rural settings, or in varied geographic regions of the country.

Studies are also beginning to appear in the literature which investigate factors affecting nurses' job satisfaction, including turnover, recruitment and workload. An increasing number of these studies examine the effects of burnout in nurses who provide AIDS patient care.

The most significant and important finding in the literature review , however, related to the lack of progress in moving the state of research beyond the level of surveying nurses attitudes, knowledge and beliefs about HIV/AIDS. There is a large gap in the literature which relates nurses' knowledge, attitudes, and beliefs to their caregiving behaviors, and more specifically, to patient care outcomes.

Although much of the research remains at the descriptive or exploratory level, the studies do show that nurses who care for AIDS patients experience enormous personal stress; they also show that the experience of caring for an AIDS patient can produce a strong emotional response in the nurse and may, at times, affect the behavioral responses of nurses toward those patients.

Patient Response to HIV/AIDS

A vast amount of literature describes the patient's perspective of HIV. The experience of the patient with HIV/AIDS has been examined from many different perspectives and numerous studies have been published by health care workers in all disciplines. This review of literature on patient responses to HIV/AIDS is limited to the quality of life and HIV/AIDS literature.

Quality of Life and HIV/AIDS

An increasing number of studies of the quality of life in relation to HIV/AIDS are beginning to appear in the literature which provide important information on the meaning and dimensions of HIV/AIDS from the perspective of the patient. The term quality of life is frequently employed in medical literature. Although there is no universally accepted definition of the quality of life, there is some agreement as to what may detract from the quality of life (Burgess & Catalan, 1991). Ganz et al. (1993) describes health related quality of life as a multidimensional construct that is generally accepted to include several important dimensions: functional status, disease and treatment related symptoms, psychological functioning, and social functioning. Quality of life has been studied in relation to numerous diseases. More recently, the quality of life literature has been extended to persons with HIV/AIDS (Holzemer & Wilson, 1995).

Although health-related quality of life is a subjective phenomenon, it can be reliably measured using a variety of psychometrically valid instruments. A number of scales have been developed specifically for use in HIV/AIDS outcome studies. For example, Holzemer, Henry, Stewart, and Janson-Bjerkile (1993) assessed the performance of the HIV Quality Audit Marker (HIV-QAM) on 201 hospitalized patients with Pneumocystis carinii pneumonia (PCP). The HIV-QAM measured changes in self care, Ambulation, and psychological distress, relative to nursing care. A second example includes the Living with HIV scale developed by Holzemer and colleagues (1997) based on interviews with a sample of racial and ethnically diverse HIV/AIDS patients. The scale has a high reported reliability (.84). Two subscales, HIV Reverence and HIV Struggles contain items which reflect a patient's satisfactory resolution of HIV related issues, or the continued struggle with the demands of the illness. In their recent review of literature, Holzemer and Wilson (1995) provided an in-depth discussion of other measures used in the evaluation of quality of life issues in patients with HIV/AIDS.

A total of 30 studies were reviewed which looked at the quality of life in relation to HIV/AIDS. The following discussion presents quality of life concerns in each of the following dimensions: 1) stages of HIV disease, 2) qualitative studies of the patients' perspective, 5) special populations with HIV/AIDS.

Quality of Life and Stages of HIV Disease

Studies are beginning to appear in the literature which relate the quality of life to the stage of HIV disease. They report considerable variability in the quality of life throughout the stages of HIV disease.

A study completed by Ganz et al. (1993) provided detailed information on the wide range of problems that patients with HIV disease experience, including psychological problems. A HIV-specific quality of life measure (HOPES-HIV Overview of Problems-Evaluation System) was used to collect data from a groups of 318 persons across all stages of disease. Overall, HIV positive, asymptomatic patients experienced fewer psychosocial problems than patients with ARC, AIDS, and AIDS with cancer. Although asymptomatic patients had a lower frequency of psychosocial problems than other patients, they experienced equal levels of psychological distress, worry, stigma, communication problems with friends, anxiety in medical situations, and compliance problems (p. 116).

A second study also measured changes in the quality of life across the full spectrum of HIV disease. Lubeck and Fries (1992) evaluated changes in the overall health status and disease progression in 1,575 patients at various stages of HIV disease. The authors concluded that AIDS patients had a diminished quality of life compared to asymptomatic HIV positive patients. Patients who progressed to the stage of having one or more serious opportunistic infections experienced the greatest impact on their quality of life, especially in the areas of functional ability, global assessment, and symptom management.

A third study also examined the quality of life across all stages of HIV disease. Ragsdale and Morrow (1990) studied 95 infected patients in a major southwest urban area in an effort to identify key variables related to their quality of life. Their findings show that the psychosocial impact of HIV disease is higher than the physical impact in each phase of illness. The greatest impact on the quality of life was experienced by patients with ARC (AIDS related complex).

Two subsequent qualitative studies by Ragsdale and her colleagues limited their focus to the quality of life concerns in hospitalized, terminally ill AIDS patients. Ragsdale, Kotarba & Morrow (1992a) described the quality of life from the viewpoint of patients hospitalized in a dedicated AIDS unit. The study described 6 strategies which patients used to manage and control problems generated by the disease, thereby increasing their quality of life (Loner, Activist, Victim, Time Keeper, Mystic, Medic). Ragsdale and her colleagues (1992b) also conducted an ethnographic study of ways in which hospitalized AIDS patients "worked" to manage their illness to improve their quality of life. When patients were able to manage work-related activities associated with their disease, their quality of life was enhanced. It is unclear whether quality of life in these studies is a process or an outcome.

Wachtel and his colleagues (1992) assessed the performance of the Medical Outcomes Study (MOS) Short Form Health Survey, a quality of life measure, on 520 patients with HIV disease attending health services programs at seven sites in 6 states. Patients over the age of 50 scored lower on the dimensions of physical, role, and social functioning; they also had a poorer health perception. Women scored worse than men in areas of role and social functioning and in mental health (p. 134). Intravenous drug users had lower scores in all dimensions (physical function, role function, social function, mental health, health perception, and pain); the authors suggested that this finding may reflect their lack of available health care. The study did not address issues relating to social support and their specific relationship to HIV/AIDS.

Qualitative Studies of the Patient's Perspective

Nine recent qualitative studies provided descriptive data on the quality of life, including the varied psychological responses that persons with HIV disease experience. The studies provided insight into how patients "live with HIV/AIDS" and cope with their illness, rather than focus exclusively on "AIDS as a death sentence." Although the studies described numerous adverse psychological effects of HIV/AIDS, they identified positive themes of hope and determination associated with "living with HIV disease."

O'Brien and Pheifer (1993) interviewed 133 HIV positive gay men every three months over a three year span of time. The authors identified two predominant physical issues (fatigue and weight loss) and six psychological issues (self-concept, loneliness, sexual integrity, home management, impaired communication, and spiritual distress) that persons with HIV disease experience. The authors presented a sample of case studies which described these concerns.

Laryea and Gien (1993) studied stigma, rejection and loneliness experienced by a group of 25 Canadian patients with HIV disease. Fear was described as the major factor in their life, including fear of disclosure of their disease, and fear of rejection by others. Fear often disrupted relationships with family members and friends, curtailed social life, and affected employment. Most of the patients were lonely and distressed by the fact that they were not always able to discuss their feelings openly with others.

Gloersen and her colleagues (1993) used a qualitative approach to study the subjective experiences of 16 persons with AIDS who viewed themselves as "doing well." Study participants exhibited two general ways of doing well by conceptualizing AIDS as 1) an opportunity for self actualization, and 2) a manageable, chronic illness (p. 46). Categories of doing well which were identified included accepting, being active, masterful living, relating mind and body, being positive, participating in health care, and experiencing support.

Nokes and Carver (1991) used Parse's Theory of man-living-health as a conceptual framework for exploring the meaning of living with AIDS. Fourteen men and women who were interviewed identified three core ideas: 1) prevailing thoughts about mortality surfaced and subsided, 2) relationships fluctuated as priorities changed, and 3) shifting expectations lead to thoughts of spirituality. The subjects described ways in which the news of a devastating illness helped them change priorities and "find new meaning in experiences" (p. 177). They described the gradual shift from experiencing shock and horror to "living one day at a time" and focusing more on the present. They spoke about dreams of reconciling relationships, leaving legacies for children, and hopes for a cure. The findings in this study may be similar for other groups with terminal illnesses, however, the authors do not make comparisons.

Weitz (1990) described how AIDS stigma affected the relationships of 23 gay and bisexual men with family, friends, colleagues, and health care providers. Each respondent in the study reported that at least one family member ceased contact after learning of an AIDS diagnosis. Some family members adopted extreme anti-contagion measures while others provided support and warmth. Some of the subjects described abandonment by friends and family once the diagnosis was known. Patients in this study avoided stigma by concealing their diagnosis from others, or "masking the signs of illness if they are visible, and lie about those signs that cannot be masked" (p. 37). They also avoided stigma by reducing contact with friends and relatives who were not supportive or by using bravado to convince others they were still functioning human beings.

Gaskins and Brown (1992) used Grounded Theory methodology to describe feelings and experiences of one female and nine male patients with HIV disease. Although the subjects described the devastating impact of receiving an HIV diagnosis, the overall theme of "Fighting to Survive" emerged. Seven categories emerged which described changes that were made in every day lives in order to cope better with their illness. The categories included: 1) living with uncertainty, 2) accepting homosexuality, 3) experiencing changing feelings, 4) protecting confidentiality, 5) dealing with the health care professions, 6) handling multiple losses, and 7) living with a terminal illness.

Longo, Spross, and Locke (1990) interviewed 34 homosexual males with AIDS in an effort to identify their major concerns. The following themes emerged: 1) uncertainties about the future, 2) the desire to maintain physical and psychological health, 3) social unacceptability, 4) fatigue, and 5) weight loss. The majority of the persons with AIDS sought out family, friends, and lovers for support; they reported a hopeful outlook and believed that they were adjusting well to the illness. The themes which emerged in this study are similar to those found in the other qualitative studies.

McCain and Gramling (1992) completed a phenomenological study of the lived experience of coping with HIV disease in 36 men and women with HIV disease. Three processes evolved: 1) living with dying, 2) fighting the sickness, and 3) getting worn out. These themes may be similar to responses of patients with cancer or other terminal illnesses, however, the authors did not describe their unique relationship to HIV/AIDS.

Bennett (1990) also used a phenomenological methodology to study 10 male homosexual patients in New Orleans. Prevalent themes which emerged included feeling rejected by families, friends, roommates, and employers. Subjects used "downward social comparisons of other patients with AIDS" to decrease fears and align more with a positive image.

Coward (1994) also used a phenomenological methodology to study the experiences of 10 women and 10 men with HIV/AIDS. Half of the women in this study were from minority groups, compared to only one male subject. Although the men and women in this study experienced equally high levels of fear, other responses varied by gender. Themes identified by the men included taking care, seeking out challenges, creating a legacy, accepting of HIV/AIDS, and connecting with others. Women experienced uncertainty, used others as role models, talked about inner strength, and reached out toward others.

Three of the quality of life studies included descriptive data on the response of patients with HIV/AIDS to health care workers. The study by Weitz (1990) provided a clear description of the negative effect that AIDS stigma had on the relationships between health care workers and patients with HIV/AIDS. Numerous subjects who participated in this study on AIDS stigma described rejection by health care providers. One subject stated, "They cannot refuse to provide care but can make their ignorance and prejudice painfully obvious" (p. 30). A second study by Gaskins and Brown (1992) included a clear description of patient response to negative health care provider behaviors. Patients in that study described their frustrations at not being able to obtain adequate care, feelings of rejection, and a sense of feeling contagious. The previously cited study by Ragsdale, Kotarba, and Morrow (1992a) described patient responses to positive nursing actions, including diminished loneliness and increased feelings of acceptance.

In summary, studies on quality of life in patients with HIV/AIDS based on qualitative research methodologies provided rich, descriptive data on the wide variety of strategies that patients with HIV/AIDS use to cope with the varying stages of HIV disease. They also identify quality of life issues across the stage of illness.

Quality of Life and Special populations and HIV Disease

Few studies addressed quality of life concerns in relation to special populations with HIV/AIDS, including women, minorities, the homeless, injection drug users, and older adults. The majority of the quality of life literature describes issues and problems of homosexual men.

Although women were included as subjects in three of the qualitative studies, their issues were not clearly defined. The literature base on women and HIV/AIDS is rapidly expanding with the primary focus being on prevention, epidemiology, and the clinical nature of the disease progression. Few studies exist which focus on the unique quality of life issues in women.

One qualitative study was found which provided descriptive information of the health concerns in women with HIV/AIDS. Rose (1993) interviewed 6 African-American and 5 white women with AIDS in an urban southeastern area of the United States in order to learn more about their health concerns. This study described and classified common health behaviors of women into three categories: environmental, health-behavioral, and psychological response categories. Caring for children superseded a concern for personal health. In a later study, Rose (1996) examined quality of life and coping styles in a sample of 52 HIV positive women with children. Scores on the Padilla Quality of Life Scale indicated that social quality of life was the highest concern, and psychological concerns were the lowest. The women in the study reported that they used confrontive styles of coping rather than emotive or passive styles.

One recent study described the experiences of womens' disclosure of their HIV status. A qualitative study by Moneyham and colleagues (1996) explored issues presented by 19 women through focus group interviews. Major concerns about disclosure included fear of discrimination and concern about confidentiality. The context in which they disclosed their HIV status was also described as an important concern. The increased use of supportive health care services resulted from these concerns.

Only two recent studies were found which examined the unique quality of life concerns of injection drug users with HIV/AIDS. Morrison (1993) used a series of qualitative interviews to examine the experiences of female and male injection drug users in Scotland. The subjects reported a greater degree of openness concerning their HIV status. They reported observing signs of illness in acquaintances and friends but minimized their thoughts about this. Some subjects reported behavioral changes in relation to needle sharing but few indicated any decrease in high risk sexual behaviors. All subjects were fully aware of the risks of being infected and of infecting others (p. 200).

Stowe et al. (1993) investigated social support networks in injection drug users in Australia. Subjects who became infected were more likely to receive support from other IV drug users and friends rather than from biological families; they were also more open about their status with friends than families. The study noted a lack of association between the number of supports and the quality of that support.

The computer literature search revealed no quality of life studies which focused on the unique problems of homeless persons or minority groups. Although studies are beginning to appear in the literature on the unique effects of HIV disease in patients over 50 years of age, there are no studies of quality of life for this population.

Summary of Findings on the Quality of Life in HIV/AIDS

In summary, the review of the literature on quality of life in HIV/AIDS produced important data on the physical and psychological consequences of this disease, and it also identified factors which may impact on nurse-patient relationships in HIV/AIDS care settings. The studies which were reviewed indicate that HIV disease can diminish the most basic and important aspects of life, including physical comfort, relationships with others, the ability to work, being independent, and also happiness (Wu & Rubin, 1992). Although this review of literature identified beginning studies on quality of life issues, it also indicated that further work is needed in defining and measuring the dimensions of the quality of life in persons with HIV/AIDS, especially in women. minorities, and persons over 50. For those who are interested in future research in this area, numerous valid and reliable instruments are available to study quality of life issues (Holzemer & Wilson, 1995). Nursing research on quality of life in persons with HIV/AIDS is currently limited.

HIV/AIDS Patient Responses to Health Care Providers

An extensive computer search which focused on patient responses to health care workers in AIDS health care settings produced only six studies. Three of the studies focused on patients' responses to health care providers in outpatient HIV/AIDS treatment settings; each study lacked psychometrically valid instruments. Three additional studies related to hospitalized patients. The extensive search also revealed no research instruments for measuring HIV/AIDS patient responses to nursing behaviors.

A study by Valdiserri, Tama & Ho (1988) surveyed the level of care provided to a group of 27 persons in an AIDS clinic at the University of Pittsburgh. The findings in the study identified the need for more effective communication between patients and physicians. The majority of the patients in the study felt that they were given inadequate information regarding their illness, including partner notification and specific precautions to take with household members who were not sexual partners. Eighteen percent of the patients with AIDS surveyed by Kass et al. (1992) reported that they had been refused treatment by physicians or dentists.

Meeks-Festa and her colleagues (1994) measured levels of patient satisfaction with selected aspects of nursing and social work services provided to 20 adult patients with HIV/AIDS who received care at an infectious disease clinic in a university teaching hospital. The authors developed an open-ended, semi-structured interview form that also included a number of Likert scale items. The nursing questions addressed the effectiveness of teaching and anticipatory guidance offered during treatments.

One study addressed the responses of patients toward health care workers in a hospital in Sweden. Wilde and colleagues (1993) used a Grounded Theory approach to investigate quality of care issues from the perspective of the patient. The investigators interviewed 10 men and 10 women, diagnosed with infectious diseases as pneumonia and meningitis. The subjects were interviewed on three occasions, at the beginning of hospitalization, at discharge, and again two months later. Four quality of care dimensions identified by the patients included the medical-technical competence of the caregivers, the physical-technical condition in the care organization, the degree of identity-orientation in the attitudes of the caregivers, and the socio-cultural atmosphere of the organization. A quality of care model, proposed by the investigators, was based on these four dimensions.

Only two studies specifically addressed the responses of hospitalized patients with HIV/AIDS toward nurses. Although the primary purpose of a study by Van Servellen and her colleagues (1990) was to evaluate the effectiveness of health care delivery systems for patients with HIV/AIDS, this study compared the experiences of patients in AIDS special care units to those in integrated units of general medicine and oncology. Patients in dedicated AIDS care units experienced lower levels of stress associated with hospitalization than patients in integrated units. The patients on the integrated units were "bothered by factors associated with ambiguity about their care and condition and feelings of abandonments and impersonal or discriminatory treatment" (p. 235).

In a phenomenological study, Kermode (1995) explored the experiences of eight male patients who were hospitalized in a dedicated AIDS unit in Australia. The patients in this study were asked to describe helpful and unhelpful nursing actions. Psychological support interventions were seen as most helpful, in fact, patients related these interventions to high quality care. Unhelpful nursing actions included carelessness and inadequate medication teaching. Although the findings from this small study are limited, the study is important in that it represents an initial effort to describe nurse-patient encounters in AIDS care settings, from the perspective of the patient.

Summary of Findings on Patient Response to Health Care Providers

In summary, this review of studies on the response of patients with HIV/AIDS to health care providers, including nurses, identified a large gap in the literature. Very little nursing research has been conducted on the impact of HIV/AIDS on patient-provider interactions, from the perspective of the patients. This review highlights the need for continued research in this area.

Theoretical Framework

The nursing systems framework of quality of care, proposed by Holzemer (1992), based on work by Donabedian (1982), provides a useful model for synthesizing the vast amount literature on the responses of AIDS patients and the reactions of nurses to

HIV/AIDS, and for examining patient responses to nurses. Holzemer's model also provides a way for viewing factors which impact on the quality of care and patient outcomes in HIV/AIDS health care settings.

The model (see Table 2-1) is based on a systems framework of inputs (patient problems), process (nursing activities), and outcomes (patient status). Holzemer (1994) states that the horizontal axis is a systems axis of context or input, processes and outcomes. The three components in the vertical axis which should be evaluated prior to conducting a research study include the client, provider, and the setting.

Table 2-1
Outcomes Model for Nursing Research

	Input/Context	Processes	Outcomes
Client			
Provider			
Setting			

Source: Holzemer, W. (1994). The impact of nursing care in Latin America and the Caribbean: a focus on outcomes. Journal of Advanced Nursing, 20, 6.

In a manner similar to Donabedian's model, Holzemer's three part model links inputs with the process of nursing activities, and then with outcomes, or changes in patient status. A change in one of the elements creates a change in the elements that follow or precede it, and affect the quality of care that is provided.

The review of literature on patient and nurse responses to HIV/AIDS described inputs which influence the process of nursing care and outcomes which are linked to that process. In this instance, patients with HIV/AIDS seek care and treatment for acute exacerbations of a debilitating and uniformly fatal disease. Their problems are compounded by complex social, psychological, physical needs, and by their stage of illness and high levels of acuity. The providers in this study are the nurses in acute, inpatient settings. Nursing inputs to the model which may have affects on the outcomes of care include levels of experience in AIDS patient care, knowledge about HIV/AIDS, attitudes, beliefs, levels of fatigue, occupational stress, and workload. The literature review also showed that many nurses and patients are dissatisfied with their clinical encounters, or interactions.

In order to meet the challenges set by AIDS patients, nurses will have to change and improve the quality of nurse-patient interactions. Nursing behavior is unlikely to change unless nurse-patient interactions can be associated with outcomes of care. A program of systematic research which measures the outcomes of provider-patient interactions, based on inputs, would ultimately improve their effectiveness. Nurses would be able to use the research findings to change their inputs to the process of nurse-patient interactions. They would also be able to use the findings to demonstrate outcomes of care, an important consideration in a time when cost control and quality care are increasingly emphasized.

CHAPTER THREE

METHODOLOGY

Research Design

This two phase study was undertaken to construct a brief, practical scale that could be used by patients with HIV/AIDS to report their behavioral responses to nurses in AIDS health care settings. Phase I of the study, initiated during April 1995, was concerned with the development of scale items and the construction of the Patients' Responses to Nurses Behaviors scale (PRNB). During phase II of the study, the scale was completed by a sample of hospitalized, and recently hospitalized, patients with HIV/AIDS and preliminary evidence for reliability and validity was obtained. Phase II of the study was initiated during April, 1996. This chapter will present a discussion of the methodology used in conducting this research study. For purposes of clarity, the chapter will be organized into two separate sections, each representing a phase of the study.

Research Context-Phase I: Scale Development

The critical incident technique, a factual approach to gathering information, was used to identify the behavioral responses of patients with HIV/AIDS and to generate scale items, based on those responses. The listing of behavioral responses formed a pool for scale item development. Items were developed to correspond with the categories identified in phase I of the study, and a preliminary version of the scale was developed.

Subjects

Inclusion/Exclusion Criteria

Subjects selected for Phase I, the scale development phase of this study, included a purposive sample of male and female veteran patients with an AIDS defining diagnosis who had been hospitalized for at least 3 days. The use of purposeful sampling allowed the investigator to maximize variation of individual perspectives and responses by hand selecting the cases, based on the judgment of the extent to which participants met the selection criteria (Woods & Catanzaro, 1988). Subjects were selected from the following AIDS subgroups: homosexual and bisexual men, male and female injection drug users, and male and female patients of racial and ethnic minorities. The subjects were 18 years and older, mentally alert, and able to read and write English. Subjects who presented clinical indications of AIDS dementia, as noted the chart, or who were too ill or debilitated were excluded from the study. The size of the sample was determined by the adequacy of the critical incidents with a planned minimum of at least 150 subjects.

In order to generate critical incidents which would be more representative of all AIDS subgroups, beyond the sample of predominantly male veterans, the study was expanded to include females who had been recently hospitalized. A total of thirty five females who had been hospitalized within four months were actively recruited through two community agencies and also through two widely circulated newsletters for women with HIV/AIDS. The subjects who were recruited came from broad socioeconomic and cultural backgrounds and included homeless women, IV substance abusers, prostitutes, and middle class professional women. Since these subjects are frequently difficult to recruit, the decision was made to offer them a small cash reimbursement for study participation.

Sample Description

During Phase I, a total of 118 male and female AIDS patients, representing all AIDS subgroups were contacted and agreed to participate in the study. Although the original proposal specified a total of 150 subjects for Phase I, saturation of content was achieved following 118 subject interviews. A total of 83 male patients were recruited through the VA hospitals in Palo Alto and San Francisco and 35 female subjects were recruited through the community agencies and newsletters. Subjects ranged in age from 26 to 78 years (mean age=45.14 yrs.). An ethnically diverse background included Asian Pacific Islander 2.6% (n=3), African American 35.9% (n=42), Hispanic 9.4% (n=11), and Caucasian 52.1% (n=61). The mean CD4 count was 117.3/mm^3, with an average length of 1.84 years since receiving an AIDS diagnosis. At least 65% of the subjects were hospitalized more than once. Demographic data is presented in Table 3-1.

Table 3-1

Demographic Data-Phase I (N=118)

Variable	Range	Mean	SD`	Frequency
Age	24-78 yrs.	45.14	9.27	118
CD4 Self Report	0-600	156.7	143.8	93
CD4 Chart Report	0-500	117.3	121.5	83
Length of HIV Self Report	.01-13 yrs.	5.18 yrs.	3.57	108
Length of HIV Chart Report	0-17 yrs.	6.1 yrs.	3.85	73
<u>Sex</u>				
Male				83 (51.2%)
Female				35 (21.6%)
<u>Education</u>				
Jr. High				4 (3.4%)
High School				44 (37.6%)
Jr. College				11 (9.4%)
College				48 (41%)
Other				2 (6.8%)
<u>Ethnicity</u>				
Asian/Pacific Islander				3 (2.6%)
African American				42 (35.9%)
Hispanic				11 (9.4%)
Caucasian				61 (52.2 %)
<u>Risk Factors</u>				
Male-male sex				36 (30.8%)
IVDU				21 (17.9%)
Sex/IVDU				11 (9.4%)
Sex/ bisexual				2 (1.7%)
Sex/hemophiliac				0 (0.0%)
Sex/transfusion recipient				0 (0.0%)
Transfusion recipient				1 (0.9%)
Work in lab				0 (0.0%)
Don't know				46 (39.3%)
<u>Previous Hospitalizations</u>				
Yes				77 (65.8%)
No				40 (34.2%)

Critical Incident Technique

The critical incident technique developed by Flanagan (1954) was used to collect data on patients' behavioral responses; the listing of behaviors obtained through this technique formed a pool for scale item development. The critical incident technique is a systematic, open-ended procedure designed to gather factual reports of behaviors. This technique was originally developed by Flanagan and other members of the Aviation Psychology Team during World War II to list critical role behaviors for key military personnel including air traffic controllers and pilots. This intensive method of interview, often combined with observation, is designed to pinpoint facts and reduce judgment or personal opinions. In more recent studies, this technique has been effectively used to identify the responses and behaviors of acutely ill patient in studies of quality in health care settings (Ruben, 1993; Cox, Bergen, & Norman, 1993; Norman et al., 1992; Longo et al., 1993; Hehn, 1985). Flanagan (1954) defines an "incident" as "any observable human activity that is sufficiently complete in itself to permit inferences and predictions to be made about the person performing the act" (p. 324). In this technique, in order for an incident to be critical, it must make a significant difference in the outcomes of a behavior (Fivars & Gosnell, 1966, p. 16).

Validity of the Data

According to Flanagan, incidents from memory can be recalled to provide adequate data. Only simple types of judgment are required from the observer and only reports from qualified subjects are included. Observations become fact when a number of independent observers make the same report (Flanagan, 1954, p. 335). Evidence regarding the accuracy of reporting is contained in the incidents themselves (Flanagan).

When full details are given, it can be assumed that the information being recalled by the subjects is accurate; vague reports which lack detail suggest that the incident is not well remembered and may be incorrect (Flanagan, 1954).

The investigator applied the following criteria, specified by Flanagan, to the incidents as they were being collected: a) is the actual behavior reported? b) were all the relevant factors in the situation reported? c) has the observer made a judgment regarding the critical nature of the behaviors? d) was the behavior observed by the subject? e) has the subject made it clear just why he or she believes the behavior was critical? In this study, critical incidents of patient behaviors were collected through two methods: 1) critical incident interviews and 2) direct observation.

1) <u>Structured critical incident interviews</u>: Flanagan's format for interviewing was applied during each subject interview. Following an explanation of the purpose of the study, subjects were asked to recall brief descriptions of both positive and negative nurse-patient events and report their behavioral responses to those events. The investigator also discussed the general aim of the critical incident technique and specified types of relevant behaviors. In order to obtain the reporting of unbiased incidents, the data collector remained neutral. Clarifying statements were used in an effort to encourage subjects to continue their behavioral descriptions or to bring out additional, relevant details of an incident.

2) <u>Direct observation</u>: An additional procedure identified by Flanagan is to observe and record incidents as they happen, in as great detail as possible. In this study, critical incidents were also collected through the use of direct observation by the data collector at each of the inpatient sites. In order to obtain as much data as possible, the

observations were unstructured (Flanagan, 1954). A data collector was trained to document all behaviors of patients and nurses which occurred during and immediately after caregiving events. Observations were recorded as they happened in as great detail as possible in a clinical log. The behaviors of nurses and a subset of approximately 25% of the patients who participated in the study were observed during intense care-giving events (bathing, changing IV's, treatments) on all three shifts, and on all days of the week. Each of the patients was observed for a period of 2 hours. Nurses were also observed during shift report.

A pilot study conducted with 5 subjects determined that the critical incident format could easily be used by hospitalized patients and that the incidents could be collected in sufficient detail for the study.

Human Subjects Assurance-Phase I

The study protocol for Phase I was submitted to the University of California, San Francisco, Committee on Human Research. Approval from the Institutional Review Board was also obtained from each of the VA Medical Centers and community agencies.

Data Collection Methods

Sources of Data

The following two V. A. Hospitals in the San Francisco Bay area served as clinical sites for this research study: 1) the Palo Alto V. A. Medical Center in Palo Alto, California (this includes the Menlo Park and Livermore divisions), and 2) the Fort Miley V. A. Medical Center in San Francisco, California. Two clinical agencies served as sites for recruitment of additional female subjects included 1) the VNA AIDS Project in San Jose, CA and 2) the UCSF Women's Specialty Clinic in San Francisco. Advertisements were also placed in two widely circulated newsletters for women with HIV/AIDS in the Bay area of California.

Procedure

Access to each of the VA Medical Centers was obtained through the Chief Nurses, Associate Chiefs for Nursing Research and the Nursing Research Committees. Access to the VNA AIDS Project was through the Director and research committee. Access to subjects at the USCF Women's' Specialty Clinic was through the HIV/AIDS nurse practitioner and research committee.

Data Collection

In each of the VA hospital inpatient sites, the AIDS coordinator, nurse manager, or staff nurse was approached and asked about potential patients who would meet the study criteria. Patients were then approached and asked about their desire to participate in this study. If subjects agreed to participate in the study, permission was obtained and consent forms signed (see Appendix A). Each subject was assured that all data would be anonymous and no personal identifying data published. Since the collection of information in this part of the study had the potential for affecting the relationships between the subjects and their nurses, the investigator was respectful of the sensitive nature of the data and of the need to maintain confidentiality. Patient charts were audited for indications of AIDS dementia and also to obtain information which confirmed the AIDS defining diagnosis and stage of illness. The investigator was also alert to the sensitive nature of the HIV/AIDS diagnoses and the for respecting subject confidentiality. In order to minimize disruption to nursing care or medical treatment, appointments were scheduled at convenient times for each subject. Since chart verification of an AIDS diagnosis was not feasible for female subjects recruited through the community agencies and newsletter, confirmation of diagnosis was obtained through contact with the health care provider or through written official documentation provided by the subject, confirming their diagnosis.

Each subject received a research packet containing a cover letter, a demographic data sheet, and two critical incident forms (see Appendix B). The cover sheet described the interview based on the critical incident forms and information about the purpose of the study. Each subject was asked to complete a demographic data sheet which included age, ethnic background and length of illness. Subjects who completed critical incident form I were asked to recall positive descriptions of nurse-patient events, describe their behavioral response to the event, and provide a brief explanation of why the nurses' action affected their behavior. Critical incident form II was used to record responses to negative events. The research packet required approximately 30 minutes to complete. Subjects who had difficulty responding to a written form were personally interviewed by the data collector. In order to minimize disruption of nursing care and medical treatment, the critical incident interviews were administered at conveniently scheduled times.

Data Analysis-Phase I

The critical incidents were analyzed by the researcher through an inductive classification process. The content analysis of data was facilitated by a computer program (ETHNOGRAPH) which allowed for the creation of coding systems and the refinement of coded items into behavioral response categories. Patient behaviors that were similar were grouped together and a continued refinement and modification of categories took place as incidents were collected. Incidents were collected until additional data produced only minor variations in the categories, and a representative listing patient behaviors was included. The groupings were tentatively labeled and defined and submitted to two HIV/AIDS experts for review. Demographic data analyzed through the use of descriptive statistics will be presented in Chapter IV.

Item Development and Scaling

Scale items were written to correspond with the behavioral categories that resulted from sorting and grouping the critical incidents. Once the items were generated, a preliminary draft of a scale was developed and given to a sample of 6 hospitalized AIDS patients and also 6 nurses who had experience in caring for hospitalized AIDS patients. The patients and nurses were asked to evaluate the clarity of the wording, the appropriateness of the content items, and also the utility of the scale for hospitalized patients. They were also asked to make recommendations in relation to the elimination of scale items and items were modified as indicated.

Research Context-Phase II: Psychometric Testing

The goal of phase II was to complete psychometric testing and provide preliminary evidence for reliability and validity the scale.

Subjects

Inclusion/Exclusion Criteria

A convenience sample of hospitalized male and female veteran patients with an AIDS defining diagnosis were selected for Phase II of the study. In a manner similar to

Phase I of the study, subject groups included both hospitalized veteran patients and also additional female subjects recruited through community agencies. Subjects included the following AIDS subgroups: homosexual and bisexual men, male and female injection drug users, and male and female patients of racial and ethnic minorities. The subjects were 18 years or older, mentally alert, and able to read and write English. Subjects who presented clinical indications of AIDS dementia, as noted in the chart, or who were too ill or debilitated were excluded from the study. The size of the sample was dependent on the number of scale items and also on the requirements of the multi-trait multimethod analysis. Since the completed scale was anticipated to include 10-15 items, the planned sample size was from, 150-200 subjects. The planned sample size of 10 subjects for each scale item would insure stability of the correlation which formed the basis for the analysis (Nunnally, 1978).

In order to generate critical incidents which would be more representative of all AIDS subgroups, beyond the sample of predominantly male veterans, the study was expanded to include females who had been recently hospitalized. Female subjects who had been hospitalized within four months were actively recruited through two community agencies and also through two widely circulated newsletters for women with HIV/AIDS. Subjects who were recruited came from broad socioeconomic and cultural backgrounds and including homeless women, IV substance abusers, prostitutes, and middle class professional women. Since these subjects are frequently difficult to recruit, the decision was made to offer them a small cash reimbursement for study participation.

Sample Description

A total of 162 male and female AIDS patients, representing all AIDS subgroups participated in Phase II of the study. The total number of subjects included 102 males and 60 females who were recruited through 9 sites, including 5 VA Hospitals, two community agencies, and a newsletter for women with HIV. Subjects ranged in age from 25 to 65 years with a mean age of 43.3 years. The ethnically diverse sample included Asian/Pacific Islanders at 1.9% (n=3), African American at 45.1% (n=73), Hispanic at 7.4% (n=12), and Caucasians at 45.1% (n= 73). The mean CD4 count for the sample was 151mm^3, with an average time since acquiring an AIDS diagnosis of 28.5 months (SD 29.4). Sixty eight percent of the subjects reported being in the hospital at least twice since receiving an AIDS diagnosis. Demographic data for the total sample is presented in Table 3-2.

As part of the demographic data, subjects were asked the question, "How do you think that you got exposed to the HIV virus?" The results of their responses are presented in Table 3-3. Forty nine of the subjects, or 39% or the total sample, reported that they contracted HIV through male-to-male sex. The increasing role of IV drug use in the transmission of HIV/AIDS is also reflected in this sample. Twenty eight percent (n=46) of the subjects reported that they contracted the virus through IV drug use; sex with an IV drug user was named as a risk factor by 20% (n=33) of the subjects. Twenty seven percent of the respondents in this study (n=44) stated that they didn't know how they contracted the HIV virus.

Within the total sample of 162 subjects, 32 subjects identified multiple risk factors for HIV/AIDS, including 10 who named three high risk factors, and two who named four.

Of the 32 subjects who named multiple risk factors, 70% (n=21) were female IV drug users and the remainder were male IV drug users (30%, n=9).

Table 3-2

Demographic Data-Phase II (N=162)

Variable	Range	Mean	SD`	Frequency
Age	24-65 yrs.	43.3 yrs.	8.2	162
CD4 Self Report	0-600	151.7	134.6	122
CD4 Chart Report	1-582	132.1	143.6	101
Length of HIV Self Report	0-180 mos.	74.2 mos.	45.8 mos.	159
Length of HIV Chart Report	0-168 mos.	68.2 mos.	47.5 mos.	75
Times hospitalized with AIDS	1-5 times	2.3	1.5	162
LOS	1-105 days	12.8 days	14.0	146
Years of Education	3-22 yrs.	12.9 yrs.	2.4 yrs.	162
Mortality				
No				146 (90)
Yes				16 (10)
Sex				
Male				102 (63%)
Female				60 (37%)
Ethnicity				
Asian/Pacific Islander				3 (1.9%)
African American				73 (45.1%)
Hispanic				12 (7.4%)
Caucasian				73 (45.1%)

Table 3-3

Phase II: Demographic Data: HIV/AIDS Risk Factors (N=162)

Risk Factor	n	(%)
Male/male Sex		
Yes	49	(30.2%)
No	113	(69.8%)
IV Drug Use		
Yes	46	(28.4%)
No	116	(71.6%)
Sex with IV Drug User		
Yes	33	(20.4%)
No	129	(79.6%)
Sex with Bisexual		
Yes	21	(13%)
No	141	(87.0%)
Sex with Hemophiliac		
Yes	--	--
No	162	(100%)
Sex with Transfusion Recipient		
Yes	3	(01.9%)
No	159	(98.1%)
Transfusion Recipient		
Yes	10	(06.2%)
No	152	(93.8%)
Work in Health Care Setting or Lab		
Yes	1	(0.6%)
No	161	(99.4%)
Don't Know		
Yes	44	(27.2%)
No	118	(72.8%)

A comparison of demographic data by gender is presented in Table 3-4. The group of female subjects in this sample had an increased percentage of minorities, lower levels of education, and a higher relationship to IV drug use. Sixty one percent of the female subjects reported their level of education to be at the level of high school or below while only 34% of the male subjects reported the same level of education. A larger percentage of the females attributed their HIV infection to IV drug use (46.7%) or to sex with an IV drug user (46.7%). In contrast, only 22% of the males subjects reported acquiring the HIV virus through the same risk behaviors. The majority of male subjects (48.4%) identified male-to-male sex as a risk factor for acquiring HIV.

Table 3-4

Subject Characteristics by Gender (N=162)

Variable	Male (N=102) M (SD)	Female (N=60) M (SD)
Age	45.5 (8.02)	35.9 (7.05)
Years of Education	13.3 (13)	12.1 (2.08)
Length of HIV	82.1 (84)	62.2 (39.9)
Length of AIDS (months)	29.6 (23)	27.0 (21.8)
CD4 Self Report	133.9 (74)	173 (138)
Number of Symptoms	18.4 (9.86)	22.6 (11.9)
Hospital Times Since AIDS	2.3	2.1
	N (%)	N (%)
Ethnicity		
Asian/Pacific Islander	1 (01%)	2 (3.3%)
African American	42 (41.6%)	31 (51.7%)
Hispanic	6 (5.9%)	6 (10.2%)
Caucasian	52 (51.5%)	21 (22.6%)
Risk Factors for HIV		
Male-male sex	49 (48%)	--
IV drug use	18 (17.6%)	28 (47.6%)
Sex with IV drug user	5 (4.9%)	28 (47.6%)
Sex with bisexual	2 (2%)	19 (31.7%)
Sex wit hemophiliac	--	--
Sex with transfusion recipient	--	3 (5%)
Transfusion recipient	5 (4.9%)	5 (8.3%)
Work in health care setting/lab	--	1 (1.7%)
Don't know	33 (32.4%)	11 (18.3%)

Description of the Sample by Site

Subjects in the first five sites (San Diego, West Los Angeles, Miami, San Francisco, and Palo Alto) included hospitalized veteran patients, with a total of 102 males and 4 female subjects. Based on the VA National AIDS Patient Registry, it was anticipated that the number of female subjects recruited through the VA hospital sites would be low, or approximately 2% of the sample. In this instance, the sample of women was low, (4%) but slightly higher than originally anticipated. Sites 6 through 9 included a total of 56 females with AIDS, recruited through community agencies in the Bay Area of California (UCSF Women's' Clinic, VNA AIDS Project, World Newsletter, and Other Friends). All of the female subjects from these sites were hospitalized within the past 4 months. Since the subjects from these community agencies were interviewed in community settings, chart data was not available to the investigator. Subject characteristics by site are presented in Table 3-5.

Table 3-5

Demographic Characteristics by Site (N=162)

Variable	San Diego n % N=17	West LA n % N=16	Miami n % N=35	San Francisco n % N=32	Palo Alto n % N=6	UCSF Women's Clinic n % N=25	VNA AIDS Project n % N=0	World Newsletter n % N=12	Others n % N=19
Sex									
Male	17.(100)	14 (88)	33 (94)	32 (100)	6 (100)	--	--	--	--
Female	--	2 (12)	2 (6)	--	--	25 (100)	--	12 (100)	19 (100)
Ethnicity									
Asian/Pacific Islander	--	1 (6)	--	1 (3)	--	--	--	1 (8)	--
African American	--	7 (44)	26 (74)	9 (28)	1 (17)	14 (56)	--	7 (58)	9 (47)
Hispanic	--	1 (6)	1 (3)	3 (9)	1 (17)	2 (8)	--	--	4 (21)
Caucasian	17 (100)	7 (44)	8 (23)	19 (59)	4 (67)	8 (32)	--	4 (33)	6 (31)
Discharge Site									
Home	10 (59)	9 (56)	29 (83)	21 (66)	6 (100)	16 (64)	--	11 (91)	10 (53)
Skilled nursing facility	5 (29)	--	2(6)	2 (6)	--	--	--	--	--
Hospice	--	--	--	--	--	--	--	--	--
Other	--	3 (19)	1 (3)	4 (13)	--	5 (20)	--	1 (8)	7 (37)
Unknown	2 (12)	4 (25)	3 (9)	5 (16)	--	4 (16)	--	--	2 (11)

Table 3-6 presents demographic data on the severity of illness for each of the nine sites included in the study. Subjects at the Palo Alto and San Diego VA Hospital sites reported the lowest CD4 counts with mean scores of 91mm^3 and 96mm^3, respectively. Highest mean scores for CD4 levels at 241mm^3 were reported by the female subjects recruited through the World newsletter for women with HIV/AIDS. Subjects at the Miami and Palo Alto VA Hospital sites reported the shortest duration of HIV infection at 47.4 months (SD 47.9) and 66.8 months (SD 20.6) months respectively, while the subjects at the San Francisco VA Hospital reported the longest length of HIV infection at 95.9 months (SD 46.9). Subjects at the Miami site also reported the shortest duration of an AIDS diagnosis, with 19 months by self report and 13 months by charting documentation. Interestingly, in addition to the shortest reported lengths of HIV and AIDS, the Miami site also reported the highest mortality rate at 20%. The site with the longest reported length of an AIDS diagnosis is San Francisco with a mean of 35.6 months (SD 25.2), followed by San Diego at 32.8 months. Subjects at the San Diego VA reported the highest number of times in the hospital, at 2.8 (SD 1.7), since receiving an AIDS diagnosis, and Palo Alto reported the lowest number of times at 1.7 (SD 1.2).

Table 3-6

Subject Characteristics by Site: Severity of Illness Variables

Variable	San Diego n=17 M (SD)	West LA n=16 M (SD)	Miami n=35 M(SD)	San Francisco n=32 M (SD)	Palo Alto n=6 M (SD)	UCSF Women's Clinic n=25 M (SD)	VNA AIDS Project n=0 M SD)	World Newsletter n=12 M (SD)	Others n=19 M (SD)
CD4-Self Report	91 (105)	186 (197)	149 (133)	137 (147)	96 (90)	168 (104)	**	241 (122)	163 (129)
CD4-Chart Report	74 (97)	147 (169)	156 (161)	129 (127)	139 (159)	Data not available	**	Data not available	Data not available
HIV length-Self Report (mos.)	93 (53)	69.8 (45.8)	66.7 (47.9)	95.9 (46.9)	66.8 (20.6)	68.6 (36.9)	**	47.4 (37.7)	65.3 (41)
HIV length-Chart Report (mos.)	89 (48)	65 (52)	61 (45)	65 (47)	48 (34)	Data not available	**	Data not available	Data not available
AIDS length-Self Report (mos.)	32.8 (25.2)	24.3 (33.3)	19.1 (32.5)	35.6 (40.4)	21.6 (17.3)	30.9 (22.8)	**	25.6 (29)	25.1 (11)
AIDS length-Chart Report (mos.)	27 (18)	29 (50)	13 (19)	30 (34)	24 (--)	Data not available	**	Data not available	Data not available
Hospital times since AIDS diagnosis	2.8 (1.7)	2.4 (1.7)	2.4 (1.5)	2.1 (1.5)	1.7 (1.2)	2.0 (1.3)	**	1.8 (1.1)	2.6 (1.7)
Length of Stay (Days)	9 (7.2)	21 (25.9)	14 (13)	10.9 (12.6)	8.2 (8.9)	15.2 (12.4)	**	6.5 (5.1)	11.9 (11.8)
	N %	N %	N %	N %	N %	N %	N %	N %	N %
Mortality									
Yes	2 (12)	3 (18)	6 (20)	5 (16)	1 (16)	-1 (4)	**	--	--
No	15 (88)	13 (81)	29 (89)	27 (84)	5 (84)	24 (96)	**	12 (100)	19 (100)

**No subjects identified from this site.

Human Subjects Assurance-Phase II

The study protocol for Phase II was submitted to the University of California, San Francisco, committee on Human Research. In order to increase the sample size and also the diversity of the subject population, the study was expanded to include three additional VA hospitals in highest AIDS prevalence areas, including Miami, Florida, San Diego California, and West Los Angeles, California. Approval from the Institutional Review Board was also obtained from each of the VA Medical Centers and community agencies.

Data Collection Methods

Sources of Data

The following two VA Hospitals in the San Francisco Bay area continued to serve as clinical sites for Phase II of the study: 1) the Palo Alto VA Medical Center in Palo Alto, California, and 2) the Fort Miley VA Medical Center in San Francisco. Three additional VA hospital sites in highest AIDS prevalence areas were added as data collection sites during the second phase of the study. Those additional sites included 3) the San Diego VA Medical Center in San Diego, California 4) the West Los Angeles VA Medical Center in Los Angeles, California and 5) the Miami VA Medical Center in Miami, Florida. The VNA AIDS Project in San Jose, California and the UCSF Women's' Specialty Clinic in San Francisco also continued to serve as recruitment sites during Phase II of the study. Advertisements concerning Phase II were placed in two widely circulated newsletters for women with HIV/AIDS in the Bay area of California.

Procedure

Gaining Entree

Access to the San Diego and West Los Angeles VA Medical Centers was obtained through the Chief Nurses, the Associate Chiefs for Nursing Research, and the Nursing Research Committees. The Associate Chiefs for Nursing Research assisted with recruitment of data collectors at each site. The Associate Chief for Nursing/Psychiatry served as a coordinator for the research study at the Miami VA Hospital. A site PI was appointed at each of the five VA hospital sites, per VA research protocol, who served as site coordinator and assisted with recruitment of data collectors.

Data Collector Training

A manual was developed to insure a consistent format for training of data collectors at each of the VA Hospital sites (see Appendix C). Following a discussion of the contents of the manual, each data collector observed the investigator administer the questionnaires. This was followed by a question and answer session. Each data collector was then given an opportunity to administer questionnaires under the supervision of the investigator. Again, this was followed by a question and answer session. During the study, the investigator was continually available to the data collectors as questions arose.

Data Collection

At each of the inpatient sites, the AIDS coordinator, nurse manager, or staff nurses were approached and asked about potential patients who would meet study criteria. As appropriate subjects were identified, the data collector audited their chart to confirm the

AIDS diagnosis, to identify stage of illness, and also determine any indication of AIDS dementia prior to an invitation to participate in the study. In a manner similar to that described in Phase I of the study, patients were then approached by the data collector and asked about their desire to participate in this study. If subjects agreed to participate in the study, permission was obtained and consent forms were signed (see Appendix D). Each patient who volunteered to participate received a packet containing a demographic data sheet, a draft of the scale (Patient Responses to Nurses' Behaviors), two measures used in the testing of convergent and discriminant validity and the HIV-QAM (see Appendix E). In order to minimize disruption of care, the data collector scheduled appointment at the convenience of the subject. The estimated time for patients to complete all three scales included in the packet was 30 minutes. The completed packets were collected by the data collector. Veteran patients who had difficulty responding in writing to the questionnaires were personally interviewed by the data collector.

Additional female subjects recruited through newspapers and community agencies in the Bay area of California who responded to advertisements also received the same research packet. In order to confirm the presence of an AIDS diagnosis, subjects were asked to present written documentation from their health care provider or a public agency. As in Phase I, the female subjects who met study criteria and participated received a cash payment immediately following their participation in the study.

Data Analysis-Phase II

Reliability:

The internal consistency was evaluated by the Cronbach's alpha. This was used to provide a measure of the degree of homogeneity of the instrument's items. A value for the total scale and any potential subscales which equal or exceed Cronbach's alpha of 0.80 was determined an acceptable score.

Validity:

Content validity

Content validity was determined by asking a sample of AIDS patients (n=6) and AIDS care nurses (n=6) to evaluate the clarity of the wording and the appropriateness of the content items. The patients and nurses were also asked to make recommendations in relation to the elimination of scale items.

Construct validity

Construct validity was assessed through factor analysis, a mathematical procedure for analyzing interrelationships among variable, and reducing factors (Nunnally, 1978). A principal components analysis with a varimax rotation was used to identify the minimum number of common factors present and to evaluate the construct validity of the scale and subscales. Construct validity was also assessed by determining convergent and discriminant validity through a method proposed by Campbell and Fiske (1959). Scores from the PRNB (Patients Responses to Nurses' Behaviors) were correlated with scales that do and do not measure the same construct. High correlation between conceptually similar measure provide evidence for convergent validity; low correlation of conceptually dissimilar measures provide evidence of the instrument's discriminant validity. The Patient Reactions Assessment (Galassi, 1992) was used to test convergence and the Beck Depression Inventory (BDI) was used to measure divergence. Both scales have adequate reliability and validity for use in this analysis.

Predictive Validity

It would be expected that having a positive experience as assessed by the PRNB might result in a decreased length of stay and an increased functional status at discharge. The PRNB scores were correlated with length of stay and also with scores on the HIV-Quality Audit Marker (HIV-QAM), an instrument designed to measure changes in the functional status of hospitalized AIDS patients due to nursing care (Holzemer et. at, 1993). In order to determine if the PRNB scores predicted length of stay, a regression analysis was completed using PRNB scores as the predictors and length of stay as the criterion variable. To asses if PRNB scores predicted HIV-QAM scores, a second regression analysis was completed with the HIV-QAM as criterion scores.

CHAPTER FOUR

RESULTS

This chapter will present a discussion of the data from both Phase I and Phase II of the study. The discussion related to Phase I will present results of the critical incident interviews, the process used in the development of scale items, and scaling. A separate section within this discussion will compare differences among the sample based on ethnicity, gender, risk factors, and severity of illness (as measured by CD4 counts, length of HIV/AIDS, and hospital times). The data presented in the discussion on Phase II relates to psychometric testing, including measures of both reliability and validity.

Phase I-Scale Development

Critical Incident Data Analysis

Subjects who participated in the first phase of the study were asked to describe their behavioral responses toward nurses. The critical incident interview format, presented in Table 4-1, was used to ask subjects to describe nurse-patient encounters in which they were treated with and without respect. After providing an incident, each subject was asked specifically, “How did this affect your behavior?” A listing of behaviors was generated from their responses.

Table 4-1

Critical Incident Interview Questions

Form I.

1) Think about a time a nurse treated you with respect. When did this happen?
2) What were the circumstances which led up to this event?
3) What exactly did the nurse do?
4) How did you respond to the nurse?
5) How did the nurses' actions affect your behavior?

Form II.

1) Think about a time a nurse treated you without respect. When did this happen?
2) What were the circumstances which led up to this event?
3) What exactly did the nurse do?
4) How did you respond to the nurse?
5) How did the nurses' actions affect your behavior?
6) What would have been helpful to you?

A total of 273 critical incidents were generated through both subject interviews and observations. Within those 273 incidents, subjects identified a total of 393 behavioral responses to nurses. Although a total sample of 150 subjects was planned, saturation of content was achieved after interviews with 118 subjects. Most frequently reported behaviors included cooperating with the nurses, opening up and talking to the nurses, matching a nurse's behaviors, staying away from nurses, complaining to nurses, being quiet and accepting what the nurses do, and saying thank you to the nurses.

As data was obtained, it was entered into the computer. The content analysis of data was facilitated by a computer program (ETHNOGRAPH) which allowed for the creation of coding systems and the refinement of coded items into behavioral response categories. Once similar behaviors were grouped together, they were defined and labeled. A total of 12 behavioral response categories were generated by the inductive content analysis. The top ten categories included: participation, anger, appreciate, come close, stay away, matching respect, matching disrespect, dependent, complaint, and self care A listing of the ten categories by frequency of critical incidents is presented in Table 4-2. A description of each behavioral category is summarized in Table 4-3. A review of the categories by two AIDS experts confirmed the listing of behavioral categories.

Table 4-2

Domain Occurrence

Domain	Behavioral Responses (n=393) Frequency/Percent	Patient Responses (n=118) Frequency/Percent
Participate	61 (15.5%)	48 (40.6%)
Anger	48 (12.2%)	39 (33.0%)
Appreciate	43 (10.9%)	34 (28.8%)
Dependent	37 (09.4%)	19 (16.1%)
Matching Respect	35 (08.9%)	33 (27.9%)
Staying Away	28 (07.1%)	23 (19.5%)
Coming Close	27 (06.8%)	23 (19.5%)
Matching Disrespect	26 (06.6%)	19 (16.1%)
Complaint	22 (05.6%)	18 (15.3%)
Self Care	20 (05.0%)	16 (13.5%)

Table 4-3

Patient Behaviors: Major Domains

Domain	Patient Definition
Participating in care	Working as a team member with the nurse. Being compliant with nursing care. Putting extra effort into helping the nurse. Cooperating with the nurse. Trying not to interfere with nursing care.
Anger	Expressing frustration over the lack of nursing response. Showing increased irritability with disease progression. Responding to nurses with irritability, anger, or sarcasm. Becoming verbally or physically abusive to the nurse. Being demanding or aggressive toward the nurse. Showing retaliation toward the nurse.
Showing appreciation to the nurse	Expressing gratitude toward the nurse. Apologizing to the nurse. Keeping a memory of a special nurse. Returning to visit a nurse. Trying to make the nurses' job easier. Trying to give something back to the nurse.
Being dependent on nursing care	Passively accepting nursing care. Silent compliance. Feeling too weak to reply. Not asking for items to meet needs. Not wanting to offend the nurse.
Matching Respect	Matching nurses' positive and respectful behaviors. Acting polite and considerate in return to the nurse. Treating a nurse "swell" in return.
Staying Away from the nurse	Avoiding any confrontation with the nurse. Minimizing interaction or ignoring the nurse. Withdrawing or waiting for another nurse who might be more helpful.
Coming Close to the nurse	Sharing feelings and emotions about HIV with the nurse. Confiding in the nurse. Trusting the nurse. "Opening up" and talking with the nurse.
Matching Disrespect	"Behaving badly" when treated badly. Matching a nurse's negative or disrespectful behaviors.
Complaining about a nurse	Reporting the nurse to the physician or hospital administrator. Indirectly complaining to a friend or family member about the nurse. Expressing negative feelings to other nurses.
Self Care	Showing independence. "Taking matters into my own hands". Expending energy to meet needs when a nurse is unavailable.

The largest behavior category reflected the subjects' positive responses to nurses and involvement in their own care. In the largest category, 41% of the respondents described ways in which they participated actively in their care. Subjects recounted incidents where they assisted in their care by working as a "team player" with the nurse and by not trying to interfere with nursing care. They also described ways in which they worked to "make the nurses' job easier by being respectful of the nurses time." As one subject stated, "I try to be efficient and organized when I talk to the nurses so I won't waste their time." Subjects also described ways in which they put "extra effort into helping the nurses." One subject stated, "I go out of my way to do everything I need to help the nurse...no matter how detailed." The following examples represent frequently stated behaviors in this category:

> "When the nurse wanted me to do something, I did it right away without an argument or a fight. I followed the nurse's directions and did what she told me to do."
>
> "I put a lot more effort into taking care of things. I wasn't cranky...I put more effort into helping. The nurse made me more willing to participate in my own care."
>
> "I try hard not to give the nurses trouble. I try not to jump them. I try not to call them for every little thing."
>
> "I tried to put more effort into blowing into the machine (spirometer) and doing what I had to do."

The second largest behavior category reflected the difficult and angry behaviors frequently reported by health care workers in HIV/AIDS treatment settings. One third of the subjects listed angry behaviors which were directed at nurses The subjects admitted that they frequently had difficulty managing anger and irritability and readily described incidents where angry behavioral responses were directed toward nurses. Twenty percent of the respondents reported “yelling at the nurses.” Others stated that they “slammed things around” “talked sharply to the nurses,” “told the nurses off,” or “threw stuff at a nurse.” Behavioral descriptions of anger frequently reflected a subject’s increased irritability during stages of advancing illness or intense psychological responses toward the AIDS diagnosis. Additionally, subjects reported that their behaviors toward the nurses reflected a violent, angry style of relating to others in street settings. One subject stated “If you’re strong and aggressive, you retaliate...when you get mean, it makes you stronger and that’s how I do it with the nurses.” The following examples represent angry behaviors described by the subjects:

> “I’m thinking that now that I’m really sick, I’m much more irritable. I’m much more demanding. I’ve really been terrible to the nurses at times.”
>
> “Some of the nurses have trouble with addicts, much less HIV and pregnant like me. I really get pissed off and yell ‘You ain’t touchin’ me!”
>
> “The nurse was rough when she put me on the bedpan. She was trying to hurry up and get me to x-ray. I used some choice words like ‘Bitch...get outa my face...I’m going through all of this and you’re trying to kill me.’ Then I grabbed the food tray and threw it deliberately on the floor.”
>
> “When a nurse has an attitude, I says angry things to hurt them like ‘you damn retard...people like you shouldn’t be allowed to be in nursing.”
>
> “When I came outa surgery the nurse said I couldn’t have water. I got mad. I wanted water. I grabbed her and yelled “I want water!...get me some!” I held onto the nurse’s arm and shook it. After I found out that she put me on report for assaulting her, I screamed at her and told her she had a bad attitude.”

The responses in the third category, appreciation, accounted for 28.8% of the behaviors. A listing of behaviors in this category included “saying thank you,” “paying attention to the nurse," and "joking and smiling back at the nurses." The following examples describe additional behavioral responses which subjects used to express appreciation toward nurses:

> "I found out the nurses names so I could be more personal and I can remember them. It's my way of appreciating them and giving them something back. It's making it more personal and trying to give them some support in their work."
>
> "I showed my appreciation by smiling and talking nice to the nurse. I actually went back to see that nurse."
>
> "When the nurse is like this (helpful), I really try to show my appreciation. I sure grinned at her."
>
> "I'll be thanking that nurse. I got up and walked out to the desk and said, 'Hey...I got to holler at you before you leave and tell you that if it wasn't for you, I'd still be stuck in that bed, doing nothin'.

Two of the behavioral response categories related to "matching" nurses behaviors. Subjects frequently stated that they "pretty much treat them the way they treat me" or they "give it back to them...it's a two-way street!" Behaviors which matched respect included "treating the nurse swell in return," "laughing and smiling back when the nurse is happy and cheerful toward me," and "treating the nurse good too." As one subject stated:

> "The nurse treated me with respect so I reacted toward her like she's the nurse and I'm the patient. I gave her respect back."

Matching disrespect included "being irritable back to the nurse in return." The following examples describe behaviors which matched disrespect::

> "If they're nice...goodness flows. When they're bad, it's like a black cloud or a dirty mirror. My behaviors changed to reflect the way I was treated."
>
> "I was nasty to the nurse...just the way she gave it to me!"

> "My own mind shut off the nurse. I don't respect her and I don't need anything like that at this point in my illness. I closed her out."

Two categories related to distancing from nurses included "coming close" and "staying away." "Coming close" behaviors included "opening up and talking to the nurse," "hugging a nurse," "crying with the nurse," and "feeling free to ask the nurse for the things I needed." Subjects provided the following examples:

> "I opened up and talked to the nurse. I told her all about how my family reacted to my HIV. It was helpful to talk to her."

> "I opened up and talked with the nurse. I was worried about my kids and I told her all about that. I cried with her and when she was there, I felt safe enough to fall asleep."

Examples of "staying away" behaviors included "withdrawing from the nurses," "cutting the nurse off," "saying little to the nurses," and "not calling the nurses when I needed something." Two of the subjects revealed the following:

> "I do what I can to minimize my interactions with nurses. In this instance, I held out my arm so the nurse could take the blood from my line. I said little...looked away. Did what I had to do to get rid of her."

> "I withdrew from the nurse. I stayed quiet and stood there. I find that I stay away from the nurses more and more and only get them when I need something."

Subjects who described dependent behaviors stated "I don't say much to the nurses but I should." Others added "I'm too weak to argue with the nurses...I just lay here quietly and accept what they do."

An additional response category related to complaints. Patients described complaining behaviors which were directed toward the nurses, the physician, or hospital administration. The self care category described behaviors that patients' used to meet their immediate needs when a nurse was not available to them.

A Comparison of Behavioral Domains

The comparison of behavioral domains by gender, presented in Table 4-4, shows that the behavioral category, participation, remained the largest response category for both males and female subjects (males=44.5%; females=47.1%). An examination of the behavioral domains by gender reveals patterns of differences between male and female subjects in five of the behavioral response categories: coming close to nurses, matching respect, matching disrespect, anger, and appreciation. Female subjects reported coming close behaviors in 29.4% of the incidents while male subjects reported a lower rate of 16.4%. Female subjects also reported increased incidents of matching both respectful and disrespectful behaviors at a rate nearly twice that of male subjects. The largest difference between the subject groups related to the frequency of listing angry behaviors; 43% of the female subjects reported that they directed angry behaviors toward nurses compared with only 28.9% of the male subjects. Male subjects reported an increased number of incidents compared to female subjects in only one response category, appreciation (males=32.5%; females 23.5%).

Table 4-4

Domain Occurrences by Gender (N=118)

Domain	Male Patient Responses (n=83) Frequency/Percent	Female Patient Responses (n=35) Frequency/Percent
Participate	37 (44.5%)	16 (45.7%)
Anger	24 (28.9%)	14 (41.2%)
Appreciate	27 (32.5%)	8 (22.8%)
Dependent	23 (27.7%)	9 (25.7%)
Match Respect	22 (26.5%)	14 (41.2%)
Stay Away	15 (18.0%)	8 (22.8%)
Come Close	14 (16.9%)	10 (28.6%)
Match Disrespect	10 (12.0%)	9 (25.7%)
Complaint	12 (15.5%)	6 (17.1%)
Self Care	10 (12.0%)	5 (14.2%)

A comparison of behavioral response categories by ethnicity is presented in Table 4-5. Consistent with the findings of the overall sample, the category participation remained the largest response category for each of the ethnic groups. Caucasians reported the greatest number of complaint behaviors at 29.5% of the incidents, compared to Hispanic (18.2%) or African American (21.5%); they also reported a greater number of dependent behaviors (Caucasian 30.6%; African American 21.5%; Hispanic 18.2%) As in the previous discussion of domain differences by gender, the largest differences between the groups related to the category of anger. African American subjects described angry behaviors in 40.5% of the incidents as compared to 27.3% for Caucasians and 27.9% for Hispanics.

Table 4-5

Domain Occurrences by Ethnicity (N=118)

Domain	Asian/Pacific Islander (n=3) Frequency/ Percent	African American (n=42) Frequency/ Percent	Hispanic (n=11) Frequency/ Percent	Caucasian (n=62) Frequency/ Percent
Participate	2 (66.7%)	20 (47.7%)	6 (54.5%)	25 (40.3%)
Anger	1 (33.3%)	17 (40.5%)	3 (27.3%)	17 (27.4%)
Appreciate	0 (00.0%)	12 (28.6%)	2 (18.2%)	21 (33.8%)
Dependent	2 (66.7%)	9 (21.5%)	2 (18.2%)	19 (30.6%)
Match Respect	0 (00.0%)	17 (40.5%)	4 (36.4%)	15 (24.2%)
Stay Away	2 (66.7%)	9 (21.5%)	2 (18.2%)	10 (16.1%)
Come Close	1 (33.3%)	7 (16.7%)	2 (18.2%)	14 (22.6%)
Match Disrespect	0 (00.0%)	9 (21.5%)	1 (09.1%)	9 (14.5%)
Complaint	1 (33.3%)	5 (11.9%)	1 (09.1%)	11 (17.7%)
Self Care	1 (33.3%)	5 (11.9%)	2 (18.2%)	7 (11.3%)

Scale Development

The preliminary draft of the PRNB (Patients' Responses to Nurses Behaviors) was generated, using patient behaviors as scale items. Wording of the scale items was based on verbatim patient responses. The preliminary draft of the scale (see Table 4-6) included a total of 52 items from each of the ten behavioral response categories. The items were randomized and placed into a Likert scale format with a rating range of 4 (almost always), 3 (often), 2 (sometimes), and 1 (never) and 0 (no experience).

Table 4-6

PRNB Scale Items by Behavioral Category (Draft I)

Behavioral Response Category	Scale Item
Participate	I cooperated with the nurses
	I did what the nurses told me to do
	I let the nurses go ahead and do their job
	I tried not to hassle the nurses
	I put more effort into doing what I had to do
Anger	I yelled at the nurse
	I gave the nurses a terrible time
	I got angry when the nurses didn't answer my buzzer in a timely way
	I got mad at the nurses attitude about my HIV
	I did not cooperate with the nurses
	I'm more irritable now that I'm sicker
	Even though I'm sick, I let my thoughts be known
Appreciate	I told the nurses "Thank you"
	I smiled and joked with the nurses
	I paid attention to the nurses
	I tried to make the nurses job easier
Dependent	I'm too weak to argue with the nurses
	I don't do much to offend the nurses
	I don't say much to the nurses, but I should
	I did what the nurses told me to do
	I got quiet and did what the nurses told me to do

Behavioral Response Category	Scale Item
Match Respect	I gave the nurses the same respect they gave me
	I treated the nurses swell because they were good to me
	I treated the nurses good too
	I laughed and smiled back at the nurses
	I gave the nurses the same respect and admiration
Stay Away	I stayed away from the nurses
	I wouldn't deal with the nurses
	I don't say anything to the nurses
	I get quiet and stay to myself around the nurses
	I withdrew from the nurses
	I tried to keep from calling the nurses
Come Close	I talked to the nurses about my HIV
	I opened up and talked to the nurses
	I hugged the nurses
	I cried with the nurses
	I wasn't afraid to ask the nurses for the things I needed
Match Disrespect	When I've been treated badly, I behave badly
	I can be as mean as I can be nice
	I treated the nurses the same way they treated me
	I was irritable back to the nurses
	The negative behaviors in me came out
Complaint	I reported a nurse's behavior to other nurses
	I reported a complaint about the nurses to my doctor
	I filed a formal complaint about the nurses
	I complained back to the nurses
	I contacted the patient representative
Self Care	I tried to help myself as best I could
	I took matters into my own hands
	I had to take care of myself
	I could rest and save my strength
	I didn't have to use a lot of physical energy, trying to get help

The initial pool of 52 items was evaluated for face and content validity by a group of 4 AIDS patients and 6 AIDS care nurses. In response to the comments, 16 poorly performing items were eliminated, including all 5 items in the Self Care category. Both

the nurses and the patients consistently expressed difficulty with the items in the self care category. The strong validity in the scale items was frequently expressed by both groups. Patients stated, “Yes!...I do that” and “Boy is this true, I do this.” Nurses stated, “I’ve seen that happen a lot” and “That’s really true.”

A listing of the items deleted from the preliminary draft of the PRNB, based on the comments of the AIDS care nurses and the patients appears in Table 4-7.

Table 4-7

Deleted Scale Items from Preliminary Draft of PRNB

Behavioral Domain	No. of Items Deleted	Scale Item
Participate	1	I put more effort into doing what I had to do
Anger	2	I'm more irritable now that I'm sick Even though I'm sick, I let my thoughts be known
Appreciate	0	
Dependent	1	I got quiet and did what the nurse told me to do
Match Respect	1	I gave the nurse the same respect and admiration
Stay Away	2	I withdrew from the nurse I tried to keep from calling the nurse
Come Close	0	
Match Disrespect	1	The negative behaviors in me came out
Complaint	1	I contacted the patient representative
Self Care	5	I tried to help myself as best I could I took matters into my own hands I had to take care of myself I could rest and save my strength I didn't have to use a lot of physical energy, trying to get help

The revised draft of the PRNB, presented in Table 4-8, includes 39 items from the 9 remaining behavioral response categories.

Table 4-8

PRNB Scale Items by Behavioral Category (Draft II)

Behavioral Response Category	Scale Item
Participate	I cooperated with the nurses I did what the nurses told me to do I let the nurses go ahead and do their job I tried not to hassle the nurses
Anger	I yelled at the nurse I gave the nurses a terrible time I got angry when the nurses didn't answer my buzzer in a timely way I got mad at the nurses attitude about my HIV I did not cooperate with the nurses
Appreciate	I told the nurses "Thank you" I smiled and joked with the nurses I paid attention to the nurses I tried to make the nurses job easier
Dependent	I'm too weak to argue with the nurses I don't do much to offend the nurses I don't say much to the nurses, but I should I did what the nurses told me to do
Match Respect	I gave the nurses the same respect they gave me I treated the nurses swell because they were good to me I treated the nurses good too I laughed and smiled back at the nurses
Stay Away	I stayed away from the nurses I wouldn't deal with the nurses I don't say anything to the nurses I get quiet and stay to myself around the nurses
Come Close	I talked to the nurses about my HIV I opened up and talked to the nurses I hugged the nurses I cried with the nurses I wasn't afraid to ask the nurses for the things I needed

Behavioral Response Category	Scale Item
Match Disrespect	When I've been treated badly, I behave badly
	I can be as mean as I can be nice
	I treated the nurses the same way they treated me
	I was irritable back to the nurses
Complaint	I reported a nurse's behavior to other nurses
	I reported a complaint about the nurses to my doctor
	I filed a formal complaint about the nurses
	I complained back to the nurses

Phase II-Scale Validation

This section of the chapter presents a discussion of the results of the psychometric testing of the scale developed during Phase I of the study. The beginning sections will discuss methods used in the evaluation of construct validity, including factor analysis and convergent and discriminant validity. Scale reliabilities are also presented. Other results generated by the study are also reported.

Missing Data

Before conducting a factor analysis, data from the PRNB scale (Patients' Responses to Nurses' Behavior) were examined for missing responses. A total of 162 subjects completed the 5 point, 39 item Likert-type scale. The total number of potential responses for the PRNB was 6,297. Subjects completed a total of 6,259 responses, or 99.4% of all scale items. Missing responses were noted in 16 questionnaires. On the 16 questionnaires, the range of missing responses per questionnaire was from 1 to 3 items, with the majority of subjects missing only one response per questionnaire. A visual inspection of the frequency displays revealed no consistent pattern of missing items. Since the majority of the 16 subjects missed only one item, and no subject missed more than 5% of the responses, the decision was made to retain all of the subjects with missing data. Eight subjects were not able to complete the questionnaire because of fatigue. A pairwise missing values treatment was selected. This technique deals with missing data by calculating correlation coefficients between pairs of variables based on all cases with complete information, regardless of whether those cases have missing data or not (SPSS, 1993).

Literature provides varying guidelines for determining sample size in factor analysis. Traditionally, the rule of thumb has been, "the more participants, the better." The most widely accepted tradition has been a subject-to-variable ratio or 4:1 or 5:1 (Nunnally, 1978; Floyd & Widaman, 1995). More recent recommendations vary from the older rules. For example, Streiner (1994) recommends 5 participants per variable, as long as there are 100 subjects in the sample; ten participants per variable should be considered when there are less that 100 subjects in the sample. Guadagnoli and Velicer (1988) stated that factor saturation and the size of factor loadings should be equally important as sample size in determining factor stability. A sample size of 150 subjects, for example, would provide an adequate factor solution when at least 10 variables load at .40 on each factor. Based on the above recommendations, it was determined that the sample of 162 subjects would provide for an accurate factor solution.

Item Deletion

Three of the items on the PRNB were deleted prior to factor analysis. Two items were deleted because a large number of subjects stated that the items were not meaningful to them. They repeatedly asked for clarification and questioned the relevancy of item number 6 ("When I've been treated badly, I behave badly.") and item number 21 ("I can be as mean as I can be nice."). Item 26, an inadvertent duplication of item 9 ("I did what the nurses told me to do.") was also deleted. The remaining 36 items were then submitted to factor analysis.

Factor Analysis

Prior to conducting a factor analysis on the remaining 36 items of the PRNB scale, the following decision rules were imposed for retaining items. A factor was to be retained if the Eigenvalue exceeded 1 and the factors above 1 accounted for at least 5% of the variance (Floyd & Widaman, 1995; Kim and Mueller, 1978). Since there is no universally accepted criteria for determining the size of factor loadings, researchers choose an arbitrary number. In this instance, the decision was made to retain items which loaded above a cut-point of .50. Communalities above .3 would also be retained.

In an effort to understand the underlying factor structure, an exploratory factor analysis, followed by a rotation to an oblique solution was conducted, using all 36 items of the PRNB scale. Since the PRNB was designed around 10 behavioral response categories, the investigator felt that there might be potential for interrelated domains. The oblique rotation was selected by the investigator since it allows the factors to correlate, and does not impose the rigid factor structure associated with orthogonal rotation (Nunnally, 1978). Floyd and Widaman (1995) encourage researchers to look at oblique solutions since this method of rotation may provide an insightful evaluation of the underlying factor structures. If an underlying factor order is orthogonal, the oblique rotation will return a solution with essentially orthogonal factors (Floyd & Widaman, 1995; Kim & Mueller, 1978). This analysis, which was more exploratory in nature, provided an initial assessment of the PRBN scale, and suggested a two factor solution.

Following this exploratory analysis, the 36 item PRNB scale was submitted to a principal components factor analysis, with a forced two factor solution. The initial extraction resulted in two factors with Eigenvalues above 1 that accounted for 29% of the variance. Nine items failed to have any substantive high loadings and were deleted from the analysis. The reduced set of items from the PRNB was again factor analyzed, using the principal components analysis, with a varimax rotation. Nine additional items were deleted because the factor loadings were below the established criteria of .50. When the remaining items were resubmitted to factor analysis, two additional items which failed to load on factor one above .50 were also deleted. The solution identified a total of 16 items that displayed the desired pattern of high loadings on a single factor with negligible or low loadings on other factors. A total of eight items loaded at .54 or higher on Factor one and an equal number of items loaded above .557 on Factor 2. The items accounted for 46.8% of the variance. The factor loadings for the final solution are presented in Table 4-9.

Table 4-9

Factor Structure After Varimax Rotation (N=162)

Variables	Factor 1	Factor 2	Communality
I reported a complaint about the nurse	**.804**	-.123	.662
I gave the nurses a terrible time	**.724**	-.022	.526
I complained back to the nurses	**.696**	-.148	.506
I filed a formal complaint about nurses	**.670**	.197	.489
I reported a nurse's behavior to nurses	**.654**	-.258	.494
I was irritable back to the nurses	**.648**	-.100	.431
I got angry about the buzzer	**.634**	-.058	.404
I got mad at the nurses attitude about HIV	**.557**	-.206	.352
I treated the nurses good too	-.064	**.799**	.643
I treated the nurses swell because	.107	**.714**	.521
I let the nurses do their job	-.214	**.687**	.518
I did what the nurses told me to do	-.162	**.644**	.441
I laughed and smiled back at nurses	-.084	**.643**	.420
I tried to make the nurses job easier	-.047	**.602**	.364
I gave the nurses the same respect	-.031	**.598**	.359
I paid attention to the nurses	-.229	**.542**	.346
Eigenvalue	4.67	2.81	
Percent Variance	29.2%	17.6%	

Note: Bold faced items loaded onto one factor

The negative correlation between Factor 1 and Factor 2 (-.67759) presented in Table 4-10, indicated the presence of two independent or inverse factors.

Table 4-10

Factor Transformation Matrix

	Factor 1	Factor 2
Factor 1	.73544	-.67759*
Factor 2	.67759	.73544

*Negative correlation

All 8 items loaded on Factor I with high loadings (.804-.557). The items which loaded on Factor 1 included “reporting a complaint about nurses” (.804), “giving the nurses a terrible time” (.725), “complaining back to nurses” (.696), “filing a formal complaint about nurses” (.671), “reporting a nurse’s behavior” (.654) and “being irritable back to the nurses” (.649). The content of this factor suggested an aggressive or angry responses to nurses. The items in this factor primarily reflected the behavioral response categories of anger and complaint. A comparison between the behavioral response categories is presented in the next section in Table 4-13.

Factor 2 contained 8 items with similarly high loadings (.799-.542). Items loading on this factor included “treating the nurses good too” (.799), “treating the nurses swell because they were good to me” (.714), “letting the nurses go ahead and do their job” (.687), and “doing what the nurses told me to do” (.645). The items in this factor reflected a positive behavioral response to nurses. They also reflected three of the behavioral response categories: participate, match respect, and appreciate. A comparison of the items loading on this factor to the behavioral response categories is presented in the next section.

As a result of factor analysis, two separate 8-item scales were developed. The Participation scale is presented in Table 4-11 and the Anger scale is presented in Table 4-12.

Table 4-11

Participation Scale Items

I did what the nurses told me to do

I laughed and smiled back at the nurses

I let the nurses go ahead and do their job

I paid attention to the nurses

I treated the nurses good too

I tried to make the nurses job easier

I gave the nurses the same respect they gave me

I treated the nurses swell because they were good to me

Table 4-12

Anger Scale Items

I reported a nurse's behavior to other nurses
I was irritable back to the nurses
I gave the nurses a terrible time
I reported a complaint about the nurses to my doctor
I got angry when the nurses didn't answer my buzzer in a timely way
I filed a formal complaint about the nurses
I complained back to the nurses
I got mad at the nurses attitude about my HIV

Comparing Factors to Behavioral Response Categories

A comparison between the Anger scale items and a listing of items in the behavioral domains, presented in Table 4-13 shows that the Anger scale items are drawn entirely from three domains: anger, complaint, and match disrespect. All of the original items in the complaint domain were included in the Anger scale. Two items were deleted from the anger domain. Only one item was included from the match disrespect domain.

Table 4-13

Comparison of Behavioral Domain Items to Anger Scale Items

Behavioral Domain Items	Anger Scale Items
Anger	
I gave the nurses a terrible time	
I was irritable back to the nurses	
I got angry when the nurses didn't answer my buzzer in a timely way	
I got mad at the nurses attitude about my HIV	
I did not cooperate with the nurses *	I gave the nurses a terrible time
I yelled at the nurses *	I was irritable back to the nurses
	I got angry when the nurses didn't answer my buzzer in a timely way
Complaint	
I reported a nurse's behavior to other nurses	I got mad at the nurses attitude about my HIV
I reported a complaint about the nurses to my doctor	I reported a nurse's behavior to other nurses
I filed a formal complaint about the nurses	
I complained back to the nurses	I reported a complaint about the nurses to my doctor
	I filed a formal complaint about the nurses
Match Disrespect	
I was irritable back to the nurses	I complained back to the nurses
When I've been treated badly, I behave badly *	
I can be as mean as I can be nice *	
I treated the nurses the same way they treated me *	

* Deleted scale items

A comparison between the Participation scale items and the items in the behavioral domains shows that the Participation scale items are drawn entirely from three domains, participate, appreciate, and match respect (see Table 4-14). All of the items from the match respect domain were included in the scale. Two items were deleted from the participate domain and two items also were deleted from the appreciate domain.

Table 4-14

Comparison of Behavioral Domain Items to Participation Scale Items

Behavioral Domain Items	Participation Scale Items
<u>Participation</u>	
I did what the nurses told me to do	
I let the nurses go ahead and do their job	
I tried not to hassle the nurses *	
I cooperated with the nurses *	
	I did what the nurses told me to do
<u>Matching Respect</u>	I let the nurses go ahead and do their job
I gave the nurses the same respect they gave me	I gave the nurses the same respect they gave me
I treated the nurses swell because they were good to me	I treated the nurses swell because they were good to me
I treated the nurses good too	I treated the nurses good too
I laughed and smiled back at the nurses	I laughed and smiled back and the nurses
<u>Appreciate</u>	I paid attention to the nurses
I paid attention to the nurses	I tried to make the nurses job easier
I tried to made the nurses job easier	
I told the nurses "Thank you" *	
I smiled and joked with the nurses *	

* Deleted scale items

Reliability

The internal consistency was evaluated for both the Participation scale and the Anger scale by computing Cronbach's alpha for the total sample. The alpha for the 8 item Participation scale was .82; the alpha for the 8 item Anger scale was also .82.

Convergent and Discriminate Validity

Construct validation of the Participation scale and the Anger scale was evaluated by determining convergent and discriminant validity. The method includes correlating test scores with conceptually similar and dissimilar measures. The correlations are presented within a matrix, in a manner similar to that proposed by Campbell and Fiske (1959). High correlations between similar measures of the same trait provide evidence of a scale's convergent validity, and low correlations between measures of unrelated traits provide evidence of discriminant validity.

Two scales described below, the Patients' Reactions Assessment (PRA) and the Beck Depression Inventory (BDI) were used in the evaluation of convergent and discriminant validity. A discussion of each scale follows:

Patient's Reactions Assessment (PRA)

The PRA is a brief scale developed by Galassi, Schanberg, & Ware (1992) designed to be completed by patients to measure their perceptions of patient-provider relationships and also to rate behaviors of health care providers. This scale has 15 items, each rated on a 7 point Likert scale with ratings of 1 (Very Strong Disagree) to 7 (Very Strongly Agree), with a midpoint rating of 4 (Unsure). The coefficient alpha for the PRA is 0.91. For the three 5 item subscales, Patient Information Index, Patient Affective Index, and Patient Communication Index, the values were .87, .91 and .90 respectively. Although the PRA was constructed and tested with a sample of 237 acutely ill cancer patients, the items are not cancer specific but rather are designed to be used in a variety of health care settings. Replicated confirmatory factor analysis on a second sample of 197 patients supported the conceptual model on which the scale was based. Since this measure has been used to rate reactions of acutely ill Cancer patients, a serious illness frequently compared to HIV/AIDS, it was used here for comparative purposes.

As assumed in establishing convergent validity, all correlations between the PRA, and each of the three subscales, and the Participation scale were expected to be positive. Since the PRA Affective subscale "taps the extent to which the patients believe the caregiver values, understands and respects them, or is concerned and interested in what they have to say"(Galassi, Schanberg, and Ware, 1992, p.347), the correlation between this subscale and the Participation scale was expected to be positive and significant. The Communication subscale of the PRA which "taps the ease or difficulty patients experience in initiating communication with a caregiver with some aspect of their illness or treatment" (p.347) was also expected to show positive correlations with the Participation scale. Only low to moderate correlations were anticipated with the Information subscale since this relates to the extent that patients perceive their caregiver as providing explanations about their illness or treatments, and to the extent that the patients understand the information.

Beck Depression Inventory (BDI)

The Beck Depression Inventory is a 21 item, 4 choice per item, self-report instrument with validity and reliability widely reported. This scale demonstrates high internal consistency with coefficient alpha ranging from .81 to .86. Test retest coefficients ranged from .48 to .86 for psychiatric respondents and .6-.9 for non psychiatric respondents. The BDI measures the intensity of three primary depression factors representing negative attitudes toward the self, performance difficulties, and somatic complaints (Hersen & Bellack, 1988). In this study, the Beck Depression Inventory was used to test discriminate validity. Because of it's overall purpose as a clinical rating scale of patient symptoms rather than reactions to health care providers, a negative correlation was predicted between the BDI and both the Participation scale and Anger scale.

Based on the observations of the investigator which evolved during the course of the study, a separate evaluation of the constructs in the Participation and Anger scales was conducted using three scales, specifically developed for rating physiologic and psychological responses of patients with HIV/AIDS. The scales include the Living with HIV scale, the HIV-QAM, and the HIV Symptom Checklist. A description of each scale follows:

Living with HIV scale

This 32 item scale was developed from a grounded theory called Salvaging the Quality of Life (Holzemer, Spicer, Wilson, Kemppainen, & Coleman, 1997) based on interviews with a sample of racial and ethnically diverse HIV/AIDS patients, care givers, and expert nurse clinicians. Each item is rated on a 5 point Likert scale with responses of

0=No experience/not applicable, 1=Never/not true, 2=Sometimes true, 3=Usually true, and 4=Always true. The scale overall alpha for this study was 0.84. The Living with HIV scale contains two subscales, HIV Reverence and HIV Struggles. The HIV Reverence subscale contains items which reflect a patient's satisfactory resolution of HIV related issues. The items in the HIV Struggles subscale reflect difficult issues faced by patients who struggle with the demands of their illness; domain items in this subscale include juggling medications and treatments, loss, death calculations, and avoiding the fear zone.

The expectation was that subjects who achieved higher scores on the HIV Reverence subscale would be more willing to participate in their care and also be more responsive to nurses. A positive correlation was anticipated between the Participation scale and the HIV Reverence subscale, and a low correlation with the HIV Struggles subscale.

HIV/QAM

This 10 item scale, designed to be completed by a nurse data collector, measures changes in the status of hospitalized AIDS patients due to nursing care. Coefficient alpha for the three subscales include .89 (Self care), .88 (Ambulation), and .84 (Psychological Distress). Construct validity for this scale was supported by factor analysis and by multi-trait—multimethod scaling analysis (Holzemer, Henry, Stewart, & Janson-Bjerkile, 1993). Psychometric testing of this scale also demonstrated convergent and divergent validity. It was anticipated that patients who reported higher scores on the HIV-QAM scale would be more likely to participate in their care. A positive correlation was expected between the

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Participation scale and the HIV-QAM, and a low or non significant correlation was expected between the HIV-QAM and the Anger scale.

HIV Symptom Check-List

This 41 item check list asks subjects to rate the number and intensity of symptoms on a Likert-type format, ranging from Mild, Moderate, and Severe. This scale was developed based on a literature review and also expert nurse clinician input. This scale produced high reliability with the sample in this study at .94. The average number of symptoms reported by subjects in this study was 19.98 (SD 10.80). It was expected that patients who report a decreased number of symptoms would be more likely to participate in their care (Reilly, Holzemer, Henry, Slaughter, & Portillo, in review).

The mean scores, standard deviations, and reliability for the instruments used in the testing of convergent and discriminant validity are presented in Table 4-15,. Each scale was found to have high reliability, ranging from .70 to .94. The reliability of the Participation and Anger Scale are high (.82) and within that range.

Table 4-15

Scale and Subscale Reliability (N=162)

Scale	No. of Scale Items	Mean	SD	Range	Coefficient Alpha
HIV Symptom Checklist	43	35.7	22.2	1-4	.94
Anger Scale	8	10.0	16.9	0-4	.82
Participation Scale	8	28.6	18.4	0-4	.82
PRA Scale	15	72.2	15.4	1-7	.87
PRA Subscale (Information)	5	22.6	6.6	1-7	.81
PRA Subscale (Communication)	5	24.8	6.9	1-7	.84
PRA Subscale (Affective)	5	24.9	6.2	1-7	.83
HIVQoL Scale	32	90.6	15.9	0-4	.84
HIVQoL (HIV Struggles)	14	30.5	9.2	0-4	.79
HIVQoL (HIV Reverence)	13	38.7	6.6	0-4	.70
HIV-QAM	10	34.8	5.4	1-10	.89
HIV-QAM subscale (Self Care)	6	21.4	4.1	1-10	.89
HIV-QAM subscale (Ambulation)	2	7.5	1.2	1-10	.92
HIV-QAM subscale (Psychological Distress)	2	5.9	1.5	1-10	.83
Beck Depression Inventory	22	17.7	9.6	0-3	.86

Evaluation with PRA and BDI Scale

Table 4-16 displays the correlation matrix established between the Participation scale, the PRA (and subscales), and the BDI. An examination of the matrix shows that, as expected, the three subscales of the PRA were highly correlated with a range from .39 to .82. The correlation between the Participation scale and the PRA ranged from .121 to .477. The correlation between the Participation scale and the BDI was -.068.

As expected, the correlation between the Participation scale and the total PRA scale was significantly positive at .361 (p<.001). The strongly positive correlation between the Participation scale and the Affective subscale was highly significant at .477 (p<.001), suggesting a positive relationship between a patient's rating on the participation scale and the extent to which patients perceive that the nurse values, understands or respects them. The Information subscale had a lower, yet significant correlation with the Participation scale at .269 (p<.001). Contrary to expectation, the correlation between the Communication subscale and the Participation scale was low and non significant at .130. This suggests that the scores on the Participation scale do not relate to the ease or difficulty a patient experiences in initiating communication with nurses. As predicted, correlations between scores on the BDI (Beck Depression Inventory) and the Participation scale were low and non-significant at -.068.

Discriminant validity of the Participation scale was supported by a pattern of significant correlations with the PRA and two of it's subscales, and also by the absence of a significant correlation with the BDI. With the exception of the PRA subscale on Communication, the results of the discriminant and convergent validity were in the

predicted direction. These results provided preliminary evidence for the construct of Participation.

Table 4-16

Inter-correlation Matrix for the Participation Scale with PRA and BDI

Variable	1	2	3	4	5	6
1. Participation score	---					
2. Total PRA Score	.361***	---				
3. PRA subscale (Affective)	.477***	.828	---			
4. PRA subscale (Communication)	.121	.767	.492	---		
5. PRA subscale (Information)	.269***	.750	.478	.309	---	
6. Beck Depression Inventory	-.068	-.280***	.229***	-.293***	-.132*	---

*p<.05 **p<.01 ***p<.001

Table 4-17 presents a correlation matrix established between the Anger scale, the PRA and it's subscales, and the BDI. Correlations between the Anger scale and the PRA ranged from -.158 to -.482. The correlation between the Anger scale and the BDI was .192.

A comparison of the PRA and it's subscales to the patient Anger rating scale shows negative yet highly significant correlations. As expected, the correlation between the Anger score and the total PRA score is significant at -.378 (p<.001). The strong, highly significant correlation between the Anger scale and the PRA Affective subscale (-.482, p<.001) suggests that anger increases when patients perceive that their nurses do not value, understand, show respect for them. The remaining two subscales, Communication and Information also show positive, moderate correlations with the Anger scale. The negative correlations between these subscales and the Anger scale suggest that patients' anger increases when nurses do not provide them with information about their illness, or when they experience difficulty asking nurses for information about some aspect of their disease. As predicted, correlations between the BDI and the Anger scale were low and non significant.

Discriminant validity of the Anger scale was supported by a pattern of significant correlations with the PRA and all subscales, and by the absence of a significant correlation with the BDI. The results of the discriminant and convergent validity were in the predicted direction and provided preliminary support for the construct of Anger.

Table 4-17

Inter-correlation Matrix for the Anger Scale with PRA and BDI

Variable	1	2	3	4	5	6
1. Anger Score	---					
2. Total PRA Score	-.377***	---				
3. PRA subscale (Affective)	-.482***	.828	---			
4. PRA subscale (Communication)	-.259***	.767	.493	---		
5. PRA subscale (Information)	-.158*	.750	.482	.309	---	
6. Beck Depression Inventory	.192	-.280***	-.229***	-.293***	-.132*	---

*p<.05 **p<.01 ***p<.001

Evaluation with Three HIV Related Scales

The correlation matrix established between the Participation scale and three HIV related scales (Living with HIV, HIV-QAM, and the HIV Symptom Checklist) is presented in Table 4-18. The positive correlation between the Participation scale and the HIV Reverence subscale was significant at .345 (p<.001), suggesting that patients who report increased respect for their HIV disease status also show increased levels of involvement in their care during periods of hospitalization. As expected, the correlation between the HIV Struggles subscale is lower, and non-significant. Two of the subscales on the HIV-QAM had low, yet significant correlations with the Participation scale (Ambulation=.135, p<.01; Psychological Distress=.138, p,.01). As one would likely expect, hospitalized patients who are more ambulatory also show increased levels of participation and involvement with their care; the findings also suggest that patients who are rated as having increased levels of anxiety or depression also show increased involvement with nurses. The HIV Symptom Checklist had a low and non-significant correlation with the Participation scale. Interestingly, the HIV-QAM subscale on psychological distress shows a low yet significant correlation with both of the subscales on the HIV QoL scale (Struggles, -.299, p<.001; Reverence, .173, p<.01).

Table 4-19 presents the correlation matrix established between the Anger scale and the Living with HIV Scale, HIV-QAM, and HIV Symptom Checklist. As expected, the Living with HIV Struggles subscale is moderately and significantly related to the anger scale (.294, p<.001), suggesting that patients who struggle with the issues presented by HIV/AIDS also report that they direct higher levels of angry behaviors toward the nurses during periods of hospitalization. The Anger scale also had a lower, yet significant correlation with the HIV Symptom Checklist (.177, p<.01). It is interesting to note the moderate and significant correlation between the HIV-QAM Psychological Distress subscale and the Living with HIV Struggles subscale (-.299, p<.001).

An overall summary of the finding of the second evaluation between the Participation and Anger scales and the three HIV/AIDS related measures identified a pattern of relationships between the scales. The HIVQoL subscales appear to show a relationship to both the Participation and Anger scales. The Participation scale shows a moderate yet significant correlation with the HIV Reverence subscale and the Anger scale shows a moderate, yet significant correlation with the HIV Struggles subscale. A more in-depth investigation of these relationships is beyond the scope of this current study but in themselves, these relationships will merit investigation in a future study.

Table 4-18

Inter-correlation Matrix for the Participation Scale with Living with HIV (HIVQoL), HIV-QAM, and the HIV Symptom Checklist

Variable	1	2	3	4	5	6	7	6
1. Participation Scale	--							
2. HIVQoL Struggles	.235	--						
3. HIVQoL Reverence	.345***	.278	--					
4. HIVQAM Scale	.086	-.060	.129	--				
5. HIVQAM Subscale (Self Care)	.049	.027	.097	.942	--			
6. HIVQAM Subscale (Ambulation)	.135*	.040	.123	.593	.540	--		
7. HIVQAM Subscale (Psychological Distress)	.138*	-.299***	.173*	.383	.087	.152	--	
8. Symptom Check List	-.127	.359***	.058	.034	.088	.037	-.116	--

*p<.05 **p<.01 ***p<.001

Table 4-19

Inter-correlation Matrix for the Anger Scale with Living with HIV (HIVQoL), HIV-QAM, and the HIV Symptom Checklist

Variable	1	2	3	4	5	6	7	8
1. Anger Scale	--							
2. HIVQoL Struggles	.294***	--						
3. HIVQoL Reverence	.085	.278	--					
4. HIVQAM Scale	-.041	-.060	.129	--				
5. HIVQAM Subscale (Self Care)	-.008	.027	.097	.942	--			
6. HIVQAM Subscale (Ambulation)	-.083	.040	.123	.593	.540	--		
7. HIVQAM Subscale (Psychological Distress)	-.103	-.299***	.174*	.384	.087	.152	--	
8. Symptom Check List	.177*	.360***		.034	.088	.037	-.116	--

*p<.05 **p<.01 ***p<.001

Comparing Scale Scores by Demographic Variables

A review of Table 4-20 shows differences in the scores for both the Anger scale and the Participation scale. Scores on the Anger scale differed significantly by gender ($p<.003$) and by two of the HIV risk factors, male-to-male sex ($p<.005$) and sex with an IV drug user ($p<.002$). Scores on the Participation scale also differed significantly by gender ($p<.003$) and by the HIV risk factor, male-to-male sex($p<.005$). Scores between the remaining variables were non-significant.

Table 4-20

Demographic Variables by Anger and Participation Scores (N=162)

	Mean	SD	Mean	SD	t	df	p*
Gender	Male		Female				
	(n=102)		(n=60)				
Scale							
Anger	9.15	3.0	11.36	5.1	-3.04	81.64	.003*
Participation	29.4	3.7	27.1	4.9	3.08	95.7	.003*
	African American		Caucasian				
	(n=73)		(n=73)				
Scale							
Anger	10.80	4.2	9.59	3.5	1.89	143	.061
Participation	28.15	4.4	29.15	3.4	-1.54	136	.125
Education	<12		>12				
	(n=79)		(n=83)				
Scale							
Anger	10.85	3.7	10.78	4.55	.08	71	.941
Participation	28.67	4.7	28.49	3.9	.26	159	.795
Age	<50		>50				
	(n=135)		(n=27)				
Scale							
Anger	10.08	4.3	9.44	2.2	1.13	72.95	.263
Participation	28.41	4.5	29.37	3.5	1.05	160	.297

	Mean	SD	Mean	SD	t	df	p*
Risk Factor	IVDU (n=46)		Not IVDU (n=116)				
Scale							
Anger	10.21	4.4	9.87	3.9	.48	60	.634
Participation	27.58	4.4	28.97	4.3	-1.86	60	.065
	Male/male sex (n=49)		Not Male/male sex (n=113)				
Scale							
Anger	8.75	3.2	10.50	4.3	-2.57	119.7	.005*
Participation	29.83	3.3	28.04	4.6	2.84	126.8	.005*
	Sex/IVDU (n=33)		Not Sex/IVDU (n=129)				
Scale							
Anger	11.91	4.0	9.48	3.9	3.15	160	.002*
Participation	27.21	3.9	28.93	4.4	-2.07	160	.040
	Sex/ Bisexual (n=21)		Not Sex/Bisexual (n=141)				
Scale							
Anger	11.19	3.5	9.79	4.1	1.47	160	.142
Participate	28.76	3.2	28.55	4.5	.21	160	.836
	Don't know (n=44)		Do know (n=118)				
Scale							
Anger	9.41	2.3	10.17	4.5	-1.38	146.5	.169
Participation	29.15	3.6	28.36	4.5	1.05	160	.297

*alpha .05/9=.006

Predicting Participation Scores

Demographic data (gender, ethnicity, and HIV/AIDS risk factor) and severity of illness variables (length of HIV, times hospitalized with an AIDS diagnosis, mortality, and the number of symptoms) were entered into a stepwise multiple regression, with the participation scale as the dependent variable. Scores on the PRA subscales (PRA Affective, PRA Communication, PRA Information) and the Living with HIV subscales (HIV Struggles, HIV Reverence) were also entered into the analysis (see Table 4-21). The analysis indicated that 42.3% of the overall variance was explained by the predictor variables, with the PRA Affective subscale accounting for 31.4% of the variance and the HIV Reverence subscale accounting for 5%. The PRA Affective subscale was determined to be a strong predictor of scores on the participation scale.

Table 4-21

Demographic, Severity of Illness, PRA Subscales, Living with HIV Subscales as Predictors of Participation Scores

Variable	R^2Change	df	Cum R^2	p
Gender	.052	142	--	.1962 (NS)
PRA Affective	.314	142	.366	.0000
HIV Reverence	.05	141	.423	.0003
Ethnicity				NS
Male/male sex				NS
IVDU				NS
HIV length				NS
Hospital times				NS
Mortality				NS
Symptoms				NS
PRA Communication				NS
PRA Information				NS
HIV Reverence				NS

Predicting Anger Scores

In a separate analysis, demographic data (gender, ethnicity, and HIV risk factors) and severity of illness variable (length of HIV, mortality rate, number of symptoms, and times in hospital since AIDS) were entered into a stepwise multiple regression, with the Anger score as the dependent variable. Scores on the PRA subscales (Affective, Communication, and Information) and subscale scores on the Living with HIV scale (HIV Struggles, HIV Reverence) were also entered into the analysis (see Table 4-22). The analysis indicated that 29.5% of the overall variance was explained by the predictor variables in the model, with ethnicity contributing 2.4%, the HIV Struggles subscale contributing 3.5%, and the scores on the PRA affective subscale contributing 16%. Only 5.9% of the overall variance was explained by ethnicity and the scores on the HIV Struggles subscale, suggesting that these variables were not accurate in predicting scores on the Anger scale. The PRA Affective subscale was the strongest predictor of scores on the Anger scale.

Table 4-22

Demographic, Severity of Illness, PRA Subscales, Living with HIV Subscales as Predictors of Anger Scores

Variable	R^2 Change	df	Cum R^2	p
Gender	.073	156	--	.307 (NS)
Ethnicity	.024	155	.097	.05
PRA Affective	.161	154	.258	.0000
HIVStruggles	.035	153	.295	.0065
IVDU				NS
PRA Communication				NS
HIV Reverence				NS
HIV Long.				NS
Hospital Times				NS
Mortality				NS
Symptoms.				NS

Other Demographic Data Results

A study finding related to knowledge about disease status in a subgroup of respondents raised worrisome concerns. As part of the demographic data, all of the subjects who participated in Phase II of the study were asked to report their CD4 count, length of HIV and also the length of AIDS. While the majority (98%) of the subjects stated that they knew the length of their HIV status, 17% of the subjects in the total sample admitted that they had difficulty answering the question which asked, "How long have you had an AIDS diagnosis?" Additionally, 20% of the subjects in the total sample reported that they could not answer the question which stated "Do you know your CD4 count?"

An analysis of this data by each site is presented in Table 4-23. In the most notable finding, 47%, or nearly half of the subjects at the Miami VA Hospital stated that they did not know the length of their AIDS diagnosis. The West Los Angeles VA Hospital had the highest number of subjects who reported difficulty answering both of the questions. Twenty five percent of the subjects admitted that they were unable to answer the question on the length of their AIDS diagnosis, and an equal number of subjects admitted that they did not know their CD4 count. Data on knowledge of the length of the AIDS diagnosis for the other sites ranged from a high of 21% in the group of "Others" (friends of women recruited through community agencies and newsletters) to a low of 11% at the San Diego VA Hospital. All of the subjects recruited through the World Newsletter and through the Palo Alto VA Hospital provided data on the length of their AIDS status. Data on subjects who did not know their CD4 counts ranged from a high of

50% at both the Palo Alto VA Hospital site and the World Newsletter site to a low of 4% at the UCSF Women's Clinic site.

Anecdotally, subjects stated that they "didn't know," "didn't care," and "didn't want to find out." As one subject stated, "I don't know...I try to keep from having AIDS so I purposely don't ask about it." In reply to the questions, many of the subjects also added "What's the difference between AIDS and HIV?" Other subjects stated that their lack of knowledge about length of AIDS and CD4 status related to patterns of non-compliance with treatment. As one subject stated, "I never bother to go those appointments...I really don't pay no attention to that stuff... I only come here when I'm really sick and somebody makes me come." Six acutely ill, hospitalized subjects interviewed at the Miami Site asked the investigator, "What's a CD4 count?" Subject replies reflected both a lack of understanding about disease process in HIV/AIDS and also the lack of interest in treatment.

Table 4-23

Frequency Counts of Subject Knowledge of HIV/AIDS Status by Site

	San Diego (n=17) M (SD)	West LA (n=16) M (SD)	Miami (n=34) M (SD)	San Francisco (n=32) M (SD)	Palo Alto (n=6) M (SD)	UCSF Women's' Clinic (n=25) M (SD)	World Newsletter (n=12) M (SD)	VNA AIDS Project (n=0) M (SD)	Others (n=19) M (SD)
Know CD4 Count?									
Yes	15 (88%)	12 (75%)	17 (100%)	28 (87%)	3 (50%)	24 (96%)	6 (50%)	**	17 (89%)
No	2 (12%)	4 (25%)	0 (00%)	4 (13%)	3 (50%)	1(04%)	6 (50%)	**	2 (11%)
Know Length of HIV?									
Yes	17 (100%)	16 (100%)	31 (91%)	31 (97%)	6 (100%)	25 (100%)	12 (100%)	**	18 (95%)
No	0 (00%)	0 (00%)	3 (09%)	1 (03%)	0 (00%)	0 (00%)	0 (00%)	**	1 (05%)
Know length of AIDS?									
Yes	15 (89%)	12 (75%)	18 (53%)	27 (84%)	5 (83%)	25 (100%)	12 (100%)	**	15 (79%)
No	2 (11%)	4 (25%)	16 (47%)	5 (16%)	1 (17%)	0 (00%)	0 (00%)	**	4 (21%)

** No data available for this site

A comparison of data on CD4 counts, length of HIV, and length of AIDS reflects patterns of differences between self report data and chart documentation. Since both sets of data were only available for the hospitalized subjects, the analysis was limited to sites 1 through 5. Chart data was not available to the investigator for the female subjects in sites 6 through 9.

The comparison of data for the subsample of hospitalized subjects presented in Table 4-24, reflects significant differences between self reports and chart data for CD4 count (t=2.11, p=.039) and length of HIV status (t = -2.66, p = .010) but not for length of AIDS (t = .43, p= .672). The findings suggest that subjects reported higher CD4 counts and a shorter length of time with HIV infection when compared to chart documentation.

Table 4-24

Comparison of Self Report Data with Chart Data for Hospitalized Subjects

Between-Group Comparison	n	M (SD)	t	df	p
CD4 Count					
Self Report	71	137.8 (146.6)	2.11	70	.039
Chart Data	71	124.6 (134.4)			
Length of HIV					
Self Report	75	68.3 (47.5)	-2.66	74	.010
Chart Data	75	76.9 (50.6)			
Length of AIDS					
Self Report	40	28.2 (30.1)	.43	39	.672
Chart Data	40	26.1 (29.4)			

a = Sites meeting the criteria include Sites 1 through 5

b = p values are 2 tailed based on paired comparisons

Table 4-25 presents data on self report and chart documentation for CD4 counts, length of HIV and AIDS at each of the nine research sites. With only two exceptions, the comparison between self reports and chart data reflected the patterns noted in the analysis for the subgroup of hospitalized subjects. Instead of reporting higher CD4 counts than chart data, subjects at both the Miami and Palo Alto VA reported a reversed pattern. Mean scores for CD4 self reports at the Miami VA Hospital site were lower than those noted in the charts (148.9=self report, 153.8=chart data). A similar pattern was noted for the subjects as the Palo Alto VA Hospital site with the mean score for CD4 self report (96.0) lower than mean score for chart data (138.5).

Table 4-25

A Comparison of Chart Data versus Self Report Data on HIV/AIDS Disease Status by Site

	San Diego (n=17)	West LA (n=16)	Miami (n=34)	San Francisco (n=32)	Palo Alto (n=6)	VNA AIDS Project (n=0)	UCSF Women's Clinic (n=25)	World Newsletter (n=12)	Others (n=19)
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	M (SD	M (SD)	M (SD)	M (SD)
Self Report	91.3 (105.0)	186.4 (197.2)	149.8 (132.8)	136.9 (146.7)	96 (90.0)	**	167.5 (103.9)	241 (121.9)	162.8 (129.1)
Chart Report	73.6 (96.8)	146.6 (168.6)	153.8 (163.0)	129.2 (127.1)	138.5 (158.9)	**	Chart Data not available	Chart Data not available	Chart Data not available
Length of HIV in mos.									
Self Report	93.1 (53.2)	69.8 (45.8)	68.5 (47.4)	95.9 (46.8)	66.8 (20.6)	**	68.6 (36.9)	47.4 (37.7)	65.3 (41.0)
Chart Report	89.4 (48.2)	63.6 (52.0)	61.1 (44.9)	65.1 (47.3)	48 (33.9)	**	Chart Data not available	Chart Data not available	Chart Data not available
Length of AIDS in mos.									
Self Report	32.8 (25.2)	24.3 (33.2)	19.1 (32.5)	36.6 (40.4)	21.6 (17.3)	**	30.9 (22.8)	25.9 (29.0)	25.1 (11.1)
Chart Report	26.9 (18.2)	28.8 (50.0)	13.3 (18.8)	30.2 (33.7)	24.0 (0.0)	**	Chart Data not available	Chart Data not available	Chart Data not available

** No data available from this site

CHAPTER FIVE

DISCUSSION OF RESULTS

This chapter discusses the meaning and significance of the findings from this study, which developed and empirically tested a scale for the measurement of AIDS patient behavior toward nurses. AIDS patients are highly dependent on nurses during acute events associated with their illness; the behavior of nurses who provide care during these acute phases of illness can in turn, greatly impact on the behavioral response of these patients. An assumption in this study was that acutely ill AIDS patients would be able to clearly describe their behavioral responses to nurses, and that these descriptions could be incorporated into the development of an outcome measure. The resulting scales were developed and designed to provide nurses with outcome data which reflects the effects of their practice in AIDS care settings.

The discussion is presented in three sections. The first section discusses the results of the critical incident interviews used to elicit behavioral descriptions from a sample of 118 hospitalized, and recently hospitalized AIDS patients. The second section of this chapter discusses the significance of the results of psychometric testing of the scales with a second sample of 162 hospitalized, and recently hospitalized AIDS patients. A third section provides a discussion of the strengths and limitations of this study, and the implications for nursing research and practice.

Critical Incident Interviews

Through the use of the critical incident technique, an empirical procedure for collecting direct observations on human behaviors (Flanagan, 1954), a set of categories was derived that identified the behavioral response of AIDS patients toward their nurses during periods of hospitalization. The results of the critical incident interviews indicated ten major behavioral response categories. These ten behavioral response categories which emerged, highlight the complex and challenging issues currently facing nursing in the provision of AIDS patient care. Several of the behaviors described have a potential for negatively impacting on nurses and contributing to the unprecedented stresses and demands which result in the high levels of burnout so frequently reported in literature. Two of the categories, matching respect and matching disrespect, describe the reciprocal nature of nurse-patient interactions in AIDS care settings; these categories highlight the fact that the behavior of nurses greatly affects the nature of the behavioral response returned by the patient. Several of the response categories also reflect behavioral conditions associated with HIV/AIDS. Each of the behavioral response categories which emerged from the study are addressed in the following section, followed by a discussion of the significance of the findings for nursing.

Participation

In the largest behavioral category, 41% of the respondents described ways in which they participated in their care. Consistent with the findings of the overall sample, this category remained the largest response category for both male and female subjects (males=44.5%; females=44.5%), and also for each of the ethnic groups (African American=47.7%; Caucasian=40.3%; Hispanic=54.5%). This finding is not surprising. From the first years of the epidemic, patients with HIV/AIDS have demanded a role in the decision making taking place regarding their care. In response to their demands, concern for their participation has usually been included in all levels of planning for care delivery.

Nurses who care for HIV/AIDS patients know that they can expect high levels of participation from their patients (Scheitinger & Daniels, 1996). Although the ever increasing literature base on the attitudes and behaviors of nurses toward patients with HIV/AIDS reports an overwhelmingly negative responses to these patients, subjects in this study repeatedly described incidents where they participated in care as a direct result of a nurse's positive action. The following example is representative of numerous incidents which the subjects described:

> "After surgery, I had fluid in my lungs. The nurse was very persistent at getting me to do my breathing treatment. She also made me get up out of bed and encouraged me as we walked down the hall together. She kidded me into doing the breathing treatments. How did I respond? I kidded her back, but more than that, I tried to put more effort into my breathing treatment and also into doing what I had to do."

Anger

In an unexpected finding, 28% of the subjects in the overall sample reported that they directed angry behaviors toward nurses. One study appearing early in the epidemic reported that patients with HIV/AIDS experienced higher levels of anger than those who were seronegative (Kelly & St. Lawrence, 1988). The majority of the subjects in this earlier study were homosexuals who reported that their anger resulted from feared progression of the disease, the lack of medical treatments, and discrimination from others, including health care workers. Although anecdotal descriptions of anger frequently appear in literature, there have been no further studies in this regard.

In the current study, the investigator found numerous additional factors associated with descriptions of angry behaviors. For example, the listing of angry behaviors, previously described in Chapter 4, differed most notably by gender, with 43% of the females reporting angry behaviors toward nurses, compared with 28.9% of the males. The largest majority of women who described angry behaviors in this study reported acquiring AIDS through their association with IV drug use. Although there are no empirical studies present in the literature, anecdotal reports indicate that anger is a common theme in dealing with AIDS infected women who are IV drug users. Since drug abusing women already bear the stigma associated with drug abuse, the added diagnosis of AIDS places these women in an entirely different position, one in which there is a greater misunderstanding of fear, both in others and in themselves. Since they have no safe outlet, they "take it out" on others by directing their angry behaviors toward those who are around them (Hardesty & Grief, 1994). In this study, women who were IV substance abusers described numerous incidents when anger was directed toward nurses, especially around demands for pain medication and over site choices for initiating IV lines.

Subjects in this study who were dual or triple diagnosed with the added combinations of AIDS, substance abuse, and mental illness, and male subjects who were actively "using" drugs, frequently described angry behaviors which were directed toward nurses. Additionally, African American subjects reported angry behaviors in 40.5% of the incidents compared to a lower rate for Hispanics at 27.9% and 27.3% for Caucasians. Several subjects reported that the ethnicity of the nurse affected their degree of anger. There are no studies available which address the issues of anger in AIDS patients, related to ethnicity or diagnostic status. The overall predominance of anger expressed by the subjects in this study has strong implications for nursing education and research.

Appreciation

In the third largest behavioral category, 28.8% of the subjects described behaviors which they used to show appreciation toward nurses. A comparison by gender shows that male subjects reported an increased number of appreciating incidents over female subjects (males=32.5%, females=22.8%). A comparison by ethnicity indicates that 33% of the Caucasian subjects reported appreciating behaviors, African American subjects reported 28% and Hispanics, 18%. The appreciative behaviors described by subjects in this study were associated with reports of increased quality of care.

Matching Respect/Disrespect

Subjects in this study described behaviors which matched those of the nurses they encountered in hospitals. In the interest of developing questionnaire items for a scale which would identify patient behaviors, these categories were divided into matching respect and matching disrespect. In theory, however, the behaviors in both of these categories reflect a single concept of reciprocity as proposed by Hall and her colleagues (1988). This concept states that patient behaviors are directly related to provider behaviors. Patients respond negatively to negative talk; negative talk also negatively influences participation in care. Positive talk, on the part of the provider, conveys understanding and acceptance, and is associated with compliance and participation in care. In this study, subjects simultaneously reported that their behaviors were directly related to the nurse-patient encounters. Subjects who reported that a nurse listened to them and treated them with respect behaved similarly toward that nurse. Subjects who felt disrespected by a nurse also reported a matching negative response toward that nurse. As one subject stated, “Whatever they do to me in here, I do it right back!...I treat them like they treat me." In this current study, female subjects reported a greater number of incidents where they matched a nurse's respectful behaviors than male subjects (males=26.5%, females=40%). A similar pattern was noted with matching disrespectful behaviors (males=12%, females=25.7%). Female subjects, in this study, reported that they were more affected by nurses behaviors. African American subjects reported greater numbers of matching respectful behaviors at 40.5% of the incidents, compared to 36.4% for Hispanics, and 24.2% for Caucasians.

Coming Close

The number of behaviors described which brought subjects "closer" to nurses included 19.5% of the total sample. A comparison of domain difference by ethnicity shows little variation between the groups. Female subjects reported a greater increase in frequency of coming close behaviors (28.6%) compared to males (16.9%). The following example reflects the need for increased support required by these patients:

> "It's been a rough month. I had to put my partner in a hospice. He's so young, he's 27. The nurse listened to me while I opened up and talked to her about what was going on. It felt good to get that off my chest by telling the nurse. I felt close to that nurse."

Staying Away

Behaviors which described ways in which subjects stayed away from nurses comprised 19.5% of the incidents. There was a smaller difference noted in a comparison by gender with the total number of incidents reported by males at 18% and 22.8% by females. Few differences were noted in the rate of reporting across ethnicity, with African American subjects reporting 21.5%, Hispanics 18.2% and Caucasians 16%. A frequently reported cause of staying away behaviors related to mistrust or suspicion of health care workers by “street people.” Staying away behaviors also represented depression or other psychological distress over the AIDS diagnosis, or stage of illness. In the following example, a subject related staying away behavior to increased depression:

> “The nurses come and they go. I don’t have a personal connection with them. I’m so withdrawn from them. I stay away from them. Last month I was suicidal. I’ve been so depressed. I lost my home and my job as a dental assistant because of CMV.”

Current literature confirms that depression is a common co-morbid condition associated with HIV/AIDS (McEnany, Hughes, & Lee, 1996; McClure et al., 1996; VanServellen et al., 1996).

Dependent

Sixteen percent of the subjects described dependent behaviors. A comparison of this behavioral domain by gender shows little difference between the scores (males=27.7%, females=25.7%). A comparison by ethnicity, however, shows that Caucasian subjects reported increased rates of dependent behaviors at 30.6%, with African American subjects reporting 21.5% and Hispanics reporting the lowest rate of 18.2%. No studies currently explore the issues of dependency in patients with HIV/AIDS.

Complaint

Complaint behaviors were reported by 15% of the subjects who participated in the study. This included reporting a complaint about a nurse to other nurses, hospital administrators, or friends and family. Only a slight difference was noted in a comparison of this category by gender with females reporting complaint behaviors in 17% of the incidents, and males reporting complaint behaviors in 15% of the incidents. Differences were noted by ethnicity, however, with Caucasians reporting the greatest number of complaint behaviors at 29.5%, compared to Hispanics at 18.2% and African Americans at 21.5%. Complaint behaviors were found to be related to anger over quality of care.

Self Care

Self care behaviors referred to expending energy to meet ADL needs when a nurse was not available to assist. Even though subjects who participated in the first phase of the study offered incidents in this regard, AIDS patients who participated in the content analysis of the PRNB scale had difficulty relating to scale items derived from this category. They stated that the items were not meaningful to them.

Significance of Behavioral Reports

A review of the behavioral incidents provided by the subjects who participated in this study highlighted numerous significant issues and challenges for nursing. Patients are known to be capable of describing their responses to health care workers, including nurses, and also describing the quality of health care which they receive (Rubin, 1990). Even through many of the patients who participated in this study were acutely ill and debilitated, they were able to report clear and vivid descriptions of their behavioral responses toward nurses. They also indicated a strong interest in assisting with the study. As one subject stated, "Nurses SHOULD speak to you and find out if what they've done has improved your situation."

Although numerous studies have been conducted which identify behaviors resulting from the patient-provider relationships between physicians and patients (Henderson, 1981; Hall, Roter & Katz, 1988; Roter, 1988; Joos & Hickman, 1990), no studies, were identified which asked AIDS patients to describe their behavioral responses toward nurses. Only one recent qualitative study by Kermode (1995) was found which asked recently discharged AIDS patients to describe their experiences with nurses. In this study, eight patients were asked to describe their experiences with nurses and offer suggestions for improving quality of care. The focus in the study, however, was on the actions and attitudes of the nurses, and did not identify patient behaviors.

The categories of participating, appreciating, and matching respect contained positive behavioral descriptions. Subjects reported that their positive behaviors occurred as a direct result of a nurses positive action and high quality care. Subjects comments, in this study, contrast sharply with current literature which continues to place emphasis on the overall negative prevalence of nurses' attitudes and behaviors (Tierney, 1995; Horsman & Sheeran, 1995; Wang, 1997). In the incidents described by patients in this study, many nurses received recognition for the high quality nursing care which they provided. The following examples represent most frequent subject comments:

> "When you're treated well by a nurse, like I was, it makes your outlook positive and hastens your recovery."
>
> "A nurse who's good gives you a reason to keep on trying. It gives you a boost and extra courage."

Several significant issues which emerged from this study reflect the changing nature of the AIDS epidemic and the unique needs of women, minorities, and substance abusers. For example, descriptions of stigmatizing incidents provided by the subjects in this study related primarily to their status as an IV drug user, rather than to their AIDS diagnosis. This seemed to be especially true for female IV drug users in this study. This finding also correlates with recent literature (Durham, 1994). Subjects shared the following incidents:

> "I could tell the nurses were disgusted with me because I'm an addict not because I have AIDS. I could see it in their faces."

> "When I went to the ER because I got hit on the head with a shoe, I could hear the nurses talking about me. They said, 'She's just a dope fiend!' I could see them looking at my track marks."

> "When I asked the nurse for morphine because I was having pain after surgery, the nurse said 'You just want it because you're an addict and you want to get high.' She shrugged her shoulders, rolled her eyes, and walked away from me without getting the medicine."

Injection drug users in this study voiced a need for greater understanding and acceptance by nurses, and also a need for them to become more informed about substance abuse issues. Subjects offered the following advice to the investigator and asked that it be shared with nurses:

> "Don't make value judgments. A disease is a disease--it doesn't matter how I got it. Please don't judge me, just take care of me."

> "Nurses have trouble with addicts...they discriminate against them. I'm using for the past 33 years and I ain't gonna change now. Nurses gotta start realizing that."

> "Treat us equal...it's no difference for addicts 'cause we ARE equal. Just because I used to use drugs and now take Methadone, I still bleed red and I still have a mind and eyes!"

Similar comments were recently reported by Scheitinger and Daniels (1996). These comments point to an urgent need to prepare nurses to meet the challenges presented by substance abusing patients. Education programs which address the sensitivities and needs of substance abusing patients would be useful in providing nurses with increased skill to meet the needs of this increasing group of patients.

An unexpected finding related to the numbers of AIDS patients who were excluded from the study because of intense psychological and behavioral problems. The investigator found that a large numbers of AIDS patients were unable to participate in the study, not because of anticipated fatigue or AIDS dementia, but because of acute behavioral issues. Examples included patients who were restrained because of their potential for striking out at nurses, or who were actively hallucinating and unable to control their behavior. Several patients placed on “CO” status (continuous observation) for being actively suicidal were also excluded from the study. Observations made by the data collectors, show that nurses minimized interactions with these patients and frequently reported their own need to receive additional training on the management of the difficult behaviors which these patients presented.

Behaviors displayed by dual and triple diagnosed subjects also presented difficult and challenging behaviors which frequently precluded their participation in the study. The following example, recorded in the clinical log of the data collector, documents an example of angry behaviors by a substance abusing, schizophrenic patient with an AIDS diagnosis who refused study participation. The following short vignette also describes the frightened and stressful response experienced by the young nurse who was assigned to care for him.

> Nurse: "I stopped to see if you needed help. Your call light is on."
>
> Patient: (Screaming loudly) "Get outa here, I didn't call you!!! Leave me alone."
>
> The nurse appeared frightened and also very flustered. She accidentally dropped the papers that she was carrying in her hands. After bending down to retrieve the papers, she quickly left the room. Later, a second nurse commented on the incident.
>
> Second Nurse: "He checks everyone out that way. He really looks at you and frowns to see what you'll do. He's been here before and has done that to us in the past. He gets really agitated and then leaves. This time, the nurses found a syringe of cocaine in his belongings. The doctor said he was speedballing. He denied that and said that a friend of his accidentally left the syringe in his suitcase. This time he won't leave...he's too weak and too sick. He has a real attitude and is hard to deal with."
>
> A third nurse added: "Most of my AIDS training relates to the tasks I have to do. We're seeing more and more of these patients and we don't know how to handle them."

This incident placed additional emphasis on the need for educating nurses to manage difficult behaviors in acute AIDS care settings.

One additional finding in relation to substance abusers emerged. Several subjects declined to participate in the study because they "didn't pay attention to nurses." "Nurses can't prescribe drugs....doctors are the only one who can order drugs." Nurses were seen as peripheral to the major focus of their interest, obtaining drugs.

Subjects who reported that they "stayed away" from nurses, frequently associated their behavior with depression. Other subjects who described incidents where they "stayed away" from nurses indicated to the investigator that they did so because they were highly suspicious and distrustful of healthcare workers in general, and only sought treatment under the most dire circumstances. Many of these subjects identified themselves as "street people." Withdrawal from nurses proved to be their best effort at coping with the stressful environment of the hospital. They felt that nurses and other health care workers "did not understand them." This unexpected finding indicates the need for continued training on the needs and issues of homeless men and women with AIDS and on dealing with the behaviors presented by these patients.

Another significant finding related to the unique behaviors of women who participated in this study. A greater number of female subjects, than male subjects described "coming close" behaviors. They frequently described incidents where they reached out toward the nurses in an effort to receive support from them. One of the female subjects stated, "Nurses really have an impact on me, especially since my mother died of AIDS in '89 and now my 7 year old is HIV positive. The nurses will never know how much I depend on them." Another subject stated, "It's a devastating thing to be readmitted to the hospital with zoster. I don't have any family or friends, so I look to the nurses for replacing them. Not everybody has somebody." Women with HIV/AIDS struggle with tremendous social and economic problems (Stevens, 1995); they also suffer sexism in the AIDS care community, especially if they are minority and poor (Indyk et al. 1993). There are currently no studies of women's emotional needs during hospitalization or during the course of HIV disease.

Another significant finding was related to the subject descriptions of dependent behaviors. Several subjects who described dependent behaviors voiced their belief that these behaviors were expected of hospitalized patients. As one subject stated, " For me, the nurse is the one who is in control. I'm just here, flat in bed and sick. I quietly do what they tell me. That's the way it's supposed to be." Other subjects, however, indicated that their dependent behaviors reflected their great reluctance to speak out to the nurses about quality of care issues. Two subjects shared the following comments with the investigator:

> "Sometimes you don't like saying things to the nurses because you'll eventually have to come back to the hospital and they may remember you...you're kinda in a spot."
>
> "To tell the truth, I feel helpless. You really can't say anything to a nurse about their care. You can't piss off a nurse because you're too damn sick and you never know when you'll need that nurse. I just quietly do what I'm told."

These statements send an important message to nurses about increasing awareness of patient communication, and the need for incorporating the patient perspectives in the evaluation of nursing care.

Several of the subjects indicated that their nurses were experiencing burnout. Their comments correlate with recent studies which show high levels of burnout in nursing staff members working with AIDS patients (Catalan, 1996). The subjects in this present study, offered the following advice to nurses about burnout:

> "Treat people with respect...if you're burned out, change your job."
>
> "I can tell if a nurse wants to help me or not, and if they're vacant or not. I don't have too much to do with nurses who are vacant. I just don't call them."
>
> "If I could conduct a seminar with nurses, I'd say that certain small things are considered rude. People don't ordinarily get treated like they're inanimate objects. Nursing is not a pill pushing thing. You're wasting your time if all you can do is mechanically walk into a patient's room and plop down a cup of pills."

In summary, the patient generated critical incidents provided a listing of behavioral responses useful for scale construction. In addition, the critical incidents provide an important perspective on nurse-patient encounters in acute HIV/AIDS care settings. This research also indicates that nurses play a key role in determining the behavioral responses of patients with HIV/AIDS. Each of the behavioral response categories generated by this study warrants further research. The previous discussion highlights numerous issues with important significance for nurses who plan for AIDS patient care. An understanding of the behavioral categories is imperative if nurses are to effectively intervene with AIDS patients.

Instrument Validation

Phase II of the study examined the psychometric properties of the PRNB scale in a second sample of hospitalized, and recently hospitalized patients with AIDS. The representative sample of AIDS patients included minorities, women, and also subjects from each of the risk factor groups. A principal components factor analysis of the original draft of the PRNB yielded a two factor solution. Sixteen of the original 39 items were retained. An examination of items loading on the first factor described angry behaviors which were directed toward nurses. Items loading on the second factor described participating behaviors.

Rather than a single anticipated scale, the factor analysis identified two separate and independent scales, the Participation scale and the Anger scale. Items for each scale fit logically together and are closely related to the behavioral response categories generated through the critical incident interviews during Phase I of the study. Overall, each scale demonstrated high reliability at 0.82. Scale scores were computed by summing the ratings of all the items. Since the scales had a high degree of independence, each scale was analyzed separately.

Both the Participation and Anger scales reflected promising patterns of convergent and discriminant validity. In this study, a broader testing of convergent and discriminant validity through the use of multiple traits and multiple methods as described by Campbell and Fisk (1959) was not feasible because of the increased demands this would place on acutely ill, hospitalized patients. The testing in this study was instead, limited to two reliable and valid measures which could be easily managed by the patients. The Patient Reactions Assessment (PRA), a similar measure of patients' responses to health care workers, was used the testing of convergence. The PRA demonstrated high reliability and validity. The Beck Depression Inventory, a dissimilar measure, was used to test divergence.

Both the Participation scale and the Anger scale were significantly correlated with the Patients' Reactions Assessment (PRA). Moderate convergent validity was determined for the Participation scale with the PRA and two of the three subscales (Affective and Information). The positive relationship between the participation scale and the PRA Affective subscale suggests a positive relationship between a patient's rating on the participation scale and the extent to which that patient perceives that a nurse values, respects, and understands them. To a lesser extent, the Participation scale was also correlated with the PRA-Information subscale, suggesting a positive relationship between a patient's participation in nursing care and the extent to which the patient perceives that a nurse provides information about his or her illness. Failure to achieve convergence with the Communication subscale indicated that that items in this subscale of the PRA did not measure the same traits than those in the participation scale.

Similar patterns of convergence were noted between the anger scale and the PRA. Positive correlations between the anger scale and each of the three subscales suggest that patients' anger increases when nurses do not value or respect them, or when they fail to provide patients with information about HIV disease status. Anger also increases when patients experience difficulty in communicating with nurses concerning some aspect of nursing care.

Additionally, there was good evidence for the discriminant validity for each scale. Both the Participation scale and the Anger scale demonstrated discriminant validity from the Beck Depression Inventory.

Interesting correlations were noted between the Participation scale and three HIV/AIDS related measures used in the evaluation of physical and psychological status of patients. The significant correlations between the Participation scale and the Living with HIV subscale, HIV Reverence suggest that patients who report increased respect for their HIV disease status, also show increased levels of participating in nursing care. The positive correlation between the HIV Struggles subscale and the anger scale suggest that patients who struggle with the demands of HIV/AIDS also report directing higher levels of anger toward nurses.

Demographic data, severity of illness variables, scores from the PRA, and also three HIV/AIDS related measures were entered into a stepwise regression analysis with the Participation scale as the dependent variable. Analysis indicated that 42% of the variance was explained by the predictor variables, with a PRA subscale accounting for 31.4% of the variance, and a Living with HIV subscale accounting for 5%. A separate regression analysis of the Anger scale indicated that 29.5% of the variance was explained by the predictor variables, with the scores on a PRA subscale contributing 16%, ethnicity contributing 2.4%, and 3.5% contributed by scores on the Living with HIV subscale.

General findings show that demographic characteristics, including gender and HIV risk factors contribute to the differences in scores. Female subjects scored significantly higher on the Anger scale than male subjects. Female subjects who acquired HIV/AIDS through sex with an IV drug user also scored significantly higher scores on the anger scale. Subjects with the risk factor of male-to-male sex scored significantly higher scores on the participation scale.

Strengths and Limitations of the Study

Strengths

One of the strengths of the study is that of obtaining patient perspectives on the outcomes of nursing care. Research thus far has focused on the effects of HIV/AIDS on nurses. The patients with HIV/AIDS who participated in this study provided thoughtful and useful information on key issues affecting nurse-patient relationships in AIDS health care settings. The clear behavioral descriptions provided by the patients in this study which were used in the development scale items, also increased the validity of these scales. Additionally, the critical incident interviews were conducted in hospitals, with patients reporting their immediate responses to nurses.

A strength for this study related to the systematic process used in the development of the scales and to the close adherence to Flanagan's critical incident technique. During Phase II of the study, when the scales were being tested at multiple sites, the investigator remained aware of the potential for variation in data collection practices. A standard format for training data collectors was developed and implemented at each site. The investigator also conducted frequent site supervision visits to monitor the quality of the data, and the ongoing process used in data collection. The investigator remained available to the data collectors at all times to answer and clarify questions.

Throughout the study, the investigator minimized any potential threats to the validity of the data which could be created by the subjects recruited through community agencies. Since chart data was not available for these subjects which confirmed the presence of an AIDS diagnosis, it was necessary to obtain validation through a clinic, case worker or other written documentation. Each subject was assessed for their ability to participate in the study since unreliable reports given by even a small number of subjects have the potential for affecting the reliability of data (Carroll, 1995). The investigator was alert for indications of AIDS dementia, problems with memory and concentration due to recent substance use, the presence of psychosis, or other issues which could affect study participation. On several occasions, for example, it became necessary to discontinue an interview when a subject's behavior indicated recent drug use. Since the subjects recruited through community agencies were reimbursed for the interviews, the investigator maintained established study guidelines to minimize the highly manipulative efforts on the part of several subjects. Detailed records of study participants were maintained. In one example, a subject who participated in the study two days previously, called for appointment, insisting that she had not ever been in the study. In another instance, a subject who had already participated in the study, scheduled an interview but used another name in an effort to obtain a second cash reimbursement.

Limitations

The study presented several potential limitations. By excluding the large number of patients who presented behavioral problems, a potential selection bias may have been created. Additionally, several subjects who initially agreed to participate in the study, refused when they saw the word AIDS on the consent form. Even through their CD4 counts, and chart documentation confirmed the presence of an AIDS diagnosis, a number of potential subjects refused study participation, insisting that they were only HIV positive. A small number of patients became highly suspicious of the consent form and refused to participate. Despite clear explanations on the part of the data collectors, numerous subjects misinterpreted the intent of the form. In one example, a patient stated, "If I sign that paper, I'll sign away the rights to my house and everything that I own."

Some of the participants in this study may have been influenced to some extent by social desirability bias. Despite precautions to maintain confidentiality, some subjects may have had difficulty rating the behaviors of nurses that they knew they would have to continue to rely on for care. A majority of the patients who participated in this study had few options for health care, and throughout the course of their HIV illness, continued to return again and again to the same acute care setting.

Face-to-face interviews may be affected by problematic behaviors displayed by the subjects (Hutchinson & Wilson, 1992). Problematic behaviors displayed by several subjects included intimidation, hostility, and impulsiveness. These behaviors may have influenced the nature of the data which was recorded by the data collectors on the critical incident forms.

Nursing Implications

Patient focused outcome measures continue to play an ever increasing role in planning for future nursing care, and in developing standards for today's rapidly changing health care market. By measuring behavioral responses of patients, nurses can begin to identify crucial issues surrounding nurse-patient relationships in HIV/AIDS care settings, and also document the outcomes of their practice. By adding data on the patient's perspective, nurses will obtain a greater understanding of what changes would influence outcomes in patient behaviors. Knowledge of patient reports can also be useful for planning HIV/AIDS educational programs and providing direction for future nursing research.

Future Research

The brevity of both scales, and their relative ease of administration, make them highly suitable for research with acutely ill patients in a variety of AIDS care settings. Their straightforward assessment of patient responses suggest a unique contribution to the literature on the HIV/AIDS patients experiences with nurses. Continued research with the scales will focus on an extension of construct validation with other similar measures of responses to health care workers. Also, testing in this study was limited to geographic regions where the AIDS epidemic is wide spread (California and south Florida). Testing of the scales should be expanded to include samples of AIDS patients in broader geographic regions, especially in smaller cities and rural areas of the South which are currently experiencing a rapid increase in the numbers of AIDS cases. The scales should also be compared across a variety of HIV/AIDS health care settings. Future work would compare the relationship between scores on the patient anger and participation scales with

nurses' willingness to provide AIDS patient care It would be useful to contrast high and low scorers on the patient anger scale with nurse ratings on anxiety and burnout scales. It would also be useful to measure the effect of stress levels in nurses on patient participation scores. Further work would include a continued evaluation of the relationship between the constructs of participation and anger and the Living with HIV subscales, HIV Struggles and HIV Reverence. Additional research is needed to determine the range of applicability of both scales to other communicable illnesses.

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APPENDICES

Appendix A

Consent Forms-Phase I

Subject Interview Receipt

Consent Form Phase I - Community Interviews

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SAN FRANCISCO VETERAN'S AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Developing a Measure of Patients' Responses to Nurses
Phase I-Scale Development

A. PURPOSE AND BACKGROUND

William L. Holzemer, RN, Ph.D., Professor at UCSF School of Nursing, and Jeanne K. Kemppainen, RN, MSN, Doctoral Candidate at UCSF School of Nursing are conducting a study to learn how hospitalized patients with HIV/AIDS respond to nurses' behaviors.

The findings from this study should provide important information for teaching nurses how best to provide care to patients with HIV/AIDS. I have been asked to participate in this study because I was recently hospitalized and am in the best position to describe my experiences with nurses.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be interviewed once. A research nurse will explain the study to me. If I agree to participate in the study I will be asked to sign a consent form.

2. If I sign and agree, I will take part in a 30 minute interview. A research nurse will read an open ended questionnaire to me and ask me talk about my responses to nurses behaviors. I will be asked to talk about my opinions. The interview will be conducted in a private place so my answers won't be accidentally overheard. My answers will be filed in a locked place immediately after the interview.

C. RISKS/DISCOMFORTS

Participating in this study may cause some feelings of discomfort. Being asked to recall responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction with nursing care which may surface may affect on my interactions with nurses. If I become uncomfortable, however, I will be able to stop participating in the study at any time.

Participation in this research study may involve a potential loss of privacy, however, my records will be handled as confidentially as possible. All interviews will be conducted in a private place so that my answers will not be accidentally overheard. The only way that a nurse will know my answers will be if I tell them. Immediately after the interview, my records will be filed in a locked place. Only Dr. Holzemer and Jeanne Kemppainen will have access to my responses from the questionnaires. My responses will be kept confidential and my name will never be used. All records will be destroyed after the study is finished.

D. BENEFITS

There will be no direct benefit to me from participating in this study. However, the answers that I provide may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will be reimbursed $20.00 in cash immediately following participation in this study.

G. QUESTIONS

This study has been explained to me by Dr. Holzemer, Jeanne Kemppainen or the research nurse. If I have further questions, I may call Dr. William Holzemer at (415) 476-9713 or Jeanne Kemppainen at 510-490-0111.

If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00 Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient.

If I agree to participate, I should sign below.

______________ ______________________________
Date Signature of study Participant

______________ ______________________________
Date Signature of Person Obtaining Consent

UCSF CHR Approval No. : H642-11088-01

Subject Interview Receipt

This is to certify that ______________________________ has participated in a study of how the behavior of nurses affects patients with HIV/AIDS at the University of California on __________________. She received $20.00 for her time, effort, and experience involved.

_________________________ _____________________________

Nurse Researcher Signature

____

Social Security No.

____

Date

Consent Form Phase I - Hospitalized Subjects

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SAN FRANCISCO VETERAN'S AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Developing a Measure of Patients' Responses to Nurses
Phase I-Scale Development

A. PURPOSE AND BACKGROUND

William L. Holzemer, RN, Ph.D., Professor at UCSF School of Nursing, and Jeanne K. Kemppainen, RN, MSN, Doctoral Candidate at UCSF School of Nursing are conducting a study to learn how hospitalized patients with HIV/AIDS respond to nurses' behaviors.

The findings from this study should provide important information for teaching nurses how best to provide care to patients with HIV/AIDS. I have been asked to participate in this study because I am in the hospital and am in the best position to describe my experiences with nurses.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be interviewed once during my hospital stay. Approximately three days after entering the hospital, a research nurse who does not work on my unit will explain the study to me. If I agree to participate in the study I will be asked to sign a consent form.
2. If I sign and agree, I will take part in a 30 minute interview. A research nurse will read an open ended questionnaire to me and ask me talk about my responses to nurses behaviors. I will be asked to talk about my opinions. The interview will be conducted in a private place so my answers won't be accidentally overheard. My answers will be filed in a locked place immediately after the interview.
3. A research nurse will also complete a review of my inpatient chart.

C. RISKS/DISCOMFORTS

Participating in this study may cause some feelings of discomfort. Being asked to recall responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction with nursing care which may surface may affect my interactions with nurses. If I become uncomfortable, however, I will be able to stop participating in the study at any time.

Participation in this research study may involve a potential loss of privacy, however, my records will be handled as confidentially as possible. All interviews will be conducted in a private place so that my answers will not be accidentally overheard. The only way that a nurse will know my answers will be if I tell them. Immediately after the interview, my records will be filed in a locked place. Only Dr. Holzemer, and Jeanne Kemppainen will have access to my responses from the questionnaires. My responses will be kept confidential and my name will never be used. All records will be destroyed after the study is finished.

D. BENEFITS

There will be no direct benefit to me from participating in this study. However, the answers that I provide may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will not be reimbursed for participating in this study.

G. QUESTIONS

This study has been explained to me by Dr. Holzemer, Jeanne Kemppainen or the research nurse. If I have further questions, I may call Dr. William Holzemer at (415) 476-9713 or Jeanne Kemppainen at 510-490-0111.

If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00 Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient.

If I agree to participate, I should sign below.

______________	________________________________
Date	Signature of study Participant
______________	________________________________
Date	Signature of Person Obtaining Consent

Consent Form Phase I - Hospitalized Subjects at Palo Alto VA Hospital

Informed Consent

Are you participating in any other studies? _____yes _____no

Date: Nov. 19, 1996

Title: Developing a Measure of Patient Responses to Nursing Behaviors-Phase I

You are invited to participate in a study which will learn how the behavior of nurses affects patients with AIDS. The findings from this study should provide important information for teaching nurses how best to care for these patients. Patients who are in the hospital are in the best position to describe their experiences with nurses. Your answers will provide important information for this study.

If you decide to participate in this study, you will be asked to describe how you were affected by nurses' behaviors on a questionnaire. The questionnaire will take approximately 30 minutes to complete. There will be no risks or physical discomfort associated with completing this questionnaire. We cannot and do not guarantee or promise that you will receive any benefits from this study.

No payment will be provided for this project. there will be no additional cost to you for participation in this study. It is not expected that this study will cause you any discomfort and only minimal inconvenience.

There will be no direct benefits to you but you will help provide important information for teaching nurses to provide the best possible care in the future Our purpose is to learn about patient responses to nursing behaviors. Your treatment will not be withheld.

Any information that may be published in scientific journals will not reveal your identity. All data will be reported as group data. Patient information may be provided to Federal and regulatory agencies as required.

While participating in this study, you should not take part in any other research projects without approval from the investigators. this is to protect you from possible injury arising from such things as extra blood drawing, extra x-rays, interaction of research drugs, or similar hazards.

____

Signature and date

Title: developing a Measure of Patient Responses to Nursing Behaviors Date: Nov. 19, 1996

You will be told if any new information is learned which may affect your condition or influence your willingness to continue participation in this study. At the discretion of the principal investigator subjects may be taken out of this study.

Your decision whether or not to participate will not prejudice you or your medical care. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice to you or effect on your medical care. If you have any questions, we expect you to ask us. If you have any additional questions later, Jeanne Kemppainen MSN at (415) 493-5000, ext. 22205, or Dr. William Holzemer at the University of California at San Francisco at (415) 476-9713 will be happy to answer them.

All forms of medical diagnosis and treatment, whether routine or experimental, involve some risk of injury. In spite of all precautions, you might develop medical complications from participating in this study. If such complications arise, the researchers will assist you in obtaining appropriate medical treatment but this study does not provide financial assistance for additional medical or other costs. You do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write the Administrative Panel on Human Subjects in Medical research, Administrative Panels Office, Stanford, California 94305-5532. In addition, if you are not satisfied with the manner in which this study is being conducted or if you have any questions concerning your rights as a study participant, please contact the Human Subjects Office at the same address and telephone number.

In the unlikely event you are injured as a result participation in this study. V. A. Palo Alto Health Care System will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provision of the Federal tort Claims Act and/or 38 U. S. C. section 1151 (formerly section 351) (for veteran participants only). For further information, contact the V. A. District Counsel at (415) 750-2288.

____

Signature and Date

Informed Consent

Title: Developing a Measure of Patients' Responses to Nursing behaviors Date: Nov. 19, 1996

Experimental Subject's Bill of Rights

Persons who participate in a medical experiment are entitled to certain rights. These rights include by are not limited to the subject's right to:

be informed of the nature and purpose of the experiment; be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized;

be given a description of any attendant discomforts and risks reasonable to be expected;

to given an explanation of any benefits to the subject reasonable to be expected, if applicable;

be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits;

be informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise;

be given an opportunity to ask questions concerning the experiment or the procedures involved;

be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice;

be given a copy of the signed and dated consent form;

and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HE STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

____

Signature and Date

____

Signature of Investigator or Witness

Approval Date:____________________ Expiration Date:______________________

Appendix B

Research Packet-Phase I

Demographic Data Form

Critical Incident Form A

Critical Incident Form B

Demographic Data Form Phase I

Date: ________
Site: ___________
Ward: __________
Subject No. ______

Directions: Each question has several possible answers. Please place a circle (0) around the answer that best describes your situation or fill in the blank.

1. Age ______

2. Sex
   a. Male
   b. Female

3. Highest level of education completed:
   a. Junior High School
   b. High School
   c. Junior College
   d. College
   e. Other _________________

4. Were you ever hospitalized before learning that you had HIV/AIDS?
   a. Yes
   b. No

If yes, why?

____

____

5. On a scale from 1 to 5, with 5 being "the best" and 1 being "the worst", how would you rate your experiences with the nurses at that time?
   a. 5
   b. 4
   c. 3
   d. 2
   e. 1

6. On a scale from 1 to 5, with 5 being "the best" and 1 being "the worst", how would you rate your experiences with the nurses during this hospitalization?
   a. 5
   b. 4
   c. 3
   d. 2
   e. 1

7. How long have you had an AIDS diagnosis?

_________________________month/year

8. How do you think you got exposed to HIV?
   a. Male-male sex
   b. IV drug use
   c. Male-female sex with IV drug user
   d. Male-female sex with bisexual man
   e. Male-female sex with hemophiliac
   f. Male-female sex with a transfusion recipient
   g. Transfusion recipient
   h. Work in health care setting or lab
   I. Don't know

9. Do you know your CD4 count?
   a. Yes
   b. No

If yes, __________mm3

Date: ____________
Site: ____________
Ward: ____________
Subject No. _______

Chart Audit Data

Length of HIV+ ________________________________(months)
Length of AIDS ________________________________(months)
CD4 count ____
AIDS defining diagnosis _______________________________
____
Current diagnosis _____________________________________
____
____
____

Risk factors:
Male-male sex ____
IV drug use ____
Male-female sex with IV drug user ____________________
Male-female sex with bisexual man ____________________
Male-female sex with hemophiliac _____________________
Male-female sex with transfusion recipient ____________
Transfusion recipient _________________________________
Work in health care setting or lab ____________________
Unspecified ____

Ethnicity:
Asian/Pacific Islander ________________________________
Black (not Hispanic) __________________________________
Hispanic ____
Caucasian ____
Not specified ____

Length of Stay: __________________Days

Incident Questionnaire: Form I

Date: ____________
Site: ____________
Ward: ___________
Subject No. _______

Incident Questionnaire: Form I

Think about a time a nurse treated you well. When did this happen? ______________________________

____

____

____

____

What were the circumstances which led up to this event? ______________________________________

____

____

____

____

Exactly what did the nurse do? ____

____

____

____

____

How did you respond to the nurse? ____

____

____

____

____

____

How did the nurse's actions affect your behavior? ____

____

____

____

____

____

Incident Questionnaire: Form II

Date: ________
Site: ________
Ward: ________
Subject No. _____

Incident Questionnaire: Form II

Think about a time that a nurse did not treat you well. When did this happen? ____________________

What were the circumstances which led up to this event? ____________________

Exactly what did the nurse do? ____________________

How did you respond to the nurse? ____________________

How did the nurse's actions affect your behavior? ____________________

What would have been helpful to you? ____________________

Appendix C

Training Manual/Subject Log

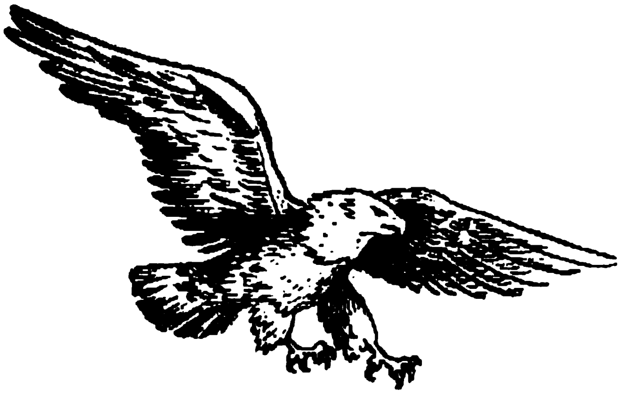
Miami

VA Medical

Center

Subject Log/

Training Manual



Data Collector Training
Miami VA Medical Center

Research Project: Developing a Measure of Patients' Responses to Nurses

Principal Investigator: Lisa Burton, RN

1. Each data collector will be trained by the associate investigator, Jeanne K. Kemppainen, RN, doctoral candidate at the University of California, San Francisco, and Clinical Nurse Specialist at the Palo Alto VA Health Care System in Palo Alto, CA. The training session will be two hours in length.

2. The training session will include a discussion of the following items:;

   A. Purpose of the Study: The data collector will be instructed in the overall purpose of the study: 1) to develop a practical, brief outcome measure (Patient's Responses to Nurse Behaviors) which documents the behavioral responses of patients with HIV/AIDS to nurses' behaviors, and 2) to complete psychometric testing of the outcome measure and provide initial evidence for reliability and validity.

   B. Inclusion Criteria: The following inclusion criteria will be reviewed with opportunities for questions:

      1. Male and female veteran patients with an AIDS defining diagnosis.
      2. Age 18 years and older.
      3. Hospitalized in a Medical-Surgical ward for at least 3 days.
      4. Able to read and write English
      5. Mentally alert.
      6. Subjects are selected from all AIDS subgroups, including homosexual and bisexual men, male and female injection drug users, and male and female patients of all racial and ethnic minorities.
      7. Hospitalization may be for any diagnosis, not just AIDS-related treatment.

   C. Exclusion Criteria: The following exclusion criteria will be reviewed with opportunities for questions:

      1. Subjects who present clinical indications of dementia, or who have a diagnosis of AIDS dementia documented in their hospital record.
      2. Subjects who are too ill or debilitated to participate.
      3. Subjects who deny or are sensitive to their AIDS diagnosis.
      4. Subjects who present disruptive, aggressive, acutely psychotic, or self-destructive behaviors. (Examples may include a patient on constant observation because of suicidal precautions or a patient who is actively hallucinating.)
      5. Subjects hospitalized in a Nursing Home Care Unit, drug treatment program, or psychiatric unit.

D. Consent Form: The consent form will be reviewed in detail.

1. Purpose and background.
2. Procedures-questionnaires, chart audit
3. ***Risks/Discomfort***: The data collector will be instructed in the rights of the subject to discontinue the study at anytime and also issues surrounding confidentiality. The confidentiality of each subject will be respected and all records associated with the study will be sent to the principal investigator for storage in a locked file. No names or addresses or other identifying data will be used.
4. ***Potential risks***: The data collector will be taught that this study is not expected to cause any physical or psychological discomfort for the subjects and only minimal inconvenience. The training session will emphasize that the collection of information may affect the relationship between subjects and their nurses. Participation in this study may cause feelings of dissatisfaction to surface which may affect nurse-patient relationships. Training will include emphasis on respecting the sensitive nature of the data and confidentiality. All interviews will be conducted in a private place so that any conversation between the data collector and the subjects would not be accidentally overheard. Immediately after the interview, all patient records and questionnaires will be filed in a locked place.
5. ***Benefits***: The discussion will emphasize the fact that there will be no direct benefit to the subjects, however, the answers provided by the subjects may provide important information for teaching nurses how best to care for patients with AIDS.
6. ***Costs***: The discussion will include the fact that there are no costs to the patient for participation in the study.
7. ***Questions***: The discussion will include order of who subject needs to speak with it he or she has questions and the role of the University of California, San Francisco Committee on Human Research in this study.
8. ***Consent***: The discussion will include directions for giving the subject a copy of the attached consent form, the voluntary nature of this study, and the important that participation or no participation will not affect the quality of care.

E. Recruitment of Subjects: The nurse manager or staff nurse will be approached and asked about potential patients who would meet the study criteria. Patients will then be approached by the data collector and asked about their desire to participate in this study. Informed consent will be obtained from each subject. The data collector will also audit patient charts for indications of AIDS dementia and to obtain information which confirms the AIDS presence of an AIDS defining diagnosis and stage of illness. Each subject will receive a packet containing a cover letter, a demographic data sheet, a draft of the instrument (Patients' Responses to Nurses), questionnaires necessary for psychometric testing, the HIV/QAM, and a chart audit form. In order to minimize disruption of care, the data collector will be taught to schedule an appointment at the convenience of the subject.

The estimated time for subjects to complete the written questionnaires is 30 minutes. Experiences with patients at both the Palo Alto and San Francisco VA Medical Centers show that most of the patients prefer to have the questionnaire read to them; this diminishes fatigue and increases patient participation.

The data collector will complete the HIV/QAM and also the chart audit form after the patient has completed the questionnaires.

F. General issues:

1. The research packet should be checked for completeness before each interview. Each page in the packet should have the subject's ID number at the top right hand corner. All subject numbers from the Miami VA Medical Center will be preceded with a "3".
2. **It is important to review the forms once the subject has completed them and observe each page for missing or ambiguous data. Clarify any issues with the subject before concluding the interview and complete any missing data.**
3. Do not hesitate to call Jeanne Kemppainen at any of the numbers listed below if there are any questions.
4. Following each interview, please fax the original data sheets to Jeanne Kemppainen

Fax: 1-800-___-____ Code Number = __

Fax Alternate Number: 510-___-____

Phone: (415) ___-____, Ext. _____ (work), (510) ___-____ (home)

Suggested Script for Subject Recruitment

Experiences recruiting subjects during Phase I of the study showed that patients were much more willing to participate if the following introduction were used. Do not hesitate, however, to use your own style of approach in recruiting subjects.

"My name is ___________. I'm a VA nurse. We are conducting a research study which looks for ways to improve the quality of health care provided to veterans with AIDS. Your opinions would help us find ways to teach nurses about ways to improve their care. Would you be interested in helping with this?"

If patient expresses interest, then begin a more detailed explanation.

Study Participants: VA Medical Center, Miami

Subject No.	Date	Subject Name	Social Security No.
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
15.			
16.			
17.			
18.			
19.			
20.			
21.			
22.			
23.			
24.			
25.			

Study Participants: VA Medical Center, Miami

Subject No.	Date	Subject Name	Social Security No.
26.			
27.			
28.			
29.			
30.			
31.			
32.			
33.			
34.			
35.			
36.			
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Appendix D

Consent Forms-Phase II

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SAN FRANCISCO VETERAN'S AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Developing a Measure of Patients' Responses to Nurses
Phase II-Psychometric Testing

A. PURPOSE AND BACKGROUND

William L. Holzemer, RN, Ph.D., Professor at UCSF School of Nursing, and Jeanne K. Kemppainen, RN, MSN, Doctoral Candidate at UCSF School of Nursing are conducting a study which tests a questionnaire that measures how the behavior of nurses affects patients with HIV/AIDS.

The findings from this study should provide important information for teaching nurses how best to provide care. I have been asked to participate in this study because I was recently hospitalized and am in the best position to describe my experiences with nurses.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be participate once. A research nurse will explain the study to me. If I agree to be in the study, I will be asked to sign a consent form.
2. If I sign and agree, I will be asked to complete three written questionnaires, and rate how my the behaviors of nurses affected me. Completing the questionnaires will take about 30 minutes. I will be asked to write about my opinions. The questionnaires will be answered in a private place so my answers won't be accidentally seen. My answers will be filed in a locked place immediately afterward.

C. RISKS/DISCOMFORTS

Participating in this study may cause some feelings of discomfort. Being asked to recall some responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction with nursing care which may surface may affect my interactions with nurses. I will be able to stop participating in the study at any time if I become uncomfortable.

Participation in research may involve a potential loss of privacy: however, my records will be handled as confidentially as possible. The questionnaires will be filled out in a private place so that my answers may not be accidentally seen. The questionnaires will be collected by the research nurse and filed in a locked place immediately after they are completed. Only Dr. Holzemer and Jeanne Kemppainen will have access to my responses from the questionnaires. My responses will be kept confidential and my name will never be used. All records will be destroyed after the study.

D. BENEFITS

There will be no direct benefit to me from participating in this study. However, the answers that I provide may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will be reimbursed $20.00 in cash immediately following participation in this study.

G. QUESTIONS

This study has been explained to me by Dr. Holzemer, Jeanne Kemppainen or the research nurse. If I have further questions, I may call Dr. William Holzemer at (415) 476-9713 or Jeanne Kemppainen at 510-490-0111.

If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00 Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient.

If I agree to participate, I should sign below.

Date ______________ Signature of study Participant ______________________________

Date ______________ Signature of Person Obtaining Consent ______________________________

UCSF CHR Approval No. : H642-11088-01

This is to certify that ______________________________ has participated in a study of how the behavior of nurses affects patients with HIV/AIDS at the University of California on ___________________. She received $20.00 for her time, effort, and experience involved.

_________________________	_____________________________
Nurse Researcher	Signature
	_____________________________
	Social Security No.
	_____________________________
	Date

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SAN FRANCISCO VETERAN'S AFFAIRS MEDICAL CENTER
CONSENT TO BE A RESEARCH SUBJECT

Developing a Measure of Patients' Responses to Nurses
Phase II-Psychometric Testing

A. PURPOSE AND BACKGROUND

William L. Holzemer, RN, Ph.D., Professor at UCSF School of Nursing, and Jeanne K. Kemppainen, RN, MSN, Doctoral Candidate at UCSF School of Nursing are conducting a study which tests a questionnaire that measures how the behavior of nurses affects patients with HIV/AIDS.

The findings from this study should provide important information for teaching nurses how best to provide care. I have been asked to participate in this study because I am in the hospital and am in the best position to describe my experiences with nurses.

B. PROCEDURES

If I agree to be in the study, the following will occur:

1. I will be participate once during my hospital stay. Approximately three days after entering the hospital a research nurse who does not work on my hospital ward will explain the study to me. If I agree to be in the study, I will be asked to sign a consent form.
2. If I sign and agree, I will be asked to complete written questionnaires, and rate how my the behaviors of nurses affected me. Completing the questionnaires will take about 30 minutes. I will be asked to write about my opinions. The questionnaires will be answered in a private place so my answers won't be accidentally seen. My answers will be filed in a locked place immediately afterward.
3. A research nurse will also complete a review of my chart.

C. RISKS/DISCOMFORTS

Participating in this study may cause some feelings of discomfort. Being asked to recall some responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction with nursing care which may surface may affect my interactions with nurses. I will be able to stop participating in the study at any time if I become uncomfortable.

Participation in research may involve a potential loss of privacy: however, my records will be handled as confidentially as possible. The questionnaires will be filled out in a private place so that my answers may not be accidentally seen. The questionnaires will be collected by the research nurse and filed in a locked place mmediately after they are completed. Only Dr. Holzemer and Jeanne Kemppainen will have access to my responses from the questionnaires. My responses will be kept confidential and my name will never be used. All records will be destroyed after the study.

D. BENEFITS

There will be no direct benefit to me from participating in this study. However, the answers that I provide may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

E. COSTS

There will be no costs to me as a result of taking part in this study.

F. PAYMENT

I will not be reimbursed for participating in this study.

G. QUESTIONS

This study has been explained to me by Dr. Holzemer, Jeanne Kemppainen or the research nurse. If I have further questions, I may call Dr. William Holzemer at (415) 476-9713 or Jeanne Kemppainen at 510-490-0111.

If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00 Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

I have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future status as a patient.

If I agree to participate, I should sign below.

Date	Signature of study Participant
Date	Signature of Person Obtaining Consent

Informed Consent

Are you participating in any other studies? _____yes _____no

Date: Nov. 19, 1996

Title: Developing a Measure of Patient Responses to Nursing Behaviors-Phase II

You are invited to participate in a study which will learn how the behavior of nurses affects patients with AIDS. The findings from this study should provide important information for teaching nurses how best to care for these patients. Patients who are in the hospital are in the best position to describe their experiences with nurses. Your answers will provide important information for this study.

If you decide to participate in this study, you will be asked to complete three written questionnaires, and rate how the behavior of nurses affected you. Completing the questionnaires will take about 30 minutes. The questionnaires will be answered in a private place so your answers won't be accidentally seen. Your answers will be filed in a locked place immediately afterward. A research nurse will also complete a review of your chart. There will be no risks or physical discomfort associated with completing this questionnaire. We cannot and do not guarantee or promise that you will receive any benefits from this study.

No payment will be provided for this project. there will be no additional cost to you for participation in this study. It is not expected that this study will cause you any discomfort and only minimal inconvenience.

There will be no direct benefits to you but you will help provide important information for teaching nurses to provide the best possible care in the future Our purpose is to learn about patient responses to nursing behaviors. Your treatment will not be withheld.

Any information that may be published in scientific journals will not reveal your identity. All data will be reported as group data. Patient information may be provided to Federal and regulatory agencies as required.

While participating in this study, you should not take part in any other research projects without approval from the investigators. this is to protect you from possible injury arising from such things as extra blood drawing, extra x-rays, interaction of research drugs, or similar hazards.

____

Signature and date

Title: developing a Measure of Patient Responses to Nursing Behaviors Date: Nov. 19, 1996

You will be told if any new information is learned which may affect your condition or influence your willingness to continue participation in this study. At the discretion of the principal investigator subjects may be taken out of this study.

Your decision whether or not to participate will not prejudice you or your medical care. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice to you or effect on your medical care. If you have any questions, we expect you to ask us. If you have any additional questions later, Jeanne Kemppainen MSN at (415) 493-5000, ext. 22205, or Dr. William Holzemer at the University of California at San Francisco at (415) 476-9713 will be happy to answer them.

All forms of medical diagnosis and treatment, whether routine or experimental, involve some risk of injury. In spite of all precautions, you might develop medical complications from participating in this study. If such complications arise, the researchers will assist you in obtaining appropriate medical treatment but this study does not provide financial assistance for additional medical or other costs. You do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write the Administrative Panel on Human Subjects in Medical research, Administrative Panels Office, Stanford, California 94305-5532. In addition, if you are not satisfied with the manner in which this study is being conducted or if you have any questions concerning your rights as a study participant, please contact the Human Subjects Office at the same address and telephone number.

In the unlikely event you are injured as a result participation in this study. V. A. Palo alto health care system will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provision of the federal tort claims act and/or 38 u. S. C. Section 1151 (formerly section 351) (for veteran participants only). For further information, contact the v. A. District counsel at (415) 750-2288.

____

Signature and Date

Informed Consent

Title: Developing a Measure of Patients' Responses to Nursing behaviors Date: Nov. 19, 1996

Experimental Subject's Bill of Rights

Persons who participate in a medical experiment are entitled to certain rights. These rights include by are not limited to the subject's right to:

be informed of the nature and purpose of the experiment; be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized;

be given a description of any attendant discomforts and risks reasonable to be expected;

to given an explanation of any benefits to the subject reasonable to be expected, if applicable;

be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits;

be informed of the avenues of medical treatment, if any available to the subject after the experiment if complications should arise;

be given an opportunity to ask questions concerning the experiment or the procedures involved;

be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice;

be given a copy of the signed and dated consent form;

and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HE STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

____

Signature and Date

____

Signature of the Investigator or Witness

Approval Date:____________________ Expiration Date:______________________

VETERANS AFFAIRS MEDICAL CENTER-SAN DIEGO
CONSENT TO ACT AS A RESEARCH SUBJECT
PHASE II-Psychometric Testing

Jeanne K. Kemppainen, RN, MSN, Doctoral Candidate at UCSF School of Nursing, and William Holzemer, RN, Ph.D., Professor at UCSF School of Nursing are conducting a study to learn how hospitalized patients with HIV/AIDS respond to nurses' behaviors. The findings from this study should provide important information for teaching nurses how best to provide care to patients with HIV/AIDS. Your have been asked to participate in this study because you are currently in the hospital and are in the best position to describe your experiences with nurses.

If you agree to be in this study, the following will happen to you:

1. You will be interviewed once during your hospital stay. Approximately three days after entering the hospital, a research nurse who does not work on your unit will explain the study to you. If you agree to participate in the study, you will be asked to sign a consent form.
2. If you sign and agree, you will be asked to complete three written questionnaires and rate how the behavior of nurses affected you. Completing the questionnaires will take about 30 minutes. You will be asked to write about your opinions. The questionnaires will be answered in a private place so your answers won't be accidentally seen.. Your answers will be filed in a locked place immediately afterward.
3. A research will also complete a review of your inpatient chart.

Participation in this study may involve some added risks or discomforts. These include:

1. Being asked to recall some responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction with nursing care which may surface may affect your interactions with nurses. You will be able to stop participating in the study at any time if you become uncomfortable.
2. Participation in this study may involve a potential loss of privacy, however, your records will be handled as confidentially as possible. The questionnaires will be filled out in a private place so that your answers may not be accidentally seen. The questionnaires will be collected by the research nurse and filed in a locked place immediately after they are completed. Only Jeanne Kemppainen and Dr. Holzemer will have access to your responses from the questionnaires. Your responses will be kept confidential and no names will be used. All records will be destroyed after the study.

You will not be paid for participating in this study.

If you are injured as a direct result of being in this study, treatment will be available. If you are eligible for veteran's benefits, the cost of such treatment will be covered by the Veteran's Administration. If not, the costs of such treatment may be covered by the Veteran's Administration and the University of California depending on a number of factors. The Veteran's Administration and the University do not normally provide any other form of compensation for injury. For further information about this, you may call the VA District Counsel at (619) 557-6718 or the Human Subjects Committee Office at UCSD at (619) 534-4520.

There will be no direct benefit to you from participating in this study. However, your answers may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

Jeanne Kemppainen RN, Dr. Holzemer, or the research nurse has explained this study to you and answered your questions. If you have other questions or research-related problems, you may reach Jeanne Kemppainen at (510)-490-0111 or Dr. Holzemer at (415) 476-1814.

Participation in research is entirely voluntary. You may refuse to participate or withdraw at any time without jeopardy to the medical care you will receive at this institution.

Research records will be kept confidential to the extent provided by law.

You have received a copy of this consent document to keep and the "The Experimental Subject's Bill of Rights."

You agree to participate.

Subject's Signature	Witness	Date

XX LOW RISK ____ MEDIUM TO HIGH RISK STUDY # 0001

Department of Veterans Affairs

VA RESEARCH CONSENT FORM

VAMC WEST LOS ANGELES, WADSWORTH

Subject Name: ______________________ **Date** __________

Title of Study: Developing a Measure of Patients' Responses to Nurses: Phase I

Principal Investigator:	Leslie Evans, R.N., M.S.	Phone	(310) 478-3711 X49115
Co-Investigators:	Jeanne Kemppainen, R.N., M.N.	Phone	(415) 493-5000 X2205
		Phone	
		Phone	

ESCRIPTION OF RESEARCH BY INVESTIGATOR

1. Background and Purpose of the Study and How long it will last:
   The purpose of this study is to learn how the behavior of nurses affects patients with AIDS. The findings from this study should provide important information for teaching nurses how best to provide care to patients with HIV/AIDS. I have been asked to participate in this study because I am in the hospital and can describe my experiences with nurses. My participation is a one time interview which will take about 30 minutes. I am one in 150 patients participating in this study and one of fifty from this Medical Center.

2. Description of the Study and Procedures to be used:
   I will be interviewed once during my hospital stay. I will be asked to complete a written questionnaire about my responses to nurses' behaviors. I will be asked to write about my opinions. Completing the interview will take about 30 minutes. A research nurse will complete a review of my inpatient chart.

3. Description of Procedures that may result in discomfort or inconvenience:
   Being asked to recall my responses to nurses' behaviors may produce some unpleasant feelings. I will be able to stop participating in the study at any time if I feel too uncomfortable. The collection of this information may affect the relationship between myself and nursing staff. I may experience feelings of dissatisfaction related to my care. The investigator will respect the sensitive nature of the information and confidentiality will be maintained. All interviews will be conducted in a private place so that any conversation between the nurse researcher and myself would not be accidentally overheard.

ECT'S IDENTIFICATION (I.D. plate or give name–last, first, middle)

COMMITTEE ON HUMAN STUDIES APPROVED

3-18-96

VOID AFTER 3-11-97

VA FORM JAN 1990 **10-1086**

STUDY # 0001

Department of Veterans Affairs

VA RESEARCH CONSENT FORM

(Continuation Page 2 of 3)

VAMC WEST LOS ANGELES, WADSWORTH

Subject Name: ______________________ **Date** __________

Title of Study: Developing a Measure of Patients' Responses to Nurses: Phase I

Principal Investigator: Leslie Evans, R.N., M.S. **Phone** (310) 478-3711 X49115

Co-Investigator: Jeanne Kemppainen, R.N., M.N. **Phone** (415) 493-5000 X2205

Phone __________

Phone __________

4. Expected and Potential risks of the Study:
   There is no risk to me by participating in this study other than the discomfort from unpleasant feelings.

5. Expected and Potential Benefits of the Study:
   There will be no direct benefit to me from participating in this study. However, the answers that I provide may provide important information for teaching nurses how best to care for patients with HIV/AIDS.

6. Other Treatment Available:
   This is not a treatment study.

7. Use of Research Results:
   My confidentiality will be maintained. All my records and questionnaires will be filed in a locked place. My responses will be combined with the responses from other patients. I will not be identified at any time in reporting study results. The findings will be used to develop a tool for nurses to use in providing care to HIV/Aids patients. Ultimately the findings of this study will be reported in the nursing literature and at research conferences.

8. Special Circumstances:
   There will be no cost to me as a result of taking part in this study. I will not be reimbursed for participating in this study. If I have any comments or concerns about participating in this study, I may contact the Chair of the Human Subjects Subcommittee at (310) 268-4434. Confidentiality may be compromised by review of research records by government agencies as required by law.

COMMITTEE ON HUMAN STUDIES APPROVED

3-18-96

VOID AFTER 3-17-97

STUDY # 0001

Department of Veterans Affairs

VA RESEARCH CONSENT FORM

(Continuation Page 3 of 3)

Subject Name: ______ VAMC WEST LOS ANGELES, WADSWORTH **Date** ______

Title of Study: Developing a Measure of Patients' Responses to Nurses: Phase I

Principal Investigator: Leslie Evans, R.N., M.S. **Phone** (310) 478-3711 X49115

Co-Investigator: Jeanne Kemppainen, R.N., M.N. **Phone** (415) 493-5000 X2205

______ **Phone** ______

______ **Phone** ______

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. Dr. Leslie Evans has explained the study to me and answered all of my questions. I have been told of the risks or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty or loss of VA or other benefits to which I am entitled.

The results of this study may be published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Dr. Leslie Evans (310)478-3711x49115 during the day and Dr. Leslie Evans at (310)641-3831 after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

______ ubject's Signature

______ Date

______ ignature of Subject's Representative*

______ Subject's Representatives

______ ignature of Witness

______ Witness (print)

______ ignature of Investigator

*Only required if subject not competent.

COMMITTEE ON HUMAN STUDIES
APPROVED
3-18-96
VOID AFTER 3-17-97

MORE THAN ONE PAGE IS USED. EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

Standard Form 507 **R E S E A R C H** [illegible] GPO

CLINICAL RECORD

RESEARCH SUMMARY SHEET
Report on ____________
or
Continuation of S. F. ____________
(Strike out one line) (Specify type of examination or data)

RESEARCH STUDY TITLE: Developing a Measure of Patients to Nurses: Phase I

STUDY NUMBER 0001

RESPONSIBLE PHYSICIAN/INVESTIGATOR(s)	PHONE NUMBER
Leslie Evans, R.N., M.S.	(310) 478-3711 X49115
Jeanne Kemppainen, R.N., M.N.	(415) 493-5000 X2205

PURPOSE: The purpose of this study is to learn how the behavior of nurses affects patients with AIDS.

DRUGS: ____________ **SPECIAL PROCEDURES** ____________

ANTICIPATED DURATION OF STUDY FOR THIS PATIENT ____________

OTHER PERTINENT INFORMATION: (Such as laboratory work over and above routine medical tests, x-rays, biopsies, etc.) (Contradictive drugs which should not be given, etc.)

CONTENTS OF THIS RESEARCH PACKAGE:

WHITE - Research Summary Sheet
YELLOW - Med-High Risk Patient Consent Form
d/or GREEN - Low-Risk Patient Consent Forms
WHITE - Research Approval VA Form 10-1223
**List all drugs given on VA Form 10-2970, Medication/Treatment Form
**Indicate progress on Progress Notes, SF 409

Mark one of the following at termination of subject's participation in study.

——COMPLETED STUDY ——WITHDREW VOLUNTARILY ——DROPPED FROM STUDY*

*why ____________

(Continue on reverse side)

PATIENT'S IDENTIFICATION *(For typed or written entries give: Name—last, first, middle; grade; date; hospital or medical facility)*	REGISTER NO.	WARD NO.

REPORT ON ______ **or CONTINUATION OF** ______

STANDARD FORM 507
General Services Administration and
Interagency Committee on Medical Records
FPMR 101-11.80 6-8
October 1975 507-106

Research

Department of Veterans Affairs

REPORT OF SUBCOMMITTEE ON HUMAN STUDIES

NEW PROTOCOL
Revised Patient Consent Form

STUDY #0001

Project/Program Title Developing a Measure of Patients' Responses to Nurses: Phase I

Principal Investigator Leslie Evans, R.N., M.S.

VAMC West Los Angeles, CA

Review Date March 18, 1996

COMMITTEE FINDINGS:

1. The information given in the Informed Consent under the <u>Description of Research by Investigator</u> is complete, accurate, and understandable to a research subject or a surrogate who possesses standard reading and comprehension skills.
☒ YES
☐ NO

2. The informed consent is obtained by the principal investigator or a trained and supervised designate under suitable circumstances.
☒ YES
☐ NO

3. Every effort has been made to decrease risk to subject(s)?
☒ YES
☐ NO

4. The potential research benefits justify the risk to subject(s)?
☒ YES
☐ NO

5. If subject is <u>incompetent</u> and surrogate consent is obtained, have all of the following conditions been met: a) the research can't be done on competent subjects; b) there is no risk to the subject, or if risk exists the direct benefit to subject is substantially greater; c) if an incompetent subject resists, he will not have to participate; d) if there exists any question about the subject's competency, the basis for decision on competency has been fully described.
☐ YES
☐ NO
☒ NA

6. If the subject is paid the payment is reasonable and commensurate with the subject's contribution.
☐ YES
☐ NO
☒ NA

. Comments: (<u>Indicate if Expedited Review</u>)

RECOMMENDATION: ☒ APPROVE ☐ DISAPPROVE/REVISE

IGNATURE OF CHAIRMAN
Karl Syndulko
KARL SYNDULKO, Ph.D.

DATE
3/18/96

A FORM
AN 1990 **10-1223**

DEPARTMENT OF VETERANS AFFAIRS
Medical Center
West Los Angeles
11301 Wilshire Boulevard
Los Angeles CA 90073

691/151
In Reply Refer To

RIGHTS OF HUMAN SUBJECTS IN MEDICAL EXPERIMENTS

Any person who is requested to consent to participate as a subject in a research study involving a medical experiment or who is requested to consent on behalf of another has the right to:

1. Be informed of the nature and purpose of the experiment.

2. Be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.

3. Be given a description of any attendant discomforts and risks reasonably to be expected from the experiment.

4. Be given an explanation of any benefits to the subject reasonably to be expected from the experiment, if applicable.

5. Be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous to the subject, and their relative risks and benefits.

6. Be informed of the avenues of medical treatment, if any, available to the subject after the experiment if complications should arise.

7. Be given an opportunity to ask any questions concerning the experiment or the procedure involved.

8. Be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation in the medical experiment without prejudice.

9. Be given a copy of any signed and dated written consent form used in relation to the experiment.

10. Be given an opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on the subject's decision.

Department of Veterans Affairs

VA Research Consent Form

Page 1 of 3

Subject Name: Date:

Title of Study: Developing a Measure of Patients' Responses to Nurses - Phase I

Principal Investigator: Lisa Burton, ARNP, MSN VAMC: Miami

PURPOSE OF THE STUDY AND HOW LONG IT WILL LAST: We are conducting a study to learn how patients in hospitals with HIV/AIDS respond to nurses' behaviors. The findings from this study should provide important information for teaching nurses how best to provide care to patients with HIV/AIDS. You have been asked to help with this study because you are in the hospital and are the best one to describe your experiences with nurses.

DESCRIPTION OF THE STUDY INCLUDING PROCEDURES TO BE USED:

About 150 patients will take part in this study. If you agree to be in this study, the following will happen to you:

1. You will be interviewed once during your hospital stay. About three days after entering the hospital, a research nurse who does not work on your unit will explain the study to you. If you agree to help with the study, you will be asked to sign a consent form.
2. If you sign and agree, you will take part in a 30 minute interview. A research nurse will read an open ended questionnaire to you and ask you to talk about your responses to nurses behaviors. You will be asked to talk about your opinions. The interview will be conducted in a private place so your answers won't be accidentally overhead. Your answers will be filed in a locked place immediately after the interview.
3. A research nurse will also complete a review of your inpatient chart.

The answers from the patients will be used to develop a questionnaire which can help nurses learn more about patients' responses to their care. The principal investigator can take you out of this study if for any reason it is in your best interest to do so or if your help needs to be stopped for administrative reasons.

Subjects Identification (I.D. plate or give name-last, first, middle)

DESCRIPTION OF ANY PROCEDURES THAT MAY RESULT IN DISCOMFORT OR INCONVENIENCE: It is not expected that helping with this study will hurt you but there may be a small inconvenience. Your help with this study will include only a single, 30 minute interview. There will be no physical pain associated with this study.

VA Form 10-1086
JAN 1990

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name:

Date:

Title of Study: Developing a Measure of Patients' Responses to Nurses - Phase I

Principal Investigator: Lisa Burton, ARNP, MSN

VAMC: Miami

EXPECTED RISKS OF STUDY: Helping with this study may involve some added risks or discomforts. Being asked to recall responses to nurses' behaviors may produce some unpleasant feelings. Feelings of dissatisfaction which may surface may affect your interactions with nurses. If you become uncomfortable, however, you will be able to stop helping with the study at any time.

Helping with this study may involve a potential loss of your privacy, however, your records will be handled as confidentially as possible. All interviews will be conducted in a private place so that my answer will not be accidentally seen. The only way that a nurse will know about your answers will be if you tell them. Immediately after the interview, your records will be filed in a locked place. Only Lisa Burton, RN, and the research nurse will have access to my responses from the questionnaires. Your responses will be kept confidential and your name will never be used. All records will be destroyed after the study is finished.

EXPECTED BENEFITS OF STUDY: No benefit can be promised you from helping with this study.. However, your answers may provide important information for teaching nurses how best to care for patients with HIV/AIDS. The results of the study will be available upon request at the end of the study.

OTHER TREATMENTS AVAILABLE: Because this phase of the research study asks about patients' pinions, there are no alternative treatments.

SE OF RESEARCH RESULTS: Your name or other information identifying you will not be used and ll answers will be kept confidential.

ou will be told and given in writing any new information that might affect your decision to be in this udy.

ou may ask any question you want about the study and we will try to answer them. You can refuse to be the study or stop being in the study at any time. If you do refuse or stop, the care you are entitled to at e VA will not be affected in any way.

you have any questions about your rights or about medical care because of problems caused by being in is research study, you can call the Chief of Medical Administration or his representative at extension 51.

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 3 of 3

Subject Name: Date:

Title of Study: Developing a Measure of Patients' Responses to Nurses - Phase I

Principal Investigator: Lisa Burton, ARNP, MSN VAMC: Miami

Research Subjects Rights: I have read or have had read to me all of the above. Lisa Burton, ARNP, MSN, or a research nurse has explained the study to me and answered all of my questions. I have been told of the risks or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to help will involve no penalty or loss of right to which I am entitled. I may withdraw from the study at any time without penalty or loss of VA or other benefits to which I am entitled.

The results of this study may be published, but my records will not be revealed unless required by law.

In case there are questions, I have been told I can call Lisa Burton, ARNP, MSN, at (305) 324-4455, extension 4688 (daytime) or (305) 225-0143 (nighttime).

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Subject's Signature Date

Signature of Witness Witness (print)

Signature of Investigator

Appendix E

Research Packet-Phase II

Demographic Data Form

HIV Symptom Checklist

Patients' Responses to Nurses' Behaviors scale (PRNB)

Patient Reactions Assessment (PRA)

Living with HIV scale

Beck Depression Inventory

HIV-QAM

Demographic Data Forms Phase II

This study looks at ways to improve the quality of nursing care for patients with HIV/AIDS. The findings from this study should provide important information for teaching nurses how best to care for patients with HIV/AIDS.

Your answers will be kept confidential and will never affect the quality of nursing care you receive. Your name will never be used.

Thank you for helping with this study.

Date:_____________

Site:______________

Subject No.________

Directions: Each question has several possible answers. Please place a circle (o) around the answer that best describes your situation or fill in the blank. Thank you!

A. Age_______

B. Sex

1. Male
2. Female

C. Years of education___________

D. How long have you known that you were HIV positive?

_________months __________years

E. How long have you had an AIDS diagnosis?

_________months __________years

F. How many times have you been hospitalized with an AIDS diagnosis?

1. Once (this time)
2. Twice
3. Three times
4. Four times
5. More than four times

G. How do you think you got exposed to HIV? (Pick as many as appropriate)

1. Male-male sex
2. IV drug use
3. Male-female sex with IV drug user
4. Male-female sex with bisexual man
5. Male-female sex with hemophiliac
6. Male-female sex with a transfusion recipient
7. Transfusion recipient
8. Work in health care setting or lab
9. Don't know

H. Do you know your CD4 count?

1. Yes
2. No

If yes, _________________mm3

Date:____________

Site:____________

Subject No.______

Completed by Research Assistant

Chart Audit Data

Length of HIV+______________________________

Length of AIDS diagnosis__________________________

CD4 Count________________________________

Current Medical Diagnosis_________________________

____

____

Risk Factors:

Male-male sex______________________________

IV drug use________________________________

Male-female sex with IV drug user____________________

Male-female sex with bisexual man____________________

Male-female sex with hemophiliac____________________

Male-female sex with transfusion recipient________________

Transfusion recipient____________________________

Work in health care setting________________________

Unspecified________________________________

Ethnicity:

Asian/Pacific Islander______________________________

Black (not Hispanic)______________________________

Hispanic______________________________

Caucasian______________________________

Not specified______________________________

Discharge Site:

Home______________________________

Skilled nursing facility______________________________

Hospice______________________________

Other (please specify)______________________________

Unknown______________________________

Length of Stay:____________**Days**

Mortality:____________

HIV Symptom Checklist

Below is a list of potential problems that you may be experiencing today. If you have the problem, rate the degree of intensity which best describes the extent of the problem you're experiencing. If you do not have the problem, leave it blank.

	MILD	MODERATE	SEVERE
Shortness of breath at rest	( )	( )	( )
Shortness of breath with activity	( )	( )	( )
Coughing	( )	( )	( )
Wheezing	( )	( )	( )
Diarrhea	( )	( )	( )
Loose stools	( )	( )	( )
Constipation	( )	( )	( )
Nausea	( )	( )	( )
Vomiting	( )	( )	( )
Gas/bloating	( )	( )	( )
Abdominal pain	( )	( )	( )
Lack of appetite	( )	( )	( )
Concern over weight loss	( )	( )	( )
Sore throat	( )	( )	( )
Thrush	( )	( )	( )
Insomnia/can't sleep	( )	( )	( )
Anxiety	( )	( )	( )
Depression	( )	( )	( )
Fear	( )	( )	( )
Memory loss	( )	( )	( )
Difficulty concentrating	( )	( )	( )
Disorientation	( )	( )	( )

	MILD	MODERATE	SEVERE
Dizziness	( )	( )	( )
Headaches	( )	( )	( )
Numbness/tingling of arms or legs	( )	( )	( )
Night sweats	( )	( )	( )
Day sweats	( )	( )	( )
Fever	( )	( )	( )
Chills	( )	( )	( )
Swollen glands	( )	( )	( )
Fatigue	( )	( )	( )
Weakness	( )	( )	( )
Painful joints	( )	( )	( )
Muscle aches	( )	( )	( )
Dry mouth	( )	( )	( )
Thirst	( )	( )	( )
Rash	( )	( )	( )
Itchy skin	( )	( )	( )
K.S. lesions	( )	( )	( )
Heart racing	( )	( )	( )
Chest pain	( )	( )	( )
Other (specify)_____________	( )	( )	( )
Other (specify)_____________	( )	( )	( )

Used with permission: Holzemer, 1994

Patients' Responses to Nurses' Behaviors scale (PRNB)

How did you react toward the nurses who took care of you while you were in the hospital? Circle the number that best applies to you . If you have no experience with a statement, circle n/a.

4 = Almost Always
3 = Often (Most of the time)
2 = Sometimes
1 = Never
n/a = No Experience With This

	Almost Always	Often	Sometimes	Never	No Experience
I cooperated with the nurses.	4	3	2	1	n/a
I yelled at the nurses.	4	3	2	1	n/a
I told the nurses "Thank you."	4	3	2	1	n/a
I talked to the nurses about my HIV.	4	3	2	1	n/a
I stayed away from the nurses.	4	3	2	1	n/a
When I've been treated badly, I behave badly.	4	3	2	1	n/a
I'm too weak to argue with the nurses.	4	3	2	1	n/a
I reported a nurse's behavior to other nurses.	4	3	2	1	n/a
I did what the nurses told me to do.	4	3	2	1	n/a
I wouldn't deal with the nurses.	4	3	2	1	n/a
I smiled and joked with the nurses.	4	3	2	1	n/a
I was irritable back to the nurses.	4	3	2	1	n/a
I got quiet and stayed to myself around the nurses.	4	3	2	1	n/a
I opened up and talked with the nurses.	4	3	2	1	n/a
I laughed and smiled back at the nurses.	4	3	2	1	n/a
I let the nurses go ahead and do their job.	4	3	2	1	n/a
I paid attention to the nurses.	4	3	2	1	n/a
I don't say anything to the nurses.	4	3	2	1	n/a

	Almost Always	Often	Sometimes	Never	No Experience
I hugged the nurses.	4	3	2	1	n/a
I don't do much to offend the nurses.	4	3	2	1	n/a
I can be as mean as I can be nice.	4	3	2	1	n/a
I gave the nurses a terrible time.	4	3	2	1	n/a
I cried with the nurses.	4	3	2	1	n/a
I treated the nurses good too.	4	3	2	1	n/a
I reported a complaint about the nurses to my doctor.	4	3	2	1	n/a
I did what the nurses told me to do.	4	3	2	1	n/a
I got angry when the nurses didn't answer my buzzer in a timely way.	4	3	2	1	n/a
I tried not to hassle the nurses.	4	3	2	1	n/a
I tried to make the nurses job easier.	4	3	2	1	n/a
I gave the nurses the same respect they gave me.	4	3	2	1	n/a
I filed a formal complaint about the nurses.	4	3	2	1	n/a
I don't say much to the nurses, but I should.	4	3	2	1	n/a
I complained back to the nurses.	4	3	2	1	n/a
I treated the nurses swell because they were good to me.	4	3	2	1	n/a
I didn't ring for the nurses, except when I had to.	4	3	2	1	n/a
I wasn't afraid to ask the nurses for the things I needed.	4	3	2	1	n/a
I treated the nurses the same way they treated me.	4	3	2	1	n/a
I did not cooperate with the nurses.	4	3	2	1	n/a
I got mad at the nurses attitude about my HIV.	4	3	2	1	n/a

Patient Reactions Assessment (PRA)

Think about your recent contacts with the nurses who primarily cared for you in the hospital today. Then answer the following questions by circling the number that best describes how you feel about your recent contacts with those nurses. Use the following to guide your answers:

1 = Very Strongly Disagree
2 = Strongly Disagree
3 = Disagree
4 = Unsure
5 = Agree
6 = Strongly Agree
7 = Very Strongly Agree

	Very Strongly Disagree	**Strongly Disagree**	**Disagree**	**Unsure**	**Agree**	**Strongly Agree**	**Very Strongly Agree**
1. I understand the possible side effects of treatment.	1	2	3	4	5	6	7
2. If these persons tell me something that is different from what I was told before, it is difficult for me to ask about it in order to get it straightened out.	1	2	3	4	5	6	7
3. These persons are warm and caring toward me.	1	2	3	4	5	6	7
4. If I don't understand something these persons say, I have difficulty asking for more information.	1	2	3	4	5	6	7
5. These persons told me what they hope the treatment will do for me.	1	2	3	4	5	6	7
6. These persons make me feel comfortable about discussing personal or sensitive issues.	1	2	3	4	5	6	7
7. It is hard for me to tell these persons about new symptoms.	1	2	3	4	5	6	7

	Very Strongly Disagree	Strongly Disagree	Disagree	Unsure	Agree	Strongly Agree	Very Strongly Agree
8. It is hard for me to ask about how my treatment is going.	1	2	3	4	5	6	7
9. These persons really respect me.	1	2	3	4	5	6	7
10. I understand pretty well the medical plan for helping me.	1	2	3	4	5	6	7
11. After talking to these persons, I have a good idea of what changes to expect in my health over the next weeks and months.	1	2	3	4	5	6	7
12. When I talk to these persons, I sometimes end up feeling insulted.	1	2	3	4	5	6	7
13. I have difficulty asking these persons questions.	1	2	3	4	5	6	7
14. The treatment procedure was clearly explained to me.	1	2	3	4	5	6	7
15. These persons don't seem interested in me as a person.	1	2	3	4	5	6	7

Used with permission: Galassi, 1992

Living with HIV scale

Please rate the degree to which each statement is true for you, your life, and your experiences with HIV. If you have no experience with a statement, circle n/a - not appropriate for me at this time.

4 = Almost Always
3 = Often
2 = Sometimes
1 = Never
n/a = No Experience

	Almost Always	Often	Sometimes	Never	No Experience
It's important to be in charge of this disease	4	3	2	1	n/a
I have a meaningful life	4	3	2	1	n/a
I am comfortable and well cared for	4	3	2	1	n/a
It's hard to give up doing things I like	4	3	2	1	n/a
I want to stay home to receive treatments	4	3	2	1	n/a
My family is embarrassed to see me	4	3	2	1	n/a
I have no energy to fight back	4	3	2	1	n/a
I have <u>not</u> had a good experience with a church	4	3	2	1	n/a
I draw strength from my family	4	3	2	1	n/a
My financial situation is distressing	4	3	2	1	n/a

	Almost Always	Often	Sometimes	Never	No Experience
I live my life from day to day	4	3	2	1	n/a
I want to be independent and take care of myself	4	3	2	1	n/a
I am afraid to die	4	3	2	1	n/a
I have a lot of regrets about my life	4	3	2	1	n/a
My medicines are taking over my life	4	3	2	1	n/a
My pain is hard to manage	4	3	2	1	n/a
I feel somewhat disconnected and alone	4	3	2	1	n/a
I am not enjoying life at all	4	3	2	1	n/a
I feel more spiritual as I near the end	4	3	2	1	n/a
I use my time wisely	4	3	2	1	n/a
It frightens me that I have so little control over my illness	4	3	2	1	n/a
I need some help to let go	4	3	2	1	n/a
My family does what needs to be done	4	3	2	1	n/a
I am afraid of pain and suffering	4	3	2	1	n/a
I have so many things in my life yet undone	4	3	2	1	n/a

	Almost Always	Often	Sometimes	Never	No Experience
Loss of my independence is very painful for me	4	3	2	1	n/a
I take time for the important things in life	4	3	2	1	n/a
I may choose to self-deliver (suicide) near the end	4	3	2	1	n/a
I need to make the extra effort to do special things	4	3	2	1	n/a
I don't have to keep fighting any more	4	3	2	1	n/a
I am embarrassed by the way I look	4	3	2	1	n/a
I want to die at home	4	3	2	1	n/a
Loosing my looks is devastating to me	4	3	2	1	n/a
I don't want technology to keep me alive when I am ready to die	4	3	2	1	n/a
Being back in my home town would mean allot to me	4	3	2	1	n/a
I feel no sense of purpose in this life	4	3	2	1	n/a
It is very important to be surrounded by people I love	4	3	2	1	n/a
I don't know about tomorrow so I live for today	4	3	2	1	n/a

Used with permission: Holzemer & Wilson, 1996

Beck Depression Inventory

Instructions: On this questionnaire are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the PAST WEEK, INCLUDING TODAY! Circle the number beside the statement you picked. Select one response for each group. Be sure to read all the statements in each group before making your choice.

1. 0 I do not feel sad.
1 I feel sad.
2 I am sad all the time and can't snap out of it.
3 I am so sad or unhappy that I can't stand it.

2. 0 I am not particularly discouraged about the future.
1 I feel discouraged about the future.
2 I feel I have nothing to look forward to.
3 I feel that the future is hopeless and that things cannot improve.

3. 0 I don't feel like a failure.
1 I feel I have failed more than the average person.
2 As I look back on my life, all I can see is a lot of failures.
3 I feel I am a complete failure as a person.

4. 0 I get as much satisfaction out of things as I used to.
1 I don't enjoy things the way I used to.
2 I don't get real satisfaction out of anything anymore.
3 I am dissatisfied or bored with everything.

5. 0 I don't feel particularly guilty.
1 I feel guilty a good part of the time.
2 I feel guilty most of the time.
3 I feel guilty all of the time.

6. 0 I don’t feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. 0 I don’t feel disappointed in myself.
1 I am disappointed in myself.
2 I am disgusted with myself.
3 I hate myself.

8. 0 I don’t feel I am any worse than anybody else.
1 I am critical of myself for my weaknesses or mistakes.
2 I blame myself all the time for my faults.
3 I blame myself for everything bad that happens.

9. 0 I don’t have any thoughts of killing myself.
1 I have thoughts of killing myself, but I could not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. 0 I don’t cry anymore than usual.
1 I cry more now than I used to.
2 I cry all the time now.
3 I used to be able to cry, but now I can’t cry even though I want to.

11. 0 I am no more irritated now than I ever am.
1 I get annoyed or irritated more easily than I used to.
2 I feel irritated all the time now.
3 I don’t get irritated at all by the things that used to irritate me.

12. 0 I have not lost interest in other people.
1 I am less interested in other people than I used to be.
2 I have lost most of my interest in other people.
3 I have lost all of my interest in other people/

13. 0 I make decisions about as well as I ever could.
1 I put off making decisions more than I used to.
2 I have greater difficulty in making decisions than before.
3 I can't make decisions at all anymore.

14. 0 I don't feel I look any worse than I used to.
1 I am worried that I am looking old and unattractive.
2 I feel that there are permanent changes in my appearance that make me look unattractive.
3 I believe I look ugly.

15. 0 I can work about as well as before.
1 It takes an extra effort to get started at doing something.
2 I have to push myself very hard to do anything.
3 I can't do any work at all.

16. 0 I can sleep as well as usual.
1 I don't sleep as well as I used to.
2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
3 I wake up several hours earlier than I used to and cannot get back to sleep.

17. 0 I don't get more tired than usual.
1 I get tired more easily than I used to.
2 I get tired from doing almost anything.
3 I am too tired to do anything.

18. 0 My appetite is no worse than usual.
1 My appetite is not as good as it used to be.
2 My appetite is much worse now
3 I have no appetite at all anymore.

19. 0 I haven't lost much weight, if any lately.
1 I have lost more than 5 pounds. .
2
3 I have lost more than 10 pounds
I have lost more than 15 pounds.

I am purposely trying to lose weight.
by eating less. Yes_____ No____

20. 0 I am no more worried about my health than usually.
1 I am worried about my physical problems such as aches and pains; or upset stomach; or constipation.
2
3 I am very worried about my physical problems, that I cannot think about anything else.
I am so worried about my physical problems, that I cannot think about anything else.

21. 0 I have not noticed any recent changes in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

HIV-QAM

1. Bathing
    4 Full self-care
    3 Requires use of equipment or device
    2 Requires assistance or supervision from another person
    1 Is dependent and does not participate

2. Toileting
    4 Full self-care
    3 Requires use of equipment or device
    2 Requires assistance or supervision from another person
    1 Is dependent and does not participate

3. Dressing
    4 Full self-care
    3 Requires use of equipment or device
    2 Requires assistance or supervision from another person
    1 Is dependent and does not participate

4. Grooming
    4 Full self-care
    3 Requires use of equipment or device
    2 Requires assistance or supervision from another person
    1 Is dependent and does not participate

5. Personal Hygiene
    4 ADLs no assistance
    3 Bathes with assistance
    2 Bed bath required
    1 Total care required

6. Physical Performance
    4 Asymptomatic
    3 Symptomatic, full ADLs
    2 Symptomatic, in bed<50% of the day
    1 Symptomatic, in bed >50% of the day
    0 Bedridden

7. Ambulation
    4 Ambulates
    3 Walk/help
    2 Chair/bound
    1 Bedfast

8. Activity
    4 Up ad lib
    3 Needs one person to assist
    2 Bed rest, turns self
    1 Bed rest, can't turn self

9. Fear
    4 None
    3 Mild
    2 Moderate
    1 Severe

10. Anxiety
    4 None
    3 Mild
    2 Moderate
    1 Severe

Appendix F

Permissions

DEPARTMENT OF VETERANS AFFAIRS
Medical Center
1201 Northwest 16th Street
Miami FL 33125

May 28, 1996

In Reply Refer To:

Jeanne K. Kemppainen, MSN,RN
43295 Noria Ct.
Fremont, CA 94539

Dear Ms. Kemppainen:

On behalf of the Nursing Service here at the Miami VA Medical Center, I am pleased to support your study "Developing a Measure of Patients' Responses to Nurses". We will be one data collection site for your study and will assist you with subject recruitment. As you know, your study has been approved by the VA Research and Development Committee.

We look forward to working with you.

Sincerely,

Amy W Mosley

Amy Mosley, RN
Chief, Nursing Service

'ancisco, CA 94143
76-1000

UCSF
The Medical Center at the University of California, San Francisco
Herbert C. Moffitt Hospital
Joseph M. Long Hospital
UCSF Children's Medical Center
Langley Porter Psychiatric Hospital
Ambulatory Care Center
Herbst Emergency Service

11 August 1995

Jeanne K. Kemppainen
43295 Noria Ct.
Fremont, CA 94539

Dear Jeanne:

Thank you for submitting your research proposal on, "Developing a Measure of Patients' Responses to Nurses" which you are conducting as a doctoral candidate at UCSF with Dr. William Holzemer as sponsor.

We have approved the Women's Specialty Clinic participation in this study as a site for data collection.

We look forward to the project and eventually to learning about the results of your research.

Best wishes,

Suzan Stringari FNP
Suzan Stringari, FNP

Ruth Greenblatt
Ruth Greenblatt, M.D.

VNA
Visiting Nurse
Association

2025 Gateway Place, Suite 260
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(408) 452-1303
Fax (408) 453-1222

Home Health & Hospice
Suite 270
(408) 452-1224
Fax (408) 452-1266

Continuing Care
Suite 234
(408) 452-1323
Fax (408) 453-1222

Jeanne K. Kemppainen
43295 Noria Ct.
Fremont, CA 94539
July 17, 1995

Dear Jeanne:

Thank you for attending our Research Review Committee Meeting last Friday and presenting your research project, “Developing a Measure of Patients' Responses to Nurses" which you are conducting as a doctoral candidate at UCSF with Dr. William Holzemer as sponsor.

Our committee unanimously approved VNA's participation in this study. We will identify appropriate study subjects from among the clients in our AIDS Project.

We look forward to the project and eventually to learning about the results of your research!

Best wishes,

Jane Hoffmann, RN, MS
Education Coordinator

Good Samaritan Health System
Good Samaritan Hospital • San Jose Medical Center • South Valley Hospital
Good Samaritan Medical Foundation • Visiting Nurse Association • Health Advantage Ventures

DEPARTMENT OF VETERANS AFFAIRS
Medical Center
West Los Angeles
Wilshire and Sawtelle Boulevards
Los Angeles CA 90073

In Reply Refer To:

January 24, 1996

Jeanne K Kemppainen,RN, PhDc
Nurse Manager
Palo Alto VA Health Care System (118)
3801 Miranda Ave
Palo Alto, CA 94304

Dear Dr Kemppainen:

The WLA VAMC supports the conduct of the study "Developing a Measure of Patients' Responses to Nurses" at this facility. Ms Leslie Evans has been appointed the coordinator of the project at this site. The WLA R&D Committee has approved the project.

Thank you for seeking our participation in this important study.

Sincerely,

Janice M Roper

Janice M. Roper RN, PhD
ACNS/R