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Caregiver caring behaviors as perceived by HIV -positive African -American women.

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CAREGIVER CARING BEHAVIORS AS PERCEIVED BY HIV-POSITIVE AFRICAN AMERICAN WOMEN

by

DAPHNE KENNEDY WILLIAMS

A DISSERTATION

Submitted to the graduate faculty of The University of
Alabama at Birmingham, in partial fulfillment of
the requirements for the degree of
Doctor of Science in Nursing

BIRMINGHAM, ALABAMA

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ABSTRACT OF DISSERTATION
GRADUATE SCHOOL, UNIVERSITY OF ALABAMA AT BIRMINGHAM

Degree D.S.N. Program Educator of Nursing

Name of Candidate Daphne Kennedy Williams

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Title Caregiver Caring Behaviors as Perceived by HIV-Positive African American Women

The purposes of this descriptive study were to ascertain (a) whether there is a relationship among the demographic variables socioeconomic status, educational level, age, marital status, and patients' perceptions of caring behaviors; (b) how much of the variability in perceptions of caring behaviors can be explained by diagnosis; (c) whether there is a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection; and (d) whether there is a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection. Leininger's cultural care theory and Watson's caring theory formed the conceptual framework for the study. Using the Caring Behavior Inventory developed by Wolf (1986), data were collected in three outpatient clinics in the Southeast. The subjects were 60 African American women: 30 were HIV positive and 30 were diagnosed with sickle cell disease. The findings indicated an association among demographic variables and perceptions of caring behaviors ($\underline{R}^2$ = .206) with 21% ($\underline{P}$ = .012) of the variability in perceptions of caring behaviors being explained by marital status, educational level, and type of health care coverage. The findings of this study failed to support all the selected variables as predictors of perceptions of caring behaviors. A considerable amount of variance remains unexplained. The findings also indicate a difference in the ranking of importance of caring behaviors between HIV-positive and HIV-negative patients. The subjects in both groups ranked "calling you by your preferred name" as the most important caring behavior. However, the ranking of most important caring behaviors, between subjects with different diagnoses, was not consistent. Although, "attentively listening to you" ranked number one among the entire subject group, there was no consistency in the ranking of least important caring behaviors between subjects, by diagnosis.

DEDICATION

This dissertation is dedicated to my grandmother, the late Lucy Griffin, who lived a beautiful example of life, thus giving me insight, wisdom, and the courage to do anything that I choose to do.

This dissertation is also dedicated to my uncle, Ledell Griffin, who encouraged me to pursue the doctoral degree; my daughter, Natasha, who told others how proud she was of me; my son, Damon, for helping me make it through the last year; my husband, Wayne, who constantly told me "don't give up, remember you are a descendent from Kings and Queens and we as people have the strength to endure anything," and to Sydney Nicole Kennedy-Walker, the essence of the strength and determination that is charactertistic of Griffin women. To my mother, Versie Griffin Morrow, and my father, Early Merriweather, who have expressed their feelings of parental neglect during this process. I hope the pride they feel when reading this dissertation will make my time away from the family's midst seem worthwhile.

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CHAPTER 1

INTRODUCTION

Americans are currently facing one of the greatest epidemics in the history of infectious diseases. This epidemic is caused by HIV, a retrovirus that infects human T-cells and replicates itself before destroying the host cell. When an individual has AIDS and T-cell depletion becomes advanced, the person becomes susceptible to opportunistic infections and, eventually, fatal immunosuppression (Larson, 1984). HIV is responsible for causing the fatal disease AIDS. Since the implementation of the 1993 definition of the disease, effective October 1994, approximately half of all cases are being reported based upon the immunologic criterion of a T-cell count less than 200, rather than the number of AIDS-related conditions the individual develops. As a result of this change in criteria, the number of cases reported each year has decreased (Centers for Disease Control [CDC], 1995). The initial knowledge regarding the clinical presentation of HIV infection was derived from cohorts composed primarily of men (Smeltzer & Whipple, 1991). Although recent data pertaining to HIV-infected women indicate that there is little gender difference in opportunistic processes and progression, women do appear to have gynecological manifestations that are influenced by their HIV infection (Cotton & Watts, 1997). According to Smeltzer and Whipple, when women seek treatment for gynecologic infections, the diagnosis of HIV infection may be delayed because it is not suspected. One must bear in mind that the development of AIDS occurs fairly late in the natural history of the disease. Most of the people now living with HIV infection have not yet developed AIDS. Those who have already developed AIDS are those who were infected up to a decade ago or even earlier. Therefore, much of the AIDS data presented in the literature reflect HIV transmission that took place years ago (CDC, 1998).

Over the past 17 years, rigorous research has revealed a great deal of new information. The methods of transmission have gradually been identified. HIV is transmitted by sexual contact with an infected person, by sharing needles and or syringes with an infected person, and by transfusions from infected blood or blood products (CDC, 1994). Babies born to HIV-infected women or breast fed from infected women may become infected as well (CDC, 1994). In the health care environment, caregivers have occasionally been infected with HIV after a skin puncture with a needle that contained HIV-infected blood. Transmission may also occur after infected blood or body fluid gets into an opening in the skin or is splashed into or onto a mucus membrane (CDC, 1994). Therefore, careful attention must be given by the caregiver to avoid contact with a patient's blood or body fluids.

AIDS is a public health crisis that warrants serious concern. Infection with HIV causing AIDS is one of this country's greatest health challenges. The first AIDS case was reported in 1981, and, 10 years later, over 250,000 Americans had developed AIDS and more than 170,000 had died, triple the number of persons killed in the Vietnam War. AIDS is a burden of serious magnitude on our society. Eighteen years after the first reported case, the worldwide total of HIV/AIDS cases has exceeded 30 million. According to the Agency for Health Care Policy and Research (1994), the World Health Organization projected that between 30 and 40 million men, women, and children around the world will be infected with HIV by the year 2000. It was also postulated that by the turn of the century, AIDS would be the third most common cause of death in the United States (Agency for Health Care Policy and Research, 1994). Current statistics are showing that these projections are increasingly becoming a reality. In 1996, the nationwide cumulative total of HIV-infected individuals exceeded one million, with an estimated cost associated with treating these individuals in that year alone exceeding 2.5 billion dollars (CDC, 1996). As of June 1998, 665,357 persons with AIDS have been reported to CDC (CDC, 1998). AIDS incidence increasingly represents persons who were not diagnosed with HIV infection until they developed AIDS, people who did not access treatment, or people for whom treatment failed. Therefore, the proportion of infected persons tested is expected to increase and the representativeness of the HIV data will increase accordingly (CDC, 1998). Upon scrutiny of the data, the urgency and importance of identifying the proper therapeutic responses on the part of the health care providers becomes apparent.

People of all ages and all races have been infected with HIV. AIDS is rapidly becoming a family disease. According to the CDC (1996), AIDS ranked among the top 10 causes of death in children 1 to 4 years of age. In the 31 states that report cases of HIV infection to the CDC, 17,311 persons with HIV infection and not AIDS were reported from July 1997 through June 1998. Originally considered a disease of homosexual men and men using intravenous drugs, AIDS is affecting women in increasing numbers. A woman is much more likely to acquire sexually transmitted HIV infection from a man than a man is from a woman (Smeltzer & Whipple, 1991). Among the 17,311 new cases, women accounted for 32% of all adult cases and 49% of persons 13 to 24 years of age (CDC, 1998). Taking a closer look at the impact of HIV among young people in the United States, the majority of new infections are being diagnosed among African Americans and women. Among women, African Americans and Hispanics accounted for 78% of the newly reported cases (CDC, 1998). Over the last decade, AIDS incidence among African American women has increased dramatically. In 1992, the nationwide incidence of newly diagnosed AIDS cases reached 31.3 per 100,000 among African American women, compared with 14.6 per 100,000 among Hispanic women and 1.8 per 100,000 among Caucasian women

(Cruise & Dunn, 1994). In 1994, the incidence of reported cases increased to 62 per 100,000 among African American women, compared with 26 per 100,000 among Hispanic women and 4 per 100,000 among Caucasian women (Cotton & Watts, 1997). In 1995, DiClemente and Wingood indicated that African American women had markedly higher seropositive results for HIV than did women in other ethnic groups. In 1996, an estimated 6,750 African American women were diagnosed with AIDS (CDC, 1997). From 1985 through 1996, the reported cases of women with AIDS increased from 7% to 20%. By the end of 1996, HIV infection was deemed the third leading cause of death among women 25-44 years of age and the leading cause of death among African American women in this same age group (CDC, 1997). In 1997, 92,242 women were diagnosed with AIDS; of these, 51,410 were African American women (CDC, 1997). As of December 1997, 641,086 Americans have been reported with AIDS. Estimates suggest that 650,000 to 900,000 Americans are now living with HIV and at least 40,000 new infections occur each year (CDC, 1998). Although African Americans and Hispanics represent 21% of the total United States population, these minorities account for more than 50% of all reported AIDS cases. Although AIDS does not discriminate by gender, age, ethnicity, or socioeconomic level, the disease affects African American and Hispanic women (CDC, 1998).

Another measure of the epidemic's impact on women is the ranking of HIV infection among causes of death for women. HIV infection is ranked the fourth leading cause of death among women ages 25-44 years old in cities with population greater than 100,000 and located in eight east coast states (Cotton & Watts, 1997). Currently, AIDS deaths total 401,028. Among these, 56,111 are women, and of that 56,111, 31,373 are African American women (CDC, 1998). These statistical findings reported over the years by the CDC, as well as other sources, make it apparent that AIDS is growing faster among African American women than any other ethnic group. African American women, who are at high risk for HIV/AIDS, are members of a historically marginalized group and are, therefore, likely to be stigmatized. Unfortunately, contracting the AIDS virus is likely to increase the stigma upon these individuals.

The literature also indicates that African Americans with sickle cell anemia are often stigmatized and experience negative reactions from health care workers. Sickle cell anemia is a genetically transmitted disease in which the abnormal hemoglobin causes changes in the shape of the red blood cell that result in painful vaso-occlusive crises (Alleyne & Thomas, 1994; Lorenzi, 1993; Murray & May, 1989). According to Fincher (1992), the prevalence of sickle cell disease among African Americans is about 1 in every 400. However, sickle cell anemia is termed the neglected disease. According to Alleyne and Thomas (1994), sickle cell disease has forced into the health care delivery system ethnic and racial groups who historically have experienced less

less availability of care or acceptability within the system. Likewise, Fincher indicated that the sickle cell patient shares the stereotypes of the minority group to which they belong and are often perceived to be on welfare, noncomplaint, and difficult. Many minority patients feel that nursing staffs are insensitive to the needs of individuals with sickle cell disorders (Alleyne & Thomas). Adult patients with sickle cell often describe the health care system as being rude, callous, and having a disdainful attitude (Fincher). Both HIV-positive patients and those with sickle cell disease are suffering from illnesses that lead to death. Both groups have illnesses for which we currently have no cure, and, ironically, both African Americans with sickle cell disease and African Americans who are HIV positive are stigmatized as a result of race and disease.

Farmer and Kleinman (1989) stated that the suffering and dying of persons with AIDS is a master symbol of human suffering. They expressed the belief that the ethical and emotional responses to AIDS and its related symptoms are collective representations of how societies deal with suffering. The literature indicates that society's response to the AIDS epidemic is much like the response to polio, small pox, and other similar viruses (Farmer & Kleinman, 1989; Hall, 1992; Steven & Muskin, 1987). From the perspective of suffering, Farmer and Kleinman speculated that reactions to AIDS rank with reactions to small pox, bubonic plague, and leprosy, all diseases that have no cure, are known to decrease quality of life, and have high mortality rates.

Research findings indicate that there is very little sympathy for the victims of AIDS (Farmer & Kleinman, 1989). This lack of sympathy may be attributed to the fact that the early victims of HIV infections were members of groups often viewed as socially undesirable such as homosexual men, Haitian immigrants, and drug addicts. The hostility, violence, and discrimination experienced by people with HIV infections may be explained by their association to these early groups of victims. In addition, the normal compassion and empathy for victims of HIV may be missing because the mode of transmission of the virus creates fear (Steven & Muskin, 1987). To explain the reason that the diagnosis of AIDS or HIV suggests forbidden behavior and often leads to devaluing the person with HIV, Steven and Muskin cited Freud's 1920 work: "Empathy relies upon the ability to find some similarity between ourselves and the rest of the world" (p. 545). Humans frequently fear, or even hate, any individual or group that they view as different. Research findings clearly indicate that attitudes of health care workers are negative toward homosexual men. Therefore, any research examining perceptions of caring behaviors in which homosexual men were included in the sample would yield biased results. Unlike men, among whom the majority of cases are attributed to homosexual contact, most cases of AIDS in women can be attributed directly or indirectly to injection of drugs (Cotton & Watts, 1997).

Humans relate to their environments by a frame of reference and extract meaning through the metaphors that they use (Hall, 1992). Diseases are no exception, and they are often understood by the metaphors that are used to describe them (Hall). In the case of HIV, society has chosen to associate it with sexual promiscuity, drug abuse, and sin. As a result of these associations, people diagnosed with this disease are often judged by the values with which society has endowed the disease. Hall sees the stigma and personal reactions to persons with HIV as negatively affecting patients' responses to their diagnosis, treatment, and care.

However, some people fear that HIV might be transmitted in other ways not yet identified by the CDC. Although the CDC (1994) has found no scientific evidence to support additional fears of transmission, these fears have contributed to a significant decrease in the quality of life that HIV-positive patients in the United States are experiencing. Research has shown that the behavior of nurses toward their patients affects the physical and emotional outcomes of patients (Brooten & Naylor, 1995). These results indicate that negative noncaring behavior may result in poor patient outcomes. Meisenhelder and LaCharite (1989) identified four behaviors that characterize the fear of HIV: avoidance, attempting extreme precautions, lack of regard for the victims, and manifestations of fear regarding transmission of the disease. Although health care workers have historically interacted with those who have contagious diseases, several important studies have documented the stigmatization and rejection that HIV-positive persons and patients with AIDS have experienced from health care providers (Hall, 1992). The unprecedented global health threat of AIDS has produced an abundance of educated health professionals who want to separate themselves from casual contact with HIV-infected individuals (Forrester & Murphy, 1992; Laschinger & Goldenberg, 1993; Meisenhelder & LaCharite, 1989; Plant & Foster, 1993; Robbins, Cooper, & Bender, 1992; Van Wissen & Siebers, 1992). Research has shown that health care professionals react more negatively toward homosexuals with AIDS and those who acquired the virus by needle sharing. Attitudes are more positive toward females who acquired the virus through sexual contact with men and those females who acquired the virus through a contaminated blood transfusion (Douglas, Kalman, & Kalman, 1985). Research shows that there is still evidence of an unwillingness among some health care workers to provide care to HIV-positive patients (Barrick, 1988; Cole & Slocumb, 1994; Douglas et al., 1985; Forrester & Murphy, 1992; Henry, Campbell, & Willenbring, 1990; Laschinger & Goldenberg, 1993).

In an attempt to examine the attitudes of nursing students toward AIDS patients, Lester and Beard (1988) administered a questionnaire to 177 baccalaureate nursing students at various levels of their studies. The majority of the subjects thought that AIDS patients were entitled to the same care as any other patient. However, 49% preferred not to provide care for AIDS patients. Turner (1993) reviewed literature on the AIDS-related knowledge, attitudes, and risk of nurses for HIV infection. She identified knowledge deficits, negative attitudes, and prejudicial beliefs that may adversely affect the quality of care provided to patients who are HIV positive. The existence of these attitudes is problematic because nurses, physicians, and other health care providers have an ethical responsibility to provide care to HIV/AIDS patients. Research is leading to new regimens and paradigms of treatment that will extend the life expectancy of HIV-positive individuals. Nurses, in all areas of specialization, will be confronted with patients in various stages of HIV infection. Providing compassionate care to the growing numbers of patients with HIV infection is one of the greatest challenges facing health care providers in this decade. AIDS surveillance data continue to indicate that the HIV/AIDS epidemic is having a growing impact among women. Surveillance data have indicated that African American women are 16 times more likely to be diagnosed with AIDS than any other ethnic group (DiClemente & Wingood, 1996). With the awareness that the largest proportion of AIDS patients is likely to be African American women, it is important for nurses to be aware of both the stigma often placed upon African Americans and the uncaring behaviors often experienced by HIV-positive patients. The role of nurse educators in the 21st century must include nurturing a caring demeanor in nurses toward these patients.

Conceptual Framework

Two major works contribute to the conceptual framework underlying this study: Leininger's culture care theory (Cohen, 1991; Gaut & Leininger, 1991; Leininger, 1991; Leininger & Watson, 1990; Morse, Bottorff, Neander, & Solberg, 1991) and Watson's caring theory (Cohen, 1991; Leininger & Watson, 1990; Morse et al., 1991; Watson, 1994). The major components of both of these perspectives were integrated to provide a framework for a study of caring behaviors of caregivers toward HIV-positive African American women.

Leininger's Culture Care Theory

The culture care theory focuses on describing, explaining, and predicting nursing similarities and differences in caring within human cultures. The theory was constructed to discover the universal and diverse features of care as the major and central component of nursing (Leininger, 1991). Leininger stated that "what people need most in order to grow, remain well, avoid illnesses, survive or to face death is human caring; care is the essence of nursing and the distinct, dominant central and unifying, focus of nursing" (p. 5). To care is to provide physical assistance and emotional support and to facilitate the meeting of actual or anticipated needs for an individual or family (Leininger, 1991). Some critics and researchers argue that caring is not unique to nursing, but is embedded in the work that women in Western society do in and outside the home (Morse et al., 1991). However, Leininger differentiates the generic sense of caring from professional caring by defining the latter as culturally learned behaviors, techniques, processes, and patterns of doing that enable the nurse to help individuals, families, or communities to improve or maintain a favorable or healthy state (Cohen, 1991). Leininger postulated that culturally congruent care is the responsibility of nursing and uses cultural variation to explain that different caring expressions or emphases form different and unique caring modalities (Morse et al., 1991).

Leininger's transcultural theory of nursing reflects her belief that human caring is a universal phenomenon that varies in expressions, processes, and patterns among cultures (Leininger, 1988). In a later work, Leininger (1991) elaborated on this theory, describing caring as a humanistic mode of being with others to assist in times of need or to help maintain well-being or health. Humanistic expressions of compassion and care include touching, comforting, assisting, and supporting (Leininger, 1988, 1991). She expanded on this, stating that the thrust of the culture care theory is to discover those human care diversities and universalities in relation to world view, social structure, and other pertinent dimensions. Leininger (1988, 1991) believed that nurses must discover culturally relevant ways of assisting all clients, regardless of ethnic groups, to maintain or regain their well-being or to assist them to face death in a culturally appropriate way. The objective underlying the theorizing is to improve and to provide culturally congruent and beneficial care to people (Leininger, 1991). It can be concluded that the culture care theory was based on the following premises: Care is nursing; care is healing; care is the nurse's way of being with and helping people; care is the heart and soul of nursing; care makes the difference in wellness or illness states; and care can cure (Leininger, 1988, 1991).

According to Wolf (1986), Leininger believed that caring varies among cultures, as do the caring practices. This belief of cultural variance suggests that perceptions of caring behaviors may vary among cultural groups.

Watson's Caring Theory

Watson (1994) focused on the philosophic and spiritual basis of caring and postulated that it was the ethical and moral ideal of nursing. Watson saw caring as the heart of nursing and the foundation for our acts, which involve a deep level of commitment to patients, families, and communities. According to Cohen (1991), Watson's framework is derived from many disciplines and provides a very useful metaphysical, philosophical, and spiritual dimension to nursing. Watson viewed transpersonal caring as an important component of caring, which occurs when the nurse and patient form a spiritual union. This union must transcend self, time, space, and life history. Cohen described the 10 carative factors which Watson identified in her 1979 work. Watson (1979) believed these factors to be inherent to the caring processes that help persons to attain or maintain health or to die a peaceful death. These factors form a structure and a frame of reference for research and understanding nursing as a science (Watson, 1991). These 10 carative factors compose Watson's (1994) theory: (a) a humanistic altruistic system of values; (b) the instilling of faith and hope; (c) sensitivity to self and others; (d) helping and trusting human care relationships; (e) expressing positive and negative feelings; (f) a creative problem-solving caring process; (g) transpersonal teaching-learning; (h) supportive, protective, and or corrective mental, physical, societal, and spiritual environment; (i) human needs assistance; and (j) existential phenomenological spiritual forces.

According to Watson (1979), the carative factors guide what the nurse is and does in the nurse-patient relationship and are categorized as scientific, professional, ethical, aesthetic, creative, and personalized care-giving behaviors. The first factor, the humanistic-altruistic system of values, encompasses the ability to fully appreciate divergent world views and to bring meaning to one's life through relationships with others. The second factor, the instilling of faith-hope, involves recognizing the inner power of the individual to influence the attitude and eventual healing of the patient. The third factor, sensitivity to self and others, enables the nurse, through self-actualization, to become involved with those being cared for. The fourth factor, helping-trusting human care relationship, is achieved by genuineness, empathic behaviors, and effective communication skills. The fifth factor, the expressive factor, communicates positive and negative feelings that enable the nurse and patient to develop a trusting and helping relationship. The sixth factor, the creative element, extends the nursing process and clinical knowledge to provide humanistic care for problem solving. The seventh factor, transpersonal teaching-learning, involves a collaborative effort between the nurse and the patient. The eighth factor--the supportive, protective, and corrective mental physical, societal, and spiritual environment--involves the art of nursing in doing for the patient. The ninth factor, human needs assistance, is achieved through the physical care provided by the nurse. The tenth factor, the recognition of the spiritual forces, enables the nurse to transcend to appreciate the patient's inner world and belief of the meaning of life (Watson, 1979).

According to Wolf (1986), Watson has examined the concept of caring in more depth than any other author. Watson viewed nursing as "a therapeutic interpersonal process in which the basic core of nursing is made up of the philosophy and science of caring" (Wolf, 1986, p. 89). Thus, Watson's factors set the stage for caring in nursing from a philosophical perspective.

Integration of Leininger's Culture Care Theory and Watson's Theory of Caring

Two nursing leaders, Leininger and Watson, have devoted their careers to studying and defining the meaning of caring. Both identify nursing as a humanistic science, with the concept of caring being the central unifying domain of nursing (Cohen, 1991). The anchorage of caring in the powerful feminine image of caregiver has long contributed to confusion and difficulty in specifying differences between caring linked to the nurturing and mothering role of women in society and professional nursing care (Leininger, 1991; Watson, 1990). Unlike Leininger, Watson did not differentiate between generic caring and professional caring (Cohen, 1991). Leininger believed caring to be embedded in transcultural phenomena and central to all of nursing; Watson saw caring as having human dimensions embedded in an ethical and moral ideal of human values that is accompanied by a commitment to preserve and restore the human center to nursing theory and practice (Leininger & Watson, 1990).

Both Watson and Leininger have emphasized that caring must be embedded in the core of nursing theory. According to Leininger and Watson (1990), there is a need to identify a professional nursing caring paradigm. They proposed that this paradigm become the basis of professional nursing. In order to identify a caring paradigm, nurses must arrive at a unique and unified perspective of caring. The two theorists developed a list of caring concepts. Their unified list of concepts falls into two categories. The first category includes caring concepts that emphasize humanistic expressions of feelings and concern. The second category includes concepts that involve nursing actions and skills that evidence a scientific, objective approach to problem solving. In comparison, both Leininger and Watson identified nursing as a humanistic science with concepts of caring being the central unifying focus of the domain (Cohen, 1991). This unified perspective of the conceptual frameworks of Leininger's culture care theory and Watson's theory of human caring provided the overall framework for this study of the perceived importance of caring behaviors to HIV-positive and HIV-negative African American women.

Purpose

The purposes of this study were to (a) ascertain whether there is a relationship among the demographic variables socioeconomic status, educational level, age, marital status, and the patients' perceptions of caring behaviors; (b) ascertain how much of the variability in perceptions of caring behaviors can be explained by diagnosis; (c) ascertain whether there is a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection; and (d) ascertain whether there is a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection.

Research Questions

This study was designed to answer the following research questions:

1. How much of the variability in perceptions of caring behaviors can be explained by socioeconomic status, educational level, age, and marital status?

2. What percentage of variance in perceptions is accounted for by diagnosis?

3. Is there a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection?

4. Is there a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection?

Hypothesis 1

In order to answer the first and second research questions, the following hypotheses were tested. If there is an association in either, the null hypotheses will be rejected.

Ha: There exists an association between socioeconomic status, educational level, age, marital status, diagnosis of HIV positivity, and scoring of caring behaviors.

Ho: There is no association between socioeconomic status, educational level, age, marital status, diagnosis of HIV positivity, and scoring of caring behaviors.

Hypothesis 2

In order to answer the third and fourth research questions, the following hypotheses were tested; if there is an association, the null hypothesis will be rejected.

Ha: There is a difference in ranking of least important caring behaviors and most important caring behaviors between the HIV-positive and HIV-negative patients.

Ho: There is no difference in ranking of least important caring behaviors and most important caring behaviors between HIV-positive and HIV-negative patients.

Definition of Terms

The following terms are operationally defined for the purpose of this study.

<u>Demographic variables</u>--selected factors to be assessed in this study: socioeconomic status, educational level, age, and marital status.

Socioeconomic status--operationally defined as the income level and type of health care coverage as provided by the subject.

Caregiver--any person, registered nurse, licensed practical nurse, or patient care technician who provides care services to clinic patients and who may be perceived as a caregiver.

HIV-positive patient--an HIV-infected person who is seropositive as evidenced by a positive ELISA (a diagnostic test used to confirm HIV infection), Western blot (a screening test for HIV), or both tests indicated in the medical record.

HIV-positive African American women--African American women who are seropositive for HIV confirmed by the Western blot or ELISA and attend the 1917 Clinic, located at the University of Alabama at Birmingham in Birmingham, Alabama.

HIV-negative patient--refers to patients whose HIV sero-status is negative or unknown as indicated in their medical record. For the purpose of this study, the term refers to African American women with sickle cell disease who attend the University of Alabama at Birmingham or Cooper Green Hospital Sickle Cell Clinic.

African American women with sickle cell disease--African American Women who are diagnosed with sickle cell disease and attend the UAB or Cooper Green Hospital Sickle Cell Clinic.

Age--the chronological age of the patient as obtained from the demographic data form.

Educational level--the number of years of schooling the subject has attained as obtained from the demographic data form.

Marital status--whether the subject is married, single, or divorced as indicated on the demographic data form.

Diagnosis--for the purpose of this study, the term refers to being HIV positive or having sickle cell disease.

Sickle cell disease--the diagnosis of sickle cell anemia, an inherited disorder causing abnormal hemoglobin that changes from a circular shape to a cylinder-like shape under certain adverse conditions.

Assumptions

In the course of this study, certain assumptions were made.

1. Attitudes affect behavior.

2. There is a relationship between feelings and actions.

3. Perceptions of caring behavior is an individual's appraisal of the caregiver and the attitudes of caregivers he or she encounters, and is a subjective measure that ultimately contributes to patient outcome.

Significance of the Study

Currently, there is no known cure for the HIV infection. AIDS, the fatal disease caused by HIV, has become the leading cause of death for adults including women aged 20-40 in the United States (CDC, 1998). Even with AIDS being the number one cause of death for young African American women in 10 major cities in the United States, research findings indicate that they tend to avoid HIV testing, are less likely to be enrolled in clinical trials, and die sooner (Smeltzer & Whipple, 1991). The increasing prevalence of HIV necessitates that health care providers become aware of the perceptions of HIV- positive patients of the care being provided. Feeling cared for is believed to promote a positive outcome and to enhance the quality of life the patient experiences, ultimately improving the quality of care (Brooten & Naylor, 1995). The primary contribution that nurses and other health caregivers can make in response to the AIDS crisis is to provide emotional and physical care (Robbins et al., 1992). AIDS is both a mandate and a catalyst for a new paradigm in nursing. Caring will need to be reconceptualized to accommodate sensitivity to alternative lifestyles and culturally diverse practices and customs in our new global arena (Walker & Frank, 1995). Caring is the essence of nursing; therefore, providing care to HIV-positive patients is inevitable.

Despite the increasing incidence of HIV infection and AIDS in women, few studies to date have focused on women

(Smeltzer & Whipple, 1991). Research to identify what the most rapidly growing population of HIV-positive patients perceive as caring will contribute to the body of nursing knowledge relevant to caring and to the body of nursing knowledge relevant to African American women. This study provides information regarding what patients perceive as caring behaviors experienced from their caregivers as well as caring behaviors they perceived as important. The findings from this study can serve as a guideline in designing an intervention to teach nurses as well as nursing students which caring behaviors they should project to their patients in order to portray a caring demeanor.

CHAPTER 2

REVIEW OF LITERATURE

A discussion of the research literature relevant to the study is presented in this chapter. Areas reviewed are sociodemographic variability, attitudes of nurses, knowledge of nurses, willingness to care, perception of patients with sickle cell disease, the human immunodeficiency virus and African American women, and perceptions of caring behaviors.

Sociodemographic Variables

Various sociodemographic factors have been investigated to assess their contribution to perceptions of quality of care and to patients' satisfaction with care. Very little data are available on the relationship between demographic variables such as socioeconomic status, ethnicity, age, and gender and the related perceptions of patients' caring behaviors.

The relationship between ethnicity and perceptions of caring behaviors has not been explored. However, the relationship between age and perceptions of caring behaviors has been investigated. Breemhaar, Visser, and Kleijnen (1990) conducted a study to determine whether there was a difference in satisfaction with hospital stay between young and elderly patients. They performed a secondary analysis on the pooled data collected from 2,667 patients. Data were obtained by means of a questionnaire administered during the patients' admission in the hospital. The sample was, in general, equally distributed with respect to demographic categories for age and gender. The results indicated that elderly patients were more satisfied and had a more positive perception of the care they received than the younger patients.

Arber and Ginn (1995) examined gender differences in informal caring. They performed a secondary analysis of a 1991 general household survey. The purpose of their study was to determine willingness to provide care and the relationship to gender. They set out to answer the question, "Are the majority of men providing care by default?" Caring by default was defined as individuals giving care for their spouse or parents living within the same house. The sample consisted of 2,700 adults who were providing care for another adult. They concluded that men and women are equally likely to provide informal care for someone in the same household. However, women are more likely than men to provide care for someone living in another household. In addition, they found no significant difference between married women and married men in their likelihood to provide care. These findings support the view that the majority of care provided by men is provided by default. These findings may imply or suggest that men may perceive caring and caring behaviors differently than women.

On the other hand, Clark, Pokorny, and Brown (1996) conducted a study to assess patient satisfaction with nursing care in a rural hospital emergency department. The instrument used for data collection comprised four subscales: psychological safety, discharge teaching, information giving, and technical competence. The sample consisted of 52 patients who received care in the emergency department within a 2-week period. The result of the study revealed no statistically significant effect of gender or education level on consumer satisfaction. Overall, the sample was satisfied with nursing care. However, there was a significant effect of race on satisfaction. The results indicating satisfaction with the discharge teaching subscale revealed that African Americans tended to be less satisfied with discharge teaching than Caucasians.

No studies were found in which perceptions of caring behaviors among patients with insurance were compared with those without. However, Greener and Winchell (1991) examined patterns of satisfaction with care among prepaid medical beneficiaries and compared their level of satisfaction to that of fee-per-service Medicaid beneficiaries. The subjects were 974 Medicaid-eligible individuals. The demographic characteristics of the sample were representative of the population in the area. The instrument used for data collection was a 29-item Likert scale questionnaire. Data analysis revealed five subscales: humaneness of doctor, quality of care, general satisfaction, continuity of care, and convenience of service. The predictor variables of age, ethnicity, education, source of care, and gender were used to accomplish this. Their study was designed to ascertain whether a relationship existed between general satisfaction and convenience of services. They found a significant correlation between ethnicity and the dimensions of quality, as well as between ethnicity and convenience. African Americans and Hispanics were less likely than Caucasians to be satisfied in the general satisfaction subscales. The results also indicated that the level of education was a predictor of satisfaction. Subjects with a higher education exhibited greater satisfaction on the humaneness subscale. The researchers concluded that no significant difference exists between prepaid and fee-for-service systems for the subscale of general satisfaction. However, there were significant differences between ethnicity and provider choice. Caucasian patients were more satisfied with private doctors or prepaid providers, whereas African Americans and Hispanics were more satisfied with fee-for-service Medicaid.

Furthermore, Meister and Boyle (1996) found that ethnicity and several other sociodemographic covariates influenced the importance and rating of key indicators or perceptions of quality care and satisfaction with the care received in a long-term care facility. The sample size was calculated using a power of 0.80 and included residents, families of residents, and nursing staff. The study results indicated a significant difference in perception of satisfaction and quality care by ethnicity among the nursing staff. The results also showed a significant difference in perception by ethnicity among resident and resident family members. The subjects, who were Jewish, had different perceptions from those who were African American and Asian.

No studies comparing the perceptions of caring behaviors among HIV-positive patients and patients with physiological illness were found in the literature. However, Von Essen and Sjoden (1993) conducted a study to examine perceptions of psychiatric inpatients and compared the results with perceptions of patients with somatic illnesses. In this study, they identified differences between psychiatric inpatients and nursing staff's perception of the most important and least important behaviors. They examined differences within the inpatient group and related gender, age, marital status, occupation, having or not having children, previous hospitalizations, and diagnosis regarding the caring behaviors that were perceived as most important and those perceived as least important. The subjects for this study were selected from among eight inpatient facilities in Sweden. The sample consisted of 224 subjects: 61 were patients with psychiatric disorders, 81 were patients with medical disorders, and 82 were members of the nursing staff. A modified version of the CARE-Q (Larson, 1981) was used to collect data. The data were categorized into the following six subscales: explains and facilitates, comforts, trusting relationship, anticipates, monitors and follows through, and is accessible. An analysis of variance demonstrated that the categories did not differ significantly on the CARE-Q subscales. However, younger patients had lower mean scores on the accessible subscale than older patients. Younger patients had higher mean scores on the explains and facilitates subscale than older patients. Patients with children had higher mean scores on the anticipates subscale than patients without children. Patients with children had lower mean scores on the explains and facilitates subscale than those without children.

Older staff members had higher mean scores on the anticipates subscale than younger staff (Larson, 1981). Some without children valued the trusting relationship subscale more than those with children. The staff members caring for psychiatric patients gave a lower mean value to the comforts subscale than staff giving care to somative patients. Among the 10 items ranked as most important by patients and staff, listens to the patients ranked highest. Among the 10 items ranked as least important by patients, introduces self had the lowest mean score. Staff, on the other hand, gave the lowest mean score to teaches the patient how to take care of self outside the hospital. The results of this study indicate that although patients vary minimally in their perceptions of caring behaviors by diagnoses, they vary significantly by age group.

Attitudes of Nurses

It is well established that HIV and AIDS have led to an unprecedented global health threat. Laschinger and Goldenberg (1993) related the reluctance and discomfort among nurses coming in contact with these patients to "fear of contagion and negative attitudes toward homosexuality and intravenous drug users" (p. 441). They also pointed out that, despite universal precautions, nurses exposed to AIDS-risk groups fear increased risk of contracting an HIV infection.

Robbins et al. (1992) studied the relationship between knowledge, attitudes, and degree of contact with persons who have AIDS or are HIV positive. They concluded that there was a significant relationship between increased contact, positive attitude, and little contact with negative attitudes.

In a study conducted by Plant and Foster (1993), a high proportion of nurses indicated concern about their lack of knowledge regarding AIDS and stated that they felt incompetent to provide effective care. Another study, conducted by Forrester and Murphy (1992), showed that nurses expressed significantly more negative attitudes toward patients infected with AIDS than with other illnesses. The nurses were also less willing to interact with patients with AIDS than patients who had other illnesses.

A study conducted by Robbins et al. (1992) found that one of the primary contributions nurses can make to the health crisis related to AIDS is to provide emotional support to persons who are HIV positive. They argued that nurses' ability to offer both physical and emotional care may be hampered by the uninformed inhibitions of the nurse. Douglas et al. (1985) found that health care professionals reacted more negatively toward homosexuals with AIDS than toward those who had incurred the disease through heterosexual transmission of the virus.

In support of these findings, Cole and Slocumb (1993) found significant differences in nurses' attitudes toward AIDS patients relative to the manner in which the virus was originally acquired. The attitudes were most positive toward a male patient who acquired the virus through a contaminated blood transfusion. A male patient who acquired the disease by needle sharing evoked the most negative reaction. The investigators concluded that nurses' attitudes were more positive toward females who acquired the virus through sexual contact with men than for males who were infected through homosexual interactions. Research findings by Van Wissen and Siebers (1993) indicated that the attitudes of nurses still tend to remain negative to HIV-positive patients. The importance of these findings is that the responses and reactions of the nurses to the source of infection had direct impact on their ability to empathize with the patients and affected their care-giving behaviors.

Knowledge of Nurses

The findings from the vast amount of research focusing on AIDS-related attitudes and knowledge levels indicate that, generally, the more knowledgeable a person is, the more likely one is to display a positive attitude (Turner, 1990). Lawrence and Lawrence (1989) conducted a study involving 60 registered nurses, 50 baccalaureate nursing students, 42 liberal arts college students, and 30 non-nurse lay adults. The results of this study indicated that registered nurses have more knowledge about AIDS and more positive attitudes toward AIDS patients than baccalaureate nursing students. In addition, Lawrence and Lawrence found that liberal arts students have more knowledge and more positive attitudes about AIDS than non-nurse adults. They concluded that it is possible to increase knowledge and change the prevailing attitudes among nurses, as well as among non-nurses.

The Robbins et al. (1992) study is representative of the research which found no significant relationship between increased knowledge and the subsequent quality of contact nurses had with patients. However, the preponderant body of literature negates this position.

Willingness to Care

Laschinger and Goldenberg (1993) concluded that nurses' attitudes were significant predictors of their willingness to care for HIV-positive patients. According to Laschinger and Goldenberg, research findings indicate a positive relationship between willingness to care and the number of formal lectures to which the nurse had been exposed. It has also been argued that a relationship exists among knowledge, attitudes, and behavior. These relationships were noted in a study by Henry et al. (1990). Their results showed that a relationship in inverse proportion exists between homosexual bias and willingness to care; this suggests that negative feelings about homosexuals may contribute to negative attitudes and behaviors among caregivers.

Henry et al. (1990) noted a positive correlation between knowledge about AIDS and positive attitudes and behaviors among the subjects. Their findings suggested that the more knowledgeable the nurse was, the less concerned he or she was about becoming infected with HIV while at work.

Barrick (1988) investigated the degree of association between willingness to work with patients who have AIDS and attitudes toward homosexuals. Barrick concluded that the more tolerant the subjects were of homosexuals, the more willing they were to care for AIDS patients, and vice versa. Of the 208 subjects, 25% felt that AIDS patients should be quarantined to protect the public health. Cole and Slocumb (1994) conducted a study of 322 staff nurses to ascertain the relationship of modes of acquiring AIDS to intention to provide care. In contrast to other studies, the investigators found no significant relationship between intentions to care and mode of transmission. It is noteworthy that the only significant predictor of willingness to care in this study was the amount of fear of contagion. Laschinger and Goldenberg (1993) recommended that nurse educators, in both clinical and academic settings, revise educational interventions to include factual information and exploration of feelings, attitudes, beliefs, and behavioral intentions about HIV-positive and AIDS patients.

Perceptions of Patients with Sickle Cell Disease

Alleyne and Thomas (1994) conducted a qualitative study to gain insight into the personal experiences of individuals with sickle cell disease and nurses involved in the management of their care. The patient sample was composed of 10 subjects, 8 women and 2 men, all of African Caribbean origin. The nurse sample was composed of 10 females employed on the hematology ward. Data were collected using individual and group interviews. Content analysis was used to identify categories within the data from both patients and nurses. The following categories emerged: poor pain management, anxieties about pethidine, loss of or lack of control, lack of individuality, and playing up. The poor pain management category included experiences such as difficulty in obtaining pain killers, not being asked about the severity of the pain, and no explanation for the delays in receiving pain medication. The anxieties about the pethidine category, the most commonly used analgesic during a sickle cell crisis, came primarily from the nurses' responses. This category included responses such as "this narcotic is too time consuming," and "so many young blacks are on drugs that when a patient is laughing one minute and asking for pain medications the next minute, this arouses suspicion." The patients indicated that they had to be "rolling around in agony" for the nurse to decide to give this medication instead of Tylenol (Alleyne & Thomas, p. 729). The lack or loss of control category contained descriptions of both nurses' and patients' experiences of feeling out of control and helpless. The lack of individualized care category contained descriptions of patients experiences of being called names such as "sicklers" (p. 729). The final category, playing up, emerged from the nurses' experiences of manipulation by the patients. In contrast, overall, the patients felt guilty for being a burden on the nursing staff with their frequent requests for pain relief. These findings indicated that patients with sickle cell disease experience difficulty obtaining appropriate care from their caregivers. The attitudes of the majority of nurses in this study were suggestive of one identified need in the patient with sickle cell disease, analgesic medication, and yet the data clearly indicated that nurses were not meeting this indicated basic need.

In contrast, Shapiro, Benjamin, and Payne (1997) surveyed 115 subjects to ascertain their perception of sickle cell-related pain. The sample consisted of hematologists and physicians in charge of emergency services in hospitals throughout the nation serving a large percentage of the African American population. The results were compared by regions. The findings showed that emergency department physicians and hematologists differ in their attitudes and beliefs about the patients' pain. The emergency department physicians viewed the painful episodes as shorter; they also perceived a high prevalence of addiction in the adult patients and that patients visited a number of emergency departments to receive drugs. Hematologists, on the other hand, perceived negative attitudes of the staff, incorrect use of medication, and misdiagnosis of substance abuse to be among the problems contributing to the inadequate management of pain in patients with sickle cell disease.

On the other hand, Murry and May (1989) conducted a descriptive study to describe patients' perceptions of painful sickle cell crises. Questionnaires were completed by 102 subjects, 61 women and 41 men. The questionnaire was designed to obtain information about the intensity of pain during the patients' last crisis, about the problems of the doctor's and nurses' understanding of the amount of pain, and about the problems of sickle cell disease in general. The findings indicated no differences between groups. Cold and tiredness were the factors deemed most likely to precipitate crises. There were significant differences in the degrees of pain perceived by patients and those perceived by the staff. Patients perceived their pain relief to be inadequate and their pain medication to be given too slowly in response to their request.

In an attempt to seek a solution to the problem of managing sickle cell disease, Lorenzi (1993) studied the effects of using comprehensive nursing care guidelines for sickle cell patients in crises on nurses' job satisfaction. The subjects were all registered nurses and licensed practical nurses who worked on a unit designated for sickle cell patients. The researcher developed a Knowledge Base Inventory Tool for use in the study. The subjects were asked to complete the Knowledge Base and Job Satisfaction tools. The subjects received inservice education on the use of the comprehensive nursing guidelines. This served as a means of educating them about caring for sickle cell patients. After having used the guidelines for 3 months, they were asked to complete both tools again. After 6 months, they were again asked to complete the tools. The results of this study supported the belief that education produces a change in both knowledge and behavior. The results also showed a statistically significant increase in job satisfaction in the area of the nurse having enough time to meet the biopsychosocial needs of the patients with sickle cell disease.

The Human Immunodeficiency Virus and African American Women

In an attempt to identify culturally related risk behaviors among African American women, Cruise and Dunn (1994) designed an ethnographic case study strategy. These researchers selected a sample from a group of subjects who lived within the same housing project. They formed a focus group, with one subject serving as the group leader. The data collected from the subjects during the session were analyzed using content analysis. These researchers identified several themes that provided insight into reasons for the high risk sexual behaviors among African American women. These themes included the perception of AIDS risks by low-income African American women, and cultural differences in the meanings of roles assumed in sexual behavior and the male-female relationship among low-income African Americans. From these findings, Cruise and Dunn identified barriers to reducing high risk behaviors among African American women.

Nyamathi, Bennett, Leake, Lewis, and Flaskerud (1993) conducted a study to describe AIDS-related knowledge, perceptions, and risky behaviors of impoverished African American and Hispanic women. Their sample consisted of 1,173 minority women, 18 to 75 years of age, who admitted to using intravenous drugs, being a prostitute, being diagnosed with a sexually transmitted disease, having multiple sex partners, or being homeless. Seventy-eight percent of the sample were African American. The subjects were interviewed in a homeless shelter or a drug rehabilitation center. The researchers found that knowledge related to transmission was high among all subjects, yet practice of safe sex behavior was low. The African American women reported the highest incidence of sex with multiple partners, and the Latina women reported the highest incidence of intravenous drug use. Factors identified in the African American women, that the researchers deemed contributing to the risk of HIV transmission, included early age for onset of sexual intercourse, lack of stable relationships, negative attitudes toward contraception, and the use of sex for survival.

In a similar study, Harris and Kavanagh (1995) examined the relationship of knowledge, perceptions, and high risk behaviors among 102 African American women attending four methadone clinics in Baltimore. A 66-item questionnaire was used to obtain information related to sexual practices, drug use, contraceptive usage, and treatment history for sexually transmitted disease. The participants demonstrated considerable knowledge about the transmission of AIDS, protection against AIDS, myths about AIDS, and AIDS testing. The 102 participants responded correctly to 75% of the items. The results of the data analysis indicated that the higher the knowledge score, the greater the perception score for risk of contracting AIDS. However, the reports of sexual behavior did not reflect their level of knowledge. These results also indicated that the participants' understanding of the interrelationships among AIDS, AIDS-prevention strategies, and health maintenance was limited.

On the other hand, Orr, Celentano, Santelli, and Burwell (1994) examined the relationship of symptoms of depression and risk factors for HIV acquisition among African American women. A questionnaire was administered to 173 African American women while they were waiting to be seen in a health center. The results indicated a high level of depressive symptoms in subjects who practiced high risk behaviors. The women with significant levels of depressive symptoms were more likely to have multiple sex partners, to have a sexual partner who used drugs, to be a drug user, or to have already had a sexually transmitted disease.

In order to ascertain what African American women perceived of their social support system, Hudson and Morris (1994) interviewed 5 subjects diagnosed with AIDS. Using content analysis, the researchers formulated seven themes: independence and control over one's environment, support from significant others, keeping a positive attitude, spirituality, lack of family support, appreciation for case management, and avoidance of support groups. The first theme was related to the subjects' desire to remain as independent and in control over as much of their lives as possible. The second theme was related to support from lovers, companions, and friends. The third theme was related to positive thinking, coping, and creating a desire to appreciate the support that was offered. The fourth theme was related to belief in God and having an appreciation for prayer. The fifth theme involved deviation from the cultural norm of strong family support usually seen among African Americans. The sixth theme was related to appreciation for health care workers. Social workers and case managers were held in higher esteem than were physicians and nurses. The seventh theme involved feelings and perceptions about support groups. The subjects believed support groups to be depressing and a waste of time.

In an attempt to help find a solution to the problem of risk-taking sexual behaviors identified among African American women, DiClemente and Wingood (1996) designed an intervention research study. The sample was randomly selected from a list of women receiving services at a community service center. The study design was a randomized, single-blind controlled trial using 128 subjects. The women were assigned to one of three groups: a social skills intervention group, an HIV risk-reduction training group, or a sexual assertiveness and communication training group. Follow-up assessment was performed across and between the treatment groups 3 months after the intervention. Women in the social skills intervention demonstrated increased consistent condom use, greater sexual self-control, greater sexual communication, and sexual assertiveness. DiClemente and Wingood concluded that educational risk-reduction programs are effective when they are gender relevant and culturally sensitive. They found that providing social skill training can effectively enhance consistent condom use.

Perceptions of Caring Behaviors

In order to explain what caring means to society, Hutchinson and Bahr (1991) explored and described the types and meanings of caring behaviors engaged in by elderly nursing home residents. Data were gathered through interviews and observations in the nursing home. The purpose of this study was to understand the types of caring patterns among the residents. Content analysis led to identification of four categories of caring: protecting, supporting, confirming, and transcending. The similarities between the caring concepts identified in the study supported the definition and description of caring defined by these researchers, as well as the universal concepts identified among other researchers and theorists. Hutchinson and Bahr's findings indicated that caring was an element of a higher level of need. This premise supports Maslow's theory, which served as the theoretical framework for their study. This work offered a beginning explanation of the meaning of the concept of care as identified by a specific group who engage in the study of caring behavior.

McNamara (1995) designed a qualitative descriptive study to assess how caring is perceived in perioperative nursing. The theoretical framework for the study was Watson's (1979) theory of nursing, human science and human care. The study was designed to answer questions regarding how care is operationalized in perioperative nursing. McNamara examined behaviors of perioperative nurses working with unconscious patients. The sample for the study included 5 operating room nurses. The researcher constructed an interview guide based on Watson's 10 carative factors. A content analysis of the data identified 20 themes. The recurring themes were showing concern for patients as unique human beings, communicating, touching, being sensitive to feelings, providing protection and safety, praying for, and facilitating patients' contacts with support systems. All 5 subjects stated that providing support, protecting, and promoting safety for patients were the most important caring behaviors in the preoperative period. Three of the subjects perceived physical presence with patients as the most important caring behavior in the perioperative period, whereas the other 2 perceived assessment as most important. All subjects agreed that identification of physical and safety needs best exemplified caring behaviors in the intraoperative period and that caring behaviors involving attending to safety and physical needs were most important during the postoperative period. McNamara concluded that perioperative nurses perceived themselves as caring.

Cronin and Harrison (1988) identified nursing behaviors perceived as caring by patients admitted with post-myocardial infarction. This descriptive study was based on Leininger and Watson's concepts. Watson's (1979) 10 carative factors were used as a framework for their study. The purposes of this study were to identify behaviors exhibited by nurses in the coronary care unit that were perceived by patients as caring; to ascertain which of these caring behaviors were perceived as most important and which were perceived as least important; and to ascertain if there was a relationship among demographic variables such as age, sex, educational level, number of admissions, length of stay, and patients' perceptions of nurse caring behaviors.

The sample consisted of 22 patients, 17 men and 5 women, who ranged from 35 to 83 years old (Cronin and Harrison, 1988). The educational backgrounds ranged from eighth grade to a baccalaureate degree. The instrument used to measure patient perceptions was the caring behavior assessment (CBA) developed by Cronin and Harrison. The CBA consists of 61 items divided into seven subscales: human needs assistance, teaching-learning, humanism-faith-hope-sensitivity, spiritual, supportive-protective, helping-trust, and expression of feelings. The investigators found the highest ranking behavioral subscale to be assistance with gratification of human needs, which included items such as know what they are doing, make me feel someone is there if I need them, know how to give shots and start IVs, know how to handle equipment, know when it is necessary to call the doctor, do what they said they will do, answer my questions clearly, is kind and considerate, and teach me about my illness. Cronin and Harrison found no significant differences in the perception of caring behavior between subjects based upon sex, age, or educational level.

In a similar study, most important and least important caring behaviors of nurses perceived by surgical patients were measured by Parsons, Kee, and Gray (1993), using the CBA developed by Cronin and Harrison. The respondents were asked to rank the behaviors in order of most important to least important. The sample consisted of 19 patients scheduled for outpatient surgery. The theoretical framework for the study was based upon the philosophy and science of caring described by Watson. Watson postulates that any behavior perceived as caring could fit into one of the 10 categories. The 10 carative factors described by Watson are believed to be appropriate for any setting. Therefore, this theory was selected as the framework for this study. Purposes of the study were to identify the behaviors of perioperative nurses perceived as caring; determine which caring behaviors were perceived as more important than others by the patients; determine the relationship of demographic variables such as age, sex, education, and socioeconomic status to patients' perception of nurse caring behaviors; and compare the results from this study of surgical patients to Cronin and Harrison's (1988) study of coronary care unit patients' perceptions of nurse caring behaviors.

The responses to the interview in Parson's et al. (1993) study were analyzed by content analysis to determine categories. The three most common responses from the 19 surgical patients were the reassuring presence of the nurse, expression of concern, and attention to physical comfort. The 63 items on the CBA were ranked according to the 10 most important caring behavior and the 10 least important caring behaviors. The 10 CBA items that were found to be most important all fit into the subscales for behaviors demonstrating expertise in human interaction skills. The 10 least important fit into the subscales for expression of feelings and spiritual care. Responses to the CBA were also analyzed using the subscales derived from Watson's 10 carative factors. The items that composed the human needs assistance subscale ranked most important, and items composing the expression of feelings subscale were ranked as least important. The Kruskal-Wallis one-way analysis of variance for the demographic variables showed no relationship between the perceptions of most important or least important caring behaviors and the subjects' age, sex, education, or income levels.

Bottorff and Morse (1994) attempted to observe caring behaviors by studying interaction processes. They analyzed the videotaped verbal and nonverbal behaviors of nurses during interactions with cancer patients. Four types of attending behaviors were identified: doing more, doing for, doing with, and doing tasks. These behaviors were identified by a detailed description of the behavior pattern in which recurring behavioral patterns were delineated. Four types of touch were identified: comforting touch, connecting touch, orienting touch, and social touch. The perceived needs of the patients, nature of the task, time constraints, and the sensitivity of the nurse were all factors influencing the type of attending behaviors. There were eight characteristics assessed in each type of attending: focus, eye gaze, intent, relationship, time-task ratio, dialogue, tone of voice, and type of touch. The results of the study indicated that individual patients may have different types of attending needs. The researchers concluded that the nurse must be flexible in approaches to caring in order to meet the variety of needs and achieve desired outcomes.

Larson and Ferketich (1993) measured patients' satisfaction of nursing care using an empirically derived satisfaction measurement instrument, the care/satisfaction questionnaire (CARE/SAT). The purpose of their study was to refine and test the instrument as the fourth phase of a descriptive study. The first phase of the study focused on identifying nursing behaviors that denote caring to both nurses and patients. In this phase, 50 nurse behaviors were identified and categorized into six themes of caring. The reliability and validity of the instrument were established in a pilot study. The subjects for this pilot study were cancer patients and the nurses caring for them. The design of the study was descriptive correlational using a convenience sample of 268 hospitalized adult medical-surgical patients, 48 hr prior to discharge from four hospital settings. All subjects were over 18 years old, able to read

English, and willing to complete the questionnaire. The questionnaire was a 71-item instrument with a demographic self-report sheet. Analysis of the CARE/SAT relative to the patients' appraisal of their nursing care was based upon responses to the questionnaires. Highest rankings were given to caring items that depict skill, knowledge, and judgement abilities of the nurse. A significant difference was found among subjects in the three urban hospitals and the three community hospitals.

The results of the Larson and Ferketich (1993) study supported the reliability and validity of the CARE/SAT questionnaire. Cronbach's alpha for the item total of the CARE/SAT was .94. The alpha coefficient for each of the three subscales identified by factor analysis exceeded .80. The first factor was labeled assistive and consisted of 12 items. Assistive referred to basic nurse caring behaviors such as teaching and monitoring. The second factor was labeled benign neglect and consisted of 11 items. Benign neglect referred to behaviors that were noncaring. The third factor was labeled enabling and consisted of six items. Enabling behaviors included those which assist patients in understanding and actively participating in their own care. Caring behaviors identified by the questionnaire included encouragement given, checked me frequently, knew when to call the doctor, knew how to give shots, knew how to manage equipment, explains things, gave good physical care, and provided comfort. All patients stated that they experienced caring behaviors from nurses. The results among subscales varied among hospitals. There was a significant difference in the perception of caring on the enabling subscale scores between the patients in the community hospitals and the patients in the urban hospitals. The patients in the community hospitals had higher subscale scores in the enabling category. There was a significant difference in the perception of caring on the benign neglect subscale score between the subjects in the community hospitals and the subjects in the urban hospitals. The patients in the urban hospitals had higher subscale scores in the benign neglect category. There was no significant difference in perceptions of caring between the subjects in the community hospital and subjects in the urban hospital on the assistive subscale scores.

Brown (1986) interviewed 50 patients to determine how they described feeling cared for by a nurse. The data were collected on audio tape. The data analysis led to the identification and development of eight care themes: recognition of individual qualities and needs, reassuring presence, provision of information, demonstration of professional knowledge and skill, assistance with pain, amount of time spent, promotion of autonomy, and surveillance. Caring behaviors perceived by the subjects included doing extra things for the patient, providing service that was not required, comforting, supporting, reassuring, informing, taking immediate action in a situation that is urgent, watching the patient carefully, and giving medications on time to relieve pain.

Poole and Rowat (1994) identified caring behaviors of home-care nurses as perceived by elderly patients. The sample consisted of 5 clients who received home care. The data were collected by interview. The average age of the subjects was 78 years. The data were analyzed using the constant comparative method of qualitative analysis. The researchers identified three categories of caring behaviors: attributes of the nurse, emotional support, and physical support. Fifty-six caring behaviors were reported. Attributes of the nurse accounted for 52%, emotional support for 25%, and physical support for 23%. The behaviors identified in this study were much like those of other studies. The caring behaviors identified included listening, genuineness, patience, respect, giving hope, good mood, and encouraging. The subjects also identified the doing and physical caring such as spending time, giving information, performing physical tasks, and coordinating care.

Larson (1984) conducted a study to identify important caring behaviors. Larson was in the forefront of identifying perceptions of cancer patients for the most and least important nurse caring behaviors. The purpose of this study was to determine the caring behaviors that most clearly conveyed to the patient that they were being cared for. The sample consisted of 57 adult patients diagnosed with cancer. They were selected from three hospitals: two community and one teaching. The caring assessment instrument (CARE-Q), consisting of 50 behavioral items, was used as the data collection tool. The variables tested included hospital setting, age, gender, primary cancer site, and treatment modality. The data analysis showed no statistical differences among the subjects. The 10 most important and 10 least important caring behaviors were identified. The 10 most important caring behaviors included items such as knows how to give shots, knows when to call the doctor, responds quickly to patient calls, listens to the patient, and is well organized. The 10 least important caring behaviors included items such as volunteers to do little things for the patient, helps establish realistic goals, is professional in appearance, and asks patient what name he or she prefers to be called. This study indicated that demonstration of competency in performing skills best conveyed caring to these patients.

In order to help identify the meaning of nurses' caring in nursing practice, Astrom, Norberg, and Hallberg (1995), interviewed 45 experienced nurses employed in surgical, medical, and long-term care areas. Data were collected by taped interviews, and the interviews were transcribed and analyzed. Content analysis revealed 88 narratives about nurses' experiences of care that made a difference to patients. Relief of pain and anxiety appeared in 33 of the 88 narratives. Nurses in long-term care mentioned support of patients' psychosocial and spiritual needs more often, and nurses in medical surgical areas mentioned support of patients' weakened vital functions. Almost all the narratives included items specific to the ability to understand the situation, to establish contact with the patients, and to act as patient advocate. The analysis revealed that most of the nurses had problems giving care as new nurses, but experience and maturity in nursing gave them strength. All subjects indicated that caring gave them satisfaction and pleasure, thus making their sacrifices and hard work worthwhile. Astrom et al. concluded that to the surgical nurses, caring meant meeting the patients' physical needs; to the medical nurses, caring meant understanding; and to the nurses in long-term care, caring meant maintaining comfort, autonomy, and wholeness.

Nurses' perceptions of caring were also examined by Larson (1986). The sample included 57 registered nurses who were employed in one hospital setting and were providing care to cancer patients. The 50-item CARE-Q was used for data collection. The mean scores ranged from 5.9 for the most important caring behavior to 2.5 for the least caring behavior. The 10 items ranking as most important were listens to the patient, touches, allows expression of feelings, gets to know the patient as an individual, talks to the patient, realizes the patient knows best, is perceptive of patient's needs, responds quickly, puts the patient first, and gives good physical care. Data analysis showed the nurses to be consistent in their selection of caring behaviors perceived as important in making their patients feel cared for, as well as in those behaviors perceived to be least important.

In 1987, Larson conducted a study to compare cancer patients and professional nurses' perceptions of important nurse caring behaviors. Larson drew on information derived from the two previously discussed studies, and homogeneity was determined by CARE-Q sort. The findings demonstrated a marked difference between nurses' and patients' perceptions of important nurse caring behaviors. Cancer patients perceived nurse behaviors that demonstrate being accessible, monitoring, and following through as most important. In contrast, nurses perceived comforting and trusting relationships as being most important.

Gooding, Sloan, and Gagnon (1993) examined the importance of nurse caring behaviors from the perspective of nurses and patients. The CARE-Q Sort Instrument developed by Larson in 1981 was used to measure the ranked importance of caring behaviors as perceived by oncology patients and oncology nurses. One of the intentions of the study was to determine whether there was a relationship between the patients' and nurses rankings' in order of importance and to determine whether differences existed between the subscale scores of these caring behaviors for oncology patients and nurses. The patient sample was selected from the outpatient department of two university teaching hospitals. The nurses were selected from 12 different units that provided care to oncology patients within the same two university hospitals. The sample was selected by convenience and consisted of 42 patients, 23 males and 19 females, and 46 nurses, 1 male and 45 females.

In this study, Gooding et al. (1993) used 50 nurse caring behaviors printed on cards, and participants were requested to sort the cards in rank order of importance. Each item on the cards was scored using a 7-point Likert scale. Five caring behaviors found to have the highest mean scores from patients included some items which continued repeating through all the investigations: knows how to give shots, manages equipment, responds quickly to calls, gives treatments and medications on time, knows when to call the doctor, and anticipates and plans for needs. Five caring behaviors reported to have the highest mean scores from nurses were listens to the patient, allows the patient to express feelings, includes the patient in planning, perceives patient needs, and gets to know the patient as a person. The researchers found that both patients and nurses placed acting on patient needs among the five highest mean scores. The results of this study showed a statistically significant difference between the patients' and nurses' perception of caring behaviors that are important.

In 1987, Mayer replicated Larson's (1981) study. The purpose of the study was to compare perceptions of important nurse caring behaviors of nurses with those of the patients.

The sample included 54 patients, 24 men and 30 women; their mean age was 53.8 years. The sample of nurses consisted of 28 females working in oncology. Mayer used the 50-item CARE-Q instrument developed by Larson. The results of this study showed no agreement in the five most important caring behaviors identified by the nurses and patients. The five highest ranked caring behaviors identified by Mayer's nurse subjects included listens to the patient, allows expression of feelings, realizes that the patient knows himself or herself best, touches the patient, and anticipates needs. The patient group identified as the most important knowing how to give shots and manage equipment, cheerfulness, encouraging the patient to call for assistance, putting the patient first, and anticipating needs. This replicated study by Mayer provided support for Larson's findings.

The importance of nurse caring behaviors as perceived by Swedish hospital patients and nursing staff was examined by Von Essen and Sjoden (1991a). The sample consisted of 81 patients and 105 nurses. The patient group included 46 women and 35 men from six hospitals in Sweden. The staff group was composed of nurses, nursing assistants, and secretaries employed in the six Swedish hospitals. The subjects were given the CARE-Q (Larson, 1981) instrument to rank caring behaviors that were perceived as being most important and least important.

The findings from this study (Von Essen & Sjoden, 1991b) showed statistically significant differences between the patients' and nursing staff's perception of caring behaviors on five of the six subscales. Patients identified as being most important facilitates and behaviors belonging to the explains and anticipates, and monitors and follows through subscales. In contrast, the nursing staff identified behaviors belonging to the comforts and trusting relationships subscales as being the most important caring behaviors.

Von Essen and Sjoden (1991b) also conducted another study to identify patients' and nurses' perceptions of the most and the least important caring behaviors. These searchers used the caring assessment instrument CARE-Q (Larson, 1981) to determine the importance of caring behaviors to the subjects. The sample consisted of 86 patients and 73 nurses and nursing assistants. Forty patients were from the county hospital, and 46 were from the university hospital. The staff participating were nurses and nursing assistants. Thirty-four nurses were from the county hospital, and 39 were from the university hospital. The sample, composed of patients and nurses, was selected by convenience from four large university hospitals and four county hospitals.

Von Essen and Sjoden (1991b) found significant differences in perceptions between nursing staff and patients as to what constitutes important caring behaviors. The patients assigned higher importance to behaviors such as monitoring, giving information, competent clinical skills, accessibility, following through, and listening. Nursing staff assigned higher importance to behaviors such as providing comfort, developing a trusting relationship, being accessible, and anticipating needs. The analysis of data also showed no difference in perceptions of patients in the university hospital and in the county hospital. The results of the nursing staff in the two types of hospitals also proved to be similar.

Wolf, Giardino, Osborne, and Ambrose (1994) studied the dimensions of nurse caring behaviors in a sample of 541 subjects, 263 patients and 278 nurses. The patients had all been hospitalized in a tertiary care setting. The majority of the patients were Caucasian, and all were selected from a hospital computerized list. The nurses were also selected from a computerized hospital list. The revised Caring Behavior Inventory (CBI) developed by Wolf (1986) was used as the data collection tool. The CBI used in this study included 43 items. Responses were measured using a 4-point Likert scale. Validity and reliability were established for the revised instrument. Factor analysis, using a principal components method, resulted in a six-factor solution for the combined nurse and patient responses on the CBI. Five dimensions were generated: respectful deference to others, assurance of human presence, positive connectedness, professional knowledge and skill, and attentiveness to other's experiences. The respectful deference to others factor included 12 items that incorporated a courteous regard for the other.

The assurance of human presence factor included 12 items that reflected an investment in other's needs and security. The positive connectedness encompassed nine items that indicated an optimistic and constant readiness on the part of the nurse to help. The professional knowledge and skill factor described caring as being proficient, informed, and skillful. The final factor, attentiveness to other's experiences, incorporated an appreciation of and engrossment in the other's perspective and experience. This preliminary study was used to generate dimensions of nurse caring identified by both nurses and patients, not to determine differences between groups.

Warren (1994) studied the phenomenon of caring behaviors of critical care nurses as perceived by family members of patients. Grounded theory methodology was used. The subjects were immediate family members of patients admitted to the intensive care unit. All subjects were over 18 and had experienced more than six contacts with intensive care nurses. The unspecified number of subjects was interviewed until four categories emerged: informing, enhancing, spiriting, and touching. The informing category encompasses orienting, sharing, encouraging, allowing, and dialoging. The enhancing category relates to hoping, reassuring, understanding, and knowing. The spiriting category stresses extending healing power, enhancing subjectivity, and intuiting. The touching category involves handling, holding, caressing, placing, and patting. Warren concluded that families define caring in numerous ways and that not all caring behaviors are observable.

Vincent, Alexander, Money, and Patterson (1996) examined the perceptions of nurse caring behaviors as seen by parents of patients in pediatric intensive care. The sample, selected by convenience, consisted of 10 pairs of biological mothers and fathers. The subjects were all over 18 years of age and were English speaking. Data were collected during taped interviews. Validity was established by the use of one interviewer, the use of the same setting for all of the interviews, and the use of two researchers, skilled in content analysis to review the tapes. The researchers used an ethnograph computer program to cluster the data. The following four themes were identified: characteristics of the nurse, meeting the child's needs, meeting the parent's needs, and feelings evoked by caring. All parents responded that pleasant personality--verbal and nonverbal behaviors such as hugs, cuddling, and smiles--and knowledge demonstrated by the nurse were all indicators of caring.

Although all parents identified meeting the needs of the child as an important aspect of caring, Vincent et al. (1996) found that mothers and fathers showed differences in their perceptions of caring behaviors relating to their children. They found that the women focused on touching behaviors, whereas the men focused on task-oriented behaviors such as monitoring. The researchers concluded that behaviors such as monitoring patients, providing physical care and comfort, helping patients and families feel secure, providing information, giving support, and encouraging family participation in care are all behaviors that are perceived as caring.

The literature review revealed one study investigating the perceptions of AIDS and HIV-positive subjects related to caring behaviors. Victor (1993) interviewed 21 health care administrators, 35 staff members, and 51 persons with HIV infections from six home care programs in Africa. The purpose of the study was to identify the kind of care provided to persons with HIV infection. Data were collected through a combination of interviews, observation, and document review. Various methods were used to minimize observer bias, including having one researcher collect all the data. Content analysis resulted in the following categories of care: physical care, psychological care, family care, material care, environmental care, spiritual care, and educational care. These findings suggested that caring behaviors include technical, verbal, and nonverbal acts. From this information and further data analysis, Victor developed a model of caring for persons with HIV infection. The model illustrates care as a holistic phenomenon with connected parts involving problem solving and mutual decision making. The model depicts the patient as a unique human being who is the focus of the caregiver. The patient with HIV infection is shown to need the care of family and to need assessing, nurturing, teaching, comforting, and protecting interventions, depending upon the cultural and social environmental context. Based upon the model of care, nursing behaviors may include assessing, nurturing, teaching, comforting, or protecting.

Summary

Fifty-three studies that investigated caring were reviewed. Six of 53 studies examined sociodemographic factors that may influence either perception of care or quality of care. Breemhaar et al. (1990), Clark et al. (1996), and Meister and Boyle (1996) examined variables influencing perceptions of care and patient satisfaction. Greener and Winchell (1991) examined patterns of satisfaction in relationship to provider coverage. Only one study was identified that examined the relationship of gender and willingness to provide care (Arber & Ginn, 1995). Likewise, one study was identified that compared perceptions of caring behaviors among patients with various diagnoses (Von Essen & Sjoden, 1993).

In eleven of the 53 studies, the investigators examined attitude, knowledge, and willingness to care. Seven of these studies--Cole and Slocumb (1993), Douglas et al. (1985), Forrester and Murphy (1992), Laschinger and Goldenberg (1993), Plant and Foster (1993), and Van Wissen and Siebers (1993)--examined the attitudes of nurses toward HIV-positive patients. In four studies, Henry et al. (1990), Lawrence and Lawrence (1989), Robbins et al. (1992), and Turner (1990) studied the relationship between nurses' knowledge about AIDS, and attitudes of caring for HIV infected patients. In one study, Barrick (1988) examined the relationship between nurses' attitudes toward homosexuals and willingness to provide care to patients with AIDS.

In search of a group comparable to HIV-positive African American women, the literature indicated that patients with sickle cell disease are also members of a minority group that experience negative attitudes from health care providers. Like persons with AIDS, patients with sickle cell disease are also suffering from a terminal illness. Patients with sickle cell disease are also usually African Americans who may experience negative caring behaviors as a result of the stigma that society places upon the race in general. The literature review yielded four studies in which the researchers examined perceptions among patients with sickle cell disease as well as perceptions of health care providers related to the patients' pain. In one study, Murry and May (1989) described the painful crises from patients' perspective. Alleyne and Thomas (1994) compared the patients' perception to that of the caregivers; Shapiro et al. (1997), on the other hand, described the physicians perceptions of sickle cell related pain. In order to ascertain the effects of using comprehensive guidelines for providing care to patients with sickle cell disease, Lorenzi (1993) examined the relationship of strict use of guidelines to nurses' knowledge base and job satisfaction. Overall, the African

American patients with sickle cell disease did not feel their pain was managed well, their perceptions of the behaviors of their care givers were not positive, and the research findings indicated a need for culturally relevant education for members of the health care profession.

The literature was reviewed to identify any research studies involving African American women who had AIDS or were HIV positive, as well as any research related to the perceptions of African American women in regard to the health care system. Six studies in which the investigator examined HIV risk behaviors, AIDS related knowledge, and intervention strategies among African American women were identified. Hudson and Morris (1994) described African American women's perception of the social support system. Cruise and Dunn (1994), Nyamathi et al. (1993), and Harris and Kavanagh (1995) examined high-risk sexual behavior among African American women. Whereas Orr et al. (1994) examined the relationship between depression and high risk sexual behavior among African American women, DiClemente and Wingood (1996) conducted an intervention study to identify the most effective strategy to reduce the high-risk sexual behaviors commonly identified among African American women. In essence, the findings from these six studies indicated that although African American women represent one of the fastest growing population segments in the United States to become infected with HIV, there is little evidence of avoidance of high-risk sexual behaviors. Although differences in AIDS knowledge and attitudes toward AIDS were found based on race, education, and place of birth, there was no relationship between knowledge about the disease and the practice of safe sex. In 30 of the 53 studies identified, the investigators examined perceptions of caring behaviors. These studies show how attitude and knowledge influence willingness to provide care, as well as influencing the kind of behaviors that are perceived as caring. The purposes of 11 of the 30 studies were to identify attitudes of nurses toward AIDS and HIV-positive patients and to examine the relationship among attitude, knowledge, and willingness to care for patients with AIDS. Cole and Slocumb (1993), Douglas et al. (1985), Forrester and Murphy (1992), Laschinger and Goldenberg (1993), Robbins et al. (1992), and Van Wissen and Siebers (1992) studied attitudes of nurses toward patients with AIDS. Their findings indicated that attitudes are generally negative toward HIV infected patients, but showed significant changes following education. Lawrence and Lawrence (1989) and Plant and Foster (1993) studied the relationship between knowledge and attitude to determine whether increased knowledge and a positive attitude were highly correlated. The results of these studies indicated that it is possible to increase knowledge and change attitude. Barrick (1988) and Cole and Slocumb (1994) investigated the degree of association between attitude and willingness to care, whereas Henry et al. (1990) examined the relationships among attitude, knowledge, and willingness to provide care. Although Cole and Slocumb found no significance, Barrick found a positive correlation ($\underline{r}$ =.50, $\underline{p}$ <.01) between attitudes toward gay men and lesbians and willingness to work with AIDS patients. Henry et al. also found variables such as low homophobia scores and higher AIDS knowledge scores to be highly correlated with positive behaviors and attitudes toward AIDS patients ($\underline{p}$ <.0001).

Nineteen of the 30 studies reviewed identified behaviors perceived by patients and nurses as caring. These behaviors included showing concern, touching, willingness to teach, communicating, sensitivity, praying for patients, being knowledgeable, showing kindness, making eye contact, listening, being genuine, being patient, being organized, providing comfort, and encouraging call bell use (Astrom et al., 1995; Bottorff & Morse, 1994; Brown, 1986; Cronin & Harrison, 1988; Gooding et al., 1993; Hutchinson & Bahr, 1991; Larson, 1984, 1986, 1987; Larson & Ferketich, 1993; Mayer, 1987; McNamara, 1995; Parsons et al., 1993; Poole & Rowat, 1994; Victor, 1993; Vincent et al., 1996; Von Essen & Sjoden, 1991a, 1991b; Warren, 1994). The instruments measuring perceptions of caring behaviors used in many of the studies reviewed included the CBA, CBI, care satisfaction, and the CARE-Q instrument. Three theories were tested: Ajzen-Fishbein's theory of research action, Leininger's (1991) culture care theory, and Watson's (1979) 10 carative factors. Most studies reviewed did not mention a theoretical framework. The previous research studies examined the caring perceptions of oncology nurses, perioperative nurses, staff nurses, family members of patients in intensive care, parents of pediatric patients, and home health nurses. The samples included patients with cancer, coronary artery disease, psychological disorders, surgical disorders, as well as geriatric nursing home residents. Only one study conducted by Victor (1993) examined the perceptions of care among AIDS and HIV-positive patients. The literature was reviewed for the purpose of identifying information related to demographic variables and perceptions of caring behaviors. This information is lacking in the literature; of the 53 studies reviewed, only six studies examined the relationship between demographic variables and perceptions of care. No studies were found that examined the perceptions of caring behaviors among HIV-positive African American women. Likewise, the absence of literature related to the perceptions of caring in the HIV-positive population and especially HIV-positive African American women clearly supported the need for this study.

CHAPTER 3

METHODOLOGY

The purpose of this descriptive study was to answer the following questions:

1. How much of the variability in perceptions of caring behaviors can be explained by socioeconomic status, educational level, age, and marital status?

2. What percentage of variance in perceptions is accounted for by diagnosis?

3. Is there a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection?

4. Is there a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection?

Setting

The subjects for this study were recruited from a clinic for HIV-infected patients and two sickle cell clinics in the southeastern part of the United States. Data were collected in the clinic facilities where the subjects received outpatient care. Potential subjects were identified by a contact person within each clinic. Questionnaires were administered by the investigator in the waiting room of the clinics while the subjects waited for their appointments.

Sample

The subjects for this study were 60 African American women attending three clinics in the southeastern part of the United States. The number of subjects needed was determined by the use of power analysis; 60 subjects were needed to ensure that power of 80% with alpha at .05 was obtained. The sample was selected by convenience. Because HIV infection is viewed as being on an illness continuum, the sample of HIV-positive subjects included patients who have developed AIDS. The HIV-negative sample consisted of African American female patients diagnosed with sickle cell disease.

The subjects met the following criteria for eligibility to participate in the study: (a) identified as being HIV positive or so indicated in the clinic record or (b) had sickle cell disease as indicated in the clinic record; (c) African American female as evidenced by the demographic data form and clinic record; (d) over 18 years of age; (e) able to speak and read English as identified by the clinic person, clinic record, or initial contact with subject; (f) willing to participate in the study; and (g) was a patient attending the HIV clinic or one of the sickle cell clinics.

Protection of Human Subjects

The University of Alabama at Birmingham Institutional Review Board (IRB) approved the application for the study (see Appendix A). Protection of the rights of human subjects was assured through an expedited review by the IRB. Confidentiality of all information was maintained. No identifying markers were placed on the instruments. All data were analyzed and reported as group data. The clinic for HIV-infected patients and the sickle cell clinics were all contacted to determine their willingness to permit the data collection and to assist with identification of the subjects. The subjects were informed of the purpose of the study and their right to withdraw at any time without recrimination. The subjects were asked to sign a consent form indicating their willingness to participate in the study. There was no perceived risks to the health and well-being of the patients involved in this study.

Instrumentation

In the review of caring literature, most investigators in the field refer to six instruments: the Caring Assessment Tool (Duffy, 1990), the CARE-Q (Larson & Ferketich, 1993), the Care Satsifaction Questionnaire (Larson, 1981), the Caring Attribute Scale (Nyberg, 1990), the Patient Satisfaction Visual Analogue Scales (Oberst, 1984), and the CBI (Wolf, 1986). Two of these instruments, the Care Satisfaction Questionnaire and the Patient Satisfaction Visual

Analogue Scales, were designed and used to measure degrees of satisfaction. Four of these instruments--CARE-Q, the CBI, Caring Attribute Scales, and the Caring Assessment tool--were designed and used to measure perceptions of caring behaviors. Although the instruments have been used to measure those groups' perceptions of patients, family members, nurses, and physicians, all four have consistently been used to measure those groups' perceptions of nurses' caring behaviors. No instruments were found in the literature that measured perceptions of caregiver caring behaviors of caregivers other than nurses.

The four instruments that measured perceptions of nurse caring behaviors were all considered for attributes that could be used to measure the perceptions of caregiver caring behaviors. The CARE-Q was developed by Larson in 1981 in two phases: identification of nurse caring behaviors from both the nurse and the patient perspective, and the refining of these identified behaviors into valid and reliable instrument items. The Delphi Survey Technique was the methodology used to identify these nurse caring behaviors, and qualitative analysis was used to analyze the data. To determine instrument reliability, the specific behaviors and themes of caring identified in the first phase were submitted to four review processes in preparation for the final instrument development. To establish instrument validity, two panel reviews and psychometric consultations were undertaken. In order to establish the reliability of the finalized items in the second phase of the development, test-retest of the completed instrument was carried out. Comparisons of the first sorting of the CARE-Q and the second sorting revealed a perfect correlation between the tests (Larson, 1981). Andrews, Daniels, and Hall (1996) conducted a study comparing five tools defining perceptions of nurse caring behaviors. The problems they found with the CARE-Q were the length of time required to administer the tool and the complexity of the card-sorting procedure for the participants. The mean participation time for completion was 26 min, and 20% of the subjects did not sort the Q cards correctly.

An instrument to measure caring was devised by Duffy in 1990 to analyze the relationship among nurse caring behaviors and selected outcomes of care. According to Duffy, this instrument was developed to assess the degree or quantity of nurse caring in the nurse-patient relationship. An item pool of 130 nursing behaviors was designed by Duffy to reflect Watson's (1979) carative factors. A 5-point Likert scale was chosen to quantify the frequency with which each behavior occurred. The items were written at the eighth-grade reading level. Content and face validity were supported by a panel of experts. To measure concurrent validity of the caring assessment tool, the CARE-Q (Larson, 1981) was used as a cross validation measure. Duffy found a high correlation between the two instruments, which supported concurrent validity. Internal consistency reliability was established in a pilot study using Cronbach's coefficient alpha (Duffy). According to Andrews et al. (1996), the caring assessment tool has negatively worded behaviors, which make the scores unreliable for use in a correlational design study. The average time taken to complete the form was 11.37 min, with a range of 2 to 30 min (Andrews et al.).

The Caring Attribute Scale was developed by Nyberg (1990) based on caring attributes described in the literature. A pilot study was conducted using graduate nursing students as subjects. Instrument reliability of 0.87 to 0.98 using Cronbach's alpha coefficient indicated excellent reliability for the whole questionnaire. The behaviors were rated on a 5-point Likert scale, with an average calculated for each behavior. Andrews et al. (1996) found the average time for completion of the questionnaire to be 12.38 min, with a range of 1 to 30 min.

The CBI (a collection of items that indicate caring in nurses' clinical practice) developed by Wolf in 1986 originally included 75 items generated from a review of the caring literature. The revised CBI includes 42 items. The items of the CBI are not just socially desirable terms, but are highly ranked behaviors and actions considered important to the caring process in nursing. The data were obtained through research built upon the investigations of Leininger and Watson (Wolf). The CBI was developed to be used in research that will "demonstrate the important link between nurse caring and improved patient welfare" (Wolf, p. 92).

To establish reliability of the instrument, the items were statistically analyzed using a factor analysis technique. No pattern emerged through the use of factor analysis. The median ranks ranged from 2.77 to 3.87 on a 4-point Likert scale. The caring items that ranked below 3.75 were eliminated from the CBI. Statistical analysis was performed on the remaining 42 items using the Kendall rank correlation coefficient (Wolf, 1986). The reliability on the 42 items showed an alpha of 0.96 (Andrews et al., 1996).

Sixty percent of the items of the CBI were correlated, minimally, at the .05 level of significance. It was concluded, therefore, that the items of the CBI have the same degree of meaning or caring to the various persons rating these items (Wolf, 1986).

Subjects using the CBI are asked to rank the 42 items as to frequency of occurrence on a 6-point Likert scale with the following values: 1 (<u>never</u>), 2 (<u>almost never</u>), 3 (<u>occasionally</u>), 4 (<u>usually</u>), 5 (<u>almost always</u>), and 6 (<u>always</u>). Andrews et al. (1996) conducted their study to determine which of the instruments currently used to measure perceptions of caring attributes has the greatest usefulness. They concluded that the CBI was valuable in determining perceptions of caring in both patients and nurses. Wolf (1986) found the CBI to be the most user-friendly tool among the five instruments examined. Among its desirable attributes are the following: Instructions are brief and easy to understand, it is applicable for use with descriptive statistical analysis, and it is feasible for use with high acuity patients. Wolf showed the average amount of time taken to complete the CBI was 6.26 min, with a range of 2 to 15 min.

Caring behaviors were identified in this study by both African American women with HIV infection and African American women with sickle cell disease. These subjects used the CBI (Wolf, 1986), completing the questionnaire with the investigator present (see Appendix B). The language in the items was reworded by the investigator to focus on the respondent. The review of related research shows the CBI (Wolf) to have been used primarily for measuring perceptions of caring behaviors among nurses. The instrument was used with permission of the author (see Appendix C). In this study, the instrument was extended to measuring patients' perceptions of caregiver caring behavior. Demographic data were collected using an investigator-developed tool (see Appendix D). The demographic data tool consisted of six demographic variables.

Data Collection Procedures

Following the IRB's approval to conduct the research and obtaining institutional permission, data were collected over a 1-year period. Personnel in each of the three clinics were contacted by phone on a weekly basis to identify potential subjects who met the criteria for inclusion in the study. The investigator arranged to be in the clinic at the time these potential subjects were scheduled for appointments. This process continued until the total number of subjects needed for the study was obtained.

The investigator approached the potential subjects in the waiting room of the clinics and introduced herself as a doctoral student in nursing conducting a research study to obtain information about perceptions of caregiver caring behaviors. A lab coat and identification badge were worn by the investigator at all times while in the clinic collecting data. The subjects were told about the study as outlined in the prepared script (see Appendix E). When a potential subject agreed to participate, she was given a written consent form to sign (see Appendix F). When the consent was obtained, the subject was handed a questionnaire on a clip board with an attached pen. When she completed the questionnaire, each subject was thanked for her time and effort in the endeavor.

Data Analysis Procedures

The data were analyzed using descriptive statistical and multiple regression analyses. The Statistical Package for the Social Services (SPSS) was utilized in data analysis. Descriptive statistics were used to describe the subjects in terms of the demographic variables of socioeconomic status, educational level, age, marital status, and diagnoses. Descriptive statistics were used to identify the most important caring behaviors and least important caring behaviors identified by the subjects. Stepwise multiple regression analyses were used to ascertain whether there was an association between socioeconomic status, educational level, age, marital status, diagnoses and perceptions of caregiver caring behaviors. Descriptive statistical techniques were used to analyze the mean scores on the CBI items and the relationship to ranking the 10 most caring behaviors and the 10 least important caring behaviors.

Limitations

The following were limitations to the study:

1. Subjects consisted of a convenience sample of patients from three clinics, thereby limiting the generalizability of the results.

2. HIV-positive patients experience psychosocial and psychological problems which may influence their perceptions in general.

3. Patients with sickle cell anemia experience psychosocial and physical problems necessitating pain medications which may influence their perceptions in general.

4. The patients who attend specialized clinics may have biased opinions, leading to a halo effect.

CHAPTER 4

FINDINGS

The purposes of this study were to (a) ascertain whether there is a relationship among demographic variables such as socioeconomic status, educational level, age, and marital status, and the patients' perceptions of caring behaviors; (b) ascertain how much of the variability in perceptions of caring behaviors can be explained by diagnosis; (c) ascertain whether there is a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection; (d) ascertain whether there is a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection.

In this descriptive study, data were obtained from 60 African American women attending three clinic sites. A description of the sample, the results of the statistical analysis for each research question, and the findings are presented in this chapter.

Description of the Sample

All of the 60 subjects were African American women: 30 were diagnosed HIV positive, and 30 were diagnosed with sickle cell anemia. Sociodemographic data were collected from the subjects using an investigator-developed questionnaire. These data are presented in Table 1.

Table 1

Sociodemographic Characteristics of the Sample (N=60)

Variable	*M*	Mode	*SD*	Frequency	%
Age	35	40	9.19		
Education					
Did not complete elementary school				3	5.0
High school				22	36.7
Some college or post-high school education				24	40.0
College degree				10	16.7
Graduate or professional degree				1	1.7
Marital status					
Separated				4	6.7
Widowed				4	6.7
Divorced				14	23.3
Married				10	16.7
Single, never married				25	41.7
Live with someone/roommate				3	5.0
Health coverage					
Medicare				28	46.7
Private				16	26.7
None				16	26.7
Income (annual)					
9,999 or less				34	56.7
10,000 - 19,999				19	31.7
20,000 - 29,999				7	11.7
30,000 - 39,999				0	0
40,000 - 49,999				0	0
50,000 or greater				0	0

The 60 African American women in this study ranged in age from 21 to 58 years, with an average age of 35 years. The subjects were generally educated. Although 5% had not completed high school, 93% had a high school or post-high school education, and 2% had postcollege coursework or a graduate degree.

A large number of the subjects in this sample, 42%, were single and had never been married. Whereas 10% of the subjects were married and living with their spouse, 22% were not currently with a spouse. They were either divorced, separated, or widowed. Only 27% of the subjects possessed private health care coverage, whereas the majority, 73%, were on Medicare or had no health care coverage at all. More than one half of the subjects in this sample, 56.7%, earned less than 10,000 dollars annually, whereas 43.4% earned between 10,000 to 29,000 dollars per year.

Sociodemographic characteristics of the HIV-positive sample are shown in Table 2. The 30 subjects in this group ranged from 21 to 48 years of age, with the average being 35 years. Although 10% had not completed high school, 73.3% had a high school or some post-high school education. A fairly large numbers of these subjects were well educated; 16.6% had a college or graduate school degree.

Whereas 9.7% of the subjects in this sample were married or living with someone, the majority, 83.3% were alone without a significant other in the home. Only 30% of the subjects possessed private health care coverage, whereas

70% were on Medicare or had no health care coverage at all. The majority of the subjects in this sample, 86.6%, earned less than 20,000 dollars annually, whereas only 13.3% of the subjects earned between 20,000 and 29,000 dollars per year.

Table 2

Sociodemographic Characteristics of the HIV-Positive Sample (N=30)

Variable	M	Mode	SD	Frequency	%
Age	35	40	7.82		
Education					
Did not complete elementary school				3	10
High school				10	33.3
Some college or post-high school education				12	40
College degree				4	13.3
Graduate or professional degree				1	3.3
Marital status					
Separated				4	13.3
Widowed				1	3.3
Divorced				6	20
Married				3	10
Single, never married				14	46.7
Live with someone/roommate				2	6.7
Health coverage					
Medicare				12	40
Private				9	30
None				9	30
Income (annual)					
9,999 or less				13	43.3
10,000 - 19,999				13	43.3
20,000 - 29,999				4	13.3
30,000 - 39,999				0	0
40,000 - 49,999				0	0
50,000 or greater				0	0

Sociodemographic characteristics of the sample with sickle cell disease are shown in Table 3.

Table 3

Sociodemographic Characteristics of the Sample with Sickle Cell Disease N=30)

Variable	M	Mode	SD	Frequency	%
Age	35.43	23	10.53		
Education					
Did not complete elementary school				0	0
High school				12	40
Some college or post-high school education				12	40
College degree				6	20
Graduate or professional degree				0	0
Marital status					
Separated				0	0
Widowed				3	10
Divorced				8	26.67
Married				7	23.33
Single, never married				11	36.67
Live with someone/roommate				1	3.33
Health coverage					
Medicare				16	53.33
Private				7	23.33
None				7	23.33
Income (annual)					
9,999 or less				21	70
10,000 - 19,999				6	20
20,000 - 29,999				3	10
30,000 - 39,999				0	0
40,000 - 49,999				0	0
50,000 or greater				0	0

The 30 subjects in this group ranged from 22 to 58 years of age, with an average age of 35 years. The subjects in this sample had comparable educational levels. There were no subjects who had not completed high school and no subjects who held graduate-level degrees. The majority, 80%, had a high school or some post-high school education, whereas 20 held a college degree.

A large number of the subjects in this sample, 73.34%, were alone and without a spouse, whereas only 26.33% were married or living with someone. The majority of the subjects in this sample, 70%, earned less than 10,000 dollars annually, whereas the other 30% earned between 10,000 to 29,000 dollars per year.

Instrument Data and Statistical Analysis

The CBI was used to obtain data. The subjects responded to 42 items as to frequency of occurrence on a 6-point Likert scale with the following values: 1 (never), 2 (almost never), 3 (occasionally), 4 (usually), 5 (almost always), and 6 (always). The CBI, developed by Wolf (1986), was designed for use with hospitalized patients. Therefore, some of the items on the instrument may have been difficult for a subject who only had exposure to caregivers in a clinic setting to respond to appropriately. The wording of the CBI was changed slightly for easier reading and adaptation to the clinic setting.

The mean scores for the 42 items ranged from 5.68 to 4.67, indicating that all subjects were generally positive in their perceptions of the caring behaviors they experienced in caregivers (see Appendix G). The setting from which the subjects were recruited may have contributed to these findings. The HIV clinic is a highly specialized clinic staffed by a team of health care providers who by their act of seeking and accepting employment in this agency indicated a willingness to work with and provide care for patients who are HIV-positive. The two clinics from which the subjects with sickle cell anemia were recruited were also designed exclusively for patients with this disease. Therefore, these caregivers would very likely display caring behaviors that would be perceived as positive.

In this study, the mean scores of the 42 CBI items were tabulated in respect to their fit within the dimensions of Watson's 10 carative factors. Watson (1979) identified 10 factors which were believed to be categories of caring. These categories are now known as 10 carative factors that form a structure and a framework for research related to caring behaviors. Watson theorized that any behavior that can be perceived as caring should fit within this framework. These factors are named (a) a humanistic altruistic system of values; (b) the instilling of faith and hope; (c) sensitivity to self and others; (d) helping and trusting human care relationships; (e) expressing positive and negative feelings; (f) creative problem solving caring process; (g) transpersonal teaching-learning; (h) supportive, protective, and or corrective mental, physical, societal, and spiritual environment; (i) human needs assistance; and (j) existential phenomenological spiritual forces. Wolf (1986) has used Watson's theory as a framework for much of her research. Wolf et al. (1994) used Watson's and Leininger's theory as a theoretical framework in a study to establish content validity of the CBI. Therefore, these 10 carative factors formed the subscales used in data analysis for this study, as shown in Table 4.

The subscales to which the subjects with sickle cell anemia gave the highest mean score were instilling faith and hope human needs assistance (M = 5.03) and existential phenomenological spiritual forces (M = 5.03). Likewise, the HIV-positive subjects assigned the highest mean score to the subscales existential phenomenological spiritual forces (M = 5.53), a carative factor involving the affective domain and psychosocial aspect of care. The subjects with sickle cell anemia gave the lowest mean score to the subscale supportive, protective, and corrective mental, physical, societal, and spiritual environment (M = 4.77). The HIV-positive subjects assigned the lowest mean score to the subscale transpersonal teaching-learning (M = 5). Both subject groups assigned relatively low mean scores to the subscale supportive, protective, and or corrective mental, physical, societal, and spiritual environment, which involve the art of nursing in doing for the patient. The mean scores of the patients with sickle anemia were lower on the CBI subscales than the HIV-positive patients.

Table 4

Mean Scores on Caring Behavior Inventory (CBI): Perceptions of Caring Behaviors by Subscales

Subscales	Subjects: HIV positive (n=30)	Subjects: Sickle cell (n=30)	All (N=60)
1. A humanistic altruistic system of values. (CBI items 3, 35, 39, and 41)	5.29	4.91	5.10
2. The instilling of faith and hope. (CBI item 6)	5.20	5.03	5.12
3. Sensitivity to self and others. (CBI items 4, 10, 16, 31, 32, and 37)	5.38	4.97	5.17
4. Helping and trusting human care relationships. (CBI items 11, 12, 13, 18, 21, 28, and 34)	5.32	5.00	5.15
5. Expressing positive and negative feelings. (CBI items 5, 8, 17, 20, and 25)	5.18	4.97	5.07
6. Creative problem solving caring process. (CBI items 7, 26, and 27)	5.28	4.85	5.07
7. Transpersonal teaching/learning. (CBI items 2 and 14)	5.00	4.81	4.91
8. Supportive, protective, and or corrective mental, physical, societal, and spiritual environment. (CBI items 9, 23, 29, 30, and 33)	5.11	4.77	4.94
9. Human needs assistance. (CBI items 15, 19, 22, 24, 36, 38, 40, and 42)	5.19	4.99	5.11
10. Existential phenomenological spiritual forces (CBI item 1)	5.53	5.03	5.28

Research Questions 1 and 2

Multiple regression analyses and descriptive statistical procedures were performed to test the first null hypothesis, "There is no association between socioeconomic status, educational level, age, marital status, diagnosis, and scoring of caring behaviors," and to answer the first and second research questions, "How much of the variability in perception of caring behaviors can be explained by socioeconomic status, educational level, age, and marital status?" and "What percentage of variance in perceptions is accounted for by diagnosis?"

Ten stepwise multiple regression analyses were performed using socioeconomic status, educational level, age, and marital status, as independent variables, and each of the 10 subscales was considered as the dependent variable. Diagnosis was forced in on each multiple regression. Assumptions of the regression model were evaluated and met. The criterion for including a variable into the equation was the *p* value of .25, and the criterion for excluding was the *p* value of .20. In the first analysis, the demographics were entered as the predictor variables and *a humanistic altruistic system of values* as the criterion variable. Results from the stepwise regression analysis are summarized in Table 5.

Table 5

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Humanistic Altruistic System of Values Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Married	.581	.373	.201	2.3	.385	.148	.126
Educational level	-.293	.162	-.232				
No heath care coverage	-.494	.314	-.203				
Constant	6.463	.645					

In this analysis, the status of being married was entered on step one and educational level was entered on step two. The R squared of the equation was .148. The three factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were the status of being married, educational level, and having no health care coverage, thus indicating that 15% of the variability in perception on subscale one can be explained by these variables.

In the second analysis, the instilling of faith and hope was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 6.

In this analysis, educational level was entered on step one and the status of being married was entered on step two. The R squared of the equation was .175. The three factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were educational level, the status of being married, and having no health care coverage, thus indicating that 18% of the variability in perception on subscale two can be explained by these variables.

Table 6

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Instilling of Faith and Hope Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Educational level	-.423	.157	-.339	2.9	.418	.175	.029
Married	.686	.362	-.240				
No health care coverage	-.422	.305	-.175				
Constant	6.809	.628					

In the third analysis, sensitivity to self and others was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 7.

In this analysis, having no health care coverage was entered on step one and educational level was entered on step two. The R squared of the equation was .218. The four factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were having no health care coverage, educational level, annual income and being divorced, thus indicating that 22% of the variability in perception on subscale three can be explained by these variables.

Table 7

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Sensitivity to Self and Others Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
No health care coverage	-.543	.285	-.242	3	.467	.218	.018
Educational Level	-.373	.164	-.321				
Annual income	.330	.205	.230				
Divorced	-.420	.295	-.179				
Constant	6.421	.588					

In the fourth analysis, helping and trusting human care relationships was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 8.

In this analysis, educational level was entered on step one and the status of being married was entered on step two. The R squared of the equation was .188. The three factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were educational level, being married, and having no health care coverage, thus indicating that 19% of the variability in perception on subscale four can be explained by these variables.

Table 8

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Helping and Trusting Human Care Relationships Subscales

Variable	B	SE(B)	Beta	F	R	R^2	p
Educational level	-.393	.152	-.323	3	.434	.188	.020
Married	.654	.350	-.235				
No health care coverage	-.462	.295	-.197				
Constant	6.833	.606					

In the fifth analysis, expressing positive and negative feelings was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 9.

In this analysis, educational level was entered on step one and having no health care was entered on step two. The R squared of the equation was .254. The four factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were educational level, no health care coverage, being married, and being divorced, thus indicating that 25%

Table 9

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Expressing Positive and Negative Feelings Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Educational level	-.382	.148	-.326	3.6	.504	.254	.006
No health care coverage	-.645	.279	-.285				
Married	.491	.346	.183				
Divorced	-.412	.308	-.174				
Constant	6.807	.570					

of the variability in perceptions on subscale five can be explained by these variables.

In the sixth analysis, creative problem solving caring process was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 10.

In this analysis, educational level was entered on step one and having private insurance was entered on step two. The R squared of the equation was .311. The five factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were educational level, private insurance, being on Medicare, being divorced, and annual income, thus indicating that 31% of the variability in perception on subscale six can be explained by these variables.

Table 10

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Creative Problem Solving Caring Process Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Educational level	-.655	.203	-.437	3.9	.558	.311	.002
Private insurance	.869	.544	.301				
Medicare	.708	.362	.276				
Divorced	-.677	.379	-.224				
Annual income	.478	.330	.259				
Constant	6.469	.784					

In the seventh analysis, transpersonal teaching and learning was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 11.

Table 11

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Transpersonal Teaching/Learning Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Married	.893	.404	.278	3.1	.433	.188	.020
Educational level	-.385	.176	.274				
No health care coverage	-.653	.341	-.241				
Constant	6.519	.700					

In this analysis, the status of being married was entered on step one and educational level was entered on step two. The R squared of the equation was .188. The three factors found by the stepwise multiple regression model to have the highest correlation with the variance in perception of caring behaviors were the status of being married, educational level, and having no health care coverage, indicating that 19% of the variability in perception on subscale seven can be explained by these variables.

In the eighth analysis, supportive, protective, and or corrective mental, physical, societal and spiritual environment was entered as the criterion variable. Results from the stepwise regression anlaysis are summarized in Table 12.

Table 12

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Supportive, Protective, and Corrective Mental, Physical, Societal, and Spiritual Environment Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Married	.622	.407	.198	3.2	.482	.233	.012
Educational level	-.502	.187	-.366				
No health care coverage	-.588	.332	-.222				
Annual income	.378	.252	.224				
Constant	6.426	.684					

In this analysis, the status of being married was entered on step one and educational level was entered on step two. The R squared of the equation was .233. The four factors found by the stepwise multiple regression model to have the highest correlation with the variance in perception of caring behaviors were the status of being married, educational level, having no health care coverage, and annual income, thus indicating that 23% of the variability perception on subscale eight can be explained by these variables.

In the ninth analysis, human needs assistance was entered as the criterion variable. Results from the stepwise regression analysis are summarized in Table 13.

Table 13

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Perception Within the Human Needs Assistance Subscale

Variable	B	SE(B)	Beta	F	R	R^2	P
Divorced	-.612	.299	.257	3	.468	.219	.018
No health care coverage	-.481	.289	.211				
Educational level	-.381	.166	-.323				
Annual income	.371	.208	.255				
Constant	6.229	.596					

In this analysis, the status of being divorced was entered on step one and having no health care coverage was entered on step two. The R squared of the equation was .219. The four factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were being divorced, having no health care coverage, educational level, and annual income, thus indicating that 22% of the variability in perception on subscale nine can be explained by these variables.

In the tenth regression analysis, all predictor variables were deleted and the solution terminated. These results indicated that none of the demographic variables were effective in predicting the mean score on subscale 10. The last analysis was performed using the subscale total as the criterion variable. Results from this stepwise multiple regression analysis are shown in Table 14.

Table 14

Summary of Stepwise Multiple Regression Analysis of Predictor Variables on Mean Subscale Scores

Variable	B	SE(B)	Beta	F	R	R^2	P
Married	.684	.341	.249	3.5	.454	.206	.012
Educational level	-.382	.148	-.319				
No health care coverage	-.543	.287	-.235				
Constant	6.738	.590					

In this analysis, the status of being married was entered on step one and educational level was entered on step two. The R squared of the equation was .206. The three factors found by the stepwise multiple regression model to have the highest correlation with the variance in perceptions of caring behaviors were the status of being married, educational level, and having no health care coverage, thus indicating that 21% of the variability in perceptions of caring behaviors as measured by the caring behaviors inventory can be explained by these variables.

Research Questions 3 and 4

Descriptive statistics were used to test the second null hypothesis, "There is no difference in ranking of least important caring behaviors and most important caring behaviors" and to answer the third and fourth research questions, "Is there a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection?" and "Is there a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection?" Data from the analyses are shown in Table 15.

Data analysis showed that the 10 caring behaviors that have the highest mean scores were calling you by your preferred name, showing respect for you, being honest with you, treating you as an individual, attentively listening to you, using a soft and gentle voice with you, treating your information confidentially, appreciating you as a human being, and trusting you. Although "calling you by your preferred name," had the highest mean score and ranked number one in both HIV-positive group and the group with sickle cell anemia, there was an apparent difference in the ranking of

Table 15

Rank Ordering of Mean Importance Ratings for Caring Behavior Inventory Items: The 10 Highest Score Items

Caring behavior items	Total group (N = 60)		HIV + (n = 30)		Sickle cell (n = 30)	
	Score	Rank	Score	Rank	Score	Rank
Calling you by your preferred name.	5.68	1	5.70	1	5.67	1
Showing respect for you.	5.40	2	5.60	2	5.20	4
Being honest with you.	5.35	3	5.47	5	5.23	3
Treating you as an individual.	5.32	4	5.40	6	5.23	3
Attentively listening to you.	5.28	5	5.53	3	5.03	8
Using a soft, gentle voice with you.	5.28	5	5.30	9	5.27	2
Demonstrating professional knowledge and skill.	5.27	6	5.27	10	5.27	2
Treating your information confidentially.	5.25	7	5.50	4	5.00	9
Appreciating you as a human being.	5.25	7	5.53	3	4.97	10
Trusting you.	5.23	8	5.23	11	5.23	3

the 10 highest mean items between the HIV-positive group and the group with sickle cell anemia. The caring behaviors with the 10 lowest mean scores are presented in Table 16.

Table 16

Rank Ordering of Mean Importance Ratings for CBI Items: The 10 Lowest Mean Score Items

Caring behavior items	Total group (N = 60)		HIV + (n = 30)		Sickle cell (n = 30)	
	Score	Rank	Score	Rank	Score	Rank
Helping you grow.	4.67	1	4.60	1	4.73	6
Returning to you voluntarily.	4.67	1	5.03	7	4.30	1
Spending time with you.	4.68	2	4.83	4	4.53	2
Touching you to communicate caring.	4.78	3	4.80	3	4.77	7
Watching over you.	4.78	3	4.87	5	4.70	5
Responding quickly to your call.	4.80	4	5.07	8	4.53	2
Being patient or tireless with you.	4.82	5	5.00	6	4.63	3
Knowing how to give shots, IVs, etc.	4.82	5	4.67	2	4.97	9
Putting you first.	4.85	6	5.03	7	4.67	4
Meeting your stated and unstated needs.	4.90	7	5.03	7	4.77	7

The 10 CBI items with the lowest mean scores were as follows: helping you grow, returning to you voluntarily, spending time with you, touching you to communicate caring, watching over you, responding quickly to your call, being

patient or tireless with you, knowing how to give shots, IVs, etc., putting you first, and meeting your unstated needs. Although "attentively listening to you" ranked number one among the entire group, there was no further consistency in the ranking of CBI items between the HIV-positive subjects and the subjects with sickle cell anemia. The extreme differences in what subjects perceived to be of highest important is visible in the table.

There were no similarities in the scoring between the HIV-positive subjects and the subjects with sickle cell anemia in terms of their perceptions of least important behaviors. The mean scores of the patients with sickle cell anemia were lower than those of the HIV-positive patients in both the most important category and the least important category. It can clearly be seen in Tables 15 and 16 that there is a difference in most important and least important caring behaviors identified by both groups.

Summary

A total of 60 subjects composed the convenience sample. There were 30 HIV-positive African American females and 30 African American females with sickle cell disease. The subjects ranged from 21 to 58 years of age. The mean scores for the 42 item CBI ranged from 5.68 to 4.67 on a 6-point Likert scale. Ten subscales were derived from the 42 items using Watson's (1979) carative factors. The sociodemographic variables that were the best indicators of variability in perception of caring behaviors were marital status, education, and type of health care coverage. In general, patients who were HIV positive had higher mean scores than those with sickle cell disease. There was a noticeable difference between what the HIV-positive subjects perceived as the most important and least important caring behaviors and those behaviors that were perceived as most important and least important among the subjects with sickle cell disease.

CHAPTER 5

FINDINGS, DISCUSSION, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

The purposes of this descriptive study were to (a) ascertain whether there is a relationship among the demographic variables socioeconomic status, educational level, age, marital status, and the patient's perceptions of caring behaviors; (b) ascertain how much of the variability in perceptions of caring behaviors can be explained by diagnosis; (c) ascertain whether there is a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection; and (d) ascertain whether there is a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection. Descriptive statistics and multiple regression analyses were used to describe the study sample and test the hypotheses. Leininger's culture care theory (Cohen, 1991; Gaut & Leininger, 1991; Leininger, 1991; Leininger & Watson, 1990; Morse et al. 1991) and Watson's caring theory (Cohen, 1991; Leininger & Watson, 1990; Morse et al., 1991; Watson, 1994) were integrated to provide a framework for the study. Findings, conclusions, implications, and recommendations are presented in this chapter.

Discussion of the Findings

Discussion of Sample

The sample comprised 60 African American women: 30 were diagnosed HIV positive and 30 with sickle cell anemia. The subjects ranged from 21 to 58 years of age. The subjects were generally educated; 95% had a high school or above education. The majority of the subjects (90%) were not married at the time of data collection; the majority of the subjects (73%) were on Medicare or without health care coverage. More than one half of the subjects (56.7%) earned an annual income of less than 10,000 dollars.

Results of Hypothesis Testing

In accordance with the purposes of this study, the following research questions were explored: (a) How much of the variability in perceptions of caring behaviors can be explained by socioeconomic status, educational level, age, and marital status; (b) what percentage of variance in perceptions is accounted for by diagnosis; (c) is there a difference in caring behaviors identified as most important between subjects with HIV infection and those without HIV infection; (d) is there a difference in caring behaviors identified as least important between subjects with HIV infection and those without HIV infection? Two hypotheses were tested to answer the above research questions. The findings for each of the hypotheses are presented below.

Hypothesis 1

There is no association between socioeconomic status, educational level, age, marital status, diagnosis of HIV seropositivity, and scoring of caring behaviors.

Findings. Analysis of data, utilizing the stepwise multiple regression procedure, indicated that there is some association between some sociodemographic variables and the scoring of caring behaviors on the CBI. Being married, educational level, and having no health insurance were associated with perceptions of behaviors related to showing concern and giving individualized and special attention. However, educational level, being married, and having no health insurance were significant ($\underline{P}$ = .029) in explaining the variance in perceptions of caring behaviors related to instilling faith and hope. Likewise having no health insurance, educational level, annual income, and being divorced were significant ($\underline{P}$ = .018) predictors of perceptions of caring behaviors related to showing concern, being sensitive, and spending time with the patient. Educational level, being married, and having no health insurance were significant ($\underline{P}$ = .020) predictors of perceptions of caring behaviors related to honesty, trust, empathy, and being helpful. Educational level, having no insurance, and being married and or divorced were significant ($\underline{P}$ = .006) predictors of perceptions of caring behaviors associated with feelings such as touching, patience, being cheerful, and being respectful. Educational level, having private insurance coverage, being on Medicare, being divorced, and annual income were all significant (P = .002) in explaining variability in perceptions of caring behaviors associated with decision making, autonomy, and allowing involvement in one's own plan of care. Being married, educational level, and having no health insurance were significant (P = .020) in explaining the variance of perceptions of caring behaviors associated with teaching and promoting growth. Being married, educational level, having no health insurance, and annual income were significant (P = .012) in explaining the variance in perceptions of caring behaviors related to the affective domain of nursing interventions. Being divorced, having no health insurance, educational level, and annual income were also significant (P = .018) in explaining the variance in perceptions of caring behaviors related to the psychomotor domain of nursing interventions such as being knowledgeable about infections and other techniques of medication administration, knowing how to skillfully manage hospital equipment, and providing physical care. None of the sociodemographic variables appeared to be associated with perceptions of caring behaviors related to communication and listening. Three sociodemographic variables--being married, educational level, and having no health insurance--were significant (P = .012) predictors of mean subscale scores of the CBI. These variables explained more than 20% of the variance in perceptions of caring behaviors as perceived by the African American women who participated in this study. On the basis of these findings of a significant association between demographic variables and the scoring of caring behaviors, the null hypothesis is rejected.

Hypothesis 2

There is no difference in ranking of least important caring behaviors and most important caring behaviors between HIV-positive and HIV-negative patients.

Findings. Rank ordering of the most important caring behaviors and the least important caring behaviors showed an obvious difference in ranking between the two subject groups. In addition, data analysis utilizing descriptive statistical techniques showed an obvious difference in the mean CBI scores in perceptions of caring behaviors between patients who were HIV positive and patients diagnosed with sickle cell disease. The mean scores of the patients with sickle cell disease were lower than those of the HIV-positive patients in both the most important and the least important category. The one item having the highest mean score among both groups was calling you by your preferred name. There were 23 CBI items with mean scores above 5.0. On 17 of the 23 items, the HIV-positive subjects' mean scores ranged from 5.07 to 5.70, whereas the mean scores of the patients with sickle cell disease ranged from 5.0 to 5.23 on seven of these items. There were 16 CBI items with mean scores 5.0 or less. Few similarities were found in the scoring between the HIV-positive and sickle cell anemia subjects in terms of their perceptions of least important behaviors. The one item having the lowest mean score among both groups was helping you grow. On 5 of the 16 items, the HIV-positive subjects' mean scores ranged from 4.60 to 4.87, whereas the mean scores of the patients with sickle cell disease ranged from 4.30 to 4.73 on 10 of these 16 items. On the basis of the findings that there is a difference in the ranking of importance, as well as perceptions of caring behaviors, the null hypothesis is rejected.

Discussion Related to Review of Research

The health care arena can be a hostile environment for the HIV-positive patient. Walker and Frank (1995) stated that "HIV/AIDS is both mandate and catalyst for a new paradigm for nursing and this new paradigm will make important differences in the lives of individuals and communities by using a caring tradition that embraces all, including those that society does not" (p. 314). In the present study, the caring behaviors perceived as important by African American women who are HIV positive and African American women with sickle cell disease were congruent with behaviors found to be important in studies related to perceptions of patients with various other diagnoses, as well as with those of nurses and other health care workers.

In the review of research, behaviors identified as caring included showing concern for the patient, communicating with the patient, touching, sensitivity to feelings, providing protection and safety, praying for the patients, facilitating contact with support systems, physical presence of the nurse, identifying physical needs, knowledge, and skill (Bottorff & Morse, 1994; Brown, 1986; Cronin & Harrison, 1988; Gooding et al., 1993; Larson, 1981, 1984, 1986, 1987; McNamara, 1995; Von Essen & Sjoden, 1991a, 1991b). In the present study, many of these behaviors were also noted as most important among the caring behaviors identified by the subjects. In the review of research, the behaviors identified as least important included volunteers to do little things, is professional in appearance, helps patient set realistic goals, being humorous, sits down with the patient, leaves the room neat, asks patient how they like things done, tries to see things from patient's point of view, and talks to patient about life outside the hospital. Prior research findings are consistent with the findings of this study in terms of types and categories of caring behaviors perceived as least important. In contrast to Parsons et al. (1993), the results of this study indicate an association between demographic variables and perception of caring behaviors. Annual income, health care coverage, educational level, marital status and the scoring of caring behaviors were significantly associated ($\underline{R}^2 = .206$).

Thus far, two major theories of caring have been developed for nursing: the theory of human care, developed by Watson and the theory of transcultural care diversity and universality developed by Leininger. Two major perspectives of caring developed by Leininger and Watson were selected as the theoretical framework for this study. These two perspectives of caring contribute to the philosophical, cultural, and empirical concerns of nursing. Leininger and Watson (1990) proposed to interconnect and unify the humanistic, scientific, and experiential basis of caring in order to identify a professional nursing caring paradigm. According to Leininger and Watson, the development of this paradigm has been a first step toward arriving at a theory of nursing that is based upon caring. The findings from this study indicate that the 10 carative factors can be used as cate- gories within which all caring behaviors can be categorized. These findings are congruent with those of Wolf (1986) and other researchers who used Watson's 10 carative factors as a framework.

Conclusions

Based on the findings from the present study, the conclusions of the study are summarized below.

Hypothesis 1

The first null hypothesis states "There is no association between socioeconomic status, educational level, age, marital status, diagnosis and the scoring of caring behaviors." The findings from the present study indicate that there is an association among the indicators of socioeconomic status (annual income and health care coverage) used for the purpose of this study, educational level, marital status, and the scoring of caring behaviors on the CBI. Being married, educational level, and having no health care coverage were the variables most significantly associated with the scoring on the CBI overall. However, as previously indicated, when the 42 items were grouped by subscales scales based upon Watson's 10 carative factors, there were variables that were significantly associated with the scoring on some subscales and not significantly associated with scoring on other subscales. For example, educational level, being married, and having no health care coverage were most frequently associated with scoring on most of the subscales, whereas being divorced was entered into the equation on the "sensitivity to others, expressing positive and negative feelings, creative problem solving, and human needs assistance" subscales.

The findings from the present study also suggest an association between diagnosis and the scoring of caring behaviors on the CBI. The mean scores of the subjects with sickle cell disease were lower than the subjects who were HIV positive. After viewing these findings, the researcher concluded that there is an association between sociodemographic variables and the scoring of caring behaviors.

However, the sample size was low and lacked power; thus, statistical significance could not be ascertained.

Hypothesis 2

The second null hypothesis states "There is no difference in ranking of least important caring behaviors and most important caring behaviors between subjects with HIV infection and those without HIV infection." The findings from the present study indicate that there is a difference in the rank ordering of caring behaviors between the subjects with HIV infection and the subjects who were not HIV infected--in this case, the subjects with sickle cell disease. Only 1 of the 10 behaviors of highest importance was ranked equally by both subject groups. Likewise, only 2 of the 10 behaviors of lowest importance were ranked equally by both subject groups. As a result of these findings, the researcher concludes that caring behaviors that are perceived as important to subjects who are HIV positive are different from caring behaviors that are perceived as important to subjects without HIV infection. Likewise, caring behaviors that are perceived as not important to subjects who are HIV positive are different from caring behaviors that are perceived as not important to subjects without HIV infection.

Implications

This study was an initial effort to identify behaviors that are perceived as caring to patients who are HIV positive. To reiterate, feeling cared for enhances the well-being of an individual and, as previously indicated, may have a positive influence on outcomes. The findings from this study have implications for nursing practice, nursing theory, nursing research, and nursing education. According to Leininger and Watson (1990), the imperative for nursing education is to reconceptualize professional nursing caring and undertake the effort and energy required to place this essence in the heart of nursing theory, practice, education, and research. This is the profession's challenge for the coming decade. Implications for practice, theory, research, and education are presented in this section.

Nursing Practice

The knowledge of what HIV-positive African American women perceive as caring behaviors will be meaningful to helping the nurse plan care for these patients. It may also be helpful in assisting the nurse in the awareness of the behaviors displayed during interaction and communication with African Americans in general, thus reducing the stigmatization often felt by these patients. The knowledge of the association between demographic variables and perceptions can aide the nurse in being better prepared when planning care for patients from various socioeconomic backgrounds, those with various marital statuses, and those at various educational levels.

Nursing Theory

The discipline of nursing must arrive at some common ground in terms of a theory of nursing. Identifying a pervasive conceptual framework can serve as the foundation upon which this theory can be built. The conceptual framework that guided this study was a complementary blend of Watson's (1979) and Leininger's (1991) work (or theories or models). Both ascribe to the belief that caring is the essence of nursing. Leininger's culture care theory focuses on describing, explaining, and predicting nursing similarities and differences in caring within human cultures. This current study sought to provide information in terms of how African American women perceived the caring behaviors of their caregivers. In order to predict what behaviors African American women might perceive as caring, this study sought to ascertain how much of the variance in perception could be explained by demographic characteristics. Furthermore, to describe the behaviors that would be of most importance as well as those behaviors that might be of least importance to the African American woman, this study sought to ascertain whether there was a difference in how two study groups within the African American culture might rank the importance of specific caring behaviors. The investigator used Watson's 10 carative factors in obtaining a greater understanding of caring behaviors in terms of common themes. Watson (1991) proposed these factors to be a structure and frame of reference for research and understanding nursing as a science. If these 10 carative factors prove to be inherent to the caring processes that help persons to be healthy or die a peaceful death, as Watson (1979) proposed that they do, then any behavior that could conceivably be perceived as caring could fit with 1 of the 10 factors. Each of the 42 items on the CBI, used as the data collection instrument for this study, was found to fit well within the structure of the 10 carative factors. The results of this study lend support to both the Leininger's culture care theory and Watson's caring theory.

Nursing Research

Caring research is particularly suited for investigation by nurses. According to Watson (1994), caring is the heart of nursing and the ethical and philosophical foundation for our acts. The findings of this study add to the body of research related to caring and caring theory. The sample selected for this study represents an understudied population in terms of both race and diagnosis. Recognition of HIV and AIDS has been identified for less than 20 years and is still fairly new in our society. This research study adds to the body of knowledge related to HIV-positive persons. African Americans are noted in the literature as an understudied population. Women in general are an understudied gender. Therefore, this study of the perceptions of caring behaviors as perceived by African American women contributes greatly to the body of knowledge related to women, African American women, HIV-positive African American women, African American women with sickle cell disease, and, most of all, the caring sciences.

The sociodemographic variables used in the multiple regression analysis accounted for 20% of the variance in perceptions of caring behaviors in this sample of 60 African American women. Therefore, 80% of the variance was unaccounted for in this study. Future research efforts might be directed at the identification of additional variables that may influence or predict perceptions of caring behaviors in African American women who are HIV-positive. This study serves as the foundation for building a research trajectory leading to intervention research. The results of this study indicate that intervention studies, which focus upon teaching caring behaviors and monitoring the effectiveness of the teaching intervention, are needed to improve the present negative perceptions and improve patient's outcomes.

Nursing Education

According to Walker and Frank (1995), AIDS has permeated every aspect of our lives and is now a part of the fabric of contemporary society. Thus, the HIV/AIDS epidemic is forcing nursing care and nursing education to have greater relevance to societal needs and requires nursing to recognize diversity both in the caregivers and in those for whom we care. Walker and Frank suggested that nursing educators view universities and colleges as societal institutions with a strong obligation to society. Nursing education also has an obligation to equip nursing students with the knowledge and skills necessary to practice in community-based settings as well as in institutional settings.

The findings in this study have implications for providing nursing care in a specialized community institution as well as in a county indigent care facility. As indicated earlier, the subjects attending the indigent care facility assigned lower scores to items on the CBI than patients attending the university-based specialty care facility. The results of this study will be useful in assisting nursing faculty with the design of a caring-based curriculum. Knowledge of which specific behaviors that patients perceive as caring can help faculty prepare students to project and display caring to the patients for whom they provide care. In order for nursing to be truly responsive to the needs of society and make contributions that are consistent with its roots and early origins, both nursing education and the health care delivery system must be based on human values and concern for the welfare of others. Thus, caring outcomes in practice, research, and theory depend on the teaching of caring ideology (Leininger & Watson, 1990). Results of this descriptive research can add to the scientific body of nursing knowledge that exists to educate nursing students.

Recommendations

Based upon the findings from this study, the following recommendations are offered for future research.

1. Replicate the study with a larger sample of HIV-positive African American women.

2. Replicate the study in other geographical locations to ensure that the findings are not unique to African American women in the Southeast.

3. Replicate the study and include additional variables that may influence perceptions of caring behaviors.

4. Conduct a study comparing the perceptions of inpatients and outpatients.

5. Conduct a study comparing the perceptions of Caucasian patients and African American patients.

6. Replicate the study using facilities that are all similar in type for data collection, such as all indigent care facilities or all fee-for-service facilities.

7. Conduct a study using the chi square statistical techniques for data analysis. In a replication study, a larger sample size would permit ascertaining if there is statistical significance in differences between groups.

8. Likewise, conduct a study using the Mann Whitney U statistical technique for rank ordering. In a replication study, a larger sample size would allow the investigator to obtain more statistically precise results.

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APPENDIX A

IRB APPLICATION APPROVAL

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Office of the Institutional Review Board for Human Use

FORM 4: IDENTIFICATION AND CERTIFICATION OF RESEARCH PROJECTS INVOLVING HUMAN SUBJECTS

THE INSTITUTIONAL REVIEW BOARD (IRB) MUST COMPLETE THIS FORM FOR ALL APPLICATIONS FOR RESEARCH AND TRAINING GRANTS, PROGRAM PROJECT AND CENTER GRANTS, DEMONSTRATION GRANTS, FELLOWSHIPS, TRAINEESHIPS, AWARDS, AND OTHER PROPOSALS WHICH MIGHT INVOLVE THE USE OF HUMAN RESEARCH SUBJECTS INDEPENDENT OF SOURCE OF FUNDING.

THIS FORM DOES NOT APPLY TO APPLICATIONS FOR GRANTS LIMITED TO THE SUPPORT OF CONSTRUCTION, ALTERATIONS AND RENOVATIONS, OR RESEARCH RESOURCES.

PRINCIPAL INVESTIGATOR: **Daphne Williams**

PROJECT TITLE: **Caregiver Caring Behaviors as Perceived by HIV-Positive African American Women**

____1. THIS IS A TRAINING GRANT. EACH RESEARCH PROJECT INVOLVING HUMAN SUBJECTS PROPOSED BY TRAINEES MUST BE REVIEWED SEPARATELY BY THE INSTITUTIONAL REVIEW BOARD (IRB).

_X_2. THIS APPLICATION INCLUDES RESEARCH INVOLVING HUMAN SUBJECTS. THE IRB HAS REVIEWED AND APPROVED THIS APPLICATION ON 5-3-98 IN ACCORDANCE WITH UAB'S ASSURANCE APPROVED BY THE UNITED STATES PUBLIC HEALTH SERVICE. THE PROJECT WILL BE SUBJECT TO ANNUAL CONTINUING REVIEW AS PROVIDED IN THAT ASSURANCE.

_X_ THIS PROJECT RECEIVED EXPEDITED REVIEW.

____ THIS PROJECT RECEIVED FULL BOARD REVIEW.

____3. THIS APPLICATION MAY INCLUDE RESEARCH INVOLVING HUMAN SUBJECTS. REVIEW IS PENDING BY THE IRB AS PROVIDED BY UAB'S ASSURANCE. COMPLETION OF REVIEW WILL BE CERTIFIED BY ISSUANCE OF ANOTHER FORM 4 AS SOON AS POSSIBLE.

____4. EXEMPTION IS APPROVED BASED ON EXEMPTION CATEGORY NUMBER(S) ________.

DATE: 5-3-98

Marilyn Doss
MARILYN DOSS, M.A.
VICE CHAIR OF THE
INSTITUTIONAL REVIEW BOARD

APPENDIX B

CARING BEHAVIOR INVENTORY INSTRUMENT

CARING BEHAVIORS INVENTORY

Directions:

Please read the list of items that describe nurse caring. For each item, please circle the answer that stands how often a caring was visible/obvious during your clinic visits.

Remember, you are the patient.

1. Attentively listening to you.

never	almost never	occasionally
usually	almost always	always

2. Giving instructions or teaching you.

never	almost never	occasionally
usually	almost always	always

3. Treating you as an individual.

never	almost never	occasionally
usually	almost always	always

4. Spending time with you.

never	almost never	occasionally
usually	almost always	always

5. Touching you to communicate caring.

never	almost never	occasionally
usually	almost always	always

6. Being hopeful for you.

never almost never occasionally

usually almost always always

7. Giving you information so that you can make a decision.

never almost never occasionally

usually almost always always

8. Showing respect for you.

never almost never occasionally

usually almost always always

9. Supporting you.

never almost never occasionally

usually almost always always

10. Calling you by your preferred name.

never almost never occasionally

usually almost always always

11. Being honest with you.

never almost never occasionally

usually almost always always

12. Trusting you.

never almost never occasionally

usually almost always always

13. Being empathetic or identifying with you.

never almost never occasionally

usually almost always always

14. Helping you grow.

never almost never occasionally

usually almost always always

15. Making you physically or emotionally comfortable.

never almost never occasionally

usually almost always always

16. Being sensitive to you.

never almost never occasionally

usually almost always always

17. Being patient or tireless with you.

never almost never occasionally

usually almost always always

18. Helping you.

never almost never occasionally

usually almost always always

19. Knowing how to give shots, IVs. etc.

never almost never occasionally

usually almost always always

20. Being confident with you.

never	almost never	occasionally
usually	almost always	always

21. Using a soft, gentle voice with you.

never	almost never	occasionally
usually	almost always	always

22. Demonstrating professional knowledge and skill.

never	almost never	occasionally
usually	almost always	always

23. Watching over you.

never	almost never	occasionally
usually	almost always	always

24. Managing equipment skillfully.

never	almost never	occasionally
usually	almost always	always

25. Being cheerful with you.

never	almost never	occasionally
usually	almost always	always

26. Allowing you to express feelings about your disease and treatment.

never	almost never	occasionally
usually	almost always	always

27. Including you in planning your care.

never almost never occasionally

usually almost always always

28. Treating your information confidentially.

never almost never occasionally

usually almost always always

29. Providing a reassuring presence.

never almost never occasionally

usually almost always always

30. Returning to you voluntarily.

never almost never occasionally

usually almost always always

31. Talking with you.

never almost never occasionally

usually almost always always

32. Encouraging you to call if there are problems.

never almost never occasionally

usually almost always always

33. Meeting your stated and unstated needs.

never almost never occasionally

usually almost always always

34. Responding quickly to your call.

never almost never occasionally

usually almost always always

35. Appreciating you as a human being.

never almost never occasionally

usually almost always always

36. Helping to reduce your pain.

never almost never occasionally

usually almost always always

37. Showing concern for you.

never almost never occasionally

usually almost always always

38. Giving your treatments and medications on time..

never almost never occasionally

usually almost always always

39. Paying special attention to you during the first times, as hospitalization, treatments.

never almost never occasionally

usually almost always always

40. Relieving your symptoms.

never almost never occasionally

usually almost always always

41. Putting you first.

never almost never occasionally

usually almost always always

42. Giving good physical care.

never almost never occasionally

usually almost always always

APPENDIX C

INSTRUMENT USAGE PERMISSION LETTER

LA SALLE UNIVERSITY
SCHOOL OF NURSING
PHILADELPHIA, PA 19141 • (215) 951-1430

February 5, 1997

Daphne Williams, MSN, RN
1000 Christopher Drive
Birmingham, Alabama 25215

Dear Daphne:

You have my permission to use the Caring Behaviors Inventory in your research, should you decided that it is the instrument that fits your research study. If you decide to use it, kindly notify me by E-mail and later report reliability and validity results once the dissertation is finished.

I will forward a manuscript to you as soon as I hear from a nursing journal about the status of the Caring/Satisfaction study.

Best wishes,

Zane Robinson Wolf, PhD, RN, FAAN
Professor and Graduate Director
E-mail: wolf@lasalle.edu

APPENDIX D

SOCIODEMOGRAPHIC DATA COLLECTION TOOL

DEMOGRAPHIC DATA SHEET

Today's Date: ________________ Clinic Address: ________________

1. Age: __________ ______________________________

2. Racial/Ethnic backgrounds:
   - [ ] White (not Hispanic)
   - [ ] Black (not Hispanic)
   - [ ] Hispanic
   - [ ] Asian/Pacific Islander
   - [ ] American Indian/Alaskan Native
   - [ ] Other

3. Education (highest level completed):
   - [ ] Did not complete elementary
   - [ ] Elementary
   - [ ] High School
   - [ ] Some college or post high school education
   - [ ] College degree
   - [ ] Graduate or professional degree

4. Current marital status:
   - [ ] Separated
   - [ ] Widowed
   - [ ] Divorced
   - [ ] Married
   - [ ] Single, never married
   - [ ] I live with someone/roommate

5. What type of health coverage do you have?
   - [ ] Medicare
   - [ ] Private (e.g., Blue Cross/Blue Shield-Complete Health)
   - [ ] None

6. Your annual personal income is:
   - [ ] $ 9,999 or less
   - [ ] $10,000 - 19,999
   - [ ] $20,000 - 29,999
   - [ ] $30,000 - 39,999
   - [ ] $40,000 - 49,999
   - [ ] $50,000 or greater

APPENDIX E

SCRIPT TO POTENTIAL SUBJECTS

Script

Hello Miss/Mrs.______________________

My name is Daphne Williams. I am a nurse and a doctoral student at The University of Alabama at Birmingham, School of Nursing. As a nurse, I think it is important to understand the perceptions patients have of the caring behaviors they experience from their caregivers so I chose that topic to study for my dissertation. This research study is designed to improve understanding. I would like you to complete a questionnaire that consists of 42 items. This will take 15-20 minutes. All questions are about your perception of the caring behaviors you have experienced while attending the clinic. After you read each, circle the response that best describes how important that behavior is to you. Please circle the word never, almost never, occasionally, usually, almost always, or always. Do you have any questions or concerns before we start?

APPENDIX F

CONSENT FORM FOR SUBJECTS

CONSENT FORM

TO BE RETAINED BY THE INVESTIGATOR:

My signature on this sheet indicates that I volunteer to participate in a study of:

Caregiver Caring Behaviors as Perceived by HIV-Positive African American Women.

Conducted by:

Daphne Kennedy Williams

I understand that all subjects in this study are volunteers, that I may withdraw at any time, that I have been informed of the nature of the study, that the data I provide will be anonymous, and my identity will not be revealed. I understand that my response will not affect my care at the Clinic. I have been given the opportunity to ask questions during any point of my participation.

Signature

Date

APPENDIX G

MEAN SCORES FOR CARING BEHAVIOR INVENTORY

Mean Scores for Caring Behavior Inventory (N=60; Scale 1-6)

Caring Behavior Inventory Items	M	Mode	Range	SD
Attentively listening to you.	5.28	6	4	1.01
Giving instructions or teaching you.	5.15	6	4	1.05
Treating you as an individual.	5.32	6	4	.97
Spending time with you.	4.68	6	4	1.24
Touching you to communicate caring.	4.78	6	5	1.26
Being hopeful for you.	5.12	6	4	1.08
Giving you information so that you can make a decision.	4.92	6	5	1.44
Showing respect for you.	5.40	6	6	1.03
Supporting you.	5.20	6	5	1.19
Calling you by your preferred name.	5.68	6	3	.72
Being honest with you.	5.35	6	5	1.05
Trusting you.	5.23	6	5	1.08
Being empathetic or identifying with you.	4.98	6	5	1.41
Helping you grow.	4.67	6	4	1.48
Making you physically or emotionally comfortable.	5.15	6	4	1.19
Being sensitive to you.	5.17	6	4	1.12
Being patient or tireless with you.	4.82	6	5	1.41
Helping you.	5.22	6	4	1.11
Knowing how to give shots, IVs, etc.	4.82	6	5	1.37
Being confident with you.	5.20	6	5	1.10
Using a soft, gentle voice with you.	5.28	6	3	.98
Demonstrating professional knowledge and skill.	5.27	6	3	.94
Watching over you.	4.78	6	5	1.50

(Continued)

Caring Behavior Inventory Items	M	Mode	Range	SD
Managing equipment skillfully.	5.10	6	5	1.17
Being cheerful with you.	5.18	6	4	1.10
Allowing you to express feelings about your disease and treatment.	5.18	6	5	1.28
Including you in planning your care.	5.12	6	5	1.39
Treating your information confidentially.	5.25	6	4	1.16
Providing a reassuring presence.	5.17	6	4	1.14
Returning to you voluntarily.	4.67	6	5	1.45
Talking with you.	5.10	6	4	1.24
Encouraging you to call if there are problems.	5.22	6	5	1.33
Meeting your stated and unstated needs.	4.90	6	5	1.42
Responding quickly to your call.	4.80	6	5	1.41
Appreciating you as a human being.	5.25	6	5	1.19
Helping to reduce your pain.	5.20	6	4	1.07
Showing concern for you.	5.17	6	4	1.24
Giving your treatments and medications on time.	5.17	6	5	1.26
Paying special attention to you during the first times, as hospitalization, treatments.	5.00	6	5	1.31
Relieving your symptoms.	4.95	6	4	1.19
Putting you first.	4.85	6	5	1.33
Giving good physical care.	5.12	6	4	1.22

GRADUATE SCHOOL
UNIVERSITY OF ALABAMA AT BIRMINGHAM
DISSERTATION APPROVAL FORM
DOCTOR OF SCIENCE IN NURSING

Name of Candidate Daphne Williams

Major Subject Educator of Nursing

Title of Dissertation Caregiver Caring Behaviors as Perceived by HIV-Positive African American Women

I certify that I have read this document and examined the student regarding its content. In my opinion, this dissertation conforms to acceptable standards of scholarly presentation and is adequate in scope and quality, and the attainments of this student are such that she may be recommended for the degree of Doctor of Science in Nursing.

Dissertation Committee:

Name	**Signature**
Dr. Mary Colette Smith, **Chair**	Mary Colette Smith
Dr. Ann E. Edgil	Ann E. Edgil
Dr. Charlotte B. Holley	Charlotte B. Holley
Dr. Malcolm Turner	Malcolm Turner
Dr. Anne Williams	Anne Williams
Dr. Gayle Wykle	Gayle Wykle

Director of Graduate Program Carol J. Dashiff

Dean, UAB Graduate School Joan F Lorden

Date 9/17/99