

RELATIONSHIP OF SOCIAL SUPPORT AND QUALITY OF LIFE
AMONG PERSONS INFECTED WITH HIV

A DISSERTATION
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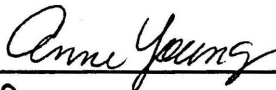
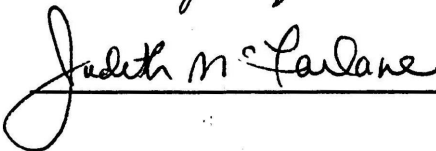
To the Associate Vice President for Research and Dean of the Graduate School:

I am submitting herewith a dissertation written by Kenn M. Kirksey entitled "Relationship of Social Support and Quality of Life Among Persons Infected with HIV". I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

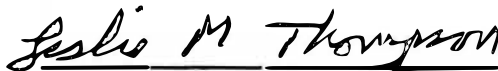


Carolyn Adamson, Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted



Leslie M. Thompson
Associate Vice President for Research
and Dean of the Graduate School

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DEDICATION

This dissertation is dedicated to three very important people in my life:

To my mother, Kay Kirksey, who instilled in me the belief that challenges are blessings in disguise.

To my aunt, Marian Weehunt, who through her example of teaching excellence whetted my desire to always reach a little further to be the best scholar and teacher that I can be. In my opinion, she has always been "Teacher of the Year."

To Robert, who taught me to dream of things that never were. He was not only my "Little Bro," but also my best buddy. Lyricist Buz Kohan wrote these words that sum up my feelings about Robert:

Like a comet blazing 'cross the evening sky
Gone too soon
Like a rainbow fading in the twinkling of an eye
Gone too soon
Shining, sparkling, and splendidly bright
Here one day, gone one night
Like the loss of sunlight on a cloudy afternoon
Gone too soon
Like a castle built on a sandy beach
Gone too soon
Like a perfect flower that is just beyond your reach
Gone too soon
Born to amuse, to inspire, to delight
Here one day, gone one night
Like a sunset dying with the rising of the moon
Gone too soon

A piece of my heart died with him last year, but I will go forward and be stronger than ever because of Robert. His body was ravaged by this terrible disease, but his spirit never faltered. I miss his smile, sparkling brown eyes, and wonderful

sense of humor, but I don't have a lot of time for sadness and tears these days. I am now busy making both our dreams come true. That's just the way Robert would have wanted it.

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RELATIONSHIP OF SOCIAL SUPPORT AND QUALITY OF LIFE
AMONG PERSONS INFECTED WITH HIV

ABSTRACT

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TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
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The purpose of this research was to determine the relationship between social support and quality of life among persons infected with the Human Immunodeficiency Virus (HIV). An exploratory, survey design was used to obtain subjects from an outpatient clinic in an urban area of the Southwest. Eighty-nine HIV-infected subjects completed a demographic data sheet, the Norbeck Social Support Questionnaire (NSSQ), and the Sickness Impact Profile (SIP). Subjects in heterosexual and homosexual male groups had NSSQ and SIP scores which indicated that social support positively affected quality of life, while heterosexual females had high social support scores, but low quality of life indexes. HIV-infected individuals had a greater disruption in psychosocial aspects of life than in physical aspects. A positive relationship between perceived health status and quality of life was found. There was also a significant relationship between social support and ethnicity.

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CHAPTER I

INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) was first recognized in homosexual males in 1981 (Mudge-Grout, 1992). From 1981 through 1991, a total of 206,392 cases of AIDS were reported to the Centers for Disease Control (CDC) in the United States (CDC, 1991a). During 1991, 45,506 cases were reported, an increase of 5% from the previous year (CDC, 1992a). In 1992, approximately 46,648 cases were reported to the CDC (CDC, 1993). Although most cases (52.7%) continue to be attributed to transmission among homosexual and bisexual men, this percentage has been decreasing. Cases involving women and heterosexual men, and particularly those who use intravenous drugs, have increased and accounted for a quarter of the 1991 cases (CDC, 1992a).

Although there are studies cited in the research literature addressing the increasing prevalence of the Human Immunodeficiency Virus (HIV) among heterosexual women, no studies have specifically examined the incidence of HIV among lesbians (Jemmott & Jemmott, 1991; Regan-Kubinski & Sharts-Engel, 1992; Siegal et al., 1992; Smeltzer, 1992; Stein, 1990; Williams, 1991). Williams noted that more than half of the women in the United States with HIV positivity or AIDS have a history of intravenous drug use.

Many diseases that cause morbidity or death have plagued Americans in the past but it is likely that none of these problems has had the profound effect on the nation's physical and psychological well-being as has AIDS (Bechtel, 1986). It is difficult to

fully understand what a diagnosis of AIDS means to patients and their significant others. Unlike heart disease and cancer, AIDS is still a disease that many have had little experience with. Caregivers, including friends and family members, are often unprepared for the suffering of their loved one and the challenges they also experience when someone close is seriously ill with AIDS. The daily patterns of life change for persons with AIDS (PWAs) and their family and friends. Life becomes more difficult as the illness progresses. Few other diseases produce such losses as does AIDS. Many PWAs lose their physical strength, mental acuity, ability to work, income, housing, and the emotional support of loved ones. It is not so uncommon for their self-esteem to fade with such catastrophic losses (National Institute of Mental Health, 1989).

Some PWAs feel guilty about having the illness. Fear of exposing others or contracting new infections are often manifested as anxiety, tension, agitation, insomnia and lapses in attention. They may get angry at themselves, the illness, the discrimination and stigma they experience, the lack of a cure and at the prospect of dying. The general public may also react negatively to PWAs because of its fear of contagion (National Institute of Mental Health, 1989).

Nurses can assist PWAs by providing physical and psychological support and by helping clients identify existing or potential sources of additional support. Support sources include family members, friends, health care professionals, and support groups composed of others with AIDS.

Problem of Study

The problem of this study was to examine the question: What is the relationship between social support and quality of life among heterosexual males and females and homosexual males diagnosed with the Human Immunodeficiency Virus?

Rationale for Study

According to the Centers for Disease Control (CDC), AIDS was first described in five sexually active gay men in Los Angeles (CDC, 1987). Since those first cases were diagnosed, the incidence of AIDS has grown at alarming rates. There are currently 242,146 cases of AIDS reported in the United States (CDC, 1992a). Seroconversion to HIV positive status or a diagnosis of AIDS results in tremendous psychological stress for the person diagnosed, family and friends. Holland and Tross (1985) pointed out that many initial psychosocial reactions are eventually manifested as physiological symptoms. Stress responses associated with a diagnosis of HIV are likely to have a profound effect on physical status.

The relationship between social support and psychological and physiological well-being is clear. Many studies have demonstrated the effect of social support on health outcomes (Berkman & Syme, 1979; Medalie & Goldbourt, 1976; Nuckolls, Cassel, & Kaplan, 1972). Social support is a highly individualized entity. What is perceived by one person as a high degree of social support may be minimal to another. Little research has been done to determine whether social support is related to the quality of life of persons diagnosed with AIDS.

Price, Desmond, and Kukulka (1985) measured perceptions and misperceptions about AIDS in high school students. These students were found to have limited or no knowledge about the disease. The primary sources of information about AIDS available to students were newspapers, magazines, radio, and television. Little information was obtained from their high schools. Price et al. stressed the importance that students be correctly informed about health care issues and pointed out that educators are in an ideal position to provide this information. The authors pointed out the importance of educators being provided with the most accurate information to disseminate to students. In order to accomplish this goal, further research on AIDS is needed in order to identify accurate data.

Authors have also studied PWAs to determine their level of knowledge about the disease and identify concerns about issues such as social support (Bechtel, 1986; Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). Wolcott et al. (1986) assessed 50 bisexual and homosexual men diagnosed with AIDS with respect to medical status, social support, illness concerns, and attitudes towards homosexuality. Social support networks tended to be lacking. Subjects reported levels of illness-related concerns comparable to cancer patients previously studied. The social support needs of these patients were variable, as was their satisfaction with the types of social support received. Illness concerns, attitudes toward homosexuality and self-image of gay men, and satisfaction with social support were significantly correlated with one another. Study findings also showed significant correlations among the previously mentioned variables with reported levels of psychologic distress and subjective measures of health

status. Wolcott et al. cited a need for further studies to document medical, psychological, cognitive, and social status of PWAs.

In a similar study, Bechtel (1986) studied the relationship between purpose-in-life and social support in gay men with AIDS. The findings indicated that support is a necessary ingredient in providing a holistic approach to the care of these individuals. Additionally, Bechtel found that psychosocial dynamics need to be investigated with this population. Examples of variables that required further investigation included quality of life, power, grief, and hope.

Mudge-Grout (1992) reported that while nursing research about HIV infection is becoming increasingly common, clinical research is still lacking, particularly regarding care aspects of practice. Groups underrepresented in published nursing research include racial and ethnic minorities, pregnant women and their newborns, the homeless, intravenous drug users, and sexually active adolescents. The author noted that not only are these groups at increased risk for acquiring HIV, they often have inadequate access to health care and are often less responsive to traditional education and counseling approaches.

Challenges to the health care system occur because of the physical and emotional devastation associated with HIV infection and AIDS (Brown & Powell-Cope, 1991). Some of these challenges have been eased by more families and significant others assuming more responsibility for PWAs. Brown and Powell-Cope conducted a study to describe the experience of AIDS family caregiving. Grounded theory provided the basis for qualitative data analysis. The authors conducted extensive interviews with 53 caregivers such as lovers, spouses, parents, siblings and friends. All of the subjects

were caring for the PWAs at home. Uncertainty was identified as the basic social psychological problem and described in the context of five caregiving subcategories. The subcategories were identified as managing and being managed by the illness; living with loss and dying; renegotiating the relationship; going public; and containing the spread of HIV. Uncertainty was defined as the caregiver's inability to predict future events and outcomes and the lack of confidence in making day-to-day decisions about the ill person's care. Uncertainty is a critical challenge for individuals and families facing life-threatening illness like AIDS.

Perhaps the primary reason for the strongly negative reactions among the general population toward PWAs is that there is no vaccine or known cure available, and the disease is usually fatal (DeVita, Hellman, & Rosenberg, 1985; Solomon & Temoshok, 1987). No effective immunization exists for the AIDS patient. Even though sufficient knowledge of the pathophysiology of this disease exists to prevent its spread, it is vital that health care professionals learn and use this knowledge (McCance, Moser, & Smith, 1991). McCance et al. surveyed physicians' knowledge and application of AIDS prevention capabilities. Using the Comprehensive Prevention Knowledge Applications Survey Instrument, respondents (n = 765) reported infrequent use of practices deemed important in AIDS prevention. Almost 60% omitted questions regarding intravenous drug use and over 40% did not routinely ask about homosexual practices. Only 18% routinely obtained sexual histories and less than 20% asked about high-risk activities.

In the United States, PWAs have been primarily homosexual and bisexual males. Little interest in supporting research and treatment efforts has been demonstrated by the

general public until recent years due to the stigma associated with belonging to these groups (Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). Since AIDS appeared first in gay men and later male intravenous drug users, AIDS is still considered by many to be a disease confined to these groups (Shilts, 1987). Smeltzer (1992) speculated that because of the stigma of gay and bisexual behaviors and intravenous drug use, many with AIDS are blamed for their own predicament. The author noted that PWAs are often held accountable for their own health care and well-being because they are blamed by society for their illness. Others (Rogers & Osborn, 1991; Dourad, 1990) supported this notion by citing a strong bias for those infected with HIV. Persons with HIV are often stigmatized and considered deviant, and often subjected to discrimination and punitive reactions from others.

As the disease has disseminated into heterosexual populations, there has been more interest in educating the general public and in increasing research efforts (Bechtel, 1986). But the process of educating the public about the disease, particularly in rural areas, has been slow because many people still believe that AIDS is limited only to homosexual males. The onset or renewal of negative feelings about homosexuality in general, and specifically toward the patient's own sexual orientation, was reported by authors who interviewed many gay men diagnosed with the disease (Nichols, 1985; Strunin & Hingson, 1987). Because of societal attitudes toward homosexuals, these individuals are often subjected to social withdrawal and alienation. Frequently, when individuals are diagnosed with AIDS, support from family and friends further deteriorates (Bechtel, 1986). Bechtel reported that most people with life-threatening diseases or illnesses knew others who withdrew from them due to fear. Bechtel noted

that AIDS has become a serious public health problem with unprecedented medical, psychological, and social implications. People with AIDS, those in danger of contracting the disease, and the networks and communities that surround persons with AIDS, are all at elevated risk for experiencing stress and its negative consequences". This problem is intensified for PWAs when caregivers and loved ones are unable to overcome the fear of contagion (Bechtel, 1986). Because of public fear of contagion, a diagnosis of AIDS has often resulted in avoidance and stigmatization of PWAs and disruption of their social network (DeVita, Hellman, & Rosenberg, 1985). Meisenhelder and La Charite (1989) noted that fear of contagion is often accompanied by irrational behavior. The Institute of Medicine (1986) reported that quarantine of all homosexuals with antibodies for HIV has been proposed. According to Kirby (1986), compulsory blood testing for the whole population has been called for. Ballard (1987) reported proposals suggesting persons with AIDS be tattooed. In a similar study, Blendon and Donelan (1988) noted that 29 percent of the individuals studied favored tattooing persons who were seropositive for the AIDS virus.

Another reason for fear among health care workers caring for PWAs is the recent emergence of a number of cases of AIDS-like illnesses called idiopathic CD4+ T-lymphocytopenia, without diagnostic HIV (CDC, 1992b; 1992c). It was at first feared that HIV had somehow metamorphosed. The patients demonstrated immune deficiency and in many cases had illnesses commonly ascribed to AIDS, such as Pneumocystis carinii pneumonia, cryptococcal meningitis, and Mycobacterium avium-intracellulare infection. Elaborate laboratory analysis has failed to identify HIV in these patients, and

extensive epidemiologic studies have identified no known risk factors for HIV infection (CDC, 1992b; 1992c).

Fedor (1992) also questioned the validity of positing HIV as the sole cause of AIDS. The author noted that there has been a tendency in formal AIDS research to overlook or ignore the possibility of cofactors such as substance abuse and psychological stress. Fedor stated that "contributing to this potentially significant oversight is the wholly reasonable fear that a link between lifestyle and AIDS will provide further evidence of the evil of homosexuality" (p. 290). The widespread use of recreational drugs such as cocaine and amyl nitrate take their toll on the immune systems of heavy users. Fedor hypothesized that toxins and stressors endemic to certain social groups may elicit immune deficiencies.

Chamberland and Bell (1992) noted that the risk of HIV transmission from health care provider to patient is remote. In early 1991, documentation of HIV transmission from an infected dentist in Florida to five of his patients made the news across the nation. The news added to the public's mistrust and suspicion of health care workers, and exacerbated the already present fear and anxiety about AIDS (Greenspan & Curran, 1991). This fear is probably unwarranted because it has been estimated that the risk of a physician infecting a patient is from 1 in 48,000 to 1 in 416,000, and the risk of a dentist infecting a patient is even lower (Wysocki, 1991; Lowenfels & Wormser, 1991).

Lack of social support has lead to poor adaptive mechanisms, stress, or at the very least, disequilibrium resulting in increased morbidity among PWAs (Cobb, 1979). Cobb stated that social support assists individuals to cope, adapt, adjust, and problem

solve during life transitions. Other authors noted that social support has a positive effect on an individual's health (Dean & Lin, 1977; Gore, 1978; Gore, 1981; Thoits, 1982). Social support may help individuals or PWAs gain or regain strength during periods where adaptation becomes difficult (Gore, 1978). Without social support needs being met, adjustment to AIDS will be difficult or impossible. Social support is a necessary adjunct to quality of life for persons with poor adaptive mechanisms (Cobb, 1979).

Burckhardt (1985) defined quality of life as the perception of the goodness of life's quality, the amount of satisfaction with life attained, physical and material well-being, personal relationships, and the ability to participate in social activities which enhance personal fulfillment, development, and recreation. Burckhardt further noted that quality of life is affected by numerous factors over which the individual has little or no control. These factors include diagnosis, predisposing characteristics, and medical treatment. There are many factors over which victims of AIDS do have control. Two such entities are whether or not drugs will be misused and modification of sexual practices. Persons with AIDS usually have decreased self-esteem and increased anxiety related to the diagnosis. These problems likely are compounded by a decrease or absence in support from family and friends. Because of high mortality rates and lack of support, these individuals may question their purpose in life. They often have difficulty adjusting to the physical and psychological trauma associated with such a disease.

In a related article, Sowell et al. (1991) reported that one of the most severe psychological stresses an individual can experience is the death of a significant other

(lover). The phenomenologic study examined the lived experience of survival and bereavement following the death of a significant other from AIDS. The sample of 8 gay males reported losses during the 18 month period prior to the interviews. Social support emerged repeatedly as a factor in bereavement, as nearly all of the participants described feelings of isolation and loneliness following their partner's death. Grieving processes were profoundly affected by the stigma associated with a diagnosis of AIDS and the homosexual lifestyle. Each participant also noted that fear of developing AIDS greatly affected his ability to effectively work through the grieving process. Individuals experienced intense and ambivalent feelings and emotions. Subjects reported isolation from friends and family. Because of the lack of social support, subjects reported "going through the motions of life, yet feeling no connection to it" (Sowell et al., p. 93). Participants experienced emotional confusion, wanting to verbalize their frustrations, yet maintaining confidentiality and anonymity because of fear of isolation. Survivors were reluctant to discuss their losses and risk the disenfranchisement and sanctions associated with revealing a gay relationship and possible HIV positivity. In summation, individuals surviving the death of a lover from AIDS generally reported poor support systems to help with bereavement.

Conceptual Framework

PWAs are often characterized by feelings of low self-esteem, worthlessness, helplessness, hopelessness, sadness, and guilt (Holland & Tross, 1985). The transition from a healthy (HIV positive) to a debilitated state (AIDS) with the prospect of death is devastating. Initially, the presence of the disease may be denied. Nichols

(1985) noted that denial may result in life-threatening behaviors such as suicidal tendencies. HIV-infected persons may also be subjected to feelings of guilt and rejection because of fear that past sexual encounters may have endangered the lives of others (National Institute of Mental Health, 1989).

Therefore, it is possible that PWAs may experience a decreased quality of life related to lack of social support. The Kirksey Perception of Social Support Model (KPSSM) was developed based on the premise that there is a relationship between these two variables. The KPSSM was based on ideas from the PRECEDE Framework and Bruhn and Philips Social Support Model. The following section presents a discussion of the KPSSM.

Kirksey Perception of Social Support Model (KPSSM)

The KPSSM (Figure 1) was developed as the conceptual framework for this research study. Essential to the KPSSM are the metaparadigm concepts of nursing, person, health, and environment. The following definitions were used for this particular model:

1. Nursing - the practice in which nurses assist individuals, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that they would perform unaided given the strength, will or knowledge. And to do this in such a way as to help them gain independence as rapidly as possible (Henderson, 1966).
2. Person - a bio-psycho-social human being in constant interaction with a changing environment (Roy, 1976).

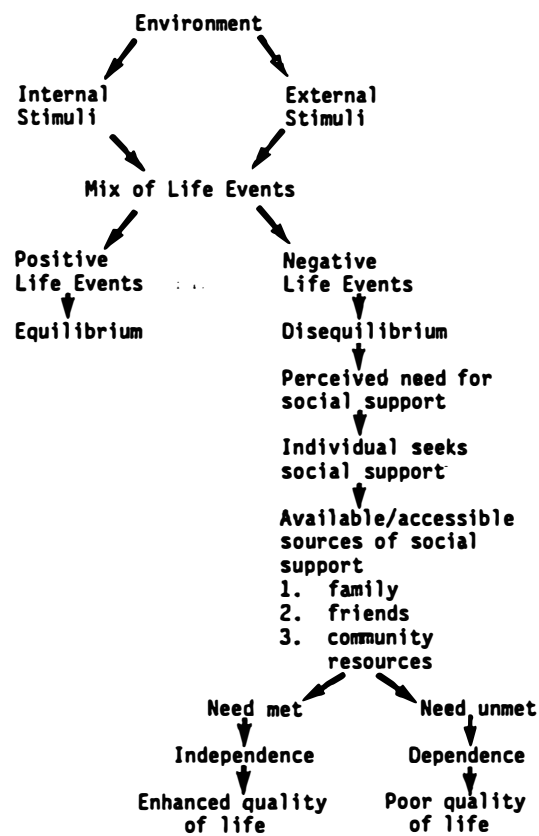


Figure 1

Kirksey Perception of Social Support Model

3. Health - a state or process of being or becoming an integrated and whole person (Roy, 1976, p. 39).
4. Environment - all conditions, circumstances, and influences surrounding and affecting the development and behavior of persons or groups (Roy, 1976, p. 39).

Description of the KPSSM

Individuals are in constant interaction with internal and external stimuli from the environment (Roy, 1980). Examples of internal stimuli are the person's knowledge, attitudes, values, and perceptions. Stimuli that can be classified as external are perceptions, values, and attitudes of others. Because of these stimuli, one experiences a mix of life events. These events may be perceived as either positive or negative. One of the roles of the professional nurse is to assist the client in preventing the development of negative life events. In the primary prevention role, the nurse assists the client to maintain equilibrium. Neuman (1974) wrote that primary prevention is employed when the individual has perceived a stressor, but before an actual reaction has occurred. If no primary prevention between the nurse and client takes place, the client may experience a negative life event (e.g., illness). When a negative event occurs, disequilibrium within and outside the person develops. If primary prevention has occurred through education of the client by the nurse, and the client has complied with the teachings of the nurse then it is likely that positive life events (e.g., health) will result. If the client practices primary prevention, equilibrium will usually be maintained. However, sometimes positive life events can result in disequilibrium.

There is feedback from the maintenance of equilibrium to the mix of life events where the process starts again.

If there have been no primary prevention measures because these measures were not understood or well received, the individual may experience a negative life event. As an example, the person who is sexually active with multiple sexual partners, refuses to practice "safer sex" or abuses illegal drugs is likely to be contributing to the breakdown of the immune system. The end result may be the development of AIDS. With such a diagnosis, the person experiences physical, psychological, and social disequilibrium. At this point, the nurse's role becomes one of secondary prevention. Neuman (1974) defined secondary prevention as interventions that are necessary when a reaction to a stressor has occurred. With the PWA, the nurse can only assist the client at this point to deal with the bio-psycho-social manifestations of the disease. At this stage, the person may perceive the need for social support. It is the nurse's role to help the individual with AIDS seek support from available and accessible sources. Examples of these types of support are: family, friends, and community resources.

If the person's need for social support is met, it is postulated that psychological adaptation, client independence, and an enhanced quality of life will result. Each of the entities mentioned is in constant interaction with the person's equilibrium. If the individual's need for social support is not met, the person may experience psychological maladaptation, become more dependent on others, and ultimately experience a poorer quality of life. Neuman (1974) defined tertiary prevention as the point where the person requires assistance in mobilizing and using energy resources.

Another way of defining primary, secondary and tertiary prevention may be more appropriate for this discussion. Primary prevention is directed at those individuals who are HIV negative. Secondary prevention is appropriate for HIV positive and those with AIDS related complex (ARC). Ragsdale and Morrow (1990) defined ARC as HIV-infected individuals who have at least two symptoms of immunodeficiency, but do not meet the CDC criteria for AIDS. Tertiary prevention focuses on PWAs and those with opportunistic infections associated with AIDS. The nurse's role is important in each of the prevention phases, but perhaps most vital in the primary phase. An example of an intervention is educating patients regarding safer sexual practices to reduce the chances of transmission of the AIDS virus. The following section presents a discussion of the PRECEDE Framework in relation to the KPSSM.

PRECEDE Framework (Figure 2)

PRECEDE is an acronym for predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation (Green, Kreuter, Deeds, & Partridge, 1980). The framework was conceived as an intervention or interventions to prevent or decrease illness and/or to enhance the quality of life through change or development of health related behavior. The model teaches one to focus initially on outcomes rather than inputs. The asking of why questions before asking how questions is facilitated by using this type of focus. The final outcome is the first step identified, followed by asking what precedes the outcome to cause it to occur.

Phase 1 presents the concept of quality of life by assessing general concerns of patients, students, workers, or consumers. The quality of life of a community could be

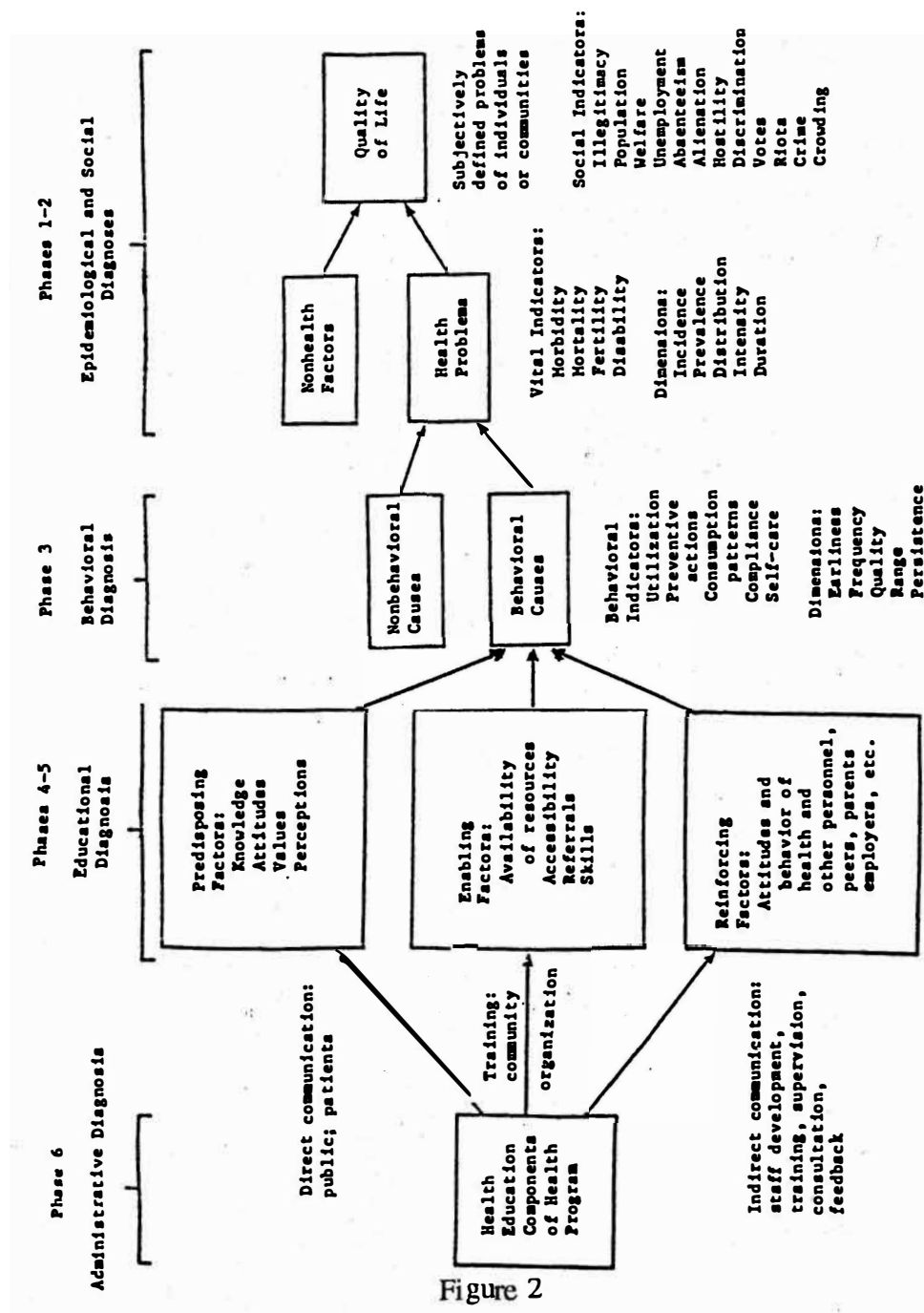


Figure 2

PRECEDE Framework
Green et al., 1980

determined by noting the kinds of social problems it is experiencing. In phase 2, specific health problems that seem to be causing the social problems noted in the first phase are identified. These data are obtained from medical and epidemiologic findings.

In phase 3, specific health related behaviors that appear to be linked to the health problems identified in the second phase are delineated. Both health problems and specific health-related behaviors are ranked according to the type and amount of intervention needed. Examples of nonbehavioral factors are identified as economic, genetic, and environmental. Behavioral causes of health problems include self-care, compliance, preventive actions, and others.

Three categories that could potentially affect health behavior are proposed in phase 4. The categories include: predisposing factors, reinforcing factors, and enabling factors. The enabling factors are barriers created by societal forces such as lack of health insurance, lack of income, and restrictive laws or statutes. One's beliefs, attitudes, and perceptions are included under predisposing factors. Reinforcing factors are related to feedback the person received from others that either positively or negatively influences behavioral changes.

Phase 5 involves making a decision about which of the factors identified in the three classes of Phase 4 are to be the focus of the intervention. The decision is based on availability of resources and the importance of the factor. The last phase is the actual development and implementation of the program. Evaluation is an integral part of the entire model and is a continuous phase of the framework.

Bruhn and Philips Social Support Model

The Bruhn and Philips Social Support Model (1987) incorporates developmental theory as a basis for learning social support. People learn to give and receive social support as they grow and develop. Social support is a need that is present throughout the life cycle. The way the need for social support is satisfied depends on the person's past experiences. An individual must be able to perceive that sources of social support such as relatives, neighbors, friends, and church members are available and accessible. Conversely, not all of these sources of support may be perceived as positive. The person needs to know how to obtain additional sources of social support when the traditional ones are unavailable.

The need for social support may be constant or episodic depending on the particular situations in a person's life. Social support that is perceived as important or necessary in one stage of a person's life may not be appropriate at another time. Maslow suggested that as the person becomes more self-actualized, less social support may be needed (Bruhn & Philips, 1987).

Bruhn and Philips (1987) suggested six themes which were integral components in the development of social support. These themes, depicted in Figure 3, were: anticipation, faith, self-esteem, autonomy, affiliation, and trust.

Anticipation (hope) was defined as an expectation that something positive is going to occur. This hopefulness is derived from support shared with and received from others and the environment (Bruhn & Philips, 1987). Fowler (1981) noted that faith assists people to define thoughts, actions, hopes, and strivings by giving them purposes and goals. Faith relates to the individual's need for social support as well as

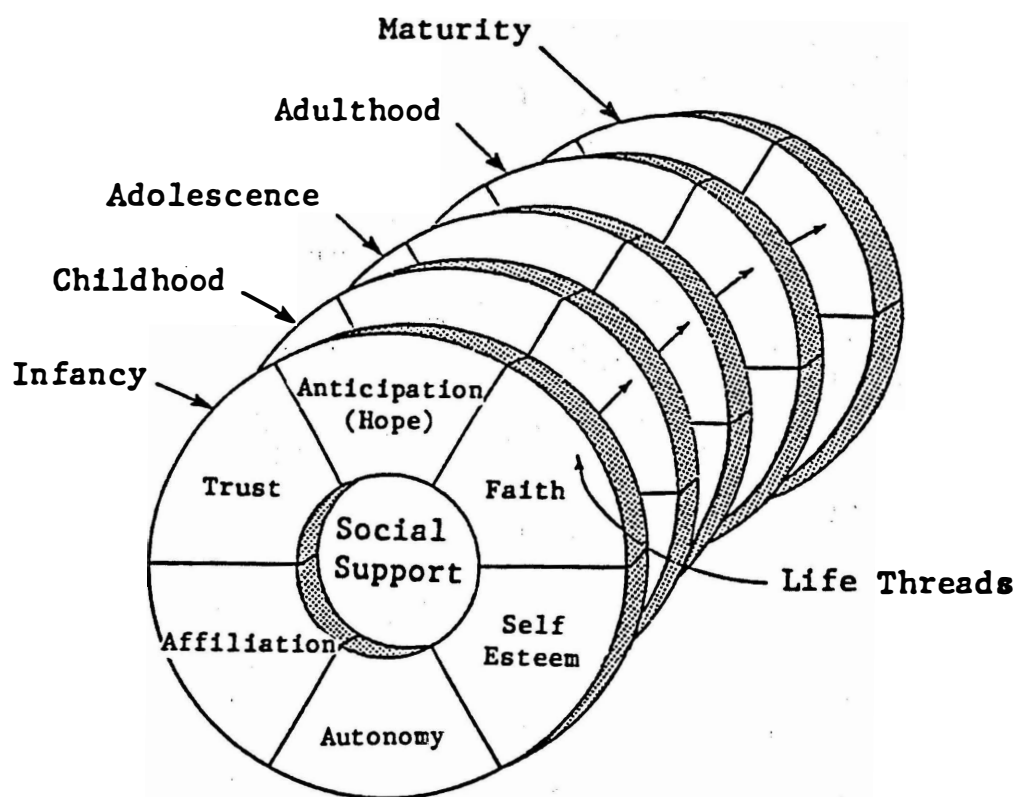


Figure 3

Relationship of Six Major Life Threads to
Social Support Throughout the Life Cycle
Bruhn & Philips, 1987

the ability to give and receive support. Self-esteem has been shown to be an effective buffer against stress (Cohen & Hoberman, 1983). Sadler & Barrera (1984) suggested that when individuals perceived they were receiving an appropriate level of support, negative effects of stress were not manifested.

Affiliation was identified as an important aspect of understanding social networks. The distinction between perceived support from family and friends was also seen as being important. Family networks are by nature of relatively longer duration. The perception of family support appears to be stable and not as easily influenced by temporary attitudinal changes. The need for support and its perceived availability and utilization are closely related to the degree of routinization of a family's day-to-day life or its established pattern of coping with daily life events (Bruhn & Philips, 1987).

Autonomy of the individual was conceived to be a very important part of the ability to give and receive social support from others (Figure 4). The person must decide that support will be received and given and then to convey those thoughts to the other individual with whom the interaction is to take place. The last theme mentioned as being vital to the development of social support was trust. If the person was not able to trust those significant others with whom interactions were to transpire, then such transactions would not be meaningful (Bruhn & Philips, 1987).

In summary, the KPSSM proposed that when individuals experience negative life events; i.e., diagnosis of HIV positivity, there is often a resultant disequilibrium experienced. Frequently, the person needs and seeks social support from family, friends, community agencies and other resources. If the support is available, the KPSSM postulates that the person has an enhanced quality of life. If no support is

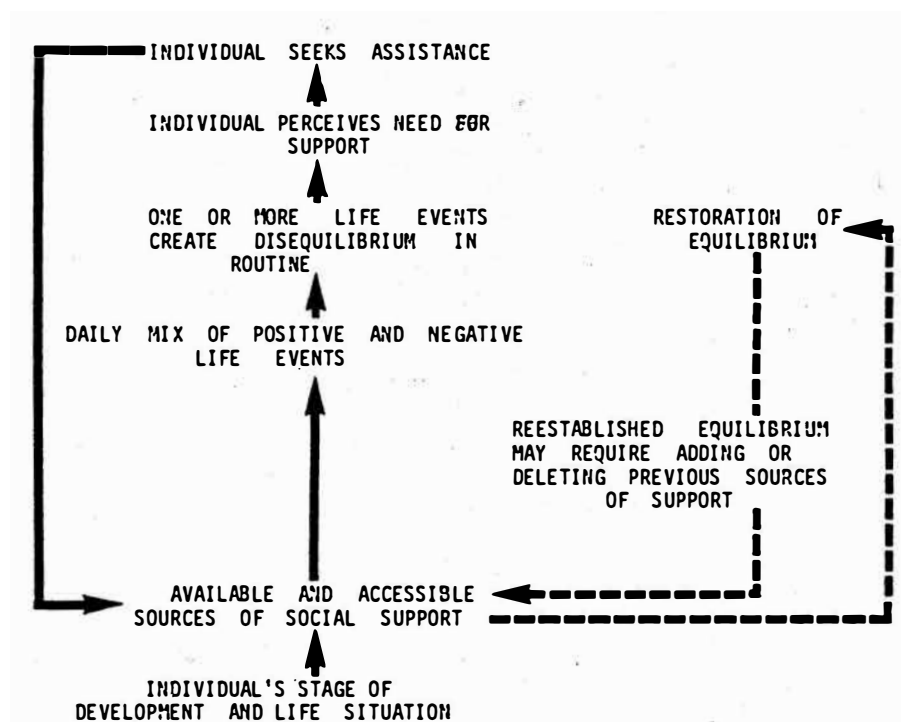


Figure 4

Interrelationship between Social Support and Life Events

Bruhn & Philips, 1987

available, which is often the case with PWAs, the individual will likely have a decreased quality of life.

Assumptions

The following assumptions were used as the basis to develop the KPSSM and were derived from the theories of the PRECEDE Framework and the Bruhn & Philips Social Support Model:

1. Change or development of health related behaviors prevents or decreases illness and/or enhances the quality of life (Green et al., 1980).
2. People learn to give and receive social support as they grow and develop (Bruhn & Philips, 1987).
3. Social support is a need that is present throughout the life cycle (Bruhn & Philips, 1987).
4. The need for social support may be constant or episodic depending on the particular situations in a person's life (Bruhn & Philips, 1987).

Research Questions

The research questions formulated for this study were:

1. What is the relationship between social support and quality of life for persons infected with HIV?
2. What are the differences among homosexual males and heterosexual males and females who are HIV positive with relation to social support and quality of life?

3. What is the relationship between perceived health status and quality of life among homosexual males, and heterosexual males and females who are HIV positive?
4. What is the relationship between ethnicity and the amount of social support of persons with HIV?
5. What is the relationship between the physical and psychosocial dimensions on the Sickness Impact Profile among homosexual males, and heterosexual males and females infected with HIV?

Definition of Terms

For purposes of this study, the following terms were defined:

1. AIDS - acquired immunodeficiency syndrome (AIDS) results from the human immunodeficiency virus (HIV), is communicable and often lethal (Wolcott, Fauzy, & Pasnau, 1985). The CDC defined AIDS as HIV positivity and the presence of one or more opportunistic infections such as Pneumocystis carinii pneumonia or Kaposi's sarcoma (CDC, 1989).
2. ARC - AIDS-related complex (ARC) refers to HIV-infected persons who have two or more symptoms of immunodeficiency, but do not meet the CDC criteria for AIDS (Wolcott et al., 1985).
3. Gay - any person who is homosexual (Mosby's Medical & Nursing Dictionary, 1986).
4. Heterosexual - a person whose sexual desire or preference is for people of the opposite sex (Mosby's Medical & Nursing Dictionary, 1986).

5. HIV± - Human immunodeficiency virus positivity includes individuals who have tested positive for antibodies. Persons who are HIV+ have minor or no symptoms (CDC, 1989).
6. Homosexual - a person who is sexually attracted to members of the same sex (Mosby's Medical & Nursing Dictionary, 1986).
7. Perceived Health Status - a relative state in which one is able to function well physically, mentally, socially, and spiritually in order to express the full range of one's unique potentialities within the environment in which one is living (Saunders Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 1987).
8. Physical Dimension - a score obtained on the Sickness Impact Profile by adding the scale values for each item checked within categories of body care and movement, mobility, and ambulation, dividing by the maximum possible dysfunction score, and multiplying by 100 (Bergner, 1976b).
9. Psychosocial Dimension - a score obtained on the Sickness Impact Profile by adding the scale values for each item checked within the categories of social interaction, communication, alertness behavior, emotional behavior, and multiplying by 100 (Bergner, 1976b).
10. Quality of Life - the degree to which one perceives that life's quality is good, that life is satisfying, that the individual has physical and material well-being, good relations with others, and the ability to participate in social/community/ civic activities, and that the individual has personal development, fulfillment, and

recreation (Burckhardt, 1985) as measured by the Sickness Impact Profile (Bergner, 1984).

11. **Social Support** - support given to an individual through social ties with other individuals or groups (Lin, Simeone, Ensel, & Kuo, 1979) as measured by the total score derived on the Norbeck Social Support Questionnaire (1986).

Limitation

The limitation of the study was that generalization of findings was limited to the study population of adult subjects who were being treated in an outpatient clinic in south Texas.

Summary

This section has presented an introduction to the problems facing PWAs and possible ways that social support affects the quality of life of these individuals. Persons with AIDS are confronted with guilt, anxiety, and fear which may prevent them from adequately coping with the disease. Nurses can assist these clients by helping them better use current sources of support or to identify new sources if none presently exist. The goal of social support is certainly not meant to change the client's prognosis, but instead is directed at providing a better quality of life.

CHAPTER II

REVIEW OF THE LITERATURE

The literature review was organized in relation to the problem to be studied: A lack of reported research regarding social support and quality of life for persons with AIDS (PWAs) has been documented in published literature. Therefore, the problem of study examined the question: What is the relationship between social support and quality of life among heterosexual males and females and homosexual males infected with the Human Immunodeficiency Virus (HIV)?

This chapter presents a review of the literature related to the areas of social support, quality of life, HIV and Acquired Immunodeficiency Syndrome (AIDS). The following review is composed of available references which are pertinent to these areas. Computer searches were conducted for materials related to the aforementioned areas.

Social Support

Social support has an effect on various physical and psychological entities in peoples' lives. The following section presents a review of literature regarding the relationships of social support to personal well-being, stress, self-esteem and social networks. Preceding the presentation of literature review related to the effects of social support on humans, a definition of social support is given.

Definition of Social Support

"Social support is behavior that gives us nurturance and provides reinforcement for our efforts to cope with life on a daily basis" (Bruhn, Sevelius, & Alles, 1986, p. 47). Bruhn et al. further elaborated that social support allows enough courage to seek new challenges, take risks, and complete difficult tasks in a successful manner. Every human being is capable of both giving and receiving social support. Social support is often only used in times of crisis, but actually it should be incorporated as a part of everyone's daily life (Bruhn et al., 1986).

The Relationship of Social Support to Personal Well-Being

Three major benefits of social support have been defined and include health, happiness, and hope (Bruhn et al., 1986). Social support can often buffer some of the adverse effects associated with prolonged stress and reduce the likelihood that illness will occur. Just because a person receives social support is no guarantee that illness will not occur or that lack of social support causes illness. Social support provides encouragement, heightens morale, and can assist one to stay well or get well when ill (Bruhn et al., 1986).

Social support can affect happiness by making persons feel needed and loved. The ability to achieve intimacy with people within and outside the family becomes an intensely felt need. Achieving intimacy is necessary for self esteem, since the ability to have friends, to love, and to be loved is highly valued. What makes the difference to well-being is not merely the nature of the problem, but the way it is experienced and reacted to. People often tend not to reach or experience their full potential in life.

Social support from others can assist in maintaining a feeling of fulfillment in life (Bruhn et al., 1986).

Hope is also a necessary component of a person's well-being. A hopeful attitude indicates that people want to look to the future, whatever it may bring. A hopeful person enjoys life despite associated problems. Through hope, communication with family, friends, jobs, and organizations is retained. Social support is an expression of hope (Bruhn et al., 1986).

The Relationship of Social Support to Stress

In a study to determine the influence of social support on the stress levels of expectant mothers and fathers, Brown (1986) compared several predictive models. The independent variables were social support and stress and the dependent variable was the expectant parents' health. The Support Behaviors Inventory, Stress Amount Checklist, and Health Responses Scale were the instruments used for the study. The sample consisted of 313 couples in the second half of pregnancy. Data were analyzed using regression analyses. The regression analyses included the variables of stress, satisfaction with other persons and spousal support, education, age, history of chronic illness, employment status, family income, and military status. The effects of the variables of chronic illness, stress, and satisfaction with spousal and support of others were tested separately for males and females. Stress and social support were found to be useful in predicting health. Both chronic illness and stress were more important for the health of pregnant women than that of their partners. It was concluded that perhaps

nursing interventions directed at stress reduction and improvement of expectant parents' satisfaction with spousal support might enhance health.

In a similar study, Ganellen and Blaney (1984) examined the effects of hardiness and social support on life stress. The two research questions designed for the study were: Are social support and the hardy personality related? Does one play a more important role in buffering the effects of life stress than the other, or are their stress-reducing effects similar? Eighty-three female undergraduate students participated in the study. Each completed the following questionnaires: the Life Experiences Survey, the Levenson Locus of Control Scale, the Alienation Test, the Social Perception Questionnaire, and the Beck Depression Inventory. These tests determined life stress, hardiness, depression, and social support. When the interactions among hardiness, life stress, and social support were considered, only alienation from self was found to moderate the effects of life stress. The results further supported the notion that social support and aspects of hardiness were not independent. The authors concluded that although other investigators found social support to be a moderator of life stress, these other studies may have in fact been indirectly measuring hardiness.

One such study which identified social support and locus of control as interactive moderators of stress was conducted by Lefcourt, Martin, and Saleh (1984). Forty-six subjects (22 males and 24 female) enrolled in a first-year introductory psychology course agreed to participate. Questionnaires that were used included: College Student Recent Life Events Schedule, Inventory of Socially Supportive Behaviors, Multidimensional-Multiattributational Causality Scale, Personality Research Form and Profile of Mood States.

A related study conducted by Bramwell and Whall (1986), examined the anxiety level of wives in response to first myocardial infarction of their spouses in terms of perceptions and interpretations of support roles and their abilities to act supportively. Study variables were identified as: role clarity, empathy, support role performance and anxiety. Exogenous variables were noted to be: previous experience in the support role, self esteem, trait anxiety, and husband's condition. There were 82 subjects who participated in the study and data were collected prior to the husband's discharge from the hospital and again three weeks later. Data analyses consisted of path analysis procedures. Findings indicated that support role performance had a negative effect on anxiety while trait anxiety exhibited a positive effect on anxiety.

The interaction of Type A behavior and social support in relation to the severity of coronary artery disease was investigated (Blumenthal et al., 1987). One hundred thirteen subjects completed a battery of psychometric tests and were also interviewed to determine the presence of a Type A personality. Blumenthal et al. found that those subjects who had low levels of social support had more severe coronary artery disease than Type A's with high levels of social support.

The relationships among genital herpes virus, stress, and social support were also examined (VanderPlate, Aral, & Magder, 1988). The study retrospectively examined the role of stress in activation of herpes lesions as mediated by social support. There were 59 subjects who reported having genital herpes for at least 10 months. Reports of herpes symptoms were examined using multiple regression. Duration of disease, and amount of social support were found to be significant moderators of the relation between stress and herpes recurrences. When disease duration was short, stress and

recurrences were positively associated. When the duration was longer, there was no relationship. When there were low levels of social support, a positive relation between stress and recurrences was found. At higher levels of social support, no association was found.

The Relationship of Social Support to Personal Relationships

Individuals generally rely on their social networks for support. Support may be available as a result of long standing relationships with significant other individuals or groups who assist the person to deal with everyday events or long-term problems (Caplan, 1974). Most often mates, parents, other family members, neighbors, and friends provide assistance. A social network provides personal contacts through which the individual maintains social identity while receiving emotional support, material aid and services and information (Walker, MacBride, & Vachon, 1987). Kaplan, Cassell, and Gore (1977) concluded that those persons undergoing major life transitions are protected, or buffered, from adverse health consequences when they experience these events in the company of significant others. Caplan (1974) suggested that buffering serves to provide a refuge for the individual while being supported during a particular life transition. This buffering is not restricted to family members and close friends but can be produced by persons who are simply perceived by the stressed party as similar in some valued respect. Although the extrafamilial network may be less durable than family relationships, there exists a committed, shared sense of helping someone to make it alone.

The Relationship Among Social Support, Self-Esteem and Social Networks

Muhlenkamp and Sayles (1986) found that 28% of the variance in positive health practices was related to a combination of self esteem and social support. These variables were also found to be related to one another. This study suggested that self esteem may be an important intervening variable to explore in explaining the relationships between available sources of support and health behavior.

The influence of social networks was found to be dependent on congruence between the network and beliefs of the person (Muhlenkamp & Sayles, 1986). Of the sample, 86% sought help for symptoms when the network advised it and the subject also believed that the symptom was serious. When there was no advice available from the network and no belief that the symptom was serious, only 14% sought help. When the subject believed in its seriousness but the network did not advise it, 65% used services; when the opposite was true only 49% used services.

The Relationship Between Social Support and AIDS

Zich and Temoshok (1987) noted benefits of social support among PWAs. They reported a significant relationship between perceived social support and levels of distress. Individuals experienced less distress as more positive support was perceived. In contrast, Donlou et al. (1985) found no significant correlations among social support, mood disturbances and self-esteem. In a related study examining social support and AIDS, no significant relationships between social support and behavior outcomes were found (Emmons et al., 1986).

Quality of Life

The following section presents a review of the literature related to the concept of quality of life. Definitions and methods of measurement of quality of life are noted.

George and Bearon (1980) noted that because different people value different things, defining quality of life is difficult. Dalkey and Rourke (1983) defined quality of life as "a person's sense of well-being, his satisfaction or dissatisfaction with life or his happiness or unhappiness" (p. 210). Ferrans and Powers (1985) defined quality of life as the degree of satisfaction with perceived present life circumstances. Another definition of quality of life was the degree to which one has self esteem, a purpose in life, and minimal anxiety (Lewis, 1982).

Ragsdale and Morrow (1990) identified variables related to quality of life among persons infected with HIV. The researchers also examined whether or not classification (HIV+, ARC, or AIDS) affected one's quality of life. A convenience sample of 95 HIV-infected persons completed a demographic data sheet, the Symptom Distress Scale (SDS) and the Sickness Impact Profile (SIP). Twenty-five percent of the participants were HIV+ only, 16% had ARC, and 59% were categorized as having full blown AIDS. HIV infection significantly affected quality of life, and multivariate statistics indicated that life quality varied according to classification. Subjects who were HIV+ only were not impacted physically and psychosocially as greatly as those subjects with ARC or AIDS.

Measurement of Quality of Life

The Quality of Life Index (QLI) "was designed to measure quality of life, taking into account the life domains noted by experts, the subjective evaluation of satisfaction with domains, and the unique importance of each domain to the individual" (Ferrans & Powers, 1985, p. 17). Subjects responded to items on a six-point Likert-type scale ranging from "very satisfied" to "very dissatisfied" for the satisfaction items, and "very important" to "very unimportant" for the importance items. Both the importance and satisfaction sections contained 32 items that measured areas such as: life goals, self acceptance, general satisfaction, stress, family, friends, physical health and functioning, and health care.

Content validity for the QLI was supported by the fact that items were based on literature review of issues related to quality of life (Ferrans & Powers, 1985). The instrument was also evaluated for criterion-related validity by using an overall satisfaction with life question as a criterion measure of quality of life. The questionnaire was administered to two groups of participants; a group of 88 graduate students and 37 dialysis patients. The correlation between scores on the QLI and life satisfaction question was $r = 0.75$ for the graduate students and $r = 0.65$ for the dialysis patients. According to Ferrans and Powers, these correlations demonstrated a high amount of overlap and supported the validity of the QLI.

Test-retest reliability for the QLI was established by administering the test a second time two weeks and four weeks after the initial testing. In both groups of subjects stability reliability was supported by correlations of $r = 0.87$ with a two-week interval (graduate students) and $r = 0.81$ with a one-month interval (dialysis patients)

(Ferrans & Powers, 1985). Internal consistency reliability of the index was supported by respective Cronbach's alphas of $r = 0.93$ and $r = 0.90$.

Another study was conducted to determine the effects of a transtelephonic electrocardiograph monitor and lidocaine injector on the quality of life in post-myocardial infarction patients. There were 238 patients who were randomly assigned to either the system or to standard medical care. Quality of life was defined in terms of subjects' social functioning, psychological status, and return to work status. The findings showed that patients in the control group (those who received standard medical care) were twice as likely to exhibit signs of clinical depression. Of subjects assigned to the experimental group, 92% had returned to work within 9 months of their infarctions as compared with 76% of patients in the control group. The authors surmised that encouraging the patient to participate in treatment can significantly improve quality of life after a myocardial infarction.

Quality of life has also been measured using the Sickness Impact Profile (SIP) (Bergner, 1984; Gilson, Gilson, & Bergner, 1975). The SIP measures dysfunction rather than disease. There are 12 areas of activity that measure sickness-related dysfunction. The areas include: communication, social interaction, alertness behavior, emotional behavior, mobility, recreation and pastimes, work, home management, eating, ambulatory, body care and movement, and sleep and rest.

In 1973, a pilot study was conducted using the SIP for the first time. The sample included 278 subjects who were inpatients from rehabilitation, audiology and speech pathology services, and outpatients seen in a family practice clinic of a teaching hospital. A fourth group of subjects consisted of group practice enrollees. The 75

inpatients from rehabilitation medicine had a mean score of 22 with a standard deviation of .11. The mean score of the 48 patients from speech pathology was 23 with a standard deviation of .15. Eighty outpatients in the third group had a mean score of 11 with a standard deviation of .09. The 75 group practice enrollees had a mean score of 4 with a standard deviation calculated as .05. Further analyses of the four groups using analysis of variance revealed an F of 57.48 and $p < .001$ (Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976b).

Acquired Immunodeficiency Syndrome

There are a multitude of articles published about Acquired Immunodeficiency Syndrome (AIDS). The following section contains sociodemographic data, a definition of AIDS and common signs and symptoms. Risk factors associated with AIDS and groups particularly susceptible to development of the virus are presented. Risk groups discussed include: adult males, adult females and adolescents and young adults. In the final sub-section nursing diagnoses and the role of nurses in assisting persons with AIDS are discussed.

Sociodemographic Data Related to AIDS

From 1981 to 1987, 50,000 cases of AIDS were reported to the Centers for Disease Control (CDC). By August 1989, 100,000 cases had been reported to the CDC (CDC, 1992a). As of September 9, 1992, 242,146 cases of AIDS have been reported. Of those cases, 136,912 were homosexual or bisexual males, 54,475 were females or heterosexual males who shared intravenous needles. Homosexual or

bisexual males who shared contaminated needles accounted for 15,203 of those persons infected. Heterosexual contact contributed to 15,221 cases of AIDS, and there were 1,953 hemophiliacs with AIDS.

The cumulative total of more than 200,000 cases reported to the CDC emphasizes the rapidly increasing magnitude of the HIV epidemic in the United States. The first 100,000 cases were reported over an 8-year period while the second 100,000 cases were reported during a 2-year period (CDC, 1992f).

It is estimated that 1 million persons are infected with HIV in the United States. Approximately 20% of those infected have developed AIDS. Approximately half of those diagnosed as HIV positive and who have severe immunosuppression (T4 lymphocyte counts < 200 cells/ μ L) meet the current AIDS case definition (Farizo, Buehler, & Berkelman, 1991). Approximately 125,000 persons who do not have AIDS defining condition (ADC) are estimated to have T4 counts < 200 cells/ μ L. The CDC has proposed expanding the AIDS definition to more accurately include all persons with severe HIV-related immunosuppression and at high risk for developing serious illnesses or death (CDC, 1991b).

The World Health Organization (WHO) estimates that 10 million individuals are HIV-infected worldwide (WHO, 1990). The costs of health care associated with AIDS through 1991 has been estimated to be about \$22 billion (Bloom & Carlner, 1988).

Evolution of the Epidemic

Precautions initiated in 1985 to ensure the safety of the blood supply have proven effective, with a decrease in AIDS cases among hemophiliacs and other transfusion

recipients (CDC, 1992f). In 1991, the proportions of reported cases increased most for females, blacks, Hispanics, heterosexuals, and residents of the South. Decreases in incidences were recorded among whites, residents of the Northeast, and homosexual or bisexual males (CDC, 1991a).

From 1981 to 1990, Dade County, Florida, ranked second behind New York City among United States metropolitan areas in cases attributed to heterosexual contact and in pediatric cases. Dade County ranked third in AIDS cases among females (CDC, 1991c). AIDS is the leading cause of death among black men and the second leading cause among black women in Baltimore, Maryland. Mortality rate among those aged 25 to 44 years in 1989 was more than twice the national average for white men and three times the national average for black men (CDC, 1992d).

Puerto Rico has the second highest overall AIDS rate and the second highest rate of cases among women. The proportion of cases related to heterosexual contact is 18%, the highest of all the United States and territories. The origin of most infections can be traced back to intravenous drug use (CDC, 1992e).

Definition of Acquired Immunodeficiency Syndrome

AIDS, as the name implies, is a syndrome of clinical events that occur because of an acquired immunodeficiency. The immunodeficiency is due to an infection with a virus. The human immunodeficiency virus (HIV) is responsible for the development of AIDS (Grady, 1989).

Pathophysiology

T lymphocytes, which represent 70-80% of the lymphocytes produced, are responsible for cell-mediated immunity (Mudge-Grout, 1992). AIDS is a serious health problem caused by a virus that attacks white blood cells (T4 lymphocytes) in the human blood. The human immunodeficiency virus (HIV) can be transmitted from one person to another during sexual contact or by sharing intravenous drug needles and syringes. This syndrome inhibits a person's ability to fight other diseases because the virus attacks the immune system. When the immune response is compromised, infections caused by bacteria, fungi, protozoa, and other viruses and malignancies, that cause life-threatening illnesses are more likely to occur (Grady, 1989).

When the HIV attacks and destroys T4 lymphocytes, antibodies are produced by the body. These antibodies can be detected usually two weeks to three months after infection by performing a simple blood test. The virus can be transmitted by a person who is infected even before the antibody test is positive (Grady, 1989).

Scientists do not agree on the exact cause of death of immune cells in persons infected with HIV (Groux et al., 1992). One theory is that HIV triggers a natural self destruct mechanism called apoptosis. Apoptosis is cell death that results from cellular suicide. T4 lymphocytes isolated from HIV-infected individuals commit cell suicide when stimulated with a range of antigens in vitro. The researchers noted that HIV primes the T4 cells for suicide, instead of proliferation, when they encounter their target antigen (Groux et al.). But the T4 suicide theory is one among many.

Speigel et al. (1992) stated that an as yet unidentified superantigen encoded by HIV may hyperactivate T4 lymphocytes causing excessive proliferation and cell death.

Another theory suggested that HIV causes an autoimmune reaction where the body attacks its own immune system, including T4 lymphocytes. A fourth theory proposed that the virus causes fusion of T4 cells, clumping them into dying masses of cells called syncytia.

Groux et al. (1992) noted that relatively few T4 cells from HIV-positive persons appear to be infected. The authors estimated that about one in 1,000 of the circulating T4 cells in peripheral blood actually contains the virus in the early years of the disease. This malfunction without infection lead researchers to conclude that direct killing by viral lysis cannot account for the loss of all these cells. Groux et al. concluded that the various proposed mechanisms for T4 cell death are not mutually exclusive and may all play a part.

Clinical Manifestations

HIV infection causes a gradual decrease in immune function that typically occurs over several years. As the T4 lymphocyte count decreases, the risk of various opportunistic infections (OIs) and lymphomas increases. The occurrence of any one of the infections is one criterion used to diagnose AIDS. Prophylactic therapies for various OIs are widely used, but these therapies can be toxic, invasive and very expensive (Phillips et al., 1992). The authors stressed the importance of carefully evaluating the risk of a specific OI as a function of the T4 count, to give appropriate treatment when the risk is high and withhold therapy when there is low risk of T4 cell involvement.

A cohort of 111 hemophiliacs were followed for a mean of 6.6 years (Lee et al., 1989; Phillips et al., 1991). All of the subjects were infected with contaminated blood products between 1979 and 1985. The patients ranged in age from 2 to 77 years with a median age of 24. Therapeutic interventions included zidovudine (AZT) for patients with AIDS since 1987, AZT versus placebo in asymptomatic persons since 1988, secondary prophylaxis with pentamidine for Pneumocystis carinii pneumonia (PCP) since 1988 (nine patients), and 29 patients received primary prophylaxis with pentamidine since 1989.

Of the 111 patients, 33 developed at least one ADC as of November 1990. Twenty-nine developed at least one ADC while three persons experienced more than two. The most commonly occurring ADC was PCP which occurred in 20 of the 33 AIDS patients. In 16 of these 20, PCP was the ADC that led to their AIDS diagnosis (Phillips et al., 1992).

The signs and symptoms of AIDS vary greatly (Mudge-Grout, 1992). Clinical manifestations depend on the magnitude of immunosuppression and the accompanying neoplasm or associated OI. Nonspecific complaints may also occur and are usually exacerbated as the disease progresses.

AIDS destroys the body's natural defense against disease and allows infections that are normally controllable to invade the body and cause additional infections. It is these OIs that usually lead to the person's death. Some signs and symptoms may include fever and persistent cough associated with difficulty in breathing. These symptoms may be indicative of PCP. A one-celled protozoan parasite causes PCP. Serological studies have shown that most persons are infected with the organism by

adolescence. Like most OIs, PCP occurs only in persons with impaired immune systems. PCP is the most common presenting diagnosis for AIDS, accounting for approximately 60% of newly diagnosed cases. Respiratory isolation is not necessary for persons with PCP because it is not transmissible from person to person (Wolfe, 1989). Another opportunistic infection frequently associated with AIDS in white homosexual males is Kaposi's sarcoma (KS). This type of cancer is characterized by multiple purplish blotches and bumps on the skin.

KS was first described over a hundred years ago by a Hungarian physician. The cancer previously occurred in older men of Mediterranean descent. In most cases, the cancer did not have any effect on life span. The variety of KS associated with HIV infection is much more aggressive. The lesions are raised and generally painless and nonpruritic. KS may occur on the face, limbs and trunk. The lesions are usually oval and approximately 1 cm in diameter. KS can involve internal viscera like the gastrointestinal tract leading to internal bleeding or the lungs causing respiratory distress. Although rare, KS can involve the lymphatic system of the legs. The resultant lymphedema results in immobility and severe pain (Wolfe, 1989).

Certain cofactors have been suggested for the development of KS (Mudge-Grout, 1992). Studies have revealed cytomegalovirus (CMV) in the nucleus of KS cells, indicating a possible viral role in the development of the cancer. The exact cause is unknown; however, other viral or genetic factors may contribute to the pathogenesis of the disease.

Generally, AIDS patients with only KS have a milder immunodeficiency than those with other OIs present. However, severe immunosuppression and invasive KS

carry a poor prognosis, although survival rates are longer than in patients with other OIs. Length of survival for persons with AIDS-related KS ranges from a few months to 5 years with a mean of 18 months (Mudge-Grout, 1992).

Lifson et al. (1990) surveyed 1,341 men with AIDS. The proportion presenting with KS declined from 79% in 1981 to 25% in 1989. Compared with other men with AIDS, men with KS had a shorter interval from HIV seroconversion to AIDS diagnosis (median, 77 versus 86 months). The risk factors of men with and without KS did not significantly differ. The authors concluded that the decline in KS may be partly due to a shorter latency period from infection to disease. HIV may also attack the nervous system and cause brain damage. HIV invades the glial cells without adequate T4 lymphocytes. Wolfe (1989) noted that nervous system involvement manifests itself as memory loss, loss of coordination, indifference, paralysis, or AIDS related dementia.

Risk Factors and Risk Groups Associated with AIDS

Sexual contact with an infected person, contact with blood and certain body fluids, and transmission from an infected mother to her unborn child have been documented as specific routes of transmission. HIV has been isolated in all body fluids, but there is no evidence that it has been transmitted via urine, saliva, tears, cerebrospinal fluid or feces. There has also been no documentation of transmission from sharing eating utensils and dishes, bathroom facilities or through insect bites (Dickerson, 1989).

There is also no known risk of transmission of HIV in routine, daily, non-sexual activities. Sharing razors, towels, toothbrushes, and kissing have not proven viable

routes of viral transmission. Family members living with PWAs are not at risk for becoming infected unless they are sexually intimate with the PWA (Dickerson, 1989).

AIDS is not a disease that is restricted to any one particular group. The disease is found in homosexuals and heterosexuals, in males and females, in adults and children, and in persons from all ethnic, socioeconomic, educational, and age groups (Leibowitz, 1989).

Adult Males at Risk

Males who are sexually active with other males are especially at risk. Approximately 59 percent of PWAs in the United States are male homosexuals and bisexuals (CDC, 1992a). Males who have multiple partners are particularly at risk. The more partners a person has, the greater the risk of becoming infected with the HIV (Leibowitz, 1989).

One study investigated the frequency of sexual encounters and risk of HIV infection in homosexual partners of men with AIDS (Osmond et al., 1988). The authors interviewed and tested 117 homosexual men for the HIV antibody. All of the men had been regular sexual partners with men who had developed AIDS. Of the subjects, 85% tested seropositive. Receptive anal intercourse and the number of different sexual partners were both risk factors. Risk was not associated with the duration or frequency of contact. The data further suggested that the potential for transmission from an HIV infected person may be greater close to or after the onset of the disease.

Females at Risk

The number and proportion of AIDS cases among heterosexuals has been increasing steadily. There is increased risk associated with having multiple sexual partners and the presence of other sexually transmitted diseases. Men and women who have unprotected sex are at increased risk for HIV infection. There are estimates suggesting that by 1995, the infection rate among non-drug using heterosexuals may be associated with a doubling of the AIDS cases acquired through heterosexual transmission (CDC, 1992a).

Women are at risk for contracting AIDS when they are: prostitutes, recipients of tainted blood or blood products, sexual partners of infected hemophiliacs, gay or bisexual men, or intravenous drug users (Buckingham & Rehm, 1987). Women are often first diagnosed when they go in to donate blood. It is now routine in most blood banks to test for the presence of the antibody when a person donates blood. A woman who considers herself healthy may be suddenly shocked by the realization that she is HIV positive (Buckingham & Rehm, 1987).

The incidence of HIV infection and AIDS in women is increasing at an alarming rate and reaching crisis proportions (CDC, 1991d). Women are one of the fastest growing risk groups for HIV infection in the United States and around the world. By early 1990 more than 3 million women worldwide were infected with HIV (Chin, 1990). In 1982 U.S. women made up approximately 6% of cases of AIDS; by 1989 that number had increased to 11% (CDC, 1991e).

Although the majority of PWAs are men, changes in the ratio of persons infected with HIV have been reported (Cowan et al., 1990). Cowan et al. noted that in some

areas the ratio of men and women infected with HIV is 1 to 1. In adolescents, more females than males are being affected (Burke et al., 1990).

Smeltzer (1992) noted that the virus affects men and women differently. There is generally a shorter length of survival in women related to differences in male and female anatomy and physiology. There have also been inadequate numbers of women included in treatment and clinical trials. Smeltzer emphasized that "given the growing number of women with HIV infection, greater attention to women with HIV infection and at risk for AIDS is warranted" (p. 152). Smeltzer attributed the lack of attention to HIV infection and AIDS among women to the initial appearance of the epidemic in men and the lasting impression of many that AIDS remains a disease of men, and specifically gay men. The author also noted that there has been a longstanding lack of serious attention to many health and social problems of women.

Efforts to prevent heterosexual transmission of HIV infection have previously focused on modifying sexual behaviors and the use of condoms (Stein, 1990). Stein noted that while effective measures of pregnancy prevention have relied on women, little attention has been placed on prevention of HIV transmission that depends on the woman and are under her control. Kirksey et al. (1993a) stated that abstinence is the only sexual practice that is completely safe. Since abstinence may not be acceptable to everyone, other options are available to help minimize the risks of contracting HIV and other sexually transmitted diseases. While condoms for males have been available for years, there are now several types available for use by females. Because of their thickness, female condoms are less likely to break or leak than male condoms. Kirksey

et al. emphasized that the availability of condoms for females has provided needed options for women to protect themselves against HIV.

Kirksey and Stephens (1993b) indicated that women are more likely than men to have risky sexual partners and to engage in unprotected sex with them because it is often awkward to bring up the subject of safer sex with potential or even long-term partners. The authors noted that it is foolish not to talk about safer sex options with sexual partners out of fear of hurting the partner's feelings or fear of rejection.

Everyone who engages in sexual practices is at risk of contracting HIV.

AIDS is the leading cause of death in women between the ages of 25 to 34 years in New York City. It is estimated that 10 times more black women than white women are infected. Of those women diagnosed with AIDS, 52% are black; 27% are white; 20% are Latin; and 1% are Asian, Native American or Pacific Islander (Fedor, 1991).

The CDC reported that women constitute the fastest growing group of persons with AIDS, representing 11% of CDC reported cases in the United States. As many as 65% get sick and die from an ADC that do not fit the CDC definition of AIDS (Fedor, 1991). These statistics support changing the current AIDS surveillance case definition to accurately include all HIV-infected persons (CDC, 1991b). The criteria has primarily been defined from studies of HIV progression among gay men, and does not include symptoms like pelvic inflammatory disease and chronic vaginitis (Fedor, 1991).

Williams (1991) conducted a qualitative needs assessment of women at risk for contraction of HIV. Interviews were conducted with 21 women who injected drugs or were heterosexual partners of intravenous drug users. Results were analyzed using the

Health Belief Model. The threat of AIDS motivated these women to practice safer sex and use drugs more safely. However, they were not convinced that the recommended health behaviors would be effective against HIV transmission. There was also concern about the significant costs associated with these behaviors.

Porcher (1992) noted that HIV infection among women and their infants is a growing health care problem in the United States. The author stated that young black and Hispanic women are particularly at risk, especially if they have sex with someone who is infected or if they use intravenous drugs. There is a direct correlation between the incidence of AIDS in infants and the incidence in childbearing women. Porcher advised including an HIV-focused history and physical, as well as laboratory tests to screen for viral and bacterial infections, as a routine part of antepartal care.

Adolescents and Young Adults at Risk

Adolescents encounter a myriad of temptations on a daily basis and are required to make important choices that are often beyond their maturity levels as peers pressure them to experiment with drugs and sex (Kirksey, Garza, & Echols, 1992). The authors noted that many teens view AIDS as a gay disease, and often engage in sexual intercourse without condoms and have multiple sexual partners. Three million teens are infected annually with sexually transmitted diseases, including HIV. Because of experimentation with chemical substances and unprotected sexual practices, adolescents constitute a potentially high-risk group for exposure to AIDS (Dorman & Rienzo, 1988).

Investigations regarding sexual behavior and change in sexual practices among teenagers and young adults due to the AIDS epidemic are sparse in the published literature. The preponderance of studies on sexual behaviors among adolescents have focused on the use of condoms. The findings indicate that only a small percentage of adolescents and young adults use condoms consistently (DiClemente et al., 1990; Kegeles, Adler, & Irwin, 1988). Hingson et al. (1990) cited that condom use was related to positive beliefs about condoms, little or no alcohol use before or during sexual intercourse, and perceived susceptibility to AIDS. In contrast, Baldwin and Baldwin (1988) found that older age at first intercourse and increased worry about AIDS were the best predictors of condom use in a sample of college students.

Jemmott and Jemmott (1991) reported that the number of cases of AIDS is increasing disproportionately among Blacks in the United States. The relatively high incidence, particularly among black adolescents, suggests the need for AIDS prevention programs to reduce risks of infection. The researchers randomly assigned 157 black adolescent males to groups receiving an AIDS risk reduction intervention aimed at increasing AIDS-related knowledge and changing attitudes toward risky sexual behavior, or to receive a control intervention on career opportunities. The teens receiving the AIDS intervention had greater knowledge about AIDS, less favorable attitudes about risky behavior, and decreased intentions to engage in risky sexual acts than those in the control group. Follow-up data collected three months after initial contact revealed that the teens receiving the AIDS intervention reported fewer occasions of intercourse, fewer sexual partners, increased condom use, and a decreased incidence of heterosexual anal intercourse than did the other adolescents.

Two hundred and forty high school students were surveyed and found to have little or no knowledge of AIDS transmission. Of those who knew about AIDS, most reported little concern about contracting the disease (Price, Desmond, & Kukulka, 1985). In a similar study, Strunin and Hingson (1987) conducted a telephone survey of 860 high school-aged students. The findings revealed that the adolescents were misinformed about the modes of transmission of AIDS. Seventy percent of the respondents reported being sexually active and only 15% of those reported changing their sexual behavior because of concern about contracting AIDS. Fifty-four percent responded they did not worry at all about contracting AIDS (Strunin & Hingson, 1987).

Three hundred and thirty-three college students were surveyed to determine knowledge and opinions about AIDS-related issues. There were 105 (32%) males and 227 (68%) females who participated in the survey. In contrast to the findings of Price et al. (1985) and Strunin and Hingson (1987), 70% of the respondents indicated that they were afraid of getting AIDS. The authors surmised that college-aged students are more worried than high school-aged students about contacting AIDS (Dorman & Rienzo, 1988). A similar study assessed 1,326 adolescents' knowledge, attitudes, and beliefs about AIDS (DiClemente, Zorn, & Temoshok, 1986). A lack of knowledge, particularly about safer sexual practices used to prevent transmission was found. The authors concluded that the development of programs to educate students about AIDS and other sexually transmitted diseases are needed in the public schools.

Kirksey et al. (1992) cited AIDS as the sixth leading cause of death among 15- to 24-year-olds, and noted that the best strategy for preventing the spread of AIDS is early

intervention. Teaching young people to avoid risky behavior is easier than changing firmly entrenched sexual practices. Sex education should begin before adolescents become sexually active.

Nursing Diagnoses and the Role of Nursing in Assisting PWAs

Several nursing diagnoses come to mind when thinking about the challenges of caring for PWAs. Howe (1980) identified some of these problems including: activity intolerance, ineffective coping, impairment in skin integrity, knowledge deficit, alteration in bowel elimination, and impaired home maintenance management. Two other diagnoses that seemed most appropriate for PWAs were the diagnoses of powerlessness and social isolation. Powerlessness is the "perception of the individual that one's own action will not significantly affect an outcome" (Howe, 1980, p. 65). Social isolation is defined as a "condition of aloneness experienced by the individual that is perceived as imposed by others and is a negative or threatened state" (Howe, 1980, p. 65). Factors that may contribute to social isolation were identified as homosexuality and life style judged unacceptable by societal standards. Characteristics of social isolation were manifested by a sad, dull affect, existence in a subculture and an alteration in the level of wellness (Howe, 1980).

The nurse is in a position to provide an atmosphere where the PWA feels accepted and understood. Nurses also help PWA's identify resources for social and physical assistance, such as social service or established support groups (Bechtel, 1986).

Nurses can be particularly effective in spreading the word about AIDS. The idea of specific risk groups for HIV is misleading. Nurses can teach the public that AIDS

can affect anyone. The virus is an equal opportunity infection, having no regard for race, gender, age, sexual orientation, or class (Fedor, 1991).

Summary

This section presented a review of the literature related to the areas of social support, quality of life, and acquired immunodeficiency syndrome. Definitions of each of the key concepts were presented. The literature review was organized in relation to the problem that was studied: A lack of reported research regarding social support and quality of life for persons with HIV has been documented in published literature. Therefore, the problem of this study examined the question: What is the relationship between social support and quality of life among heterosexual males, heterosexual females, and homosexual males diagnosed with the Human Immunodeficiency Virus?

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

An exploratory, survey design was used for the purpose of evaluating the relationship between social support and quality of life in persons infected with HIV. Using a convenience sampling technique, subjects were given the Kirksey Demographic Data Sheet (Appendix A), the Sickness Impact Profile (Appendix B), and the Norbeck Social Support Questionnaire (Appendix C) to complete. Issac and Michael (1979) noted that explanatory research is not designed to explain relationships, test hypotheses, discover meanings and implications, nor make predictions. Explanatory research is concerned with studying the relationship among two or more variables. Explanatory research is used to establish predictive relationships, to evaluate a method, program, or procedure, or to discover causal relationships (Abdellah & Levine, 1979). The purpose of this study was to examine the relationship between social support and quality of life among heterosexuals and homosexual men diagnosed as HIV positive.

Setting for the Study

The study was conducted in the south central part of the United States. Data collection was completed in a medical center located in a city with a total population of approximately 70,000 people. The medical center consists of several hospitals, one medical school, and students from two schools of nursing.

Data were collected in a 900-bed, non-profit, hospital in south Texas. The setting for data collection was the HIV outpatient clinic of the selected hospital. The staff consisted of two registered nurses and two nurse's aides. Patients diagnosed as HIV positive were seen in the clinic for evaluations including blood work and physical examinations. Some of the persons treated at the clinic had either ARC or AIDS. These patients were excluded from the sample because they were deemed too ill by clinic physicians to answer the questionnaires. The clinic was open Monday through Friday from 9 a.m. to 5 p.m. Patients diagnosed with AIDS who required inpatient hospitalization were cared for on various units throughout the hospital, but these patients were also not surveyed because the acuity of their illness prevented them from answering the questionnaires.

Population and Sample

The population for this study included all male homosexual, and male and female heterosexual patients, diagnosed as HIV positive, who attended the selected clinic. There were 219 patients treated in the outpatient clinic each month. Approximately ten percent of those patients were female. The ninety patients who were only HIV positive and had neither ARC nor AIDS were approached and invited to participate in the study, and all but one agreed to participate. All of those individuals met the criteria specified for inclusion in the study:

1. Diagnosed as being HIV positive by a physician.
2. Able to read, write, and speak English.
3. Alert and oriented to person, time and place.

The investigator or one of three graduate nursing student research assistants approached subjects each day to determine their willingness to participate in the study. The investigators were present in the clinic on Mondays through Fridays from 9 a.m. to 5 p.m. during the month of July 1988.

Protection of Human Subjects

Protection of human subjects was guaranteed by adhering to the requirements of the Texas Woman's University Human Subjects Review Committee. The study was determined to be exempt from Texas Woman's University Human Subjects Review Committee because interviewer-administered and self-administered questionnaires were given to persons 18 years of age or older (Appendix D). Agency Permission for Conducting the Study was also obtained (Appendix E). A Participant Cover Letter (Appendix F) which explained rights of participants was distributed to each subject prior to the beginning of data collection. Subjects were informed about the nature, the purpose, risks, and benefits of the study (Appendix F). The participants were assured that all information that could be identified with them would remain confidential. Subjects were assured that their names would not appear on the demographic data sheet or any other questionnaire used, nor would the participant or the hospital be identified in the research report. Subjects were informed that participation was voluntary and that they could withdraw from the study at any time without affecting their care.

Instruments

Information that was obtained from the Kirksey Demographic Data Sheet (KDDS) (Appendix A) included: age, sex, marital status, ethnic group, personal income, and educational level. Other variables assessed were: addictive behaviors, sexual practices, and perceived health status.

Additional instruments used for this study were the Sickness Impact Profile (Appendix B) and the Norbeck Social Support Questionnaire (Appendix C). A description of each of the questionnaires is contained in the following two sections.

Sickness Impact Profile

The Sickness Impact Profile (SIP) is a questionnaire developed in 1974 by two cardiologists, Drs. Betty and John Gilson (Bergner, 1984). The premise of the SIP is that it measures dysfunction rather than disease. A person can have a disease without visible sickness and be sick without any type of disease being present. The SIP questionnaire is used to assess behavior or performance and is therefore an objective measure (Gilson, Gilson, & Bergner, 1975; Bergner, Bobbitt, & Kressel, 1976a; Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976b).

The questionnaire measures sickness-related dysfunction according to 12 areas of activity. The areas include: communication; social interaction; alertness behavior; emotional behavior; mobility; recreation and pastimes; work; home management; eating; ambulation; body care and movement; and sleep and rest. The SIP consists of 136 items and completion time is approximately 30 minutes. Each category can be scored individually, or a score can be calculated for the complete SIP. Three of the categories

(mobility, ambulation, and body care and movement) can be grouped to obtain a physical dimension score. Four other categories can be grouped to obtain a psychosocial dimension score. These categories are: emotional behavior, alertness behavior, communication, and social interaction. The other five categories (sleep and rest; eating; work; home management; and recreation and pastimes) can only be scored individually (Bergner, 1984).

According to Bergner (1984), criterion-related and consensual validation of the SIP have been obtained by comparison of clinical reports of patient dysfunction and illness severity, examining the relationships between the SIP score and self-reports of dysfunction and sickness, and other measures such as the Harris Analysis of Hip Function in hip replacement patients and T4 lab tests for hyperthyroidism. Several authors have found that the SIP has good convergent and discriminant validity (Bergner et al., 1976b; Carter, Bobbitt, & Bergner, 1976; Gilson, Erickson, & Chavez, 1979).

The SIP was tested for reliability in terms of internal consistency and reproducibility on 278 randomly selected subjects from rehabilitation and audiology/speech pathology units in a large, general hospital. Fifty-three percent of the total sample were males and 47% were females. The ages of the participants ranged from 18 to 75 years. Internal consistency was $r = .90$ and 24-hour test-retest reliability was determined to be $r = .80$ for the entire instrument (Bergner et al., 1976b).

The score for each individual category was calculated by adding the scale values for each item within the category and dividing by the maximum possible dysfunction score for that category. This figure was then multiplied by 100 to obtain the category score. Two dimension scores were calculated. The physical dimension score was

obtained by adding the scale values for each item checked within categories BCM, M, and A, then dividing by the maximum possible dysfunction score for those categories, and multiplying by 100. The psychosocial dimension score was obtained using the same technique on the categories of EB, SI, AB, and C. The overall score for the SIP was calculated by adding the scale values for each item checked across all categories and dividing by the maximum possible dysfunction score for the SIP. This figure was then multiplied by 100 to obtain the overall SIP score (Bergner, 1984).

The total possible score for the physical dimension was calculated as 356.4 and the total possible score for the psychosocial dimension was calculated as 365.7. The total possible score value for the entire SIP was calculated as 1003.0 (Bergner, 1984).

Norbeck Social Support Questionnaire (NSSQ)

The NSSQ consists of 9 questions and measures functional support; size, stability, and availability of social support; and the total number of lost relationships over the past year. The instrument requires subjects to evaluate social support on a 5-point Likert-type scale. Responses on the scale range from "not at all" to "a great deal".

Validity and reliability were established initially at the time of the scale development (Norbeck, Lindsey, & Carrieri, 1981) and through subsequent testing (Norbeck, Lindsey, & Carrieri, 1983; Norbeck, 1986). Reliability of the instrument was established by internal consistency and test-retest. Internal consistency on three subscale tests was demonstrated to be $r = .89$, $r = .96$ and $r = .97$. Construct validity was established by comparing subscales of the NSSQ with composite variables of the

Fundamental Interpersonal Relations Orientation. The mean stability was $r = .76$ on test-retest (Norbeck, Lindsey, & Carrieri, 1981).

The NSSQ measures the variables of total functional, total network, and total loss. Each of these variables has three subscales. Questions 1 through 6 measure three functional components of social support: affect, affirmation, and aid. Questions 7 and 8 represent the length of time the support person has been known, and how frequently contact is made with that person. Total loss measures the number of categories of persons lost and how much support has been lost. This information is represented in Question 9 (Norbeck, Lindsey, & Carrieri, 1981).

Subjects begin by listing all available sources of support according to nine categories. For the first eight questions the participant is asked to rate each support person on a 5-point Likert-type scale. Question 9 is answered either yes or no. If the answer is yes, 9a and 9b are completed. These questions indicate the number and quality of losses of support (Norbeck, Lindsey, & Carrieri, 1981).

Procedure for Data Collection

The investigator or one of three graduate nursing students who assisted with data collection were present in the outpatient clinic each weekday from July 7 through July 25, 1988 to determine which patients met the criteria specified for inclusion and willingness to participate in the study. Each subject was given instructions about how to complete the KDDS, NSSQ, and SIP questionnaires. Participants were informed that completion of the three instruments would take approximately 1 hour. One of the four data collectors was available while subjects completed the instruments to answer

any questions. Subjects were asked to place completed questionnaires into a sealed box available in the clinic. Questionnaires were removed from the collection box each day by the investigator.

Treatment of Data

Demographic data were collected on each participant in the study. Variables examined included age, gender, educational level, marital status, ethnic group, income, sexual orientation, cigarette and alcohol use, sexual practices, current living situation, use of illegal drugs, length of time since initial diagnosis, sources of initial information about HIV, and perceived health status. Comparisons between the frequencies and percentage distributions for both the sample and population were calculated on the variables of age. Ranges, means, medians, modes and standard deviations were also calculated for both groups related to age and gender. Data about the population were obtained by reviewing the charts of all 219 patients being seen in the outpatient clinic. The investigator obtained permission to use these data from the charge nurse in the clinic. Confidentiality of data were maintained because no names were included on the information provided to the investigator.

Frequencies and percentage distributions were calculated on the variables of ethnicity, personal income, educational level, marital status, sexual orientation, current living arrangement, cigarette smoking status, number of packs smoked per day, number of years smoked, current non-smokers who formerly smoked, and the year the non-smokers quit smoking. Other variables on which frequencies and percentages

were calculated included: perception of health status, usage of alcohol, and usage of drugs not prescribed by a physician.

Inferential analyses were performed to answer each of the research questions.

The five questions and the statistical analysis selected for each are presented as follows:

1. What is the relationship between social support and quality of life for persons infected with HIV? This question was analyzed using a Pearson correlation.
2. What are the differences among homosexual males, and heterosexual males and females who are HIV positive with relation to social support and quality of life? A one-way analysis of variance (ANOVA) was selected as the statistical test to answer this question.
3. What is the relationship between perceived health status and quality of life among homosexual males, and heterosexual males and females who are HIV positive? A Spearman rho correlation was chosen as the inferential analysis to determine the relationship between these variables.
4. What is the relationship between ethnicity and the amount of social support of persons with HIV? This question was answered using a Kruskal Wallis Analysis of Variance.
5. What is the relationship between physical and psychosocial dimensions on the Sickness Impact Profile among homosexual males, and heterosexual males and females infected with HIV? One-way analysis of variance was chosen to analyze this relationship.

Summary

An exploratory, survey design was used for the purpose of evaluating the relationship between social support and quality of life among persons infected with HIV. The study was conducted in a teaching hospital in south Texas. Criteria for inclusion in the study and protection of human subjects was included. The instruments used for data collection were discussed and included. Descriptions and evidence of validity and reliability were provided for each. A discussion of the procedure for data collection and treatment of data were also included.

CHAPTER IV

ANALYSIS OF DATA

This study was conducted to describe the relationship between social support and quality of life among persons infected with HIV. Research questions were directed toward the measurement of social support and quality of life among three groups of subjects infected with HIV: heterosexual females, heterosexual males, and homosexual males.

Data were collected from 89 persons who were diagnosed as HIV positive and receiving treatment at an outpatient clinic in a southern Texas city. All 90 persons receiving care were approached and invited to participate in the study. Data were subjected to descriptive analyses. Frequency and percentage distributions were determined for all variables. Measures of central tendency and variability were determined for all variables. Frequencies and percentages were also calculated on the variables of ethnicity, income, education, marital status, sexual orientation, tobacco and alcohol usage, perception of health status, and source of initial information about AIDS. Parametric and nonparametric analyses were performed on selected variables to further illuminate the factors related to social support and quality of life.

Description of the Sample

The 89 subjects who completed the interview met the sample criteria for selection: all were patients being treated at an outpatient clinic, diagnosed as being HIV positive by a physician, able to read, write, and speak English, and alert and oriented to person,

time and place. A total of 219 persons received treatment at the clinic, but only 90 subjects diagnosed as HIV positive were invited to participate in the study. Persons with diagnoses of ARC or AIDS were excluded from the study because they were too ill according to physicians to complete the questionnaire. The 89 (40.6%) subjects who volunteered varied in age from 20 to 61 years with a mean age of 35.39 years. The range was 41 years with a standard deviation of 7.14 years. Comparison data were available for the total population. All patients varied in age from a low of 20 years to a high of 64 years, with a range of 44 years, and a mean of 36.41 years. The majority of the subjects in the population were between the ages of 30 and 44 (57.5%) while the majority of subjects in the sample were between the ages of 25 and 44 (60.1%). The population standard deviation was 7.21 years. There were 18 heterosexual females (19.1%), 20 heterosexual males (23.6%) and 51 homosexual males (57.3%) in the sample. According to the clinic records, the population reflected 24 (10.9%) heterosexual females, 55 (25.1%) heterosexual males and 140 (63.9%) homosexual males. Age and gender of the sample and population are contrasted in Table 1. The population was predominantly male, 195 (89.1%), and the proportion of the sample which was male was similar, 71 (80.9%).

Ethnicity of the participants is described in Table 2. There were 56 (62.9%) Caucasians, 14 (15.7%) Blacks, 13 (14.6%) Hispanics, and 6 (6.7%) participants who were representative of other ethnic groups. Of those, 5 (5.6%) were Asian and 1 (1.1%) was American Indian. Personal income of the participants varied from less than \$15,000 annually to a high of \$45,000. Almost half of the subjects (44.9%) reported annual incomes of less than \$15,000. Twenty-eight (31.5%) reported incomes of

Table 1
Comparison of the Population and Sample
by Age and Gender

Characteristic	Sample Frequency	Population Frequency	Sample Percent	Population Percent
<u>Age</u>				
20-24	4	12	4.5	5.5
25-29	12	39	13.5	17.8
30-34	27	42	30.3	19.2
35-39	24	56	27.0	25.6
40-44	15	28	16.9	12.8
45-49	2	26	2.2	11.8
50-54	4	10	4.5	4.6
55-59	0	5	0	2.3
60+	<u>1</u>	<u>1</u>	<u>1.1</u>	<u>0.4</u>
TOTAL	89	219	100.0	100.0
<u>Gender</u>				
Female	17	24	19.1	10.9
Male	<u>72</u>	<u>195</u>	<u>80.9</u>	<u>89.1</u>
TOTAL	89	219	100.0	100.0

\$15,001 - \$25,000 annually, 16 (18%) reported \$25,001 - \$35,000, and 5 (5.6%) noted that their annual incomes varied from \$35,001 - \$45,000. Educational levels of participants were also obtained (Table 2). The range of years of education was 14 with a minimum of 2 years and a maximum of 16 years. Sixty-two (69.6%) of the subjects

Table 2
Frequency and Percentage Distribution of Ethnicity,
Personal Income and Education

Variable	Frequency	Percentage
<u>Ethnic Group</u>		
Caucasian	56	62.9
Black	14	15.7
Hispanic	13	14.6
Other	6	6.7
TOTAL	89	100.0
<u>Education</u>		
Grades 1-8	16	18.0
Some High School	11	12.4
Graduated from High School	36	40.4
College	<u>26</u>	<u>29.2</u>
TOTAL	89	100.0

were high school graduates. Sixty (67.4%) of the participants were single. Other responses regarding marital status were: 8 (8%) married, 6 (6.7%) separated and 15 (16.9%) divorced persons.

There were 51 (57.3%) homosexuals and 38 (42.7%) heterosexuals who participated in the study. This distribution was expected since the majority of PWA cases reported nationally involve homosexual and bisexual males (CDC, 1992). None

of the female respondents reported being lesbian. Of the subjects surveyed, 32 (36%) indicated that they live with a lover of the same sex. Twenty-four (27%) stated that they live with a lover of the opposite sex, and 33 (37%) reported living alone or with someone who was not a lover. Forty-nine (55.1%) of the subjects were cigarette smokers. Over 69 (77%) of these subjects smoked a pack of cigarettes per day. The remaining 20 (22.5%) smoked 1.25 or more packs daily. Of the 40 non-smokers, only 6 (15%) had smoked previously.

A slight majority, 45 (50.6%) of those surveyed reported drinking alcohol. The amount of alcohol consumed per week varied from one glass of wine to 4 six-packs of beer. Only 6 (6.7%) of the respondents admitted to use of drugs not prescribed by a physician. None of the respondents indicated what kinds of non-prescribed drugs they were taking, nor did they indicate the frequency of drug use.

Regarding perception of health status, Table 3 illustrates that 44 (49.4%) of the participants categorized themselves as "not too healthy." An additional 14 (15.7%) labeled themselves as "very healthy," "better than most people," or "above average."

This Week in Texas, a gay publication, and television were listed numbers one and two, respectively, as the main sources of information about HIV (Table 4). Together, they accounted for 70 (78.6%) participants' initial information received about HIV. All of those respondents who listed This Week in Texas as a primary source of information about the virus were from the homosexual male group. Those who responded that television was where they first learned about HIV were represented by the heterosexual groups.

Table 3
Frequency and Percentage Distribution of
Perception of Health Status

Variable	Frequency	Percentage
Very healthy	2	2.2
Better than most people	4	4.5
Above average	8	9.0
Not too healthy	44	49.4
Very sick	<u>31</u>	<u>34.8</u>
TOTAL	89	100.0

Table 4
Frequency and Percentage Distribution of Sources of
Initial Information about HIV

Variable	Frequency	Percentage
The Advocate	6	6.7
This Week in Texas	38	42.7
Montrose Voice	3	3.4
Television	32	35.9
Radio	2	2.2
Books	3	3.4
Medical/Scientific Journals	4	4.5
Health Care Worker	<u>1</u>	<u>1.2</u>
TOTAL	89	100.0

The length of time since subjects were diagnosed as HIV positive by a physician varied from a low of 2 months to a high of 20 months. The mean length of time was 9.55 months, and the standard deviation was 3.69 months.

Findings

Descriptive analyses of selected variables were done for comparisons between the homosexual male, heterosexual male, and heterosexual female groups. Variables included in the analyses were length of time since first being diagnosed HIV positive, social support as measured by the Norbeck Social Support Questionnaire, and quality of life as measured by the Sickness Impact Profile. Means, standard deviations, and maximum and minimum scores were calculated for subsections of the Norbeck Social Support Questionnaire. Frequencies and percentages were calculated for each of the 12 subsections of the Sickness Impact Profile. Detailed discussions of each of the questionnaires is included in the following sections. Open-ended questions recorded on the interview schedule required content analyses and coding. Following the descriptive analyses, inferential statistics were used to address each of the five research questions. The level of significance for all inferential statistics was $p \leq .05$. The variables of social support and quality of life were described and compared among homosexual male, heterosexual male, and heterosexual female groups. The variable of length of time since first diagnosed as HIV positive was examined in relation to the variables of quality of life and social support.

Social Support

The variable of social support was measured using the Norbeck Social Support Questionnaire (NSSQ). The NSSQ consists of 9 questions and measures: functional support, size, stability, availability of social support and the total number of lost relationships over the past year. The instrument requires subjects to evaluate social support on a 5-point Likert-type scale. Responses on the scale range from "not at all" to "a great deal" (Norbeck et al., 1981). The Total Functional Variable is a composite score of the Aid, Affect, and Affirmation subscales of the NSSQ. Levels of social support for each subject were calculated using the Total Functional Variable from the NSSQ. Affect was defined as an expression of positive emotion. The definition of aid was the amount of material assistance received from others. Affirmation was defined as the amount of support received for personal behavior (Norbeck et al., 1983). For research question number 1, social support was further analyzed to determine the quality of support independent of the number of supporters by dividing the Total Functional Variable by the number of persons in the social network. Subjects had scores on the Total Functional Variable varying from a low of 120 to a high of 377 with a mean of 248.5 and a standard deviation of ± 9 .

Scores obtained on the NSSQ were labeled as either functional or network. Questions 1-6 measured the properties of Aid, Affect, and Affirmation related to functional social support. Network properties were measured by asking participants to list all persons in their lives that provided social support. The maximum number of persons specified was 21. The mean number of persons identified as being supportive was 10.5 with a standard deviation of 4.67. Of the persons listed in the social support

network, 39 (43.8%) were identified as either spouse or lover. The majority of the subjects, 49, (55%) listed at least one friend in their social network. Other relatives such as parents or siblings were also listed. The majority, 51, (57%) of the respondents specified at least three family members in their list of supporters. Table 5 summarizes frequencies and percentage distributions related to Total Functional Variable.

Frequencies and percentage distributions from the NSSQ questions measuring Aid, Affect, and Affirmation were calculated. Questions 1 and 2 measured affect and possible scores ranged from 1 to 139 for each question. Questions 3 and 4 measured Affirmation and possible scores varied from 1 to 119. Aid was measured by information obtained from questions 5 and 6. Possible scores varied from 1 to 119 for these two questions. Table 6 summarizes the means, standard deviations and obtained and possible maximum and minimum scores for the functional component of social support.

Quality of Life

The variable of quality of life was measured using the Sickness Impact Profile (SIP). The premise of the SIP is that it measures dysfunction rather than disease (Bergner, 1984). A person can have a disease without visible sickness and can be sick without any type of disease being present. The questionnaire is used to assess behavior or performance and is therefore considered an objective measure (Gilson, Gilson, & Bergner, 1975).

Table 5

Frequency and Percentage Distribution of Numbers of Persons, Relatives, and Friends
in Social Support Network Reported by Persons Diagnosed with HIV

Variable	Frequency	Percentage
<u>Number of Persons</u>		
01-04	3	3.4
05-08	14	15.7
09-12	44	49.4
13-16	21	23.6
17-20	6	6.7
21	<u>1</u>	<u>1.1</u>
TOTAL	89	100.0
<u>Number of Relatives</u>		
01-02	24	27.0
03-04	51	57.3
05-06	9	10.1
07-08	4	4.5
09-10	<u>1</u>	<u>1.1</u>
TOTAL	89	100.0
<u>Number of Friends</u>		
0	20	20.5
1	49	55.0
2	10	11.2
3	8	8.9
4	1	1.1
5	<u>1</u>	<u>1.1</u>
TOTAL	89	100.0

Table 6

Means, Standard Deviations, Obtained and Possible Maximum and Minimum Scores for Functional Components of Social Support

Components	Means	<u>SD</u>	Maximum Scores Obtained (Possible)	Minimum Scores Obtained (Possible)
Affect 1	38.5	9.46	65 (139)	12 (1)
Affect 2	41.5	10.50	78 (139)	5 (1)
Affirmation 1	48.5	11.38	88 (119)	9 (1)
Affirmation 2	38.5	9.36	71 (119)	6 (1)
Aid 1	41.0	10.42	80 (119)	2 (1)
Aid 2	35.0	9.50	68 (119)	2 (1)

The SIP questionnaire measures sickness-related dysfunction according to 12 areas of activity. The areas include: communication; social interaction; alertness behavior; emotional behavior; mobility, recreation and pastimes; work; home management; eating; ambulation; body care and movement; and sleep and rest. Three of the categories (mobility, ambulation, and body care and movement) can be grouped to obtain a physical dimension score. Four other categories can be grouped to obtain a psychosocial dimension score. These categories are: emotional behavior, alertness behavior, communication, and social interaction (Bergner, 1984).

The SIP consists of 136 items from which an individual chooses descriptive phrases characterizing current state of being. The instrument has been determined to be indicative of the characteristics of quality of life (Ragsdale & Morrow, 1990). The total SIP has a 24 hour test-retest ($r = .90$) and internal consistency reliability of $\alpha = .80$

for the total scale (Bergner, 1984). Pollard, Bobbitt, Bergner, Martin, and Gilson (1976) reported 24 hour test-retest reliability between .62 and .89 with a median score of .74 for the subscales of physical and psychosocial dimensions. Rasdale and Morrow noted that the subscales are calculated by summing responses to individual items. The scores on individual and subscales are expressed as percentages. The higher the percentage score, the higher the impact of illness.

Table 7 contains possible minimum and maximum scores as well as sample minimum and maximum scores for each of the 12 subscales, the dimension scales, and total SIP. Appendix G displays the total scores, frequencies, and percentage distributions for each of the 12 areas of activity described on the SIP.

Research Question 1

What is the relationship between social support and quality of life for persons infected with HIV? Prior to analyses of the relationship between social support and quality of life, analysis of covariance for quality of life by length of time since diagnosis and group was calculated. Length of time since diagnosis of HIV positivity was not found to affect quality of life measurements, nor were there significant differences among the three groups related to length of time since diagnosis. These data are summarized in Table 8.

Data contained in Table 8 were calculated based on observed means for quality of life as measured by the SIP of the three groups. The observed mean for homosexual males was 305.9. Observed means for heterosexual males and heterosexual females were 304.6 and 318.5, respectively.

Table 7

Possible Scores, Sample Scores, Means, Standard Deviations and Reliabilities of
Subscales and Dimensions on Sickness Impact Profile

SIP Subscales	Possible Scores		Sample Scores		Means	Standard Deviations	Alpha Reliabilities
	Minimum	Maximum	Minimum	Maximum			
Mobility	0	71.9	23.3	49.5	36.4	20.7	.0137
Ambulation	0	84.2	24.3	84.2	41.4	14.6	.0000
Body Care and Movement	0	200.3	25.4	64.8	37.7	15.9	.0000
Social Interaction	0	14.5	26.0	61.2	37.1	25.4	.0005
Communication	0	72.5	10.2	59.4	41.1	24.0	.0372
Alertness Behavior	0	77.7	29.5	58.4	53.2	31.4	.0745
Emotional Behavior	0	70.5	35.7	48.4	39.7	22.5	.5922
Sleep and Rest	0	49.9	29.0	49.9	40.1	24.1	.4718
Eating	0	70.5	33.6	82.5	42.4	16.7	.1857
Work	0	51.5	25.8	51.5	38.6	30.6	.4310
Home Management	0	66.8	35.6	61.2	49.7	20.7	.1563
Recreation and Pastimes	0	42.2	32.6	42.2	37.3	24.9	.5000
<u>SIP Dimensions</u>							
Physical	0	356.4	73	198.5	101.2	24.6	.0002
Psychosocial	0	365.7	101.4	227.4	174.3	31.2	.0133
TOTAL	0	1003.0	331	634	475.4	39.4	.0412

Table 8
Analysis of Covariance for Quality of Life by Time
Since Diagnosis and Group

Source of Variation	Sum of Square	Degree of Freedom	Mean Square	F	Prob.
Within	454814.23	83	5479.69		
Time Dx	4257.09	1	4257.09	.78	.38
Group	3911.68	2	1955.84	.36	.70
Time Dx by Group	7605.27	2	3802.64	.69	.50

$p \leq .05$

A Pearson correlation was chosen as the statistical test for the variables of social support and quality of life. The value calculated using the Pearson correlation coefficient was $r = .22$, $p \leq .014$. It was concluded that a significant correlation existed between the variables of social support and quality of life. As the amount of social support increased, the perceived quality of life increased.

Further analysis of the r value was done by squaring the correlation coefficient. The purpose of squaring the correlation was to indicate the percentage of variation in one variable as explained by variation in the other (Issac & Michael, 1979). Figure 5 includes a Venn diagram depicting the squared correlation (r^2) and $1-r^2$. Explained variance between the variables of social support and quality of life is indicated by r^2 . Unexplained variance between the variables is depicted by $1-r^2$. Therefore, social support accounted for 4.8% of the variation in quality of life.

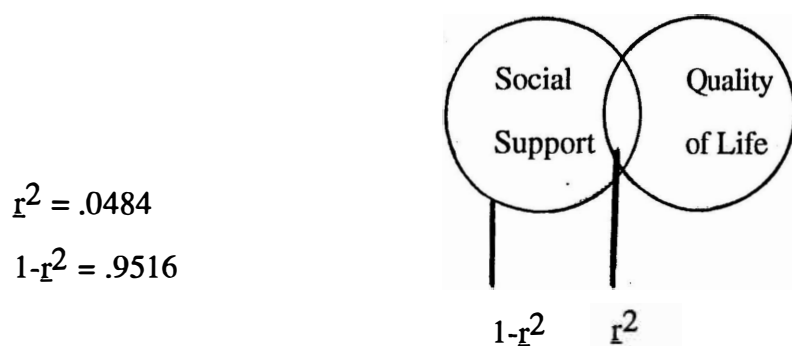


Figure 5

Variance Between Social Support and Quality of Life

Research Question 2

What are the differences among homosexual males, and heterosexual males and females who are HIV positive with relation to social support and quality of life? This question was analyzed using one-way analysis of variance (ANOVA).

An ANOVA was used to determine the variance among the three groups on the variable of social support. Significant differences were found among the three groups on the variable of social support. The F was calculated as 7.0776 and the F probability as .0014. These data are included in Table 9. Mean scores on the variable of social support were calculated for each of the three groups. Subjects in the homosexual male group had a mean of 5010.4118 with a standard deviation of 1358.9486. Mean scores for the heterosexual male and heterosexual female subjects were 355.6055 with a standard deviation of 79.5158 and 7250.000 with a standard deviation of 4592.4833, respectively. A Newman-Keuls post-hoc test revealed that the mean scores of heterosexual females were significantly higher than either of the male groups indicating that females perceived more social support than male participants (Table 10).

Table 9

Analysis of Variance for Social Support by Group					
Source	Degree of Freedom	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	2	74608452.07	37304226.04	7.0776	.0014*
Within Groups	86	453285056.2	5270756.467		
TOTAL	88	527893508.2			

Table 10

Newman-Keuls Post-hoc Test for Social Support By Group

Group	Heterosexual Males $\bar{X}_2 = 4881.9000$	Homosexual Males $\bar{X}_1 = 5010.4118$	Heterosexual Females $\bar{X}_3 = 7250.000$
Heterosexual Males $\bar{X}_2 = 4881.9000$			
Homosexual Males $\bar{X}_1 = 5010.4118$			
Heterosexual Females $\bar{X}_3 = 7250.000$	*2368.100	*2239.5882	

*P ≤ .05

An ANOVA was used to determine the difference among the three groups on the variable of quality of life. No significant differences were found among the groups as measured by the SIP. The F ratio was calculated to be .2198 and the F probability as $p = .8031$. These results are included in Table 11.

Mean scores on the variable of quality of life were calculated for each of the three groups. Subjects in the homosexual male group had a mean of 305.9216 with a standard deviation of 72.2708. The mean and standard deviation for the heterosexual male subjects were 304.6500 and 73.5829 respectively. Subjects in the female group had mean and standard deviation scores of 318.5000 and 80.6498 respectively.

Table 11
Analysis of Variance for Quality of Life by Group

Degree of Source	Sum of Freedom	Mean Squares	F Squares	Ratio	Prob.
Between Groups	2	2426.3873	1213.1937	.2198	.8031
Within Groups	86	474602.7363	5518.6365		
TOTAL	88	477029.1236			

$p \leq .05$

Research Question 3

What is the relationship between perceived health status and quality of life among homosexual males, and heterosexual males and females who are HIV positive?

Information regarding perceived health status was requested from each participant. Each subject was asked "How healthy do you think you are?" Five possible responses included: "very healthy", "better than most people", "above average", "not too healthy", or "very sick". The relationship between perceived health status and quality of life was evaluated using a Spearman rho correlation. Statistical analysis revealed a significant positive relationship between quality of life and perceived health status ($r_s = .3444$, $p \leq .016$). Those subjects who perceived themselves as "not too healthy" or "very sick" had higher scores on the SIP, whereas those persons who viewed themselves as "better than most people" or "very healthy" scored lower on the SIP instrument.

Further analysis of the r_s value was done by squaring the correlation coefficient. Figure 6 includes a Venn diagram depicting the squared correlation (r_s^2) and $1-r_s^2$. Explained variance between the variables of perceived health status and quality of life is indicated by r_s^2 . Unexplained variance between the variables is depicted by $1-r_s^2$. Perceived health status accounted for 11.9% of the variation in quality of life.

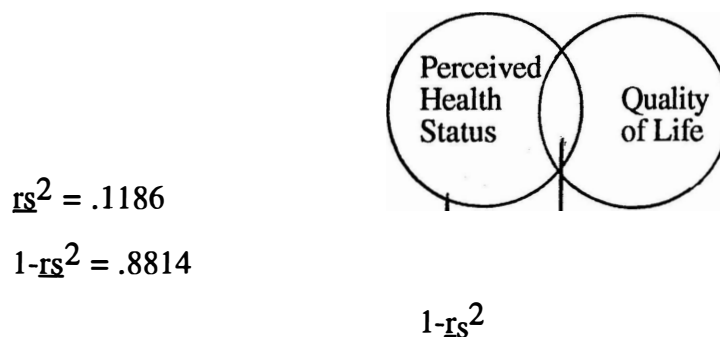


Figure 6

Variance Between Perceived Health Status and Quality of Life

Research Question 4

What is the relationship between ethnicity and the amount of social support of persons with HIV? Table 12 includes categories of ethnicity used and the amount of social support per category.

Table 12
Categories of Ethnicity and Amount of Social Support

Variable	Amount of Social Support Sum of Ranks
Caucasian	117
Black	54
Hispanic	49
Other	24

Using a Kruskal-Wallis nonparametric analysis of variance, significant differences among ethnic groups on the variable of social support were demonstrated ($\bar{X}^2 = 4.306, p \leq .015$). Caucasians ranked highest on amount of social support, followed by blacks and Hispanics. Asians and American Indians ranked lowest in terms of amounts of social support.

Research Question 5

What is the relationship between physical and psychological dimensions on the Sickness Impact Profile (SIP) among homosexual males, and heterosexual males and

females infected with HIV? One-way ANOVA demonstrated significant differences among the three groups when compared on the total physical dimension of the SIP. These data are presented in Table 13. A Newman-Keuls post-hoc test showed that heterosexual females differed significantly from subjects in both male groups. While heterosexual females reported significantly more social support than either of the male groups, their scores on the physical dimension of the SIP were higher indicating a higher impact of perceived illness. Table 14 contains the mean differences for physical dimension by group.

Table 13
Analysis of Variance for Physical Dimension by Group

Degree of Source	Sum of Freedom	Mean Squares	F Squares	F Ratio	Prob.
Between Groups	2	20543893.79	10271946.90	9.3254	.0002*
Within Groups	86	94729335.08	1101503.896		
TOTAL	88	115273228.9			

* $p \leq .05$

A one-way ANOVA also showed significant differences among heterosexual female, heterosexual male and homosexual male groups when compared on the total psychosocial dimension of the Sickness Impact Profile. The F ratio was calculated as 4.5435 and the F probability as .0133. These data are presented in Table 15. A Newman-Keuls post-hoc test showed that heterosexual females differed significantly from subjects in either male group. Females scored higher on the psychosocial

Table 14

Newman-Keuls Post-hoc Test for Physical Dimension by Group

Group	Homosexual Males $\bar{X}_1 = 1037.6667$	Heterosexual Males $\bar{X}_2 = 1068.2500$	Heterosexual Females $\bar{X}_3 = 2242.0000$
Homosexual Males $\bar{X}_1 - 1037.6667$			
Heterosexual Males $\bar{X}_2 - 1068.2500$			
Heterosexual Females $\bar{X}_3 = 2242.0000$	*1204.3333	*1173.7500	
* $p \leq .05$			

Table 15

Analysis of Variance for Psychosocial Dimension by Group

Source	Degree of Freedom	Sum of Squares	Mean Squares	F Ratio	F Prob.
Between Groups	2	8340366.835	4170183.418	4.5435	.0133*
Within Groups	86	78934040.78	917837.6835		
TOTAL	88	87274407.62			

* $p \leq .05$

dimension of the SIP indicating a higher degree of perceived dysfunction than either of the male groups. These data are summarized in Table 15.

Table 16
Newman-Keuls Post-hoc Test for Psychosocial Dimension by Group

Group	Homosexual Males $\bar{X}_2 = 1555.2500$	Heterosexual Males $\bar{X}_1 = 1559.7059$	Heterosexual Females $\bar{X}_3 = 2320.5556$
Homosexual Males $\bar{X}_2 - 1555.2500$			
Heterosexual Males $\bar{X}_1 - 1559.7059$			
Heterosexual Females $\bar{X}_3 = 2320.5556$	*765.3056	*760.8497	

* $p \leq .05$

Summary

The sample consisted of 89 persons infected with HIV who were receiving outpatient treatment at a clinic in south Texas. The majority of the participants were male, between the ages of 30 and 44 years, single, Caucasian, had annual incomes of less than \$15,000, and were high school graduates. Fifty-seven percent of the subjects were homosexual and 42% were heterosexual. All of the homosexuals who participated in the study were male. A majority of the participants also reported

smoking cigarettes and using alcohol, but only 6.7% reported using drugs not prescribed by a physician. Almost a majority categorized themselves as "not too healthy". The main sources of information about HIV were This Week in Texas and television.

The Pearson correlation coefficient yielded a positive relationship between social support and quality of life scores. Using a one-way ANOVA, significant differences were found among heterosexual females, heterosexual males, and homosexual males with relation to social support. A post-hoc test demonstrated that heterosexual females scored higher than the male groups on the variable of social support. The mean scores for the female subjects were higher than the mean scores for the male subjects on the social support questionnaire.

A significant relationship between perceived health status and quality of life was shown using Spearman rho analysis. The more ill the subjects perceived themselves, the higher their SIP scores. Inversely, those subjects who perceived themselves as healthy, scored lower on the SIP. Using a Kruskal-Wallis analysis of variance, a significant relationship was found between social support scores and ethnicity of participants. Using the Spearman rho correlation coefficient, a significant correlation was found between the physical and psychosocial dimensions. Further analyses using ANOVA demonstrated significant differences among the three groups related to the physical and psychosocial dimensions. Females had higher mean scores than subjects in male groups on these dimensions indicating a greater degree of dysfunction.

CHAPTER V

SUMMARY OF THE STUDY

The central premise of this study was: A lack of reported research regarding social support and quality of life for persons diagnosed with the Human Immunodeficiency Virus (HIV) had been documented in published literature when data were collected in 1988. Therefore, the problem of this study was to answer the question: What is the relationship between social support and quality of life among persons infected with HIV?

Summary

An exploratory, survey design was used to study the relationship between social support and quality of life in persons infected with HIV. Interviews were conducted in an outpatient clinic, and the Sickness Impact Profile and Norbeck Social Support Questionnaire were completed by 89 persons who agreed to participate from a population of 90 HIV-infected patients. The sample consisted of 51 homosexual males, 20 heterosexual males and 18 heterosexual females. There was no intention to exclude lesbians from the study, but all of the female participants indicated that they were heterosexual.

Protection of human subjects was guaranteed by adhering to the requirements of the Texas Woman's University Human Subject's Review Committee. Each participant was provided with an oral and written description of the purpose, benefits and potential

adverse effects of volunteering for the study. Data were collected between July 7 and July 25, 1988 by the investigator and three graduate nursing students. Each patient was approached individually to determine willingness to participate and whether or not the person met specified criteria for inclusion in the study.

In order to explore the problem of study, five research questions were posed:

1. What is the relationship between social support and quality of life for persons infected with HIV?
2. What are the differences among homosexual males, and heterosexual males and females who are HIV positive with relation to social support and quality of life?
3. What is the relationship between perceived health status and quality of life among homosexual males, and heterosexual males and females who are HIV positive?
4. What is the relationship between ethnicity and the amount of social support of persons who are with HIV?
5. What is the relationship between physical and psychosocial dimensions on the Sickness Impact Profile among homosexual males, and heterosexual males and females infected with HIV?

Discussion of Findings

The major findings derived from this study were a positive relationship between the amount of social support perceived by heterosexual and homosexual males infected with HIV and quality of life. Collectively, the heterosexual females reported the greatest amounts of social support, but their scores on the psychosocial and physical dimensions of the SIP were significantly higher than scores of the male participants

indicating decreased quality of life. In this study, overall mean scores for the functional components of social support (affect, aid, and affirmation) were higher in heterosexual females than in comparative studies (Padilla & Grant, 1985). These participants perceived themselves as receiving more expression of positive emotion (Affect), more material assistance (Aid), and more support for personal behavior (Affirmation). Heterosexual females listed more people in their network list when compared to previous study populations (Padilla & Grant).

Research Question 1

An analysis of covariance for quality of life by length of time since diagnosis and group was initially done. There were no significant differences among the three groups related to length of time since diagnosis with HIV. Length of time since diagnosis was also not found to influence quality of life.

Using a Pearson test, a significant positive correlation between social support and quality of life of persons infected with HIV was found. These findings supported the initial hypothesis that the presence of social support had a positive effect on quality of life. Few studies have been reported that determined the effect of social support on quality of life in homosexual males, and heterosexual males and females with HIV.

Lasher and Ragsdale (1989) described how nurses can help significant others improve the quality of life of their loved ones through social support. The authors stated that "since AIDS creates a crisis, nurses should involve significant others in the care of persons with AIDS because they can make a difference in the remaining life span of that person" (p. 252).

A positive relationship between purpose-in-life and social support among homosexual males diagnosed with AIDS-related complex or AIDS has been documented (Bechtel, 1986). Other studies have shown that quality of life is an important outcome variable in persons with cancer or other terminal diseases (Burckhardt, 1985; Ferrans & Powers, 1985; Padilla & Grant, 1985). In caring for cancer patients, the nurse's role is frequently directed at assisting the patient to manage side effects of treatment and in adjusting to body image changes. The quality of the patient's survival is dependent on the patient's inherent personal strength and the nurse's ability to help with the many changes and adjustments (Padilla & Grant, 1985).

Research Question 2

Significant differences were found among the three groups with relation to social support. The females, who were all heterosexual, demonstrated more social support than the male subjects. There were no studies concerning social support among females with HIV to use for comparison with these findings. No significant differences were found among the three groups related to quality of life. Homosexual men were found to have the least overall amount of social support. This finding was consistent with the theoretical proposition that homosexual males experience decreased social support (Burckhardt, 1985). Historically, PWAs in the United States have been primarily homosexual males. Little interest in supporting research and treatment efforts has been demonstrated by the general public until recently due to the stigma associated with belonging to this group (Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). The onset or renewal of negative feelings about homosexuality in general has been

reported by authors who interviewed many gay men diagnosed with the disease (Nichols, 1985).

Even though the traditional responses of family members and friends of homosexual males diagnosed with HIV have been to avoid them, increasing numbers of community support groups have emerged, especially in large cities (Strunin & Hingson, 1987). Perhaps these groups are more widely known among the gay population of PWAs and account for the fact that the majority of participants are homosexual or bisexual males.

Research Question 3

A positive relationship between health status and quality of life has been cited in many studies (Ferrans & Powers, 1985; Fowler, 1981; Lasher & Ragsdale, 1989; Padilla & Grant, 1985; Ragsdale & Morrow, 1990; Selye, 1976). Therefore, it was not surprising that subjects in this sample reported a higher level of quality of life when their perceived health status was better.

In one study, 135 patients with colostomies completed questionnaires that measured their overall quality of life (Padilla & Grant, 1985). Subscores were obtained related to the variables of personal control, stage of cancer, age, and length of time with colostomy. Findings indicated that as the length of time with cancer and the colostomy increased, patients reported greater psychological well-being and overall quality of life.

Another study with post-myocardial infarction patients defined quality of life in terms of psychological status, return to work, and social functioning (Follick et al., 1988). Patients ($n = 238$) were assigned randomly either to a system, including a

transtelephonic electrocardiographic monitor and lidocaine injector, or to standard medical care (control). Patients in the experimental group showed a significant decrease in concerns about physical functioning and symptoms, and over time, reported less depressive affect. At 9-month follow-up, control patients were more than twice as likely to be in the range of clinical depression. These results paralleled with the findings of this study which indicated that as perception about health status was greater, so was the quality of life measurement.

Research Question 4

The propensity toward greater amounts of social support was significantly related to the ethnicity of the subjects in this study. This finding was consistent with the findings of others who reported that social support is generally less in Hispanic and Black populations (Bruhn et al., 1986). Bruhn et al. noted that the family is still a key source of social support. The family adapted to the technological age by taking advantage of the freedom of choice that technology offers. The distinctions between male and female roles have blurred. People visit their relatives on the basis of which ones they get along with best, not on the basis of ties of genealogy. These changes have not weakened the family. It is still "the place where, when you go there, they take you in" (Bruhn et al). Bruhn et al. stated that there was less social support among Hispanic and Black families. The authors offered no concrete explanation for this theory. In the current study, differences were found among various ethnic groups related to the amounts of social support. Additional studies with more ethnic representation are needed for comparison of findings.

Research Question 5

Scores on the psychosocial dimension subscale of the SIP were higher than the physical dimension scores. Ragsdale and Morrow (1990) reported similar findings noting that psychosocial impact was greater than physical impact in subjects with HIV seropositivity, ARC, or AIDS. Other researchers reported that psychological well-being positively affected quality of life among colostomy and cancer patients (Padilla et al., 1983; Padilla & Grant, 1985). Ragsdale and Morrow noted that nurses need to be especially cognizant of the emotional needs of persons infected with HIV. The researchers stated that psychosocial well-being greatly affects the quality of life of HIV-infected persons. Particular attention should be directed at alertness and emotional behaviors, social interactions, and communication of HIV-infected individuals (Ragsdale & Morrow, 1990).

Bergner et al. (1976a) reported a positive correlation between the physical and psychosocial dimensions on the SIP. The findings of this study were consistent with Bergner's findings. The physical dimension score on the Sickness Impact Profile was comprised of total scores from the categories of ambulation (A), mobility (M), and body care and movement (BCM). The psychosocial dimension score was calculated from the categories of social interaction (SI), communication (C), alertness behavior (AB) and emotional behavior (EB). Total possible scale values for the physical and psychosocial dimensions were 356.4 and 365.7 respectively. The physical dimension score was obtained by adding the scale values for each item checked within the categories of A, M, and BCM, dividing by 356.4, and multiplying by 100. Total

scores for the psychosocial dimension were calculated by adding the scale values for each item checked within categories of C, AB, SI, and EB, dividing by 365.7, and then multiplying by 100. Further analyses revealed significant differences among the three groups of subjects on the physical and psychosocial dimensions of the SIP.

Heterosexual females scored higher on these two dimensions than either heterosexual males or homosexual males.

Findings Related to the Kirksey Perception of Social Support Model (KPSSM)

The KPSSM was developed based on the premise that there is a relationship between social support and quality of life. Clients who are diagnosed as HIV-positive generally experience internal and external disequilibrium because of the negative life event. With such a diagnosis, the person experiences physical, psychological and social disequilibrium. The results of this study demonstrated significant psychosocial and physical status disruptions among the three groups. Heterosexual females scored higher on both the physical and psychosocial dimensions of the Sickness Impact Profile (SIP) indicating higher impacts of perceived dysfunction. This finding was unexpected because other studies showed a positive correlation between social support and quality of life. Since the females reported more support than either of the male groups, one would expect a greater perception of life quality, but that was not the case. The KPSSM listed available sources of social support as family, friends and community resources. Homosexual males listed significant other (lover), gay friends and community resources as their primary sources of support. Heterosexual females listed family as their source of support. Although the research literature is filled with studies

about how little social support gay men receive because of the stigma associated with that lifestyle, the gay community has rallied together to support one another.

Formalized support groups are available in urban areas throughout the nation, but this researcher has noted that the membership of these groups has typically been comprised predominantly of homosexual and bisexual males. It is possible that the support from peers in these groups has had a profound positive effect on the gay mens' life quality. Even though these groups are open to females with HIV or AIDS, perhaps females, particularly heterosexual females, have not been as willing to participate because of the perceived stigma of associating with gay individuals. The females in this study reported the highest amounts of social support of the three groups of participants, but perhaps the type of support was not of the same quality as the support received by the homosexual males. While the homosexual males reported the least amount of social support, perhaps support from peers was more meaningful and had a greater positive effect on quality of life than the support females received from family.

The results of this study supported the KPSSM with the exception discussed in the previous paragraph. More research is needed to determine whether or not types of social support are more critical than amounts of support. The model lists available and accessible sources of social support, but another category addressing types and amounts needs to be added to the KPSSM.

Conclusions and Implications

HIV and AIDS are devastating and life changing events. As a result of this study, it would appear that health care providers need to be aware of the strengths which

family and friend networks have in supporting loved ones during times of transition and change. Bechtel (1986) indicated that nurses must assess the client's access to emotional support, instrumental information and appraisal support. The following two sections include conclusions and implications for future study.

Conclusions

The following conclusions were derived based on the results of the study:

1. Length of time since first being diagnosed with HIV was not found to affect quality of life measurements. There were no significant differences among heterosexual female, heterosexual male, and homosexual male groups related to length of time since diagnosis.
2. Significant differences were found among heterosexual females, heterosexual males and homosexual males on the variable of social support. Heterosexual females demonstrated higher mean scores on this variable than subjects from either of the male groups.
3. No significant differences were found among heterosexual females, heterosexual males and homosexual males on the variable of quality of life.
4. All subjects showed a significant relationship between quality of life and perceived health status. Those who perceived themselves as "not too healthy" or "very sick" demonstrated a decreased quality of life, whereas those persons who viewed their health status as "better than most people" or "very healthy" demonstrated an increased quality of life.

5. Significant differences were found among ethnic groups on the variable of social support. Caucasians demonstrated greater levels of social support than other ethnic groups.
6. Significant differences on the total physical dimension of the Sickness Impact Profile (SIP) were demonstrated among heterosexual females, heterosexual males and homosexual males. The females scored higher than either of the male groups.
7. Significant differences on the total psychosocial dimension of the SIP were demonstrated among heterosexual females, heterosexual males and homosexual males. The females scored higher than either of the male groups.

The conclusions did not completely support the KPSSM model. The model proported that there is a positive relationship between social support and quality of life in persons infected with HIV. The results of this study supported this hypothesis in both of the male groups. However, the female subjects reported decreased life quality even though they had the highest means of the three groups on the variable of social support.

Implications

Implications for clinical nursing practice were formulated with the knowledge that the findings of this study are preliminary, and need further validation in research.

1. The results of this study are relevant to nurses in caring for and supporting patients with HIV infection. The nurse's role in educating individuals who are

HIV negative about safer sex and intravenous drug use is critical. Nurses are also important to patients diagnosed as HIV+, ARC, or AIDS in providing social support and referral to support groups.

2. Interventions aimed at enhancing psychosocial aspects in HIV-infected individuals should be the major focus of nursing care and treatment.
3. Nurses need to incorporate strategies to enhance social support among HIV-infected persons such as referral to HIV/AIDS support groups.

Recommendations for Further Study

Recommendations for future research concerning the relationship between social support and quality of life in persons with HIV were generated from this explanatory study:

1. Replication of this study using a random sampling technique from a population of subjects categorized as HIV+, ARC, and AIDS should be undertaken to verify the effect of social support on quality of life in various stages of illness.
2. Future research should include a more precise measure of the effect of types versus amounts of social support on quality of life.
3. Examination using a random sample of females should be done to determine the effect of lifestyle risk factors on the variables of social support and quality of life.

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APPENDIX A
Kirksey Demographic Data Sheet

DEMOGRAPHIC DATA SHEET

Instructions:

Please complete the following. All of the information will be confidential. Do not put your name on any of the sheets. Your cooperation is greatly appreciated.

1. Age
2. Male
 Female
3. Ethnic Group:
 Caucasian
 Black
 Hispanic
 Other (Please specify)
4. Personal Income:
 Less than \$15,000 per year
 \$15,001-\$25,000 per year
 \$25,001-\$35,000 per year
 \$35,001-\$45,000 per year
 Greater than \$45,001 per year
5. How much education have you completed?
 Grade 1-8
 Some High School
 Graduated from High School
 College (please describe) _____
6. Are you: (check all responses that apply)
 Single
 Married
 Separated
 Divorced
 Homosexual
 Presently living with a lover of the same sex
 Heterosexual
 Presently living with a lover of the opposite sex
7. Do you smoke cigarettes? Yes No

If YES, how many packs do you smoke each day? _____
How many years have you smoked? _____

If NO, did you ever smoke cigarettes? _____
 If you did smoke, what year did you quit? _____

8. Do you drink Alcohol? _____ Yes _____ No

If YES, how much alcohol do you drink each week? _____

9. Do you use drugs that are not prescribed by a doctor? Yes
 No

If YES, what kind of drugs do you use? _____
 About how many times do you take these drugs every week? _____

10. How healthy do you think you are?

_____ Very healthy
 _____ Better than most people
 _____ About average
 _____ Not too healthy
 _____ Very sick

11. When were you first told by a doctor that you have AIDS?
 _____ (please specify in months)

12. Where did you first learn about AIDS?

- a. Gay Publications:

_____ The Advocate
 _____ This Week in Texas (TWT)
 _____ Montrose Voice

- b. Other:

_____ Television
 _____ Radio
 _____ Books
 _____ Medical/scientific journals
 _____ People who work in health areas
 (Please list type of health care worker) _____

13. Who would you consider the most influential person during your treatment of AIDS? _____

What is the relationship of this person to you? _____

Thank you again for completing this data sheet. Please proceed to the next section.

APPENDIX B

Sickness Impact Profile

THE SICKNESS IMPACT PROFILE (SIP)

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

1. I spend much of the day lying down in order to rest _____ (070-083)
2. I sit during much of the day. _____ (062-049)
3. I am sleeping or dozing most of the time - day and night _____ (063-104)
4. I lie down more often during the day in order to rest. _____ (066-058)
5. I sit around half-asleep. _____ (065-084)
6. I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently. _____ (069-061)
7. I sleep or nap more during the day. _____ (071-060)

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

1. I say how bad or useless I am, for example, that I am a burden on others. _____ (274-087)
2. I laugh or cry suddenly. _____ (272-068)
3. I often moan and groan in pain or discomfort. _____ (269-069)
4. I have attempted suicide. _____ (281-132)
5. I act nervous or restless. _____ (284-046)
6. I keep rubbing or holding areas of my body that hurts or are uncomfortable. _____ (262-062)
7. I act irritable and impatient with myself, for example, badly about myself, swear at , myself, blame talk myself for things that happen. _____ (273-078)
8. I talk about the future in a hopeless way. _____ (283-089)
9. I get sudden frights. _____ (278-074)

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|--|-------|-----------|
| 1. I make difficult moves with help, for example, getting into or out of cars, bathtubs. | _____ | (168-084) |
| 2. I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid. | _____ | (170-121) |
| 3. I stand only for short periods of time. | _____ | (155-972) |
| 4. I do not maintain balance. | _____ | (146-098) |
| 5. I move my hands or fingers with limitation or difficulty | _____ | (152-064) |
| 6. I stand up only with someone's help. | _____ | (165-100) |
| 7. I kneel, stoop, or bend down only by holding on to something. | _____ | (171-064) |
| 8. I am in a restricted position all the time. | _____ | (158-125) |
| 9. I am very clumsy in body movements. | _____ | (148-058) |
| 10. I get in and out of bed or chairs by grasping something for support or using a cane or walker. | _____ | (169-082) |
| 11. I stay lying down most of the time. | _____ | (162-113) |
| 12. I change position frequently. | _____ | (147-030) |
| 13. I hold on to something to move myself around in bed. | _____ | (143-086) |
| 14. I do not bathe myself completely; for example, require assistance with bathing. | _____ | (310-089) |
| 15. I do not bathe myself at all but am bathed by someone else. | _____ | (312-115) |
| 16. I use bedpan with assistance. | _____ | (292-114) |
| 17. I have trouble getting shoes, socks, or stockings on. | _____ | (305-057) |
| 18. I do not have control of my bladder. | _____ | (290-124) |
| 19. I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces. | _____ | (298-074) |
| 20. I spend most of the time partly undressed or in pajamas. | _____ | (302-074) |
| 21. I do not have control of my bowels. | _____ | (295-128) |
| 22. I dress myself, but do so very slowly. | _____ | (300-043) |
| 23. I get dressed only with someone's help. | _____ | (297-088) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE.

This group of statements has to do with any work you usually do in caring for your home or yard. Considering just those things that you do, please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|---|-------|-----------|
| 1. I do work around the house only for short periods of time or rest often. | _____ | (117-054) |
| 2. I am doing less of the regular daily work around the house than I would usually do. | _____ | (119-044) |
| 3. I am not doing any of the regular daily work around the house that I would usually do. | _____ | (120-086) |
| 4. I am not doing any of the maintenance or repair work that I would usually do in my home or yard. | _____ | (001-062) |
| 5. I am not doing any of the shopping that I usually do. | _____ | (106-071) |
| 6. I am not doing any of the house cleaning that I would usually do. | _____ | (119-077) |
| 7. I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry. | _____ | (107-069) |
| 8. I am not doing any of the clothes washing that I would usually do. | _____ | (111-077) |
| 9. I am not doing heavy work around the house. | _____ | (115-044) |
| 10. I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget. | _____ | (105-084) |

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|--|-------|-----------|
| 1. I am getting around only within one building. | _____ | (134-086) |
| 2. I stay within one room. | _____ | (128-106) |
| 3. I am staying in bed more. | _____ | (130-081) |
| 4. I am staying in bed most of the time. | _____ | (131-109) |
| 5. I am not now using public transportation. | _____ | (140-041) |
| 6. I stay home most of the time. | _____ | (133-066) |
| 7. I am only going to places with restrooms nearby. | _____ | (125-056) |
| 8. I am not going into town. | _____ | (124-048) |
| 9. I stay away from home only for brief periods of time. | _____ | (139-054) |
| 10. I do not get around in the dark or in unlit places without someone's help. | _____ | (121-072) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|--|-------|-----------|
| 1. I am going out less to visit people. | _____ | (028-044) |
| 2. I am not going out to visit people at all. | _____ | (029-101) |
| 3. I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help. | _____ | (003-067) |
| 4. I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily. | _____ | (015-084) |
| 5. I show less affection. | _____ | (007-052) |
| 6. I am doing fewer social activities with groups of people. | _____ | (012-036) |
| 7. I am cutting down the length of visits with friends. | _____ | (027-043) |
| 8. I am avoiding social visits from others. | _____ | (034-080) |
| 9. My sexual activity is decreased. | _____ | (039-051) |
| 10. I often express concern over what might be happening to my health. | _____ | (018-052) |
| 11. I talk less with those around me. | _____ | (002-056) |
| 12. I make many demands, for example, insist that people do things for me, tell them how to do things. | _____ | (038-088) |
| 13. I stay alone much of the time. | _____ | (023-086) |
| 14. I act disagreeable to family members, for example, I act spiteful, I am stubborn. | _____ | (029-088) |
| 15. I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them. | _____ | (024-119) |
| 16. I isolate myself as much as I can from the rest of the family. | _____ | (237-102) |
| 17. I am paying less attention to the children. | _____ | (238-064) |
| 18. I refuse contact with family members, for example, turn away from them. | _____ | (256-115) |
| 19. I am not doing the things I usually do to take care of my children or family. | _____ | (242-079) |
| 20. I am not talking with family members as I usually do. | _____ | (255-043) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|---|-------|-----------|
| 1. I walk shorter distances or stop to rest often | _____ | (050-048) |
| 2. I do not walk up or down hills. | _____ | (046-056) |
| 3. I use stairs only with mechanical support, for example, handrail, cane, crutches. | _____ | (042-067) |
| 4. I walk up or down stairs only with assistance from someone else. | _____ | (044-076) |
| 5. I get around in a wheelchair. | _____ | (057-096) |
| 6. I do not walk at all. | _____ | (052-105) |
| 7. I walk by myself but with some difficulty, for example, limp, wobble, stumble, have stiff leg. | _____ | (049-055) |
| 8. I walk only with help for someone. | _____ | (053-088) |
| 9. I go up and down stairs more slowly, for example, one step at a time, stop often. | _____ | (040-054) |
| 10. I do not use stairs at all. | _____ | (041-083) |
| 11. I get around only by using a walker, crutches, cane, walls, or furniture. | _____ | (047-079) |
| 12. I walk more slowly. | _____ | (051-035) |

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | | |
|--|-------|-----------|
| 1. I am confused and start several actions at a time. | _____ | (223-090) |
| 2. I have more minor accidents, for example, drop thing, trip and fall, bump into things | _____ | (234-075) |
| 3. I react slowly to things that are said or done. | _____ | (228-059) |
| 4. I do not finish things I start. | _____ | (227-067) |
| 5. I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things. | _____ | (224-084) |
| 6. I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is. | _____ | (231-113) |
| 7. I forget a lot, for example, things that happened recently, where I put things, appointments. | _____ | (228-078) |
| 8. I do not keep my attention on any activity for long. | _____ | (220-067) |
| 9. I make more mistakes than usual. | _____ | (225-067) |
| 10. I have difficulty doing activities involving concentration and thinking. | _____ | (217-080) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | |
|---|-----------------|
| 1. I am having trouble writing or typing. | _____ (191-070) |
| 2. I communicate mostly by gestures, for example, moving my head, pointing, sign language. | _____ (177-102) |
| 3. My speech is understood only by a few people who know me well. | _____ (179-093) |
| 4. I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly. | _____ (197-083) |
| 5. I don't write except to sign my name. | _____ (188-083) |
| 6. I carry on a conversation only when very close to the other person or looking at him. | _____ (178-067) |
| 7. I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words. | _____ (176-076) |
| 8. I am understood with difficulty. | _____ (200-087) |
| 9. I do not speak clearly when I am under stress. | _____ (201-064) |

THE NEXT GROUP OF STATEMENTS HAS TO DO WITH ANY WORK YOU USUALLY DO OTHER THAN MANAGING YOUR HOME. BY THIS WE MEAN ANYTHING THAT YOU REGARD AS WORK THAT YOU DO ON A REGULAR BASIS.

Do you usually do work other than managing your home?

Yes _____ No _____

IF YOU ANSWERED YES, GO ON TO THE NEXT PAGE.

IF YOU ANSWERED NO:

Are you retired?

Yes _____ No _____

If you are retired, was your retirement related to your health?

Yes _____ No _____

If you are not retired, but are not working, is this related to your health?

Yes _____ No _____

NOW SKIP THE NEXT PAGE

IF YOU ARE NOT WORKING AND IT IS NOT BECAUSE OF YOUR HEALTH,
PLEASE SKIP THIS PAGE.

Now consider the work you do and respond to (check) only those statements that you are sure describe you today and are related to your state of health. (If today is a Saturday or Sunday or some other day that you would usually have off, please respond as if today were a working day.)

- | | | |
|--|-------|-----------|
| 1. I am not working at all.
(IF YOU CHECKED THIS STATEMENT, SKIP TO THE
NEXT PAGE.) | _____ | (100-361) |
| 2. I am doing part of my job at home. | _____ | (094-037) |
| 3. I am not accomplishing as much as usual at
work. | _____ | (096-055) |
| 4. I often act irritable toward my work associates,
for example, snap at them, give sharp answers,
criticize easily. | _____ | (088-080) |
| 5. I am working shorter hours. | _____ | (095-043) |
| 6. I am doing only light work. | _____ | (086-050) |
| 7. I work only for short periods of time or take
frequent rests | _____ | (090-061) |
| 8. I am working at my usual job but with some
changes, for example, using different tools
or special aids, trading some tasks with
other workers. | _____ | (092-034) |
| 9. I do not do my job as carefully and accurately
as usual. | _____ | (097-062) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

THIS GROUP OF STATEMENTS HAS TO DO WITH ACTIVITIES YOU USUALLY DO IN YOUR FREE TIME. THESE ACTIVITIES ARE THINGS THAT YOU MIGHT DO FOR RELAXATION, TO PASS THE TIME, OR FOR ENTERTAINMENT. PLEASE RESPOND TO (CHECK) ONLY THOSE STATEMENTS THAT YOU ARE SURE DESCRIBE YOU TODAY AND ARE RELATED TO YOUR STATE OF HEALTH.

- | | | |
|--|-------|-----------|
| 1. I do my hobbies and recreation for shorter periods of time. | _____ | (215-039) |
| 2. I am going out for entertainment less often. | _____ | (214-036) |
| 3. I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. | _____ | (207-059) |
| 4. I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading. | _____ | (208-084) |
| 5. I am doing more inactive pastimes in place of my other usual activities. | _____ | (211-051) |
| 6. I am doing fewer community activities. | _____ | (216-033) |
| 7. I am cutting down on some of my usual physical recreation or activities. | _____ | (210-043) |
| 8. I am not doing any of my usual physical recreation or activities. | _____ | (209-077) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

Please respond to (check) only those statements that you are sure describe you today and are related to your state of health.

- | | |
|--|-----------------|
| 1. I am eating much less than usual | _____ (085-037) |
| 2. I feed myself but only by using specially prepared food or utensils. | _____ (073-077) |
| 3. I am eating special or different food, for example, soft food, bland diet, low-salt, low-sugar. | _____ (081-943) |
| 4. I eat no food at all but am taking fluids. | _____ (077-104) |
| 5. I just pick or nibble at my food. | _____ (083-059) |
| 6. I am drinking less fluids. | _____ (080-036) |
| 7. I feed myself with help from someone else. | _____ (074-099) |
| 8. I do not feed myself at all, but must be fed. | _____ (075-099) |
| 9. I am eating no food at all, nutrition is taken through tubes or intravenous fluids. | _____ (076-133) |

CHECK HERE WHEN YOU HAVE READ ALL STATEMENTS ON THIS PAGE. _

APPENDIX C

Norbeck Social Support Questionnaire

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING.

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

First Name or Initials	Relationship
1. MARY T.	FRIEND
2. BOB	BROTHER
3. M.T.	MOTHER
4. SAM	FRIEND
5. MRS. R.	NEIGHBOR

etc.

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

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University of California, San Francisco

For each person you listed, please answer the following questions by writing in the number that applies.

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 1:

How much does this person make you feel liked or loved?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 2:

How much does this person make you feel respected or admired?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

1 = not at all
 2 = a little
 3 = moderately
 4 = quite a bit
 5 = a great deal

Question 3:

How much can you confide
 in this person?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 4:

How much does this person
 agree with or support your
 actions or thoughts?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 5:

If you needed to borrow \$10, a ride
 to the doctor, or some other
 immediate help, how much could
 this person usually help?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 6:

If you were confined to bed for
 several weeks, how much could
 this person help you?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

1 = not at all
 2 = a little
 3 = moderately
 4 = quite a bit
 5 = a great deal

Question 7:

How long have you known
this person?

- 1 = less than 6 months
2 = 6 to 12 months
3 = 1 to 2 years
4 = 2 to 5 years
5 = more than 5 years

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

{29-27}

Question 8:

How frequently do you usually
have contact with this person?
(Phone calls, visits, or letters)

- 5 = daily
4 = weekly
3 = monthly
2 = a few times a year
1 = once a year or less

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

PLEASE BE SURE YOU HAVE RATED EACH PERSON
ON EVERY QUESTION. GO ON TO THE LAST PAGE.

{28-30}

Number _____ (1-4)

Date _____

PERSONAL NETWORK

First Name or Initials	Relationship
1. _____	_____ (32)
2. _____	_____ (33)
3. _____	_____ (34)
4. _____	_____ (35)
5. _____	_____ (36)
6. _____	_____ (37)
7. _____	_____ (38)
8. _____	_____ (39)
9. _____	_____ (40)
10. _____	_____ (41)
11. _____	_____ (42)
12. _____	_____ (43)
13. _____	_____ (44)
14. _____	_____ (45)
15. _____	_____ (46)
16. _____	_____ (47)
17. _____	_____ (48)
18. _____	_____ (49)
19. _____	_____ (50)
20. _____	_____ (51)
21. _____	_____ (52)
22. _____	_____ (53)
23. _____	_____ (54)
24. _____	_____ (55)

{3-4}

9. During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

(57)

- _____ 0. No
 _____ 1. Yes

IF YES:

- 9a. Please indicate the number of persons from each category who are *no longer available* to you.

_____ spouse or partner	(58)
_____ family members or relatives	(59-60)
_____ friends	(61-62)
_____ work or school associates	(63-64)
_____ neighbors	(65-66)
_____ health care providers	(67)
_____ counselor or therapist	(68)
_____ minister/priest/rabbi	(69)
_____ other (specify) _____	(70) (71-72)

- 9b. Overall, how much of your support was provided by these people who are no longer available to you?

(73)

- _____ 0. none at all
 _____ 1. a little
 _____ 2. a moderate amount
 _____ 3. quite a bit
 _____ 4. a great deal

APPENDIX D

Texas Woman's University Human Subject's

Review Committee Permission Form

APPENDIX E

Agency Permission for Conducting Study

The University of Texas Medical Branch at Galveston

Medical School
Graduate School of Biomedical Sciences
School of Allied Health Sciences
School of Nursing

Marine Biomedical Institute
Institute for the Medical Humanities
UTMB Hospitals at Galveston



July 6, 1988

MEMORANDUM

TO: Kenneth M. Kirksey, R.N., M.S.N./Carolyn Adamson, R.N., Ph.D.
Graduate Nursing Student/Faculty Sponsor
School of Nursing J29

FROM: *E. Ray Stinson*
E. Ray Stinson, Ph.D.
Director of Sponsored Programs-Academic

SUBJECT: Expedited Review, Human Subjects

Project Director: Kenneth Kirksey, R.N., M.S.N./Dr. Carolyn Adamson OSP # 88-26

Project Title: "Relationship of Social Support and Quality of Life Among
Heterosexual Males & Females & Homosexual Males with AIDS"

Under the Institutional Review Board's mechanism for reviewing minimal risk protocols, your project referenced above has been approved on July 7, 1988. I am, therefore, pleased to inform you that you may proceed with this project effective immediately.

Project Directors of approved projects are responsible for reporting to the Institutional Review Board any unanticipated adverse reactions observed during the conduct of the project as well as any severe or serious side effects whether anticipated or unanticipated.

Should your project require modification which alters the risk to the subject or the method of obtaining informed consent, the project must be reevaluated by the Institutional Review Board before the modification is initiated.

Completed subject consents should be maintained in the designated place for at least three years after the termination of the project. In order to be in compliance with the requirements of the FDA regulations, 21 CFR 56.27a, a copy of the completed consent document must be provided to the subject.

COMMENTS:

Attached is the subject consent form with the date of IRB approval. Please use this copy of the consent form with the IRB approval date and make additional copies as they are needed.

ERS/nh

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING
DENTON, TEXAS 76204

DALLAS CENTER
1810 INWOOD ROAD
DALLAS, TEXAS 75235

HOUSTON CENTER
1130 M. D. ANDERSON BLVD.
HOUSTON, TEXAS 77030

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE University of Texas Medical Branch at Galveston

GRANTS TO Kenneth M. Kirksey, RN, MSN
a student enrolled in a program of nursing leading to a Doctoral Degree at Texas
Woman's University, the privilege of its facilities in order to study the following
problem:

Relationship of Social Support and Quality of Life Among
Heterosexual Males & Females & Homosexual Males with AIDS

The conditions mutually agreed upon are as follows:

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

Date: July 7, 1988

Kenneth M. Kirksey
Signature of Student

E. Ross Starn
Signature of Agency Personnel
Carol Ann Cleburne
Signature of Faculty Advisor

* Fill out and sign three copies to be distributed as follows: Original-Student;
First copy - agency; Second copy - TWU College of Nursing.

/bc

APPENDIX F
Subject Consent Form

SUBJECT CONSENT FORM

I agree to participate in this study concerning how certain behaviors, personal support and feelings effect persons with AIDS. The potential benefits and adverse effects have been presented to me both verbally and in writing. I understand that by agreeing to participate in this study I expect no payment from Texas Woman's University or The University of Texas Medical Branch at Galveston. I have been informed that my name, my doctor, nor this hospital will be identified in the research study report. I realize that I may withdraw from the study at any time and that my care will not be affected. If I have any questions, I have been provided with the researcher's name and telephone number.

Signature of Participant

Signature of Researcher

Signature of Witness

Date

APPENDIX G

Total Scores, Frequency and Percentage Distribution of Activity Areas on Sickness Impact Profile

Total Scores, Frequency and Percentage Distribution
of Activity Areas on Sickness Impact Profile

Category	Value	Frequency	Percent
<u>Communication</u>	10.2	1	1.1
	20.1	1	1.1
	30.1	23	25.8
	39.7	27	30.3
	44.6	1	1.1
	46.6	19	21.3
	54.6	15	16.9
	56.4	1	1.1
	59.4	1	1.1
	TOTAL	89	100.0
<u>Social Interaction</u>	26.0	15	16.9
	28.7	18	20.2
	35.6	38	42.7
	43.6	3	3.4
	61.2	15	16.9
	TOTAL	89	100.0
<u>Alertness Behavior</u>	29.5	22	24.7
	43.1	29	32.6
	43.5	1	1.1
	43.9	2	2.2
	46.1	17	19.1
	46.2	1	1.1
	58.4	17	19.1
	TOTAL	89	100.0
<u>Emotional Behavior</u>	35.7	25	28.1
	38.4	11	12.4
	41.8	52	58.4
	48.4	1	1.1
	TOTAL	89	100.0

Category	Value	Frequency	Percent
<u>Mobility</u>	23.3	22	24.7
	13.6	1	1.1
	31.6	15	16.9
	33.5	2	2.2
	33.6	18	20.2
	44.2	19	21.3
	49.5	<u>12</u>	<u>13.5</u>
	TOTAL	89	100.0
<u>Recreation and Pastimes</u>	32.6	2	2.2
	35.2	1	1.1
	35.7	1	1.1
	36.1	6	6.7
	36.2	26	29.2
	42.2	<u>53</u>	<u>59.5</u>
	TOTAL	89	100.0
<u>Work</u>	25.8	2	2.2
	33.5	1	1.1
	35.7	3	3.4
	35.8	2	2.2
	35.9	10	11.2
	36.5	19	21.3
	37.8	1	1.1
	38.4	2	2.2
	39.7	1	1.1
	41.8	6	6.7
	45.9	1	1.1
	47.8	3	3.4
	47.9	22	24.7
	51.5	<u>16</u>	<u>8.0</u>
	TOTAL	89	100.0

Category	Value	Frequency	Percent
<u>Home Management</u>	35.6	2	2.2
	35.7	2	2.2
	38.4	2	2.2
	41.3	18	20.2
	41.6	3	3.4
	44.2	2	2.2
	46.7	13	14.6
	53.9	14	15.7
	55.6	1	1.1
	55.7	1	1.1
	57.2	29	32.6
	57.3	1	1.1
	61.2	11	1.1
	TOTAL	89	100.0
<u>Eating</u>	33.6	1	1.1
	33.7	26	29.2
	35.7	7	7.9
	38.4	3	3.4
	41.8	4	4.5
	42.5	19	21.3
	43.1	2	2.2
	44.2	1	1.1
	46.1	1	1.1
	52.5	23	25.8
	59.5	1	1.1
	82.5	1	1.1
	TOTAL	89	100.0
<u>Ambulation</u>	24.3	16	18.0
	24.5	1	1.1
	30.5	10	11.2
	32.6	17	19.1
	40.3	3	3.4
	41.4	18	20.2
	44.2	12	13.5
	83.1	7	7.9
	84.2	5	5.6
	TOTAL	89	100.0

Category	Value	Frequency	Percent
<u>Body Care and</u> <u>Movement</u>	25.4	3	3.4
	28.4	14	15.7
	30.7	6	6.7
	31.3	29	32.6
	33.5	9	10.1
	46.1	17	19.1
	64.8	<u>11</u>	<u>12.4</u>
	TOTAL	89	100.0
<u>Sleep and Rest</u>	29.0	23	25.8
	33.7	1	1.1
	35.6	1	1.1
	35.7	5	5.6
	38.1	21	23.6
	38.4	4	4.5
	39.7	1	1.1
	40.5	13	14.6
	41.4	1	1.1
	41.8	8	9.0
	48.1	1	1.1
	49.9	<u>10</u>	<u>11.2</u>
	TOTAL	89	100.0

APPENDIX H

Permission to Use the SIP and NSSQ



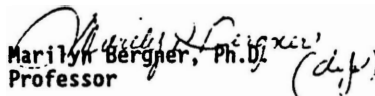
March 18, 1988

Kenn M. Kirksey, R.N., M.S.N., Ph.D. Candidate
Texas Woman's University
1130 M.D. Anderson Blvd.
Houston, Texas 77030

Dear Ms. Kirksey:

This letter grants you permission to use the Sickness Impact Profile in your research. In return, I would appreciate receiving a detailed description of the research you will be doing and a final report of the results when it is completed.

Sincerely yours,


Marilyn Berger, Ph.D.
Professor

MB:dep

APPENDIX A

Request Form

I request permission to copy the Norbeck Social Support Questionnaire (NSSQ) for use in research in a study entitled: Relationship of Social Support and Quality of Life among Heterosexual Males & Females & Homosexual Males with AIDS

In exchange for this permission, I agree to submit to Dr. Norbeck a copy of the one-page scoring sheet for each subject tested. These data will be used to establish a broad normative database for the instrument for clinical and non-clinical populations. Aside from use in the pooled data bank, no other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analyses.

Kenn M. Kirksey, RN, MSN
(Signature)

July 6, 1988

(Date)

Position and Assistant Professor Univ. of Texas Health
Full Address (Home) Science Center at San
of Investigator: 4000 Horizon Hill Blvd. #2013
San Antonio, Texas 78229

Permission is hereby granted to copy the NSSQ for use in the research described above.

Jane S. Norbeck

Jane S. Norbeck

8/1/88

(Date)

Please send two signed copies of this form to:

Jane S. Norbeck, D.N.Sc.
Department of Mental Health and Community Nursing
University of California, San Francisco
NS05-Y
San Francisco, California 94143

APPENDIX I
Oral Description

ORAL DESCRIPTION

Hello. My name is Kenn Kirksey. I am a doctoral student in Nursing at Texas Woman's University. You are invited to participate in a study concerning how certain behaviors, personal support and feelings effect persons with AIDS. If you agree to participate, you will be given three questionnaires to complete. These will be filled in at the clinic and will take about one hour to finish.

You may experience some anxiety while you are filling out the questionnaires. However, I will be in the clinic area to answer any questions or discuss your concerns.

Although you may not directly benefit from taking part in this study, the information can be used to help nurses take better care of persons who have AIDS.

I am conducting no other study at this time. You are free to be in the study or not to participate. If you do say you will participate, you may withdraw from the study at any time. Your care at this hospital will not be affected in any way whether you enter this study or do not participate. Confidentiality of the results of the study will be assured.

You, your doctor, this hospital or any person caring for you will not be identified anywhere in this research study. Coded numbers will be placed on the questionnaires to keep each participant's packet separate. No names will be placed on the questionnaires.

No injury is expected to occur while you are completing the questionnaires. However, in the event of physical injury resulting from this research, The University of Texas Medical Branch at Galveston is not able to offer financial compensation nor to absorb the costs of medical treatment. However, necessary facilities, emergency treatment and professional services will be available to research subjects, just as they are to the community generally. Texas Woman's University, the hospital and clinic will not provide any payment or medical care to you if you participate in this study.

If you have any questions, please call me at 761-1181. Thank you.

RETURN OF THESE QUESTIONNAIRES IMPLIES YOUR CONSENT TO PARTICIPATE IN THIS STUDY.

APPENDIX J
Written Description

WRITTEN DESCRIPTION

Dear Participant,

My name is Kenn Kirksey. I am a doctoral student in Nursing at Texas Woman's University. You are invited to participate in a study concerning how certain behaviors, personal support and feelings effect persons with AIDS. If you agree to participate, you will be given three questionnaires to complete. These will be filled in at the clinic and will take about one hour to finish.

You may experience some anxiety while you are filling out the questionnaires. However, I will be in the clinic area to answer any questions or discuss your concerns.

Although you may not directly benefit from taking part in this study, the information can be used to help nurses take better care of persons who have AIDS.

I am conducting no other study at this time. You are free to be in the study or not to participate. If you do say you will participate, you may withdraw from the study at any time. Your care at this hospital will not be affected in any way whether you enter this study or do not participate. Confidentiality of the results of the study will be assured.

You, your doctor, this hospital or any person caring fo you will not be identified anywhere in this research study. Coded numbers will be placed on the questionnaires to keep each participant's packet separate. No names will be placed on the questionnaires.

No injury is expected to occur while you are completing the questionnaires. However, in the event of physical injury resulting from this research, The University of Texas Medical Branch at Galveston is not able to offer financial compensation nor to absorb the costs of medical treatment. However, necessary facilities, emergency treatment and professional services will be available to research subjects, just as they are to the community generally. Texas Woman's University, the hospital and clinic will not provide any payment or medical care to you if you participate in this study.

If you have any questions, please call me at 761-1181. Thank you.

Sincerely,

Kenn M. Kirksey, R.N., M.S.N.

RETURN OF THESE QUESTIONNAIRES IMPLIES YOUR CONSENT TO PARTICIPATE IN THIS STUDY.

APPENDIX K
Interviewer Training Protocol

INTERVIEWER TRAINING PROTOCOL

The three graduate nursing students who agreed to assist with data collection received the same instructions about the proper use of the Sickness Impact Profile (SIP). The training sessions were conducted according to guidelines listed in the Administration procedures and interviewer training for the Sickness Impact Profile packet (Conn, Bobbitt, & Bergner, 1978)

A brief description of the SIP questionnaire was presented as follows:

1. Preceding the list of SIP items is an introduction that explains to the subject how he is to respond.
2. The SIP items are grouped in twelve categories, each of which is related to an area of living or type of activity. Each group or category of items begins with an introductory statement.
3. To the left of each SIP item is a number which designates its position in the category. These start with number one at the beginning of each category. To the right of the response line for each item is the SIP item number, which has been retained for the item throughout the revisions of the instrument. These SIP item numbers are used for coding and scoring.
4. At the bottom of each page of the SIP is a line or box which is checked to show that the items on that page have been read (Conn, Bobbitt, & Bergner, 1978, p. 7).

The interviewers were cautioned just to read the statements as they appear on the SIP. They were instructed to avoid interpreting or paraphrasing statements for subjects. If a subject indicated that a particular statement was not clear, the interviewers were asked to simply restate the phrase from the beginning exactly as written. The graduate students were reminded to emphasize to the participants that they should respond to items only if they were sure that they described them today and were related to the persons state of health. Following completion of the interviews, the questionnaires were returned to the principal investigator for scoring. None of the data collectors, except the principal investigator, were responsible for scoring the SIP results.