THE LIVED EXPERIENCE OF GAY MALE PARTNERS
OF MEN WITH AIDS

by

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STATEMENT BY AUTHOR

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# TABLE OF CONTENTS

LIST OF TABLES ................................................................. 7  
ABSTRACT ................................................................. 8  

CHAPTER  
1. INTRODUCTION ........................................................... 9  
   Background ........................................................... 9  
   Statement of the Problem ......................................... 13  
   Significance of the Study ........................................... 13  
      Financial Impact of AIDS ...................................... 13  
      Social Environment ........................................... 14  
      Nature of AIDS ................................................. 15  
      Emotions of AIDS Victims and Their Partners ........ 17  
   Statement of Purpose ................................................ 19  
   Research Question .................................................. 20  
   Definition of Terms ............................................... 20  
   Summary .................................................................... 21  

2. REVIEW OF THE LITERATURE AND CONCEPTUAL ORIENTATION .... 22  
   Review of the Literature .......................................... 22  
      Partners’ Health Behaviors ................................. 22  
      Partners Experiencing Unique Needs ................. 23  
      Partners and Coping ........................................... 25  
      Partners and Grieving ......................................... 27  
      Partners as Caregivers ......................................... 29  
   Conceptual Orientation ........................................... 33  
      Transition .......................................................... 34  
      Role ................................................................. 34  
      Caregiving ......................................................... 35  
   Summary .................................................................... 35  

3. METHOD ................................................................. 38  
   Research Design ...................................................... 38  
   Sample and Setting ................................................ 43  
   Protection of Human Subjects ................................... 44  
   Data Collection Methods ........................................ 47  
   Instrument ............................................................. 48  
   Data Analysis ........................................................ 48  
   Trustworthiness of the Research .............................. 52  
   Summary .................................................................... 54  

4. RESULTS ............................................................... 56  
   Description of the Sample ....................................... 56
# TABLE OF CONTENTS - Continued

Results of Data Analysis ..................................................................................... 56  
Theme Categories .................................................................................. 56  
The Diagnosis of AIDS ..................................................................... 57  
Disclosure ....................................................................................... 61  
Interactions with Physicians ......................................................... 64  
Self Care ....................................................................................... 66  
Caregiving ..................................................................................... 69  
Gains from a Relationship with a Person with AIDS .................... 71  
Internal Struggles ......................................................................... 73  
Process of Loss ............................................................................... 77  
Exhaustive Description ................................................................ 79  
Essential Structure ........................................................................ 80  

Summary ............................................................................................................ 81  

5. DISCUSSION .................................................................................................... 83  
Discussion of the Results in Relation to the Conceptual Orientation  
and Review of the Literature ................................................................................. 83  
Health Behaviors..................................................................................... 85  
Unique Needs ......................................................................................... 86  
Coping .................................................................................................... 87  
Caregiving .............................................................................................. 88  
Environment ........................................................................................... 89  
Vigilance.................................................................................................... 90  

Discussion of Other Results ................................................................................ 91  
Limitations of the Study ...................................................................................... 94  
Implications for Nursing ............................................................................. 95  
Unique Needs ......................................................................................... 95  
Caregiving .............................................................................................. 97  
Fear and Ambivalence .......................................................................... 98  
Internal Struggles ............................................................................... 99  
Transition ............................................................................................. 100  
Process of Loss ..................................................................................... 100  
Recommendations for Further Research ............................................................ 101  
Summary .......................................................................................................... 102  

APPENDIX A - FLYER .............................................................................................. 104  

APPENDIX B - SUBJECT CONSENT TO PARTICIPATE IN A RESEARCH  
PROJECT ........................................................................................................... 106
TABLE OF CONTENTS - Continued

APPENDIX C - DEMOGRAPHIC SHEET FOR PARTNER and DEMOGRAPHIC SHEET FOR PERSON WITH AIDS AS REPORTED BY PARTNER........................................................................................................112

APPENDIX D - EXHAUSTIVE DESCRIPTION OF THE LIVED EXPERIENCE OF THE PARTNER OF A MAN WITH AIDS........................................116

REFERENCES ............................................................................................................137
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Demographic Profile of Partners and Person with AIDS</td>
<td>58</td>
</tr>
<tr>
<td>2.</td>
<td>Theme Categories</td>
<td>59</td>
</tr>
<tr>
<td>3.</td>
<td>Themes and Theme Clusters for the Theme Category, The Diagnosis of AIDS</td>
<td>60</td>
</tr>
<tr>
<td>4.</td>
<td>Themes and Theme Clusters for the Theme Category, Disclosure</td>
<td>62</td>
</tr>
<tr>
<td>5.</td>
<td>Themes and Theme Clusters for the Theme Category, Interactions with Physicians</td>
<td>65</td>
</tr>
<tr>
<td>6.</td>
<td>Themes and Theme Clusters for the Theme Category, Self Care</td>
<td>68</td>
</tr>
<tr>
<td>7.</td>
<td>Themes and Theme Clusters for the Theme Category, Caregiving</td>
<td>70</td>
</tr>
<tr>
<td>8.</td>
<td>Themes and Theme Clusters for the Theme Category, Gains From a Relationship with a Person with AIDS</td>
<td>72</td>
</tr>
<tr>
<td>9.</td>
<td>Themes and Theme Clusters for the Theme Category, Internal Struggles</td>
<td>74</td>
</tr>
<tr>
<td>10.</td>
<td>Themes and Theme Clusters for the Theme Category, Process of Loss</td>
<td>78</td>
</tr>
</tbody>
</table>
ABSTRACT

The AIDS epidemic in this country continues to grow. The purpose of this study was to examine the lived experience of being the gay male partner of a man with AIDS. The conceptual orientation for this study included the concepts of transition, role, and caregiving. The research design was qualitative with phenomenology providing the philosophical perspective. Interview data were analyzed according to Colaizzi’s method (1983). Three partners volunteered for the study. All partners were HIV negative and lived with a man with AIDS. Eight theme categories emerged as characteristic of partners' experience. Partners reported worry, ambivalence, and fear as commonly experienced emotions. Limitations of this study were small sample size and cross sectional nature of the research. The study yielded information on areas where nurses can have an impact on the lives of the partners of PWA. Recommendations for further research included a larger study population to ensure saturation in all categories of data.
CHAPTER ONE
INTRODUCTION

The emergence of the acquired immunodeficiency syndrome (AIDS) epidemic has presented many challenges for health care providers, people with AIDS (PWA), and their partners. To provide optimal nursing care for persons with AIDS and their partners, an awareness of the partners’ perspective on their experience is necessary. The purpose of this study was to examine the experience of being the gay male partner of a gay man with AIDS.

Background

Little is known about the effect of AIDS on the partners of men with AIDS and the perspective of the partner. Because of the scope of the AIDS spread in this country it would be valuable to gain understanding about the partners of men with AIDS. AIDS is epidemic in the United States. The US Department of Health and Human Services, Centers for Disease Control and Prevention, estimated that in 1981 only 300 adults in America had AIDS (Centers for Disease Control and Prevention [CDC], 1994). By 1994 that figure was conservatively estimated to be 400,000 people (CDC, 1994). In addition, when considering that over one million Americans are infected with the human immunodeficiency virus, the depth and breath of this epidemic is apparent (CDC, 1994).

Gay and bisexual men continue to constitute the largest percentage of AIDS cases. The Centers for Disease Control and Prevention report that of all AIDS cases up to
June, 1994, 61% occurred among male homosexuals. The age of the victims is an additional alarming statistic. Of all reported male AIDS cases, 75% have occurred between the ages of 25 and 44 years (CDC, 1994). From these figures it is obvious the country is losing some of its most productive members of society at an unprecedented rate.

A major problem facing the person with AIDS is stigmatization. The metaphors accompanying this disease contribute to stigmatization. Hall (1992) states that metaphors are formed without regard to biological facts and yet affect the whole life of the person with the disease. Metaphors serve as a type of shorthand allowing an understanding of the disease through the use of one word. The prominent metaphor for AIDS is plague (Hall, 1992).

American society tends to see people with AIDS as sinful, promiscuous, and evil (Hall, 1992). This may reflect the views of Americans regarding homosexuals and the fact that AIDS was originally identified as a disease that predominately strikes homosexuals. Because most white, middle class, heterosexual Americans do not believe these descriptors apply to themselves, they then are able to view AIDS, homosexuals, and the partners of homosexuals as separate from the mainstream (Hall, 1992). Hall (1992) notes that most prominent is the idea that AIDS is a deserved punishment for immoral and offensive behavior. If PWA are viewed as immoral then logically their gay partners are, by association, immoral. This thinking may have the effect of leaving the general population
with a false sense of security and the person with AIDS and their partners isolated and stigmatized.

Adding to the isolation and stigmatization faced by those with AIDS is the beliefs of some health care professionals. Royce and Birge (1987) found that medical students scored significantly higher than nursing students on a devised Homophobia Scale. The 46% of participants who scored high on the Homophobia Scale were significantly more fearful of AIDS, in need of greater social distance, and less empathic towards AIDS victims compared to participants who scored lower (Royce & Birge, 1987). Most participants who did not agree that homosexuality should be accepted as an alternative lifestyle were in the least empathic group. Royce and Birge (1987) conclude that empathy for AIDS victims is strongly affected by homophobia and may result in the risk of inferior health care.

With the pervasiveness of negative attitudes in society, PWA suffer psychological distress because of their diagnosis. It appears difficult to be homosexual in America. Considering that young adults are now facing death, a special group of problems present themselves. Govoni (1988) states that young men lack financial resources and security. They are likely not to have insurance or to be settled in their careers. Many have not evolved into an intimate relationship of any duration. Related to the issue of isolation is that many gay men have not admitted to others their homosexuality. With the disclosure of the AIDS diagnosis often comes the disclosure of homosexuality at a time when young
men are least prepared to deal with the possible shock, disbelief, and anger of their families. Gay partners of men with AIDS may be facing these same issues and also be supporting their partners through diagnosis, medical treatment, financial insecurity, family upheaval, and health problems.

One issue mentioned in the literature is the special bereavement issues faced by the partner. Wolfe (1992) states that many factors affect gay grief: survivors may have AIDS themselves, partners are denied a rightful place during closure rituals, society often underplays the grief of the partner, and feelings of anxiety and depression in the partner may not be addressed. Wolfe also notes that bereavement is complicated in the gay population due to the fact that society is uncomfortable with illness, death, grief, and homosexuality. AIDS typically involves all four of these situations. Losses are not only related to death. The partner may suffer financial loss, loss of health care support, and loss of purpose in attending to the AIDS victim. Partners of PWA have not only lost their loved one but may have lost friends also. Remaining friends may be ill with AIDS and partners may be struggling to come to terms with their own positive HIV status. A pile-up of losses impacts the partner (Wolfe, 1992). With daily reminders of AIDS, there is an aura of death presently hanging over the gay community. The stigma associated with dying from AIDS creates a wall of silence making the partner often unable to mourn openly (Daugherty, 1993). Many partners even feel compelled to lie about their lovers' cause of death to escape societal judgment.
Statement of the Problem

Gay male partners of men with AIDS are in a living situation that may challenge their personal resources. There is little research reported on the perceptions of gay male partners of men with AIDS. Nursing research to explore partners' perception of their lived experience is needed as the basis for planning nursing interventions appropriate for the needs of this population.

Significance of the Study

There are several areas where gaining knowledge about the partner of a person with AIDS may prove to be important: financial impact of AIDS, social environment, nature of AIDS, and emotions of AIDS victims and their partners.

Financial Impact of AIDS

When examining the magnitude of the AIDS epidemic one must take into account the financial impact of this disease on society. Ward and Brown (1994) found that in 1993 the cumulative cost of treatment for people with AIDS had reached 7.8 billion dollars. These authors note that the total cost over a lifetime for one person with AIDS, from diagnosis to death, is estimated at $75,000 (Ward & Brown, 1994). What these figures do not include is the cost of unpaid labor provided by the partner. If these costs were included the true cost of care would become more apparent.

Ward and Brown (1994) attempted in their study to place a value on care given in the home. Caregivers were broadly defined to include the male partners. Estimates of
cost are based on wages paid in Seattle, Washington in 1988. The total yearly cost for home care was $25,857 for each person with AIDS (Ward & Brown, 1994). The cost of home care rivals what many Americans earn in a full-time job. Further, 99% of care fell under the category of companionship. It is difficult to put a price on companionship. Unpaid home care is one of the hidden costs associated with AIDS and a cost to the partners that is not only financial but emotional and physical.

Insurance carriers and the government do little to ease the financial burden to either the partners or society. Medicare has age and time restrictions that make qualifying the AIDS client, with a mean life expectancy of 11 months at stage 4 of the disease process, almost impossible (Ward & Brown, 1994). Kerley (1990) found that Medicaid pays only approximately 25% of AIDS costs, with the remaining financial burden falling to individual states. Insurance companies are doing little to stop the escalating financial burden falling on society. Regulations are currently in effect that limit access of high risk people to health and life insurance. While these rules vary from state to state, at present 43 states allow HIV screening when determining eligibility for insurance (Kerley, 1990). If partners become overburdened and unable to provide home care, society will feel the impact of dramatic increases in health care costs.

Social Environment

Nurses need to understand the social environment in which the person with AIDS and their partner are enmeshed. Chopoorian (1986) notes that of the concepts used in
nursing paradigms, environment is the least explored. The social, economic, and political environments have an impact on the person with AIDS and their partner. An example is the highly bureaucratized health care system in America. Health organizations are increasingly driven by efficiency, profit, and productivity (Chopoorian, 1986). In that gay men are a disenfranchised population and the disease of AIDS does not lend itself to efficient, profit centered care raises the question of how men with AIDS and their partners view the social environment of health care. Chopoorian (1986) charges that most practitioners are not concerned with the mundane, routine activities of everyday life. However, everyday life is the reality in which people spend most of their time.

Nature of AIDS

The person with AIDS faces many significant problems. The contagious nature of the disease does much to increase anxiety. People with AIDS fear they have unknowingly infected people in their past and this leads to guilt (Govoni, 1988). Others' fear of contagion results in the loss of affection and support. Gay men with AIDS may suffer anxiety over expressing their sexuality and indeed may fear touching another human being. These changes in physical expressions of caring can affect feelings of closeness, love, comfort, and affiliation at a time when the person with AIDS can least afford physical or emotional isolation. Research needs to be conducted to explore partners' fears and ways of coping with alterations in expressing sexuality and love.
Another significant problem for the person with AIDS and their partner is the unpredictable course of the disease and what symptoms may manifest at specific points on the continuum. The variability of AIDS presentation is great, currently with no predictors of when symptoms may occur or how fast they may progress. Duffy (1987) notes that because of this uncertainty many men practice vigilance. Health vigilance becomes a factor in daily living. Marks on the skin, a cough, or fatigue can cause acute anxiety. Vigilance also determines behavior (Duffy, 1987). Men with AIDS may seek health reassurance for what appear to be minor complaints. How men with AIDS look and feel assumes major importance. Another factor of vigilance is that it is tempered by information (Duffy, 1987). Information that is ambiguous or inconsistent can increase fear. Vigilance becomes a primary occupation, a self-absorption (Duffy, 1987). It is unknown if partners of PWA practice vigilance themselves or what effect their partners' vigilance may have on them.

For the majority of those with AIDS, the disease is fatal. Chesney and Folkman (1994) found that psychological distress is related to the disease progression. There is anxiety over disfigurement and debilitation from the disease. For men who have placed a high value on physical attractiveness this is especially anxiety provoking. Wolfe (1992) notes that the dying process is frightening. Gay men fear the indignity of dying from AIDS. Loss of bodily function, loss of mental capacities, fear of pain, and reliance on others are issues that are important to those with AIDS (Wolfe, 1992). Little is known
about partners' responses to the medical progression of the disease in a person with AIDS and partners' ways of coping with a deteriorating situation.

Emotions of AIDS Victims and Their Partners

The depressive symptoms suffered by men with AIDS have clinical significance both to the partners and to nursing. Gaskins and Brown (1992) found that in 1985, in New York City, the suicide risk for men aged 20 to 59 years was 36 times higher in men with AIDS than in men without the AIDS diagnosis. In addition, the suicide risk in men with AIDS was 55 times higher than the general population. All respondents in the study by Gaskins and Brown (1992) considered suicide at some point, with most considering it immediately after diagnosis. During such a period of emotional flux little is known about partners' coping. Partners may be experiencing emotions similar to the persons with AIDS or their emotions may be different. Feelings of depression, helplessness, and worthlessness can be overwhelming. Conflict over the wish to die and the wish to fight the disease makes the period after diagnosis a difficult time for those with AIDS and their partners.

McCain and Grambling (1992) found three common themes among PWA: living with dying, fighting the illness, and getting worn out. The significance of living with dying is that major stressors interfere to a great extent with life going on as well as possible. Learning one is HIV positive is perceived to be tantamount to a death sentence, and anger, depression, suicidal ideation, and fear of rejection are common emotions following
diagnosis (McCain & Grambling, 1992). Living with dying is the period when the reaction of family and friends becomes important. What may appear as trivial enjoyment assume major importance if life is to go on as before, and it is exactly these enjoyments that are difficult for those with AIDS to maintain. What coping strategies partners use to face the difficult expressions of emotion and maintain the status quo are unknown.

The theme of fighting the illness is important as the person with AIDS attempts to develop priorities and purpose in his life. At this time the physical illness becomes a reality and staying as healthy as possible becomes a priority (McCain & Grambling, 1992). Quitting smoking, eating healthy, exercising, and getting adequate sleep are strategies used to fight the illness. McCain and Grambling (1992) note that an emphasis is placed on mental attitude. Changes in mental attitude may be composed of rejecting negativity and maintaining a positive attitude. Keeping a positive attitude may become more difficult as physical deterioration begins to occur. How partners cope with physical deterioration of the person with AIDS is unknown.

Getting worn out is a process to which many authors allude (Duffy, 1987; Hintze, Templer, Cappelletty, & Frederick, 1993; Lazzari, Ronchi, Volterra, & Chiodo, 1993; McCain & Grambling, 1992). At the end of the illness the weariness of fighting the battle becomes apparent. Clinic appointments are missed and the feeling of letting nature take its course becomes prominent. At this period the "good death" (Lazzari, Ronchi, Volterra, & Chiodo, 1993, p.167) concept begins to arise. The end stage of the disease for the person
with AIDS is a difficult period for the partner as he watches his loved one slip away. Duffy (1987) notes that many men with AIDS have prepared for the end with suicide plans. Sparing their family, friends, and partners further grief appears to be the impetus behind these plans (Duffy, 1987). Partners will likely need assistance in letting go and respecting the person with AIDS in the wish to quit the fight. People with AIDS, not unlike the general population, wish to die surrounded by loved ones, with little pain, and feeling acceptance and love.

Bereavement is only one issue facing the partner of a person with AIDS. Partners have a wealth of knowledge regarding their experiences that is waiting to be explored. If the person with AIDS faces social stigmatization, discrimination, anxiety, depression, and multiple losses, it is possible that these same problems also are problems for their partner. It is also likely partners face unique problems of their own. These challenges, triumphs, joys, and difficulties are the aspects of the partners' lives that this study will explore.

Statement of Purpose

The purpose of this study was to describe the lived experience of being the gay male partner of a gay man with AIDS. Although much is known about the epidemiology, disease progression, and psychological issues relating to AIDS, little was known about the impact of these issues on the gay partner of a person with AIDS. Those with AIDS have partners, families, lovers, and friends; a constellation of supporting people largely ignored in the literature. This study focused on the gay male partners who live with and provide
some form of support for the person with AIDS. This research on the lived experience of partners of men with AIDS can provide nurses with greater insight into the unique challenges faced by partners.

Research Question

The research question was: What is the lived experience of being the gay male sexual partner living with a gay man with AIDS? This question was explored using a qualitative approach.

Definition of Terms

Burns and Grove (1993) suggest that in a qualitative study all variables be considered independent and defined. Terms used in this study are defined as follows:

Lived experience: the life of the partner as perceived in its totality.

Gay: a homosexual man.

Sexual partner: a gay man living in the same household as a gay man with AIDS and who is/was the sexual partner of the man with AIDS.

AIDS: having a medical diagnosis of acquired immunodeficiency syndrome with a CD T-lymphocyte count of less than 200 cells/ml or a CD 4 percentage less than 14 in persons with laboratory confirmation of HIV infection, or a CD 4 count greater than 200 cells/ml in conjunction with a list of 23 opportunistic infection (CDC, 1994).
Summary

In summary this chapter has described the impact of the epidemic of AIDS in the United States. At present AIDS is an incurable fatal disease. The process of dying from this disease is unpredictable; physical deterioration includes all body systems and care is largely palliative. While debilitating the body, AIDS also affects the emotions of those afflicted. People with AIDS suffer anxiety, fear, loss, grief, and a myriad of other distressing emotions. Stigmatization, societal rejection, and a potentially negative environment add to the suffering of this population.

The financial impact of AIDS is enormous both to an already overburdened health care system and the caregivers themselves. Studies have shown that the yearly cost for home care for a person with AIDS averages $26,000 (Ward & Brown, 1994). That most partners perform these activities free of charge does not lessen physical and emotional costs to the partner.

While assuming there are many burdens in caring for a partner with AIDS, it is theorized that factors other than caregiving are of equal importance to the partner. However, little research has been done regarding the partners' experiences or needs in their lived situation. Partners possess a wealth of information that can benefit nursing in providing meaningful health care. In light of lack of knowledge in this area, the purpose of this study is to examine the lived experience of being the gay partner of a gay man with AIDS.
CHAPTER TWO
REVIEW OF THE LITERATURE AND CONCEPTUAL ORIENTATION

Chapter Two presents review of literature and conceptual orientation for the research. The literature review focuses on partners' health behaviors when their partners have AIDS and partners and their unique needs including coping, grieving, and caregiving. Qualitative research is introduced as an inductive process and its' relation to theory development is examined. Transition, role, and caregiving, concepts assumed to be associated with the lived experience of partners, are presented.

Review of the Literature

To date, little research relates to the experience of being a gay male partner of a man with AIDS. Much of the research relating to AIDS focuses on the person with AIDS and the partner only peripherally. A portion of the existing literature, as it relates to partners, is reviewed here.

Partners' Health Behaviors

Morgan and Jones (1993) did four case studies on male homosexuals ranging in age from 26 to 38 years of age. In the cases described, all four of the HIV negative partners reported having unsafe sex with their HIV positive partner. One partner had become HIV positive. Morgan and Jones (1993) speculate that the close bonding of each of these four couples and the social isolation they shared suggests that the HIV negative men might be willing to be infected with the AIDS virus in order to share in their partner's
fate. There did not appear to be differences based on longevity of the relationships. In two of the case studies the seropositive partner had asked for help in dealing with his partner who insisted on unprotected sex. Three of the couples were counseled on unprotected sex and the response of all three seronegative partners was a firm, angry refusal to discuss the topic. None of the HIV negative partners appeared to have significant psychopathology or a history of alcohol or substance abuse. The authors concluded that partners of men who test HIV positive may have been deliberately infecting themselves with the AIDS virus as a means of maintaining a functioning partnership. The authors recommend that health care workers pay more attention to the partners of men who test HIV positive, and assess the functioning of the couple. The researchers suggest that HIV positive partners may need to be directly confronted regarding self-destructive behavior (Morgan & Jones, 1993). These recommendations should be viewed cautiously as they are based on only four case studies.

**Partners Experiencing Unique Needs**

Cowles and Rodgers (1991) conducted a preliminary field study of ten individuals, including friends, mothers, sisters, and partners, of men with AIDS. They identified four categories in which the significant others experienced unique needs. These needs were disclosure of the diagnosis, hoping in the face of hopelessness, relationship changes, and a need to be involved.
Pertinent to learning of the diagnosis was an urgent need on the part of the significant other to obtain information about the disease (Cowles & Rodgers, 1992). While many of the participants could not recall their immediate emotions following disclosure, they all recalled going to libraries, telephoning local AIDS projects, and even registering for workshops. The information sought pertained to how to protect themselves, how to talk with others about transmission, and in what ways they could be most supportive to the person with AIDS (Cowles & Rodgers, 1992).

A problem unique to the significant others in this study was the moral dilemma brought on by disclosure. The person with AIDS routinely requested that the significant other not discuss the diagnosis until the time the person with AIDS chose (Cowles & Rodgers, 1992). While wanting to respect this wish the significant other was denied needed moral support and placed in a dilemma resulting in frustration, stress, and isolation.

Maintaining hope in the face of hopelessness resulted in an emotional roller coaster effect (Cowles & Rodgers, 1992). When the person with AIDS appeared well there was an intense feeling of hope. The knowledge that no cure existed produced a simultaneous sense of hopelessness. As the disease progressed, hope turned to a desire to be with the loved one at the time of death and hoping that death would be relatively painless (Cowles & Rodgers, 1992).
A multitude of relationship changes took place for both the significant other and for the person with AIDS. Not only did the significant other have to deal with their network of family and friends but often had to act as liaison between the person with AIDS and their constellation of friends and family (Cowles & Rodgers, 1992). Changes also took place between the significant other and the person with AIDS. There was an increase in the degree of commitment to one another, a need to experience the disease process with their loved one, and a strong desire to maintain the relationship as it had been. If previous daily activities included sharing music, socialization with friends, or quiet conversation, these activities were maintained as possible during the illness.

One of the primary mechanisms for dealing with their role as significant other to a person with AIDS was the need to be actively involved. Involvement for most participants consisted of volunteering. Reasons cited for involvement in volunteer work were: sharing of personal knowledge about AIDS, serving as an advocate, and feeling more connected (Cowles, & Rodgers, 1992). This sense of connectedness may have served to offset some of the isolation the significant others suffered in not being able to openly discuss the diagnosis (Cowles & Rodgers, 1992).

**Partners and Coping**

Greif and Porembski (1988) conducted research on significant others of PWA to explore what helped or hindered coping and which significant others were most at risk emotionally. Significant other was defined to include partners as well as other significant
people in the lives of men with AIDS. Open-ended exploratory interviews with participants (N=11) lasted one to three hours. The respondents included three parents, two friends, two male lovers, three siblings, and one spouse. Three of the respondents were black and eight were white. All respondents had recently lost a significant other to AIDS.

Greif and Porembski (1988) identified eight categories that significantly altered coping. The three categories that appeared to help the significant others in positive ways were: support groups, friends of the significant others, and religion or religious affiliations. Support groups consisted of significant others of people with AIDS so respondents felt free to voice their feelings and thoughts. Five of the participants felt that speaking to friends about the death of the person with AIDS was of benefit. The six respondents who did not speak with friends cited shame and secrecy as reasons. Nine of the eleven respondents reported a renewed or continued faith in God both for themselves and for the person with AIDS. The belief in an afterlife brought comfort.

Two factors both helped and hindered coping. How the person with AIDS coped with the disease had great impact on how the significant other coped. Likewise, how health care professionals dealt with both the person with AIDS and the significant other was viewed as helping or hindering. Some health providers were viewed as friends while others were seen as taking away all hope (Greif & Porembski, 1988).
Three categories were seen by the respondents as hindering their coping (Greif & Porembski, 1988): funeral parlors; a sense of inadequate training and knowledge about AIDS; and friction between family members and significant others. Emotional tension between the lover and parent of the person with AIDS was common. In all but one family there was conflict and some rejection of the person with AIDS based on their diagnosis. One lover believed that family fighting hastened his partner's death.

Partners and Grieving

Ferrell and Boyle (1992), in their research, interviewed five gay men, ages 25 to 45 years, who had survived a partner who died of AIDS. The study was conducted after the partner's death and thus the survivors were able to provide experiential information about bereavement. The authors addressed bereavement experiences of the survivors and strategies the survivors developed to care for their partners during the terminal illness.

The four major categories of caregiving that assisted informants to cope with the anticipated loss of their partner were: commitment to care, taking care of oneself, managing alone, and dealing with the health care system. Each partner made a deliberate decision to remain in the relationship and care for the person with AIDS, a decision that was a first step in the bereavement process. In the category of taking care of oneself most of the informants made a conscious decision to continue to pursue personal plans. This decision involved conscious reflection of the partners' goals and as such helped the partners to look at the future. In managing alone none of the men sought professional
counseling during the terminal illness of their partner. Occasionally friends and family offered help, but the informants were able to totally manage the care in the early phase of the illness. In dealing with the health care system, respondents unanimously reported insensitivity and a lack of understanding from health care professionals. This led the partners to misrepresent their relationship with their lover to health care professionals. One partner was allowed to visit his dying lover in the ICU only after convincing staff he was a brother.

The three main themes Ferrell and Boyle (1992) identified during the bereavement experience were: identifying with the dying partner, seeking support of friends and families, and accepting the loss of the partner. In identifying with the dying partner the informants noted that a difficult and early task was to acknowledge their high risk for HIV infection. This reinforced their awareness of their own mortality. Once death occurred, the partners sought support of friends and family. During the illness the partners felt they were able to exert control. After death they experienced a sudden loss and feelings of helplessness. When the families of their lovers rejected the partners the grieving was further complicated. Some survivors were not allowed to attend funeral services. The last theme in the bereavement experience focused on acceptance of the death of their partner. The partners' attention and energy shifted over time from a focus on their lost one to themselves and their own needs. Their lives began to stabilize and they were able to make
plans for the future. Three of the five informants were also coping with threat to their own well-being as they were diagnosed as HIV positive (Ferrell & Boyle, 1992).

**Partners as Caregivers**

Ward and Brown (1994) conducted research on caregiving to a person with AIDS. The category of caregiver was defined to include lovers, spouses, parents, children, siblings, and friends (N=53). Two thirds were male, with a mean age of 36 years, and most were white. Households in which caregiver and the person with AIDS lived together (n=40) were the most common.

Both interview and questionnaire were used in the research. The interview consisted of open-ended questions intended to obtain qualitative data about the experience of caregiving. The questionnaire was the Time Assessment Interview Schedule (TAIS) developed by Ward and Brown (1994) for the purpose of this study. The TAIS addressed time spent in housework, additional housework hours since the person with AIDS became ill, duration of housework responsibility, percentage of total housework performed by the caregiver, and estimates of time spent assisting with six categories of caregiving: bathing and toileting, feeding and meal preparation, dressing and grooming, companionship, facilitating health care, and other caregiving activities. Caregiving tasks were divided into either housework or personal care (Ward & Brown, 1994).

Live-in and live-out caregivers did not differ significantly in the amount of time they spent providing personal care to the person with AIDS. The two caregiving groups
were similar in the amount of time spent in each category of activity with the exception that live-out caregivers spent more time in dressing/grooming activities and housework. This finding may be due to having to perform housework in two different households. Women spent more time in housework then men. The income of caregiver was inversely associated with time spent in care. Caregivers with incomes below $20,000 spent 10.4 hours per day in caregiving activities while those earning greater than $20,000 spent 6.1 hours (Ward & Brown, 1994).

The most time consuming and frequently performed activity was companionship. In this study, 99% of caregivers spent an average of 4.96 mean hours providing companionship. Qualitative analysis revealed that although caregivers acknowledged that companionship placed a significant demand on their time, they considered it one of the most important services provided. While only 30% of caregivers spent time on bathing and toileting and 28% spent time on dressing and grooming, these too were time consuming tasks, averaging over an hour and a half a day (Ward & Brown, 1994).

Ward and Brown (1994) concluded that the caregiving role is a complex one and a role that nurses must address with newly diagnosed patients and their caregivers. Caregivers must be prepared for what lies ahead: how to integrate caregiving into their lives, the time they will be able to spend outside the home in employment, and the actual time commitment in intensive home care. Acknowledgment must be given to the priority that caregivers assign to providing companionship. This priority setting may explain some
of the reluctance to use respite services. Ward and Brown (1994) note that the
consequences to caregivers of providing such intensive companionship has not been
explored.

Folkman, Chesney, and Christopher-Richards (1994) provided baseline data from
the University of California at San Francisco Coping Project, an on-going longitudinal
study of HIV positive (n=86) and HIV negative (n=167) caregiving partners of men with
AIDS, and a comparison group of HIV positive men (n=61) in relationships with partners
who are healthy. The goal of this research is to identify what contributes to maintenance
and decline of physical and psychological well-being of primary caregivers of a partner
with AIDS. Data collection began in April, 1990 and will conclude in September, 1997.
For inclusion in the caregiving group, individuals had to share living quarters with a
partner whom they identified as their main relationship. The sample is 90% white with an
average age of 36.6 years (Folkman, Chesney, & Christopher-Richards, 1994).

Data are collected through clinical assessment of depression using the CES-D.
This instrument, plus physical health, is evaluated at baseline and every 6 months
throughout the study. The participants also complete a semi-structured interview.
Baseline data from the entire sample on measures of depression, positive moods, and
instrumental needs of the partner with AIDS, and narrative data on the first 50 participants
were reported (Folkman, Chesney, & Christopher-Richards, 1994).
It was found that the HIV positive caregiver groups experienced significantly more depressive symptoms than did the HIV positive comparison group. Many factors may contribute to their depression: adjusting to the partners' unpredictable illness progression, shifting responsibility from the person with AIDS to the caregiving partner, stress of unexpected improvement in the partner's health, dealing with a virtually uncontrollable disease, role conflict, fatigue, and fears concerning their own future. While the caregivers were sad and afraid, their reactions could be interpreted as responses to reality (Folkman, Chesney, & Christopher-Richards, 1994).

Further exploration focused on the sense of well-being in the caregivers, specifically, what enabled the creation of good feelings during difficult times, and what enabled the caregivers to sustain good feelings. Two categories appeared important: creating meaning and ordinary events. Creating meaning allowed caregivers to activate deeply held beliefs and values concerning loving and being loved. Appreciating and reflecting on ordinary events allowed caregivers to step out of the maelstrom of AIDS to generate and sustain positive morale.

The authors concluded that although their research was based on a small portion of the data and thus should be considered preliminary, caregivers needed both practical and emotional support. Health professionals were encouraged to help the partners anticipate what is ahead, and guide them to appropriate resources. Also health practitioners should be prepared to discuss the variety of positive and negative emotions associated with the
caregiving role. Partners of those with AIDS need not become mired in the negativity that often surrounds them. An abundance of negative emotions can signal to health professionals that the partner is faltering and needs intensive intervention himself (Folkman, Chesney, & Christopher-Richards, 1994).

The review of literature suggests three concepts that appear germane to this study. The concepts of transition, role, and caregiving will be used as the conceptual orientation.

**Conceptual Orientation**

Some nurse authors argue that a conceptual or theoretical framework should not be used when conducting qualitative research (Field & Morse, 1985; Leininger, 1992; Morse, 1992). A conceptual orientation provides a background for a qualitative study when little previous research on the topic has been conducted (Hinshaw, 1979). Field and Morse (1985) describe qualitative research as an inductive process, leading to theory building, which occurs over a period of time. Theories begin to emerge while data collection is in progress and continue to be defined after data analysis has commenced. The qualitative researcher examines the data for recurrent descriptions, patterns and possible relationships and then returns to the setting to verify hypotheses (Field & Morse, 1985). As researchers explore in depth what the partner is experiencing, theories begin to emerge.
Transition

Meleis (1991) defines transition as a change in health, roles, expectations, or abilities. Transition requires the incorporation of new knowledge to change behavior, and therefore to change the definition of self in social context (Meleis, 1991). Commonalities characterize a transition period: disconnectedness from usual social network and support systems, loss of familiar reference points, new needs arising or old needs met in an unfamiliar way, and old sets of expectations no longer congruent with changing situations (Meleis, 1991). Transitions are processes that occur over time and can result in upheaval in personal life unless conditions easing transition are present. Schumacher and Meleis (1994) note that meanings attached to transition is one condition that an ease the change. If transition is viewed as positive and desired it will more likely be successful.

Expectations also influence transitions. People undergoing transition may believe they know what to expect only to find that belief unrealistic (Schumacher & Meleis, 1994). In that transition reflects the lived experience, the meaning and expectation related to transition is best understood from the perspective of the person undergoing transition.

The experience of living with a person with AIDS implies transition in adjustment to ongoing changes that may be physical, emotional, cognitive, and financial.

Role

It is postulated that in the lived experience of being the gay partner of a man with AIDS role change may occur. Hardy (1978) defines role as the expected and actual
behaviors associated with a position. People occupy role positions with attendant role expectations. Role stress is built into social structure, while role strain is the individuals' response to role stress (Hardy, 1978). Another concept that may be pertinent is role ambiguity. Hardy (1978) reports that lack of clarity in role expectations leads to both role ambiguity and role stress. Stress and the ambiguity of new roles may occur for partners of men with AIDS.

**Caregiving**

Skaff and Pearlin (1992) have examined role in conjunction with caregiving. When profound changes occur during assumption of the caregiving role, role strain can result. Persistent role strain adversely affects self-esteem and mastery (Skaff & Pearlin, 1992). In addition, caregiving activities may expand to a point where they have restructured and taken over roles the caregiver previously held. Skaff and Pearlin (1992) term this role engulfment or self-loss. As the caregiving role isolates the caregiver, there are fewer opportunities for outside positive feedback or sources for positive self evaluation. The greater the immersion in the caregiving role, the more vulnerable one is to self-loss (Skaff & Pearlin, 1992). Little is known about partners' perception of the effects of caregiving for a person with AIDS.

**Summary**

Qualitative research, using an inductive method, allows the emergence of theory. As data are collected and analyzed, theories emerge that are germane to the study. As
more knowledge is gained regarding human experience, comparisons can be made with existing theories. This allows the researcher not only to examine the uniqueness of each lived experience but also to view the research within the broad perspective of prior research. Due to limited knowledge regarding the lived experience of the gay male partner of a man with AIDS, qualitative research is the most appropriate approach for this study.

Research conducted to date confirms that significant others involved with men with AIDS face many difficult tasks and emotions (Ferrell & Boyle, 1992; Greif & Porembski, 1988). The difficulty of caregiving for a person with AIDS is a recurrent theme in research reports. Studies have been conducted on what constitutes caregiving, how caregiving affects partners, and companionship as an aspect of caregiving (Ward & Brown, 1994). Both positive and negative factors attached to caregiving have been reported (Folkman, Chesney & Christopher-Richards, 1994).

Some partners of gay men were better able to handle their partners' diagnosis of AIDS than others. Research shows that these partners are facing unique issues. Certain partners engage in dangerous behaviors while others are able to find meaning in the experience. Several factors affect how partners cope with having a lover with AIDS: available support systems, their HIV status, health professionals' support, and religion. The research has also explored factors that help or hinder coping during the bereavement process. Most of the negative processes appeared open to intervention by health care
professionals. However, the research also indicates that partners may not wish help during bereavement due to previous unsatisfactory interactions with health practitioners.

The conceptual orientation for this research consisted of concepts related to transition, role, and caregiving. Transition is a process that occurs over time and in which the self is altered (Meleis, 1991). Transition is best understood from the perspective of the person experiencing it. Transition may result in role change. At present it is unknown if having a multitude of roles confers benefits or risks, although current research (Skaff & Pearlin, 1992) is beginning to identify benefits. Clarification regarding role can result from exploring the partners' lived experience. The process of caregiving can involve transition and role change as one becomes a caregiver. Total immersion in the caregiving role may curtail other roles, positive feedback, and a sense of self-esteem. This may lead the caregiver to role engulfment or loss of self. Little is known about partners' perception of caregiving or what transitions or role changes the partner may undergo.
CHAPTER THREE

METHOD

Chapter Three presents the research design, sample and setting, protection of human subjects, data collection method, instrument, and plan for data analysis. Phenomenology and its relevance to this research are addressed.

Research Design

There is agreement in the literature on what type of design yields what type of information (Colaizzi, 1988; Field & Morse, 1985; Leininger, 1992; Lincoln, 1992; Taylor, 1993). Hard data, control, logic, power, instrumentation, and especially objectivity are the claims of quantitative research (Lincoln, 1992). Some nurse researchers, however, postulate that this is not the only way to conduct research (Field & Morse, 1985; Leininger, 1992). Phenomenology is gaining credence as nurse scientists acknowledge that nursing, most particularly in clinical practice, is a set of human actions having human consequences.

In qualitative research the answer to the ontology question is that there is not one reality but many. Lincoln (1992) believes these realities are multiple mental constructs held by individuals and influenced by society, culture, and geography. In examining the lived experience of the partner it is these multiple realities that can provide nursing with a meaningful description of their experience. This study was not concerned with generating numbers by counting how many people with AIDS live with partners or even how many
people consider themselves a partner. Rather this study assumed that partners exist and sought to holistically explore their realities.

In this vein the epistemological stance follows naturally. Lincoln (1992) notes that subjective epistemology places one in an interactive position. The researcher is not separate from the partner or the lived experience, but is an integral part. From the fusion of researcher, participant, and studied phenomenon emerges an entity that would not exist without that unique interaction. In qualitative research the investigator does not stand alone, but instead actively facilitates and participates in the research process.

Because of this participation the researcher does not employ a method that seeks to control, predict, or experiment. In a real sense the researcher becomes the instrument used. Constructs are illuminated through skillful questioning and empathetic listening. Interactions between researcher and participant serve to allow deeper understandings of the phenomenon of interest to emerge. Through intersubjective agreement between researcher and participant, the essence of the lived experience of being a partner to a person with AIDS can be revealed. This understanding will augment nursing's knowledge base, thus continuing to add depth and sophistication.

Lincoln (1992) makes an especially persuasive argument for the use of qualitative research when studying health related issues. Most aspects of health are social, behavioral, and community oriented (Lincoln, 1992). Health is practiced in the community and, rightly, that is where it should be studied. Health is also intricately tied to
a person's dreams, hopes, values, beliefs and attitudes. Health does not exist in a vacuum
and can not be completely understood in the sterility of a laboratory setting. Lincoln
(1992) also notes that health can no longer be viewed as simply absence of disease but
rather as a more complex interaction that encompasses more than direct causal chains. By
the use of qualitative research the subtle interplay between humans, environment, health,
and nursing can be fully explored.

When doing research with human subjects it is also important to consider the
issues of deception, control, and authority. A qualitative approach helps to control these
problematic areas. Deception is avoided in that the subjects speak for themselves. As
constructs are sought and the researcher encourages the participant to expand the lived
experience to its fullest, ultimately control and authority rests with the participants
(Lincoln, 1992). Participants control the right to say what is significant in their lives.
Deceit, control, and manipulation are removed from the inquiry process by the shift of
authority to the participant. This is appropriate since no person can define for another the
complex interplay of factors that determine their perception of their reality.

The philosophical perspective for this study was phenomenology and the tenets of
phenomenology were followed. Hycner (1985) notes that foremost one must be true to
the phenomenon and consciously open to the phenomenon as an event in its own right
with its own meaning and structure. Leininger (1992) states that in remaining open to the
phenomenon one is able to grasp the totality of life contexts, beliefs, values and sociocultural influences.

At the core of phenomenology is the belief in the value of the emic perspective (Field & Morse, 1985). Smith (1991) argues that each person structures their own world view in light of complex experiences. Human beings are participating subjects, free in situations, and able to choose meaning and values while bearing the consequences of their choices (Smith, 1991). This implies that the researcher is not the expert and at best can strive to grasp the meaning of the phenomenon only through respecting and valuing the emic point of view.

Taylor (1993) argues that phenomenology is particularly suited to studies conducted by nurses. A crucial question in deciding method of inquiry is whether people can be explained fully by physical science methods. Taylor (1993) argues that the real world of nurses involves human actions having human consequences and thus cannot be fully understood by a scientific approach that seeks to measure objective knowledge alone. Intersubjective elements such as intention and meaning can not be ignored. Rather phenomenology and nursing are equally concerned with understanding the total experiences of people as they live their day to day existence (Taylor, 1993).

Taylor (1993) reports that the aesthetics, personal knowledge, and ethics in knowing how to practice nursing are essentially qualitative concerns. Phenomenology addresses the unique humanness and wholeness of both researcher and participant and
recognizes that multiple meanings are assigned to the complex topic of health. In phenomenology the aim is to grasp the total essence of humans. Nothing that affects humans, be it social or cultural cues, emotions, or values, is ignored in the phenomenological research design (Leininger, 1992).

Phenomenology seeks to explore the nature of human reality. Reality for each person is dependent on culture, locale, values, and personal experiences. Realities are ongoing, multiple constructs that embrace not only who one is, but where one stands. Each person's reality is thus both unique and tied to the society of which one is a member. To know that reality, one must enter into it. To hear or know of another's reality exerts an influence on the researcher and in the telling the subject is influenced by the reactions of the listener. The process of interaction is the context from which the research is created (Lincoln, 1992). By comparing and contrasting constructs between researcher and participant, what emerges is better understood than constructs held previously. The researcher assumes an expansionist, nondeterministic stance and serves as a co-participant in the inquiry process (Lincoln, 1992).

The goal of phenomenology is to "know" an experience from the perspective of those living the experience. The way of knowing is through listening and immersion in the experience. Leininger (1992) sees phenomenology as a means to grasp the totality of being human. Words are the focus of phenomenology and allow perceptions, values, sociocultural beliefs, and life contexts to be revealed. As a research approach
phenomenology is useful in answering the question: "What is the lived experience of being a gay male partner of a man with AIDS?" Through phenomenology the participant is encouraged to explore the nuances of what the experience means on a personal level. As the phenomenon unfolds, the researcher is granted an understanding that far surpasses words or numbers. The gestalt of the phenomenon is captured in its explicit and implicit totality (Leininger, 1992).

Sample and Setting

The criteria for inclusion in this study were: 1) male, age 18 years of age or older, able to speak, read, and write in the English language; 2) gay/homosexual sexual preference, self described as the sexual partner, either now or in the past, of the gay male with AIDS with whom they live; 3) involved in a form of caregiving for their partner.

The sampling for this study was purposive in that subjects were consciously selected to meet the above criteria (Burns & Grove, 1993). It was expected that a homogeneous group of three to four participants would be sufficient to provide deep and rich detail regarding their experience. Large sample sizes are rarely used in phenomenological studies as data collection and analysis becomes unwieldy (Hycner, 1985).

The researcher designed flyers inviting participation in the study and obtained permission to place flyers at several local AIDS organizations. A copy of a flyer is presented in Appendix A. Self selection was the only acceptable method for inclusion in
the study. "Snowball" sampling was avoided as it could have led to a breach of confidentiality.

The researcher conducted all interviews at a place convenient and comfortable to the participants. One interview took place in a participant's home. This participant chose to have the person with AIDS present for a portion of the interview. The other two interviews took place in a room at the College of Nursing, University of Arizona, with only the participant and researcher present.

Protection of Human Subjects

The researcher obtained permission to conduct the study from the Human Subjects Committee of the University of Arizona. Several pieces of information were essential for informed consent (Appendix B): statement of the research purpose, careful selection of subjects, full explanation of procedures, description of risks and discomforts, description of benefits, disclosure of alternatives, assurance of anonymity and confidentiality, offer to answer questions, noncoercive disclaimer, option to withdraw without compromise to health care, and consent to incomplete disclosure (Burns & Grove, 1993). Consent to incomplete disclosure was important in this study as the participants' responses could not be reported in totality in order to protect privacy and confidentiality. The participants were made aware that only excerpts of their responses would be reported.

In addition to informed consent, other ethical considerations such as autonomy, confidentiality, privacy and non-maleficence may have an impact on research (Ford &
Reutter, 1990). This was especially important when conducting research with a vulnerable
group and small sample size. The size of the group and the fact that the geographic
location where the research was being conducted had a presumed relatively small
population of AIDS cases could lead to the "one-of-a-kind" phenomenon (Ford & Reutter,
1990, p.188) where certain persons have a high profile in a particular group. Because of
small group size it could have been relatively easy for participants to identify who
provided what information. This posed a threat to confidentiality. The threat to
confidentiality was addressed by the use of code numbers on data sheets and use of
pseudonyms in reporting results. Potentially identifying data, such as demographic
information, were retained to assure transferability. This research depended on quotes
which may have included information unique to the participant. Participants were
informed that all efforts were made to maintain confidentiality, but there was the potential
that quoted excerpts might be recognized as coming from the participant.

The issue of confidentiality was discussed in the original interview. One partner
had no misgivings over confidentiality as his sexual preference was known to family and
friends. Two partners were concerned that either their school peers or place of
employment would learn of their sexual orientation. After discussion of protection of
human subjects, participants decided this issue was not a deterrent to participating in the
study.
Invasion of privacy was more amenable to researcher control. Conducting the research in a location of the participant's choice allowed a degree of control over domain. Similarly, caution was exercised to minimize the intrusiveness of questions. Inquiry was kept to the phenomenon of interest. It was believed that these precautions, the signed informed consent, and the fact that participants had reached the age of majority all served to protect participants' privacy.

Non-maleficence, not doing harm, was another ethical principle that was addressed. This group was vulnerable in the stigma attached to homosexuality. Their vulnerability was also an issue because they were/are intimate with a person with HIV. In this study the potential existed for recalling painful memories. Nurses in research have an ethical obligation to remedy this situation by listening, offering support, and referral for counseling when appropriate (Munhall, 1988). The researcher obtained information on counseling services available for participants. The researcher was prepared to refer the participant for counseling, as judged necessary by the researcher and participant, to address any extreme discomfort the participant had experienced. None of the partners reported distress during the interview and none wished to seek counseling.

Another ethical consideration in research with human subjects is reciprocity. It was necessary to consider what the researcher "owed" the partners for their cooperation. Munhall (1988) proposes that through an ongoing process of informed consent the participants are actually collaborators in the research and thus are owed only the respect
given to any collaborator. Through engagement in research the participant's own construction of reality may mature (Guba & Lincoln, 1989). Partners participated in member checks and received a summary of conclusions drawn by the researcher. Participants were given the results of the study and empowered to act on them, which reflected reciprocity in the research process.

Data Collection Methods

Prior to the initiation of data collection the researcher reviewed personal assumptions regarding the phenomenon of interest and used the process of bracketing (Hycner, 1985). Bracketing is defined as writing down and setting aside any preconceived ideas or judgments (Hycner, 1985). A colleague was valuable in bringing out presuppositions of which the researcher was not aware (Hycner, 1985). The constructions formed by the researcher were not given preference over constructs from the participants (Hycner, 1985). The thesis chair, the thesis committee members, and a peer proved invaluable for addressing questions of bias and subjectivity.

An initial fifteen minute introductory contact was made to obtain informed consent and to discuss confidentiality. The participants received a written copy of the informed consent and a verbal explanation of the rights presented in the informed consent. Thereafter the researcher conducted one data collection interview ranging from 90 to 110 minutes (M = 105) with each of the three subjects. A final one hour follow up meeting took place with each participant to conduct a member check to validate findings from the
data collection interview and to leave follow up information regarding obtaining results of the study. Thus each participant was asked to donate approximately two to three hours of their time. The data collection interview was face-to-face and audiorecorded. The researcher transcribed the audiotapes, kept them in a locked file in the College of Nursing when not in use, and erased them after transcription. Field notes were made on nonverbal behavior of the participant, the environment, and the researcher's reaction to the interview.

Instrument

Each participant was asked a set of demographic questions at the start of the data collection interview (Appendix C). Then each participant was asked the following data generating question: "What is it like for you, as a gay man, to be the partner of a man with AIDS? Describe this experience as fully as possible, including your thoughts, emotions, problems, successes, and caregiving activities." The researcher gave each participant a written copy of the data generating question at the time the informed consent was signed. This allowed for a period of thoughtful consideration before interview took place. Any additional questions asked during the data collection interview were in response to the participant's comments and focused on the phenomenon of interest.

Data Analysis

Guba and Lincoln (1989) suggest that level of analysis coincides with the purpose of the study. The analytic purpose of this study was to identify themes revealed by gay partners of people with AIDS. This research used the analysis strategy outlined by
Colaizzi (1983). Following these analytical steps led to discovery of an essential structure to answer the original research question.

First all data were read and the participant's descriptions, termed protocols by Colaizzi (1983), were transcribed. Protocols were read several times to ensure immersion in the phenomenon. At this point the entire interview was transcribed on the researchers' computer using Microsoft Works. The second step involved returning to each protocol and extracting significant statements (SS). These were words or phrases and there were 671 significant statements. Repetitions and pronouns were eliminated and language was placed in more formal terms. Each significant statement was numbered in the text of the interview. The original copy was kept on disk and another copy made that eliminated all but significant statements. An example of raw data from the protocol and extraction of the significant statement follows.

Data: This was sort of like the double wammy. I found out about my brother [having AIDS] before I found out about Jason [pseudonym] So ... it's been a big roller coaster.

SS: Partner feels emotions excessive and in flux.

The third step was to formulate meaning from the significant statement by a "leap from what the subjects say to what they mean" (Colaizzi, 1983, p. 59). This step required intuition and the ability to move beyond the words while remaining true to the data. Care was taken to avoid judgments or the imposition of pre-existing theories. Formulated meanings (FM) were placed on numbered, color-coded index cards to identify the partner
and data location in the protocol so that the statement could be referred to as needed. For the third step the following formulated meaning emerged.

FM: Excessive emotions and feelings of emotional flux.

In the fourth step, formulated meanings from step three were studied for common themes. A total of 69 themes emerged from the data. All data did not fit neatly into themes and some themes contradicted others. Contradiction was dealt with by reporting each partners' belief. Themes were examined in relation to the original protocols to ensure that nothing in the protocols was left out of a theme and that themes did not move beyond that which was implied in the protocol. The above example of data was placed under the theme: partners' emotions.

An example of a common theme was ambivalence regarding remaining in the relationship with a person with AIDS. All partners discussed ambivalence, which provided the basis for a thick description of this theme. Data related to the theme of ambivalence regarding remaining the relationship follow.

Partner #1: "I guess it would have just been easier to have left earlier on"

Partner #2: "If there wasn't the AIDS situation maybe I would have concluded the relationship and moved on."

Partner #3: "There's part of me that's saying I want out ... there's part of me saying I want the relationship even though it won't be a long term relationship."
The fifth step was to integrate themes into theme clusters (Colaizzi, 1983, p. 59). Themes from all partners were analyzed to determine the theme clusters. There were 23 theme clusters.

The sixth step involved identifying the theme categories (Colaizzi, 1983, p. 61). At this stage theme clusters were reviewed for commonalities and grouped accordingly. There were 8 theme categories.

The seventh step was developing the exhaustive description (Colaizzi, 1983, p. 61). This was a narrative description of the lived experience in which each theme, theme cluster, and theme category was presented thus ensuring the experience was reported in its totality.

The eighth, and last step, was developing the essential structure. The essential structure was the formulation of a holistic description of the lived experience of being a gay male partner to a gay man with AIDS.

An example of the complete data analysis method follows.

SS: "The doctor said, 'well, no, you'll probably only be around for a couple of years' ".

RS: Person with AIDS told life expectancy less than originally believed.

FM: Medical comment viewed negatively.

Theme: Reactions to medical issues.

Theme Cluster: Medical issues perceived negatively.
Theme Category: Interactions with Physicians.

Data analysis was an on-going process. As theme clusters began to emerge they were verified by both the participants and independent auditors, including the thesis chair and committee members. This process ensured fidelity to the data. In sum, phenomenology was a process in which the researcher moved among data, thoughts, colleagues, and partners participating in the research in an effort to understand the holistic experience being studied.

Trustworthiness of the Research

Criteria by which the trustworthiness of this research was judged are credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Supporting credibility was a two-fold task in which the researcher conducted the study in a manner to support credible findings and then enhanced the credibility of the research by conducting member checks, which is verification of findings with participants (Lincoln & Guba, 1985). After the data collection interview partners were contacted once by telephone during data analysis and read portions of themes. There was agreement on theme content even when the specific theme was not one the partner had addressed. After completion of data analysis a meeting with each partner, to conduct member checks, was held and the researcher provided the subjects with a copy of the exhaustive description (Appendix D) prior to the meeting. Partners agreed that, overall, content was appropriate and had no suggestions for alterations.
Transferability is the ability to apply the findings from one study to another setting or similar population (Lincoln & Guba, 1985). The researcher cannot predict how study findings will be transferred. Thus it is the researcher's responsibility to provide sufficient descriptive data about the sample so transferability can be judged by the reader.

Transferability was addressed in two ways. First purposeful sampling was used (Burns & Grove, 1993). Second the researcher provide an example of "thick description" in this thesis to enable other researchers and clinicians to judge applicability to their own settings (Guba & Lincoln, 1989, p. 316). The exhaustive description (Appendix D) provides a thick description of the results of this study.

Dependability is an examination of the process of conducting research and a review of data to ensure accuracy (Lincoln & Guba, 1989). Dependability was ensured through the inquiry audit. The process of data analysis was verified by the chairperson of the thesis committee as each step was completed. The thesis chairperson reviewed the significant statements, restatements, formulated meanings, themes, theme clusters, and theme categories and compared them to original protocols for accuracy and completeness. In addition, the researcher provided thesis committee members with random samplings of data to verify process of analysis and accuracy of content.

Confirmability refers to the data themselves, as being separate from the researcher, and able to be substantiated objectively. Confirmability is a process by which the outcome, or essential structure, is found to be supported by the data and internally
consistent (Lincoln & Guba, 1985). Confirmability was supported by the reflexive journal in which the researcher recorded personal biases, thoughts, and emotions regarding protocols and emerging theories and used the journal to monitor data analysis. Also notes pertaining to uncertainty of content were written in margins of the protocols. The notes were reviewed by the thesis committee chairperson and either confirmed as correct or explored further. The researcher discussed information contained in the journal with thesis committee members. The thesis chairperson conducted an inquiry audit, tracking analysis of data from original transcriptions of interviews through each step of analysis.

Summary

Phenomenology as a research design is gaining increasing acceptance among nurse researchers as a method for holistically exploring concepts of person, health, and environment. Human reality is acknowledged as a complex interaction of many factors and phenomenology allows the researcher to more fully understand the reality of others. In that nursing is a human science phenomenology is germane in exploring the issues related to gay partners of men with AIDS.

The criteria for inclusion in this study and the setting in which the research was conducted have been explicated in this chapter. This research explored the lived experience of gay male partners who live with, and participate in caregiving for their partner with AIDS. To facilitate comfort, data collection took place where the participant
chose. All partners signed an informed consent and discussed the issues of privacy and confidentiality.

Data were handled in a confidential manner by the use of code numbers and pseudonyms. Security of data were assured by keeping original audiorecordings locked in the College of Nursing until transcribed, then erased. Data were analyzed using a process designed by Colaizzi (1983). Chapter Three includes examples of the process of data analysis to clarify induction from protocols to theme categories. Fidelity to data was assured by verification by both thesis committee members and partners.

Trustworthiness of the research was addressed using the concepts of credibility, transferability, dependability, and confirmability as set forth by Lincoln and Guba (1985). Partners reviewed themes, theme clusters, theme categories, and the exhaustive description and agreed that content was valid. Thick description emerged from the research. Although all participants did not discuss all themes there was significant overlap of themes to assure a similarity in the lived experience of being a gay male with a person with AIDS.
CHAPTER FOUR

RESULTS

Chapter Four presents a description of the sample and results of the study. Presentation of the results includes data from the original protocols.

Description of the Sample

The sample for this study consisted of three men who considered themselves gay males living with a gay man with AIDS. Demographic data of the partners and the person with AIDS are presented in Table 1. Partners were involved in a variety of caregiving activities. All partners reported companionship as a form of caregiving. Other caregiving activities were involvement with medical care, emotional support, financial support, running errands, and performing household chores such as meal preparation. Hours spent in caregiving activities ranged from one hour per day to three hours per day with one partner being unable to provide a time estimate.

Results of Data Analysis

From 23 theme clusters there emerged eight theme categories. The theme categories are presented in Table 2.

Theme Categories

Each theme category will be defined, discussed and excerpts illustrating the theme category are presented.
The Diagnosis of AIDS.

The theme category The Diagnosis of AIDS was defined as learning and accepting the AIDS status of both the person with AIDS and the partner and dealing with issues related to learning and accepting both. Table 3 reflects the 11 themes and 3 theme clusters that comprise the theme category The Diagnosis of AIDS. In this theme category partners learned of the person with AIDS positive HIV status, learned their own negative status, and developed strategies for coping with the newness of the diagnosis. Partners reported the person with AIDS sometimes blamed outside forces for contracting AIDS but partners did not find it an issue how the person with AIDS contracted the disease. Partners were aware of AIDS. Partners stated that both themselves and the person with AIDS experienced an abundance of positive and negative emotions related to the illness of AIDS. Partners felt ambivalence about remaining in a relationship with a person with AIDS, describing perceived gains and losses in maintaining the relationship.

The following quotation was taken from the theme, knowing the person with AIDS status.
Partner #1: "And then his doctor, he didn't have anything wrong with him, his doctor just suggested he get tested because the doctor said everyone should really. And he did and he found that out."

The following quote was taken from the theme, finding out own status.
Partner #3: "I wasn't sure of my HIV status because I had been celibate for about 10 years prior to that and the whole issue of AIDS terrified me."
<table>
<thead>
<tr>
<th></th>
<th>Partner #1</th>
<th>Partner #2</th>
<th>Partner #3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>29</td>
<td>37</td>
<td>31</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Hispanic</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td>Student</td>
<td>Educator</td>
<td>Student</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td>&lt;$15,000</td>
<td>$15,001-$35,000</td>
<td>&lt;$15,000</td>
</tr>
<tr>
<td><strong>Years of Education</strong></td>
<td>some college</td>
<td>college graduate</td>
<td>college graduate</td>
</tr>
<tr>
<td><strong>Years in Relationship</strong></td>
<td>6</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td><strong>HIV Status</strong></td>
<td>negative</td>
<td>negative</td>
<td>negative</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>PWA #1</th>
<th>PWA #2</th>
<th>PWA #3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>42</td>
<td>44</td>
<td>41</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Hispanic</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td>$15,001-$35,000</td>
<td>$15,001-$35,000</td>
<td>&lt;$15,000</td>
</tr>
<tr>
<td><strong>Years of Education</strong></td>
<td>high school</td>
<td>college graduate</td>
<td>high school</td>
</tr>
<tr>
<td><strong>Time Since AIDS</strong></td>
<td>1 year,10 months</td>
<td>10 years</td>
<td>1 year</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CD4 Count</strong></td>
<td>3</td>
<td>108</td>
<td>198</td>
</tr>
</tbody>
</table>
Table 2

**Theme Categories**

1. The Diagnosis of AIDS
2. Disclosure
3. Interactions with Physicians
4. Self Care
5. Caregiving
6. Gains from a Relationship with a Person with AIDS
7. Internal Struggles
8. The Process of Loss
Table 3

Themes and Theme Clusters for the Theme Category, The Diagnosis of AIDS

<table>
<thead>
<tr>
<th>Theme Cluster</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning and Accepting Person With AIDS Status</td>
<td>Knowing PWA status</td>
</tr>
<tr>
<td></td>
<td>Behaviors related to contracting AIDS</td>
</tr>
<tr>
<td></td>
<td>Person with AIDS blaming outside forces</td>
</tr>
<tr>
<td></td>
<td>Not an issue how contracted</td>
</tr>
<tr>
<td></td>
<td>Newness of diagnosis</td>
</tr>
<tr>
<td>Partner's HIV Status</td>
<td>Awareness of AIDS</td>
</tr>
<tr>
<td></td>
<td>Finding out own status</td>
</tr>
<tr>
<td>Issues Following Diagnosis</td>
<td>Person with AIDS reactions</td>
</tr>
<tr>
<td></td>
<td>Partners' reactions</td>
</tr>
<tr>
<td></td>
<td>Ending the relationship</td>
</tr>
<tr>
<td></td>
<td>Maintaining the relationship</td>
</tr>
</tbody>
</table>
The following quote was selected from the theme, person with AIDS reactions.

Partner #1: "First he immediately got sick. He didn't have to go to the hospital or anything but he got real depressed and would just sit around and all of a sudden he was saying he couldn't breathe and his legs hurt and this was immediately after he found out so I think it was just all in his mind."

The following data illustrated the theme, maintaining the relationship.

Partners #2: "I think it's important that ... I think that Martin [pseudonym] wants to feel that he's going to be taken care of or that he doesn't want to be by himself during this time. There's friends but I think more he wants to have a person ... you know, a partner. I accept that and I want to be there."

These four theme quotes served as examples from each theme cluster. In addition the previous data illustrated the relationship among the theme, maintaining the relationship, the theme cluster, issues following diagnosis, and the theme category The Diagnosis of AIDS.

**Disclosure.**

The theme category Disclosure was defined as the process of deciding to reveal sexual orientation and AIDS status, while weighing potential benefits and risks in revealing. Table 4 reflects the five themes and two theme clusters that comprise the theme category Disclosure. There were difficult issues surrounding disclosure of not only sexual orientation but HIV status. Decision making regarding AIDS disclosure was left to the
<table>
<thead>
<tr>
<th>Theme Cluster</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decisions Regarding Disclosure</td>
<td>Decision making</td>
</tr>
<tr>
<td></td>
<td>Who has been told</td>
</tr>
<tr>
<td></td>
<td>Pros and cons of disclosing</td>
</tr>
<tr>
<td>Danger in Disclosing</td>
<td>Burden</td>
</tr>
<tr>
<td></td>
<td>Public reactions</td>
</tr>
</tbody>
</table>
person with AIDS. Partners believed who was told about the AIDS diagnosis was a function of acceptance of the couple as gay, willingness to hear, and ability to cope with the diagnosis. Feelings of closeness entered into the decision to disclose both sexual preference and the AIDS diagnosis. Partners felt both positive and negative emotions about the person with AIDS disclosing their diagnosis. Partners feared discrimination and stigmatization while simultaneously wishing for disclosure so needed support would be forthcoming. Partners recognized the burden that disclosure placed on family and friends. In addition partners felt that public reactions to disclosure needed to be considered. The following quote illustrated the theme, who has been told.

Partner #2: "And she [partners' mother] was very ... she responded ... she very much wanted to know and she sort of maybe knew because of mothers intuition or whatever."

The theme, burden, was illustrated by the following quote.

Partner #2: "And we had to worry ... with his parents and with mine because you know the burden and you know you don't want to be a further burden."

The following quote illustrated the relationship among the theme, who has been told, the theme cluster, decisions regarding disclosure, and the inclusive theme category of Disclosure.

Partner #3: "For example, she [partners' mother] doesn't know I have a room mate. She doesn't ... I've never been out of the closet with her although I imagine she suspects very strongly. I don't think a mother can be that close to her kids and not have this sixth sense
about what's going on in their life. I don't exactly know how to come out and tell her that I'm living with Jason and Jason is HIV positive."

**Interactions with Physicians.**

The theme category Interactions with Physicians was defined as communication patterns the person with AIDS and partner had with physicians, reflecting issues related to trust, appropriate information, and medical care. Table 5 illustrates the six themes and three theme clusters that compose the theme category Interactions with Physicians. In this theme category partners had difficulties with communication with physicians. One partner was aware that physicians had made professional mistakes. Two partners felt that their expectations of physicians were not being met. Partners perceived that either not enough information was shared or that they were unprepared for what information was given. Home care and hospitalization were two areas in which partners had difficulty coping. In general the partners reacted negatively to medical issues, with one partner experiencing medical issues of his own.

The following data were drawn from the theme, mistakes.

Partner #3: "It [AIDS test] didn't say negative, it said inconclusive. But he [physician] had told Jason that that means negative, that's the same thing. Well that's not what it means you know. Negative is not the same as inconclusive."
Table 5

Themes and Theme Clusters for the Theme Category, Interactions With Physicians

<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Issues of Trust</td>
<td>Mistakes</td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
</tr>
<tr>
<td>Problems With Communication</td>
<td>Not receiving enough information</td>
</tr>
<tr>
<td></td>
<td>Not prepared for information</td>
</tr>
<tr>
<td>Medical Issues Perceived Negatively</td>
<td>Home care and hospitalization</td>
</tr>
<tr>
<td></td>
<td>Reactions to medical issues</td>
</tr>
</tbody>
</table>
The following data were from the theme, not receiving enough information.

Partner #1: "They [physicians] sat down and talked with us ... sort of ... but not really though."

The following data illustrated the theme, reactions to medical issues.

Partner #2: "I just got diagnosed with TMJ and I think a lot of it particularly in the last year, things aren't as smooth and even keel as they have been with his health and this is beginning to effect my health."

An example of the relationship among the theme, not receiving enough information, the theme cluster, problems with communication and the inclusive theme category of Interactions with Physicians follows.

Partner #1: "They [doctors] can't tell you what it was so I was just thinking they were going to remove his whole stomach and he was going to have a bag or something and it was going to be real horrible but he ended up coming out of it and recovering. It was real scary."

Self Care.

The theme category Self Care was defined as strategies of the person with AIDS and partner to maintain physical, emotional, or spiritual health. Table 6 includes the ten themes and three theme clusters that comprise the theme category Self Care. In this theme category boundaries were set by partners in their efforts to maintain a focus on self and not become enmeshed with the person with AIDS. Partners believed they had begun to
practice self care as had the person with AIDS. Volunteering was a form of self care that some partners found satisfying. Partners were able to set limits with the person with AIDS and retain a sense of independence thus fostering their emotional health. Partners believed spirituality, family, support groups, friends, and counseling were valuable forms of self care.

The following data was extracted from the theme, volunteering.
Partner #2: "One of the things I do to keep healthy is I go to a meeting and keep involved in the volunteer work."

The following quote was from the theme, maintaining independence. Partner #3: "I don't feel bound like I'm fighting to get him on my health insurance or buying a house together. I wouldn't go that far because I want to retain a little bit of independence."

The following data was drawn from the theme, support groups.
Partner #1: "I've tried to make a support network or whatever. You know my mom is real supportive about it. And I go to that group and I see that counselor there. I have another lady I talk to, a friend I met through Shanti."

An example of data processed through the theme of setting limits to the theme cluster of maintaining focus on self to the final theme category of self care follows.
Partner #2: "We'll sit down and say lets take 10 minutes to discuss this thing and move on ... we don't just go on about it for 4 or 5 hours. I do try and give him boundaries. I'm just not going to dwell on it and discuss and discuss ..."
Table 6

Themes and Theme Clusters for the Theme Category, Self Care

<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Taking Care of Oneself</td>
<td>Person with AIDS self care</td>
</tr>
<tr>
<td></td>
<td>Partners self care</td>
</tr>
<tr>
<td></td>
<td>Volunteering</td>
</tr>
<tr>
<td>Maintaining Focus on Self</td>
<td>Setting limits</td>
</tr>
<tr>
<td></td>
<td>Maintaining independence</td>
</tr>
<tr>
<td>Forms of Support</td>
<td>Spirituality</td>
</tr>
<tr>
<td></td>
<td>Family</td>
</tr>
<tr>
<td></td>
<td>Support groups</td>
</tr>
<tr>
<td></td>
<td>Counseling</td>
</tr>
<tr>
<td></td>
<td>Friends</td>
</tr>
</tbody>
</table>
The theme category Caregiving was defined as the partners' actions and emotions about caring for the person with AIDS. Table 7 illustrates the six themes and two theme clusters of the theme category caregiving. In the theme category of caregiving there was emotional depletion associated with caregiving. Partners viewed caregiving as a multitude of activities which included being there for the person with AIDS and performing activities to make life easier for the person with AIDS. However partners expressed doubt that these activities were of value. One partner felt that practicing altruism by engaging in activities for the person with AIDS's sake was a form of caregiving while one partner felt that caregiving should be a joint venture with the couple solving problems together. Partners felt frustration and helplessness in offering emotional support. One partner suffered negative effects from caregiving and perceived he had no additional resources to offer. Other partners felt an uncertainty with the caregiving role, wondering if the caregiving they gave was meaningful or helpful.

The following quote illustrated the theme, concrete examples.

Partner #3: "Say my car for example because Jason doesn't have a car. And if he has a lot of doctor things I'll let him use the car. I don't think I give any financial support. We both contribute into a pool."
Table 7

Themes and Theme Clusters for the Theme Category, Caregiving

<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Examples of Caregiving</td>
<td>Altruism</td>
</tr>
<tr>
<td></td>
<td>Concrete examples</td>
</tr>
<tr>
<td>Emotions Related to Caregiving</td>
<td>Caring as a joint venture</td>
</tr>
<tr>
<td></td>
<td>Emotional support</td>
</tr>
<tr>
<td></td>
<td>Negative aspects of caregiving</td>
</tr>
<tr>
<td></td>
<td>Uncertainty as caregiver</td>
</tr>
</tbody>
</table>
The following data was taken from the theme, uncertainty as a caregiver.

Partner #1: "And there was really nothing I could say ... except, you know, try to be there for him and, you know, be supportive."

An illustration of the theme, negative aspects, the theme cluster, emotions related to caregiving, and the theme category of caregiving follows.

Partner #3: "It's something that I've been trying to deal with with my counselor right now because bottom line is that Jason does not have any emotional support from anyone. Which means he will necessarily draw that from me. And ... I'm starting to get drained. I really am."

**Gains from a Relationship with a Person with AIDS.**

The theme category Gains From a Relationship with a Person with AIDS was defined as the partners' perception of positive aspects of partnership with the person with AIDS. Table 8 presents the five themes and two theme clusters for the theme category Gains From a Relationship With a Person with AIDS. Gaining knowledge of AIDS was viewed by the partners as an advantage of a relationship with a person with AIDS. Partners expressed trust in the person with AIDS. Partners believed that communication was integral to the relationship and felt that communication between the couple had improved since the AIDS diagnosis. An awareness of health issues was seen by the partners as an advantage of a relationship with a person with AIDS. Partners felt they had
<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growing Together</td>
<td>Trust</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Improving relationship</td>
</tr>
<tr>
<td>Learning</td>
<td>Health issues</td>
</tr>
<tr>
<td></td>
<td>Becoming philosophical</td>
</tr>
</tbody>
</table>
changed and learned to become more philosophical since being involved with a person with AIDS.

The following data were from the theme, communication.

Partner #2: "About that same time he said you know, you're right, I don't always want to talk about it [AIDS] but if you ever have any questions feel free, feel comfortable asking me. So I would and that sort of opened the door."

These data illustrated the theme, becoming philosophical.

Partner #1: "I just feel like I don't let the small things bug me anymore. And ... well I just like feel you should be more careful with your time because you never really know what's going to happen."

The following data illustrated the theme, health issues, the theme cluster, learning, and the theme category gains from a relationship with a person with AIDS. The partner gained knowledge about AIDS and the treatment of AIDS.

Partner #3: "One thing that did help a lot was learning as much as I could about the disease. Learning about the different types of opportunistic infections. Learning about the medications that are given."

Internal Struggles.

The theme category Internal Struggles was defined as partners' personal difficulties with issues related to belonging to a subculture, being in a relationship with a person with AIDS, having uncomfortable emotions, and going through transitions. Table 9 presents
Table 9

Themes and Themes Clusters for the Theme Category, Internal Struggles

<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belonging to a Subculture</td>
<td>The gay community</td>
</tr>
<tr>
<td></td>
<td>Being gay</td>
</tr>
<tr>
<td>Difficulties in the Relationship</td>
<td>Permanence</td>
</tr>
<tr>
<td></td>
<td>Partners' influence</td>
</tr>
<tr>
<td></td>
<td>Sexuality</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Sharing emotions</td>
</tr>
<tr>
<td>Uncomfortable Emotions</td>
<td>Worry</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
<td>Depletion</td>
</tr>
<tr>
<td></td>
<td>Crisis</td>
</tr>
<tr>
<td>Transitions</td>
<td>Fear of future</td>
</tr>
<tr>
<td></td>
<td>Uncertainty</td>
</tr>
<tr>
<td></td>
<td>Milestones</td>
</tr>
<tr>
<td></td>
<td>Living with AIDS</td>
</tr>
</tbody>
</table>
the 15 themes and four themes clusters in the theme category internal struggles. In this theme category partners experienced numerous internal struggles. One partner experienced a struggle in acceptance of the gay community and his sexual preference while another partner experienced a growth as a gay male. Partners perceived there were difficulties in their relationships. Partners may not have expected to be involved in a complex relationship with the person with AIDS having the ability to influence them. Partners said that expressions of sexuality were an important issue that each couple had addressed. Partners believed communication and sharing of emotions was problematic. Worry, anxiety, depletion, and crisis were uncomfortable emotions the partners felt. All partners perceived themselves in a period of transition. Fear, uncertainty, milestones, and change were felt by the partners to be part of transition. Partners felt that AIDS had had an impact on their lives. In the following quote a partner discussed the gay community.

Partner #3: "I have mixed feelings on that. I know a lot of people ... gay people ... who refer to it as the gay community. And I personally don't like that term because I think it's counterproductive to what they are trying to do."

The following data illustrated partners' influence.

Partner #1: "I don't know, it was easy for me to think positive if he did. So I guess really whatever he did effected me ... however he was acting or whatever."
The theme, crisis, was illustrated by the following quote.

Partner #3: "And then there's the more strenuous crisis like if we get into a big fight or something. Those are probably the most difficult to deal with at least for me. Either he wants to leave or I do and then the person who doesn't want it to split up is the one that gets hurt."

The following quote, while used to illustrate changes the partner experienced, also illustrated the uncertainty the person with AIDS felt.

Partner #1: "And you know from then on [after first hospitalization] things were different. He always had a bad attitude like something was going to happen and he'd get sick and we couldn't make any plans and do anything because he might get sick. And it was hard because everything was different."

In the following quote the partner described the experience of living with AIDS.

Partner #3: "I think the disease itself has kind of put a big cloud ... a dark cloud over our relationship. Whereas before we used be very outgoing, very social, very up and up ..."

An example of the theme, being gay, the theme cluster, belonging to a subculture, and the theme category internal struggles follows.

Partner #1: "I think if it [being gay] was more accepted then maybe people wouldn't be so promiscuous about it like they've been in the past. Because then you know, their relationships could have more meaning. Rather if they're not accepted they don't have any
meaning anyway ... they don't strive for a relationship. And therefore I can see that as how someone could get to promiscuous behavior. So I think that would help if that was accepted more.

Process of Loss.

The theme category Process of Loss was defined as dealing with preparation for the death of the person with AIDS while feeling fear, uncertainty, and hope. Table 10 illustrates the ten themes and four theme clusters comprising the theme category process of loss. In this theme category partners feared loss experiences even before the actual death of the person with AIDS. Two fears, representing loss to the partners, were the person with AIDS suffering from dementia or being over sedated with narcotics. Partners focused on periods of wellness when they perceived AIDS was on hold. One partner felt a fear of death while still acknowledging the probable outcome for the person with AIDS. Partners were uncertain how to behave in the face of death. Partners experienced both avoidance and acceptance of death.

An illustration of the theme, preparation, was exemplified by the following data.
Partner #2: "One of my reasons for getting involved in the volunteer work was sort of .. I don't know if selfish is the appropriate word ... I wanted to be overly prepared."

This data illustrated the theme, AIDS on hold.
Partner #1: "We just keep on doing our old normal things like going to the movies and out to eat. This and that. We try not to ... dwell on it."
Table 10

Themes and Theme Clusters for the Theme Category, Process of Loss

<table>
<thead>
<tr>
<th>Theme Clusters</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Issues Before Death</strong></td>
<td>Loss prior to death</td>
</tr>
<tr>
<td></td>
<td>Preparation</td>
</tr>
<tr>
<td></td>
<td>Decisions</td>
</tr>
<tr>
<td><strong>Maintaining Hope</strong></td>
<td>Wellness</td>
</tr>
<tr>
<td></td>
<td>AIDS on hold</td>
</tr>
<tr>
<td><strong>Death as Fearful Presence</strong></td>
<td>Fear</td>
</tr>
<tr>
<td></td>
<td>Realization of outcome</td>
</tr>
<tr>
<td></td>
<td>Death approaching</td>
</tr>
<tr>
<td><strong>Uncertainty in the Face of Death</strong></td>
<td>How to behave</td>
</tr>
<tr>
<td></td>
<td>Avoidance and acceptance</td>
</tr>
</tbody>
</table>
Fear was illustrated in the following quote.

Partner #3: "These days I'm more afraid of the things I can't see. It used to be I was afraid of monsters or whatever. But it's not like that anymore. Now I'm afraid of death."

The following data capture the ambivalence of the theme avoidance and acceptance.

Partner #2: "I say in my mind that I accept that [partners' dying] but I haven't seen a lot of the physical yet and I hope that I'm prepared for that."

An illustration of the theme, loss prior to death, the theme cluster, issues before death, and the theme category, the process of loss follows.

Partner #2: "That's [dementia] probably the most debilitating thing ... because at least you can say I love you one more time and hear a response and that means a lot but unfortunately if it's just not up there in the brain that's really difficult."

Exhaustive Description.

The next step of analysis according to Colaizzi (1983) was to form an exhaustive description of the phenomen. The exhaustive description was a narrative integration of all themes, theme clusters, and theme categories that pertained to the lived experience of being a partner to a gay male with AIDS. The exhaustive description was generated to gain knowledge of the structure of the lived experiences. The exhaustive description is presented in Appendix D.
Essential Structure.

The final step of data analysis was to define the essential structure of the lived experience of being a gay male living with a gay man with AIDS. The essential structure was the culmination of data analysis and integrated and combined common components of the lived experience of the gay male partner as they were revealed through analysis. The essential structure follows.

The lived experience of being a gay male to a person with AIDS involved an intrapersonal and interpersonal learning and acceptance of HIV status. Ambivalence regarding emotions and the relationship is worked through as the couple integrates AIDS into their lives. The period of disclosure is also fraught with ambivalence. Choices of who should be told are balanced against the knowledge of imposing a burden. The pros and cons of disclosing sexual preference and the HIV diagnosis may never be resolved. Distrust and faulty communication characterize interactions with physicians. Fear and negativity are emotions central to health issues. As the reality of living with a person with AIDS is internalized, partners and the person with AIDS begin a process of self care and support seeking in an effort to maintain self stability. Self-care involves learning new behavior and maintaining appropriate boundaries with the person with AIDS. The transition to the role of caregiver is accompanied by feelings of uncertainty and doubt. When providing specific forms of caregiving, partners experience feelings of competence. Emotional caregiving is problematic. Partners evolve in a spiral pattern through internal
struggles relating to being gay and the partner of a person with AIDS to a knowledge of
gains from the relationship. Partners perceive internal struggles as predominately negative
and difficult but the movement of the relationship toward openness, a gain of knowledge
related to AIDS, and an increase in communication provide adequate satisfaction to
maintain the relationship. Over time partners are able to develop a philosophy of life and
living with a person with AIDS which aids them in placing the lived experience in a
broader context. The process of letting go is also a period of ambivalence. While wishing
to maintain hope, partners move toward the realization that the diagnosis of AIDS will
likely result in death. Partners engage in behaviors to maintain the status quo while
simultaneously fearing and preparing for death. Behaviors and emotions reflective of
avoidance and acceptance of death characterize the process of loss.

Summary

In summary three gay males were self selected for this study. All the participants
were HIV negative. Participants had been in the relationship from two to ten years. The
participants ages ranged from 29 years to 37 years. The person with AIDS was slightly
older than the participants with ages ranging from 41 years to 44 years. All participants
reported emotional support as a form of caregiving. Time since AIDS diagnosis was
between one year and ten years. The person with AIDS CD4 counts were between 3 and
198. All participants decided on participation in the study after seeing a flyer at a local
AIDS organization. Interviews did not cause undue distress to the participants.
Data analysis proceeded according to Colaizzi's method (1983). The researcher analyzed the extracted significant statements, formed restatements, and derived formulated meanings. The data were refined in a logical progression as analysis proceed. Formulated meanings formed themes. Themes with commonalties formed 23 theme clusters, which sorted into theme categories. Eight theme categories were common to the lived experience of a gay male living with a person with AIDS. From these eight categories the researcher induced an exhaustive description of the phenomenon. The exhaustive description encompassed the lived experience for the partners involved in this research. Following analysis of the exhaustive description and all steps of analysis the researcher identified the essential structure to present a definition of the partners' lived experience.
Chapter Five presents a discussion of the findings from this study in relation to the conceptual orientation and existing knowledge regarding partners of gay men. Limitations of the study are addressed. Implications for nursing and recommendations for further research are included.

Discussion of the Results in Relation to the Conceptual Orientation and Review of the Literature

Concepts that formed the conceptual orientation for this study were transition, role, and caregiving, all concepts pertinent to this study. Meleis (1991) identified transition as a period when a change in health, roles, expectations, or abilities change. From the perspective of the partner both the person with AIDS and the partner underwent transitions. As partners became aware of the person with AIDS diagnosis they engaged in a change in health behaviors to protect their own health. New health behaviors were viewed as necessary and old health behaviors were abandoned. Roles changed with the partner beginning to take on the role of caregiver. Partners changed their expectations to be more reality based. While originally the partner may have expected the person with AIDS to live to a long life, this expectation was replaced with the knowledge that death would occur at an earlier age. New needs arose for the partners. Partners had the need for the person with AIDS to disclose the diagnosis of AIDS so that partners could seek
support. According to the partners, the process of disclosure often occurred over time and resulted in emotional distress for both the partner and the person with AIDS, which Meleis (1991) notes are common occurrences during periods of transition. Gaining knowledge was another need that arose for the partners. The meaning attached to gaining knowledge was viewed as positive for the partners and this eased the period of transition. Another transition that occurred for the partner was the decision to maintain the relationship with the person with AIDS. Partners originally had not expected a long relationship but as the partners began to see positive aspects of a relationship with a person with AIDS the partners underwent transition to a committed relationship.

Role change was the second concept relevant for the partners. Hardy (1978) notes that role is the expected and actual behaviors associated with a position. Role stress is built into social structure and results in role strain. Two partners in this study experienced role stress in their ambivalent feelings regarding their sexual orientation and relation to the gay community. Hardy (1978) also found that role ambiguity and role stress were products of a lack of clarity in role expectations. Partners often did not know what was expected of them. An example of this role ambiguity was the caregiving role. The partners reported that the person with AIDS often did not make caregiving needs evident. Partners were left to guess what was needed and this resulted in feelings of being uncomfortable with the caregiving role and role stress. The ambiguity of providing emotional support for the person with AIDS was especially problematic. Partners wished
to be available to the person with AIDS while still respecting the need for privacy and resolution the person with AIDS was experiencing. This ambiguity resulted in partners feeling confused and often helpless when considering the caregiving role and the provision of emotional support. Partners did not know what behaviors were appropriate as the end of life neared for the person with AIDS. Partners experienced confusion about how remaining time should be spent. Some partners wondered if the person with AIDS had accomplished life goals. In addition one partner had never experienced a death and was unsure of appropriate role behavior.

The concept of caregiving assumed less importance in this study than anticipated, based on the review of literature. Partners provided caregiving but were not engulfed by caregiving activities, which probably reflects the level of self care the person with AIDS was maintaining. Skaff and Pearlin (1992) report that when profound changes occur, caregiving role strain may result. Partners did not experience profound change and strain except in the area of emotional depletion. Rather partners feared what the future held for them as caregivers. There was a realistic understanding that the caregiving burden was likely to increase and partners experienced doubt and uncertainty related to meeting this burden.

Health Behaviors

Morgan and Jones' (1993) finding that partners may engage in unprotected sexual behaviors with the person with AIDS in an effort to maintain a functioning relationship
was not supported by this study. In this study, partners reported, at minimum, an effort to practice safe sex. Some partners had curtailed sexual activity with the person with AIDS. Partners reported frequent HIV testing, which implied a concern for their health.

**Unique Needs**

Cowles and Rodgers (1991) study, of which partners formed only a portion of the sample, predicted four areas where unique needs could arise for significant others of men with AIDS. The areas were: disclosure of the diagnosis, hoping in the face of hopelessness, relationship changes, and a need to be involved. (Cowles & Rodgers, 1991). The partners in this study experienced needs in all four areas. Disclosure of the diagnosis was a problem for the partner as the need to respect the wishes of the person with AIDS often conflicted with the need of the partner to be able to seek support. Partners believed it was the right of the person with AIDS to have control over diagnosis disclosure but also realized that without disclosure partners could not be free to seek support. Two partners experienced stress and isolation when disclosure was delayed. The partners also expressed maintaining hope in the face of hopelessness as a need. One partners felt hope when the person with AIDS tried experimental drugs but overall partners acknowledged that no cure existed for AIDS. Partners did maintain hope that the person with AIDS would not suffer a lingering death. Partners feared that the person with AIDS would lose their mental abilities or become over sedated by narcotics prior to death. Maintaining hope existed and partners expressed hope that the person with AIDS would
be cognitively present prior to death. Many changes took place in the relationship between the person with AIDS and the partner. Partners experienced worry and anxiety regarding the person with AIDS that had not previously been present. One partner felt he began to over identify with the person with AIDS, which had not occurred previously in the relationship. Partners were monogamous and perceived themselves in a committed relationship although the degree of commitment varied. Lastly partners wished to be actively involved in issues related to the person with AIDS. Involvement included volunteering, serving as medical advocate, and being actively involved in medical issues.

**Coping**

Greif and Porembski's (1988) research focused on what helped or hindered coping in significant others of person with AIDS. Factors found to help coping after the death of the person with AIDS were support groups, friends of the significant other, and religion. Greif and Porembski (1988) found that health professionals were viewed as helping or hindering. Likewise partners indicated that the way the person with AIDS coped with the disease had an effect on how the partner coped. Although no partners in this study had yet lost the person with AIDS to death, some findings from Greif and Porembski (1988) may nonetheless apply. The partners in this study attended support groups and found friends and religion to be sources of support. Based on these positive encounters it is possible that partners would continue to use these same support systems when death of the person with AIDS occurred. Partners in two instances did not believe that physicians
were helpful. One partner was aware that the person with AIDS physician had made errors in judgment and another partner felt that physicians did not provide enough information. The partners in this study discussed their interactions with physicians and overall they perceived their interactions as relatively negative. If the person with AIDS was hospitalized and facing an unknown diagnosis the partner suffered anxiety and fear.

**Caregiving**

In Ward and Brown's (1994) study of caregivers to a person with AIDS caregivers were broadly defined to include lovers, and the majority of caregivers in the study were white males as they were in this research. Ward and Brown (1994) reported that the most time consuming and frequently performed caregiving activity was companionship. While it is difficult to draw comparisons between companionship and emotional support, all partners in this study reported providing emotional support as a form of caregiving. Thus there may be some similarities between the definition of companionship and emotional support. Ward and Brown (1994) found that caregivers spent an average of 4.96 mean hours per day providing companionship. While partners provided caregiving they did not report the magnitude of hours reported in the study by Ward and Brown (1994).

In Folkman, Chesney, and Christopher-Richard's (1994) study, the partners were similar in race, age, and HIV status to the partners in this study. The research addresses what contributes to maintenance and decline of physical and psychological well-being in
primary caregivers of a partner with AIDS. In that study, creating meaning and ordinary events were significant themes for the partners of men with AIDS. Creating meaning related to the activation of deeply held beliefs, and appreciating and reflecting on ordinary events allowed caregivers respite (Folkman, Chesney, & Christopher-Richards, 1994). Partners in this study experienced spiritual feelings and wished for the person with AIDS to seek strength from spirituality. The use of spirituality was viewed by the partners as a form of support. Partners created meaning by developing philosophies that allowed them to place themselves and events in a broader perspective. Partners appreciated the ability of the person with AIDS to carry on ordinary events. The partners placed great emphasis on the person with AIDS ability to be remain active and engage in life. Partners spoke of the satisfaction the person with AIDS derived from ordinary events. The men with AIDS in this study were still actively involved in the mainstream of life and partners viewed this as very important to the person with AIDS's emotional and physical health. Partners feared the time when the person with AIDS would be confined to bed and no longer able to participate in everyday activities.

Environment

Chopoorian (1986) speculates on the role of environment in health. Partners in this study believed they were effected by social, economic, and political environments. Partners experienced a fear of being discriminated against and stigmatized by society. Two partners were uncomfortable that sexual preference and the person with AIDS
diagnosis would become known in society. One partner felt an economic impact as the person with AIDS was forced to curtail work hours and two other partners reported the person with AIDS as not having employment. Partners were aware of the political environment either through their roles as gay activists or through their fear that the government was stopping control of AIDS.

Vigilance

In Duffy's (1987) research on the unpredictable progression of AIDS and how uncertainty leads gay men to practice health vigilance, vigilance was defined as the monitoring for AIDS and safeguarding was defined as protecting self and others from AIDS (Duffy, 1987). Partners in this study practiced health vigilance in their repeated HIV testing and they did report the person with AIDS as practicing vigilance. Partners perceived the person with AIDS as attentive to any changes in their health. Partners experienced a change in health behaviors. One aspect in which partners did practice vigilance was the following of the person with AIDS CD4 count. Partners were able to recall any changes in the person with AIDS CD4 count and all partners made notes related to this count. Duffy (1987) also suggested that vigilance determined behavior, with PWA seeking health reassurance for minor complaints. This finding was not supported by this study. The partners believed the person with AIDS relied on health providers only to the extent necessary. One partner experienced the person with AIDS as having minor, vague complaints however the person with AIDS did not seek medical treatment. Partners
appeared to practice safeguarding as they remained in a monogamous relationship, attempted to use caution in sexual practices, and curtailed certain sexual behaviors.

Discussion of Other Results

This study uncovered concepts which may be new to the phenomenon of the lived experience of being a partner to a gay male with AIDS. Partners suffered ambivalence over a multitude of issues. Partners felt ambivalence over the disclosure of the person with AIDS diagnosis. Partners were aware that the risk of discrimination existed and wished to spare themselves and the person with AIDS further burden. Conversely partners realized that without disclosure they were forced to live with a secret and thus could not seek support. The need to have support and not be left in isolation was a central issue for the partners. Main issues for the person with AIDS were choosing whether or not to disclose the AIDS diagnosis, to whom they would disclose it, and what would be the effects of disclosure. The needs of the partner had to be balanced with the rights of the person with AIDS. One way the couple attempted to achieve a balance was to open lines of communication.

Another area in which partners experienced ambivalence was the caregiving role. The provision of emotional support caused the partner the greatest difficulty. Partners were aware the person with AIDS needed or expected emotional support. Partners also recognized that providing emotional support required expenditure of emotions that the partner sometimes did not have. Thus some partners faced the dilemma of being aware of
the person with AIDS needs but feeling an increasing inability to meet those needs. Partners also experienced ambivalence about to what extent the provision of emotional support was beneficial to the person with AIDS. Partners realized the inability to place themselves in the person with AIDS place. Thus there was ambivalence regarding the benefit of emotional support.

Partners experienced ambivalence regarding remaining in a relationship with a person with AIDS. Partners did not expect to be in a relationship of this duration and while partners chose to remain committed, they experienced a period of ambivalence prior to this commitment. Partners acknowledged a wish to avoid the sequela of involvement with a person with AIDS and one partner believed the relationship might not have endured without the wish to avoid guilt by feeling he had abandoned the person with AIDS. Thus the AIDS diagnosis made the partners both wish to stay and wish to leave.

Another issue not specifically addressed in previous studies of partners of a person with AIDS is fear. Partners experienced fear for a multitude of reasons. One cause of fear was the partners HIV status. Partners engaged in multiple testing in an effort to allay this fear. A second cause for fear was the partners interactions with physicians. One partner was aware of medical mistakes and one partner feared the person with AIDS was not receiving adequate care. One partner was fearful when physicians were unable to provide concrete diagnoses or appropriate counseling. Lack of information led partners to
be fearful of the worst occurring. In addition partners feared the future and the eventuality of death.

Much attention in the literature has been given to the concepts of self-care and caregiving. Partners in this study placed emphasis on the need for setting limits and maintaining independence as forms of self-care. Partners realized that enmeshment with the person with AIDS would be detrimental to the partner. One partner also believed caregiving should be a joint venture with the person with AIDS performing tasks consistent with physical ability. It is believed that by setting limits, maintaining independence, and expecting the person with AIDS to perform duties the partner was seeking to protect himself from role engulfment. According to Skaff and Pearlin (1992) role engulfment occurs when caregiving activities expand to the point where the partners life is restructured and previously held roles are abandoned for the role of caregiver. Partners in this study appeared, by their behaviors of self-care, to be avoiding role engulfment. Partners accomplished this task through continued enrollment in school and holding a full time job.

There is little in the literature that addresses the internal struggles partners face. One partner and one person with AIDS in this study had mixed feelings about being gay and the role of the gay community. One person with AIDS felt unhappy over his sexual orientation and some partners had not been exclusively gay in the past. Two partners embraced the gay community while one partner believed the gay community was acting
contrary to his personal beliefs. Two partners felt they had grown as gay activists and one partner was not involved in gay activities. Partners attempted to resolve internal struggles through the use of support groups and counseling.

There has been little reported on the phenomenon of partners forming personal philosophies. Partners in this study all developed philosophies over the course of their involvement with the person with AIDS. Partners appeared to find comfort in these philosophies and used them on a day-to-day basis when faced with situations which caused discomfort or confusion.

Limitations of the Study

This study was limited by the number of participants. With only three participants data saturation was not accomplished in most theme categories. The difficulty in recruiting subjects was not anticipated. The CD4 counts varied widely between the person with AIDS. This variation influenced the person with AIDS health and thus the partners reactions to certain issues. In addition, with a small sample size, clinicians need to use caution in generalizing these findings to practice.

Another limitation was the cross sectional nature of the study, with one data collection interview with each participant. The research would have benefited from ongoing communication with the participants in which issues could have been explored in depth. Prolonged engagement with participants would have benefited the study by adding to the criteria for trustworthiness.
The researcher was a neophyte at interviewing for the purpose of data collection and this limited the completeness of some data. The interviews, while remaining unstructured, could have proceeded in a manner that facilitated exploration of the topics of caregiving, role change, and transition.

Implications for Nursing

This study revealed issues pertinent to gay male partners of person with AIDS which have implications for nurses. There are nursing implications related to the unique needs of this population, fears and ambivalence experienced by partners, internal struggles, and the process of loss.

Unique Needs

One implication for nurses in clinical practice is the realization that partners of gay men with AIDS have unique needs. This was supported by both the literature and this study. Disclosing the diagnosis is a unique need experienced by partners in this study. While the person with AIDS may not perceive disclosure as a need, partners did. Partners believed that without disclosure of the diagnosis they were unable to meet their own needs for support. Thus disclosure of the AIDS diagnosis requires nursing intervention based on the potential problems it may cause the couple. These problems can become paramount if the person with AIDS does not consider disclosure a need while the partner does. One way to achieve a balance may be in dialogue between the partner and the person with AIDS. Pros and cons of disclosure could then be openly discussed with each man stating
his needs. It is theorized that through open communication regarding the difficult issue of disclosure a decision can be reached that satisfies the partner and the person with AIDS. Nurses in practice can be prepared to provide an atmosphere of impartiality where the partner and the person with AIDS can openly discuss the benefits and risks of disclosure.

Another area of intervention regarding unique needs of the partner is the ability to support the partner in a realistic balance of hope versus hopelessness. Rather than complete abandonment of hope, as the person with AIDS condition deteriorates, the nurse can support more realistic avenues such as hoping for a peaceful death. The nurse can anticipate relationship changes and through the use of interventions these potentially damaging changes can be minimized. It will likely be difficult for the partner to assume the caregiving role and the person with AIDS to accept the need for care. Many gay men have little experience with caregiving through the parenting role. With the clinician bearing in mind that for young men both receiving and giving of care are unfamiliar behaviors, the clinician may need to begin intervention with a basic explanation of caregiving concepts.

Nurses need to be aware that emotional support is a delicate issues for partners of person with AIDS. It is hypothesized that the ambivalence surrounding emotional support could be clarified through a more precise statement of need by the person with AIDS as well as feedback from the person with AIDS regarding the benefit of emotional support. Since partners perceived that emotional support was an important form of caregiving the
partners ambivalence in this area could be lessened through specific communication between the couple regarding emotional support. Communication would require the partner to assess the support they have available to offer and likewise require the person with AIDS to assess what form and amount of emotional support is valuable to them. Nurses are in a position to provide a therapeutic milieu for communication to occur.

**Caregiving**

Nurses can assess caregiver burden of the partner. Folkman, Chesney, and Christopher-Richards (1994) report that persistent negative thoughts on the part of the partner are an indication that the partner himself may require caregiving. Nurses can help the partner to avoid caregiving engulfment by directing the partner to respite and support services in the community. Nurses can provide validation of the partners goals and interests as important, thus assisting the partner to avoid rule engulfment.

Partners of PWA also experience a need to be involved with the person with AIDS in ways beyond personal caregiving. Nurses can meet this need in several ways. One way would be to provide information about opportunities for volunteer work. The nurse has the expertise to serve as the partners' advocate in interactions with the physician. Advocacy involves the partner and benefits the person with AIDS. Nurses may help the partner to interpret the plan of care for the person with AIDS and identify practical measures the partner can employ to guard the person with AIDS health. Because partners
suffer ambivalence in the caregiving role concrete information could serve to decrease
ambivalence while providing the partner with a sense of accomplishment.

Fear and Ambivalence

Clinicians can be aware of the fear and ambivalence partners feel and take active
steps to handle this uncomfortable emotion. All couples, whether heterosexual or
homosexual, experience periods of ambivalence during relationships. These periods
occur without the added strain of being in a relationship with a person with AIDS. That
partners feel ambivalent in a relationship with a person with AIDS can certainly be viewed
as normal. Nurses can provide acknowledgment and reassurance regarding the normalcy
of the partners feeling. Open acknowledgment of ambivalence can aid in validating these
emotions as topics for discussion.

Partners need reassurance that fear is a natural emotion. It is hypothesized that by
acknowledging partners fear's and clarifying what the partners fear much can be done to
allay fear. Nurses can assist the partner to identify what they fear. Partners may fear that
they will contract AIDS or fear that the person with AIDS is not receiving adequate
medical care. Partners do not know what the future holds and this may induce fear.
Nurses can provide concrete information when available. Information on topics important
to partners can do much to dispel fear. Peers may have suffered similar fears and thus
could be recruited to serve as mentors for partners.
The ambivalence partners face in maintaining the relationship is a delicate area for nurse involvement. Partners may need to be encouraged to see the advantages of a relationship with a person with AIDS while supported through the negative aspects of the relationship. The choice to remain in such a relationship is ultimately the partners’ but nurses may provide a valuable service by allowing partners to freely discuss the benefits and burdens of the relationship.

Internal Struggles

Clinicians can be of value as partners face internal struggles. That two of the person with AIDS did not utilize support groups, counseling, or the gay community could have led the partners to question the utility of these forms of support in helping clarify issues. Nurses can encourage partners to use means they find helpful in easing internal struggles regardless of the choices the person with AIDS makes.

Nurses can acknowledge the struggles over expression of sexuality, communication, worry, anxiety, and emotional depletion partners face. While these struggles are not unique to gay partners, the approach must be tailored to gay men of person with AIDS. The nurse may need to become familiar with gay expressions of sexuality and acceptable alternatives for expression of sexuality. Verbal communication of emotions among men has long been recognized as a problem in western society and the nurse needs skill and patience in helping the partner and the person with AIDS open lines of communication. Partners need concrete information and support to decrease worry and
anxiety. Acknowledgment of these emotions as common to people living with a person with a fatal disease may serve to reassure the partner. Offering concrete information can allay worry and anxiety.

Transition

Nurses may help the partner through periods of transition. Partners expressed fear about the future and uncertainty over how their role would evolve. Many changes may occur quickly. The nurse may prepare the partner for the future and assist the partner to understand likely transitions such as an increase in the caregiver role. Nurses can provide the partner with alternatives to the personal caregiver role when it is apparent the partner is unable to successfully provide caregiving. Change is problematic for partners. Nurses may need to become familiar with change theory to help partners cope with the impact of change.

Process of Loss

Lastly the nurse should be available to help the partner through the period of loss. It should be recognized that loss begins prior to actual death. Nurses may help the partner with the issue of loss by exploring what specifically the partner fears. If it is loss of independence the nurse may be able to devise ways for the person with AIDS to retain some form of independence. If the partner fears over-sedation of the person with AIDS the nurse may be able to work with the person with AIDS, partner, and physician regarding the effects of narcotics. Nurses, by therapeutic presence, can ease fears
surrounding death. Partners are uncertain how to behave in the face of death and reassurance regarding behavior will calm fears. Nurses can support partners through difficult decisions as the end nears.

Recommendations for Further Research

In that the gay population of men with AIDS continues to grow, research about the partners of men with AIDS remains necessary. Partners of men with AIDS remain an understudied population. Studies with a larger population of partners would be valuable in validating issues identified in this research.

The emotions of ambivalence, fear, and uncertainty need further exploration to uncover if they are mediated in any degree by the formation of the partners' personal philosophy regarding living with a person with AIDS. Based on the limitations of this study it is unknown if these emotions are common to the majority of partners and what, if any, factors serve to lessen the discomfort these emotions cause. Research that may result in a decrease of distress is important.

Research needs to be conducted regarding interactions with health care providers. Partners in this study spoke exclusively of physicians. It is unknown what partners' experiences with other providers, such as nurse practitioners, are. Methods of decreasing negativity associated with health issues needs exploration since this was another area in which partners expressed discomfort.
A last area that research could prove valuable is in the area of self-care and caregiving. Researchers could determine what behaviors are most effective for the partner in caring for self. Unless the partner practices self care, the partner can suffer emotional and physical depletion. By providing research on self-care nurses could assist the partner and indirectly the person with AIDS. Research addressing what behavior eases the transition into the caregiving role would be beneficial knowledge for clinicians. What forms of caregiving, in what amounts, are perceived important to the person with AIDS is another area for research.

Summary

In summary, this chapter discussed the results in relation to the review of literature and conceptual orientation for this study. Transition, role, and caregiving were assumed to be important issues for partners of person with AIDS and this proved true. Partners discussed transitions occurring in the areas of health, expectations, and abilities. Partners had heightened awareness of health issues both for themselves and the person with AIDS. Partners perceived a change in expectations. The situation of living with a person with AIDS involved a gradual change of expectations in relation to the outcome for the person with AIDS. Some partners did not expect a significantly shortened lifespan although partners acknowledged AIDS was fatal. Partners experienced transition in their ability to provide care. None of the partners had been caregivers in the past yet were able to assume care, including giving injections, when the need arose.
Partners underwent role stress related to the caregiver role. There were feelings of helpless and doubt regarding the provision of emotional care. Partners suffered ambivalence when considering that the caregiver burden would likely increase if they remained in the relationship with the person with AIDS. In addition one partners underwent role stress related to being a gay male and his place in the gay community. While one partner was open regarding his sexual preference two others were not and this resulted in role stress. Findings from this study were congruent with findings by other researchers.

Major limitations of this study were small sample size, cross sectional method of data collection, and newness of the researcher to interviewing.

Implications for nurses were numerous and focused on legitimization of partners fears, worry, anxiety, and ambivalence.

Further research needs to be conducted of the partners of men with AIDS as the population of gay men with AIDS continues to increase. Partners experienced a variety of negative emotions in living with a person with AIDS and research addressing these emotions could spare future partners distress.
APPENDIX A

FLYER
INTERESTED IN SHARING YOUR PERSPECTIVE?

I'M INTERESTED IN HEARING FROM YOU

VOLUNTEERS ARE NEEDED FOR A STUDY OF THE EXPERIENCE OF GAY MALE PARTNERS OF A MAN WITH AIDS.

THE QUESTION YOU WILL BE ASKED TO DISCUSS IS:

WHAT IS YOUR EXPERIENCE OF BEING THE PARTNER OF A MAN WITH AIDS?

CONFIDENTIAL!

Please consider sharing your perspective if you are: male, gay, currently living with a gay partner with AIDS, providing some form of caregiving, 18 years of age or older, English- speaking, and willing to donate 2-3 hours of your time to be interviewed.

If you think you may be interested or would like to talk about the possibility of participating, please contact me.

Jan Scott, RN, BSN

520-682-8581

THANK YOU!
APPENDIX B

SUBJECT CONSENT TO PARTICIPATE IN A RESEARCH PROJECT
APPENDIX B

SUBJECT CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

THE EXPERIENCE OF BEING A GAY MAN WHOSE PARTNER HAS AIDS

I AM BEING ASKED TO READ THE FOLLOWING MATERIAL TO ENSURE
THAT I AM INFORMED OF THE NATURE OF THIS RESEARCH STUDY AND OF
HOW I WILL PARTICIPATE IN IT, IF I CONSENT TO DO SO. SIGNING THIS
FORM WILL INDICATE THAT I HAVE BEEN SO INFORMED AND THAT I GIVE
MY CONSENT. FEDERAL REGULATIONS REQUIRE WRITTEN INFORMED
CONSENT PRIOR TO PARTICIPATION IN THIS RESEARCH STUDY SO THAT I
CAN KNOW THE NATURE OF THE RISKS OF MY PARTICIPATION AND CAN
DECIDE TO PARTICIPATE OR NOT PARTICIPATE IN A FREE AND INFORMED
MANNER.

PURPOSE

I am being invited to voluntarily participate in the above-titled research project. The
purpose of this project is to help nurses understand the lived experience of being a gay
male whose partner has AIDS.
SELECTION CRITERIA

I was asked to participate in this study because my sexual preference is homosexual, I describe myself as the sexual partner, either now or in the past, of a gay male with AIDS, I live in the same household as my partner, and I consider myself his main support in providing caregiving.

PROCEDURE

If I agree to participate, I will be asked to do the following. Meet the researcher at a time and place convenient to myself for an initial 15 minute interview. Two weeks later again meet with the researcher to discuss the question I was provided in the original interview. The second interview will be audiotaped and take approximately one to two hours. At the conclusion of the study I will be asked to meet for 30-60 minutes with the researcher to discuss results of the study, give my feedback, and receive information on how to obtain a report of the research.

RISKS

The only risk associated with this research is the potential for reliving painful memories.

BENEFITS

The benefit of this study is that more information will gained as to the needs of gay partners of men with AIDS.
CONFIDENTIALITY

All information associated with this study will be held in confidence and only Janet Scott, RN, BSN will have access to the information. The information I provide will be assigned a number and that number, rather than my name, will be on all documents. Only Janet Scott, RN, BSN will know my identity. Information data with the code number on it may be shared with thesis committee members for the purpose of assistance with the thesis.

PARTICIPATION COSTS

There will be no cost to you to participate in this study.

LIABILITY

I understand that side effects or harm are possible in any research program despite the use of high standards of care and could occur through no fault of mine or Janet Scott, RN, BSN. Known side effects have been described in this consent form. However, unforeseeable harm may also occur and require care. I understand that money for research-related side effects or harm, or for wages or time lost, is not available. I do not give up any of my legal rights by signing this form. Necessary emergency referrals will be provided at a cost to myself. I can obtain further information from Janet Scott, RN, BSN at 682-8581. If I have questions concerning my rights as a research subject, I may call the Human Subjects Committee at 626-6721.
AUTHORIZATION

BEFORE GIVING MY CONSENT BY SIGNING THIS FORM, THE METHODS, INCONVENIENCES, RISKS AND BENEFITS HAVE BEEN EXPLAINED TO ME AND MY QUESTIONS HAVE BEEN ANSWERED. I UNDERSTAND THAT I MAY ASK QUESTIONS AT ANY TIME AND THAT I AM FREE TO WITHDRAW FROM THE PROJECT AT ANY TIME WITHOUT CAUSING BAD FEELINGS. MY PARTICIPATION IN THIS PROJECT MAY BE ENDED BY THE INVESTIGATOR FOR REASONS THAT WOULD BE EXPLAINED. I UNDERSTAND THAT THIS CONSENT FORM WILL BE FILED IN AN AREA DESIGNED BY THE HUMAN SUBJECTS COMMITTEE WITH ACCESS RESTRICTED TO JANET SCOTT, RN, BSN OR AUTHORIZED REPRESENTATIVES OF THE COLLEGE OF NURSING. I UNDERSTAND THAT I DO NOT GIVE UP ANY OF MY LEGAL RIGHTS BY SIGNING THIS FORM. A COPY OF THIS SIGNED CONSENT FORM WILL BE GIVEN TO ME.

--------------------------------------------------------
Participant                        Date

INVESTIGATOR

I have carefully explained to the subject the nature of the above project. I hereby certify that to the best of my knowledge the person who is signing this consent form understands clearly the nature, demands, benefits and risks involved in his participation and his
signature is legally valid. A medical problem or language or educational barrier has not precluded this understanding.

Witness

Date
APPENDIX C

DEMOGRAPHIC SHEET FOR PARTNER

and

DEMOGRAPHIC SHEET FOR PERSON WITH AIDS

AS REPORTED BY PARTNER
APPENDIX C

DEMOGRAPHIC SHEET FOR PARTNER

Code Number:

Age:

Sexual Preference:

Ethnicity:

Occupation:

Please circle one:

Income:  <$15,000

          $15,001 - $35,000

          $35,001 - $55,000

          $55,001 - $75,000

          >$75,000

Please circle one:

Years of Education:  less than high school

          high school graduate

          some college

          college graduate
Type of Support Provided to Partner with AIDS: please circle all that apply

- Financial
- Companionship
- Running Errands
- Emotional
- Household Chores
- Involved with Medical Care

Assistance with: bathing, grooming, toileting, meal preparation, feeding

Other, not listed: _______________________________________

Estimated Average Length of Time Spent in Caregiving Activity Daily: ______

Length of time in this relationship: ______

If you are comfortable doing so, would you state your HIV status? ______

If HIV positive, would you state your CD4 count? ______

Would you state your partner’s CD4 count? ______
APPENDIX C - Continued

DEMOGRAPHIC SHEET FOR PERSON WITH AIDS

AS REPORTED BY PARTNER

Age:

Sexual Preference:

Ethnicity:

Occupation:

Please Circle One:

Income:  
<$15,000

$15,001 - $35,000

$35,001 - $55,000

$55,001 - $75,000

>$75,000

Please Circle One:

Years of Education:  
less than high school

high school graduate

some college

graduate

Length of Time since AIDS Diagnosis: __________
APPENDIX D

EXHAUSTIVE DESCRIPTION OF THE LIVED EXPERIENCE

OF THE PARTNER OF A MAN WITH AIDS
The partner's learning of the diagnosis of the person with AIDS (PWA) is accomplished in various ways. One way of learning is for the person with AIDS to tell the partner from the beginning of the relationship. Another way of learning occurs when the person with AIDS is tested for the HIV virus on the suggestion of a physician and upon learning the results tells the partner. Finding out the person with AIDS diagnosis can be an ordeal for both the partner and the person with AIDS. One person with AIDS had been repeatedly told his HIV status was negative only to change physicians, be tested again, and find out he was HIV positive. He then had to share his new diagnosis with his partner. There is an eventual acceptance of the AIDS diagnosis by the partners. Partners may be learning of the diagnosis for the second time if there have been previous deaths associated with AIDS. Learning of the diagnosis for a second time is perceived as a different experience from learning of the diagnosis the first time.

The person with AIDS may blame outside forces for contracting AIDS or may feel they put themselves at risk with their behaviors. Partners do not speculate how the person with AIDS contracted the disease.
Newness of the diagnosis is especially difficult when the person with AIDS moves from perfect health to full blown AIDS. The sudden diagnosis gives no time to prepare for the disease. It is easier to deal with the diagnosis of AIDS when the partner has known for some time, the person with AIDS is in good health, and there is a period of adjustment as less serious illnesses begin to become apparent.

Partners are aware of the presence of AIDS in the community. A method utilized by some partners for dealing with the threat of AIDS is to remain celibate. AIDS is personified and anger is felt towards AIDS as a personal entity. Partners worry about their HIV status because of their awareness of personal risk as gay males. While fearing the spread of AIDS some partners believe gay men have the right to not know their status.

There is fear regarding testing but also acknowledgment of the importance of testing based on the person with AIDS being HIV positive. The partners are tested periodically but there is no pattern to when they choose to be tested. Partners tend to delay testing until forming a committed relationship with a person with AIDS. There is a general feeling of worry regarding the partners' HIV status. There is an inability to believe the HIV negative result as definitive and repetitive testing may do little to lessen anxiety regarding testing. There is a feeling of guilt over a negative status. Fear of testing positive is equated to receiving a death sentence. Partners engage in repeated HIV testing. Testing and the receiving the results is a difficult issue for partners and person with AIDS.
Persons with AIDS react to their diagnosis in a variety of ways. Anger and emotional suppression are two ways of handling the diagnosis. Anger is often displaced to the partner. When emotional suppression is an accepted way of dealing with a problem it continues to be the coping mechanism employed for dealing with AIDS. The person with AIDS may become depressed and physically ill with vague complaints once receiving a positive diagnosis.

Partners also have a wide range of emotions when learning the person with AIDS diagnosis. There is a feeling of being at a loss for words and that the diagnosis is incomprehensible. Feelings of anger, sadness, and luck are common. Partners feel guilty over their perceived luck and remain in fear of contracting AIDS. There is a feeling of being overwhelmed, terrified, and unable to control thoughts or emotions when hearing the diagnosis. Partners feel that discussing the diagnosis with the person with AIDS may be an intrusion on their privacy. Partners feel an acceptance of the person with AIDS.

Partners consider ending their relationship with the person with AIDS. Partners generally had not anticipated long term commitments. There is the wish that the situation would end and acknowledgment of being able to avoid the AIDS sequela by ending the relationship. There is a feeling of ambivalence about remaining in a relationship with a person with AIDS.

Despite this ambivalence, partners want to continue their relationships. A relationship is desired even while acknowledging that it will be short term. Partners
believe they have lost little through commitment to the person with AIDS and the situation could have been worse. There is depth to the relationship that allows it to be satisfying. AIDS is not seen as a determent to forming relationships. Partners are thankful for the good times in the relationship and cherish periods when there are no AIDS complications.

Once both men are aware of, and share with each other their HIV status, the issue of whether to disclose the positive HIV status to others, and to whom they will disclose this information arises. Disclosure includes sharing the diagnosis of AIDS and disclosing sexual orientation. There is uncertainty over disclosure. Disclosure is considered on an individual basis with readiness, ability to cope with the diagnosis, and feelings of closeness being deciding factors in telling others of the AIDS diagnosis. The decision to disclose is a personal decision with the person with AIDS making the decision. Partners prefer to control the setting in which disclosure occurs. Having other gay members in the family does not ease the anxiety associated with disclosure of sexual preference.

Who knows about the diagnosis is important. Sometimes all the family and friends are told immediately, and sometimes the couple believes they will never be told. Family members may not be aware of the partners' sexual orientation or that the partner lives with a person with AIDS. For partners who have not disclosed to their family there is a reliance on mothers' intuition. Partners believe that although they have not told their mothers about the diagnosis, or about being gay, their mothers nonetheless know.
The partners feel ambivalence about the person with AIDS disclosing his diagnosis. Rather than disclosing the person with AIDS diagnosis, partners leave that decision to the person with AIDS. There are positive aspects of disclosing. Partners are able to seek support once the diagnosis is known. It is important for the person with AIDS to recognize that their partner can receive little support until the diagnosis has been shared. Disclosure is experienced as a catharsis with the release of strong emotions. Sharing the diagnosis prevents having to surprise others with the diagnosis at a later date.

Conversely when the diagnosis is not shared partners live with a burden of secrecy. The partner feels isolated and that communication is closed. This causes friction as some person with AIDS would rather face anything except disclosure. Reasons for not disclosing the AIDS diagnosis are many. People with AIDS worrying over imposing a burden on others related to the fatality of the disease. People with AIDS may be unfamiliar with sharing emotions and thus choose not to share this emotional laden issue. Both person with AIDS and their partners are aware of discrimination and lack of acceptance by the general public of those with AIDS.

Partners fear discrimination and stigmatization by association with a person with AIDS. The behavior of friends and family often changes once they learn of the diagnosis. It is sometimes easier to simply avoid disclosure.

Whatever disclosure decisions are reached, the person with AIDS and often the partner are involved with physicians. Partners are aware of mistakes being made by
physicians. Misleading information is disseminated that puts people at risk for spread of HIV. A person with AIDS may have appropriate treatment delayed and be prescribed common drugs used in care of AIDS patients while being told he is HIV negative.

Partners of person with AIDS have expectations of physicians. There is the expectation that physicians will provide the partner with concrete diagnoses. Uncertainty over diagnosis causes anxiety for the partner and erodes trust. People with AIDS believe a fear of gays by physicians may result in discrimination in health care. Some person with AIDS expect substandard care. Some partners feel physicians treat patients like children and physicians do not understand concerns of partners and person with AIDS.

Partners expect to receive information that is complete and helpful. Partners may not understand the person with AIDS plan of care and feel they receive inadequate medical counseling. Partners confer with physicians but come away feeling unsatisfied. Some physicians exclude partners from discussions of plan of care.

Physicians may offer a grave prognosis immediately with a discussion of life expectancy before the person with AIDS or the partner is prepared to hear this news. Too much information is sometimes given too quickly. Partners believe physicians give up on person with AIDS. Person with AIDS may be encouraged to enter nursing homes when this is not the couples' wish. Perceived lack of physician sensitivity causes partners surprise, anger, and anxiety. Other physicians are perceived as skilled and caring practitioners.
Partners imagine the worst outcome for the person with AIDS due to lack of adequate medical knowledge. When a person with AIDS goes to the hospital the partner may image the worst outcome, including disfigurement, due to lack of communication with the physician. Partners can be frightened over events that occur in the home. People with AIDS have drug reactions which lead to emotional and physical upset for both the person with AIDS and their partner when they perceive themselves unable to handle the drug reaction. There is hope for the person with AIDS when new treatments are tried and then disappointment as the treatments fail. If partners are giving injections in the home there is anxiety over blood exposure from the person with AIDS and lack of knowledge of how a blood exposure should be handled. Partners have difficulty experiencing hospitalization of the person with AIDS, difficulty watching suffering, and a wish to avoid observing the person with AIDS in pain.

Partners perceive health issues negatively. Open discussion of medical issues sometimes leads to arguments between the couple. Partners feel stress related to health issues. There is recognition that internalized stress may adversely affects the partners’ health. Some partners suffer a preoccupation with the person with AIDS health and over identify with the person with AIDS. Partners wish to avoid health issues because of associated frustration, pain, anger, and preoccupation.

Partners are aware they must practice self-care. One method of doing so involves learning and practicing safe sex. Partners practice routine health maintenance including
exercise and use of stress management techniques. Another way partners practice self
care is to acknowledge and process loss as it is occurring. Partners strive to avoid
misunderstandings with the person with AIDS which adds to the partners' emotional
upset.

The person with AIDS also practices self care. Partners are proud of the changes
in lifestyle the person with AIDS has made. Some person with AIDS practice health
maintenance and avoid tobacco and alcohol. Or a person with AIDS may see a
naturolpath and takes herbs and vitamins to promote his health, or may exercise on a
routine basis.

Some partners use volunteer work as a form of self care. Advantages of volunteer
work are making friends, gathering resources and preparing for the future with a person
with AIDS. Volunteer work is balanced with not letting the person with AIDS feel
neglected.

Partners practice self-care by avoiding enmeshment in the relationship with the
person with AIDS, retaining independence, and setting limits. They set limits on AIDS
discussion between the couple. When AIDS is discussed there are time limits set and
AIDS is not dwelled upon. Partners believe there is no need for preoccupation with
AIDS, and they are not willing to become martyrs. One way of retaining independence is
through continuing planned education. Another way is socializing outside the relationship
and maintaining full-time employment. Some partners are able to verbalize their own
needs, seek support, and keep a healthy focus on the self while other partners are less successful with these practices.

There are other methods that partners employ for self-care. Partners use spirituality to care for themselves. A belief in God and support from religion is a form of spirituality. Partners attend meditation, pray for the person with AIDS recovery, and pray for guidance and clarity. Partners believe it is important for the person with AIDS to have some form of spiritual connection.

There is disagreement over the amount and type of support families can offer the couple. Some partners feel that both families are extremely supportive of the couple, and there is the contrasting feeling that the person with AIDS’ family offers no support despite awareness that the person with AIDS has financial and transportation difficulties. The main type of family support offered is emotional support either to the partner or the person with AIDS. Mothers are mentioned as being supportive but there is no specific mention of other family members.

All partners report attending support groups and feel this a positive form of self care. Some partners are in counseling and also feel this is beneficial. Other partners prefer, in conjunction with the person with AIDS, to handle issues as they arise. In some cases friends are mentioned as a form of support for the partner.

As partners care for themselves so too do they perform caregiving for the person with AIDS. Altruism is perceived as a form of caregiving as the partner engages in
activity he does not enjoy for the sake of the person with AIDS. Partners offer caregiving support in their area of expertise or in ways that are comfortable to them. Concrete examples of caregiving are making medical appointments, giving injections, loaning the person with AIDS a car, paying bills, cooking, cleaning, assisting with personal care, housework, and providing transportation. Some partners offer financial support while others do not. Partners may assign household chores to the person with AIDS while the partner pursues educational goals. Some person with AIDS are able ask for help freely while others only ask as they perceive a need. Partners view their increasing involvement with the person with AIDS medical treatment as a form of caregiving. Less distinct forms of caregiving are helping the person with AIDS resolve issues, finish projects, or seek support.

Caregiving is seen by some partners as a joint venture. Both men in the relationship contribute to a money pool and help each other tackle problems. When caregiving involves both, the men perceive this as positive and tackling a problem together gives the couple a feeling of mutual accomplishment. Negative feelings ensue if one man has to face a problem alone.

Offering emotional support as a form of caregiving is important to the partners. Emotional support is defined by the partners as helping to clarify issues, helping sort things out, and being present for the person with AIDS. While emotional support is important, partners often feel helpless and uncertain of the utility of offering emotional
support. Partners worry that the burden of caregiving will increase and doubt their ability to cope with further caregiving demands. Partners experience fatigue from the added caregiving and spend increasing amounts of energy worrying about the person with AIDS. When the person with AIDS is suffering medical complications he may ask his partner for more caregiving. Some partners believe providing caregiving is a trade-off for the good times the couple is sharing. Another partner believes that when the person with AIDS is not well the partner tends to over identify with the health issues.

Negative aspects of caregiving revolve around the partners feelings of helplessness and their perception that their caregiving is minimal. As not all person with AIDS need or request specific caregiving partners feel offering emotional support may not be perceived as legitimate caregiving. Partners believe that the current level of caregiving is acceptable but worry about their ability to meet increasing caregiving needs. Some partners perceive having finite inner resources to cope with the person with AIDS. Accompanying this feeling may be the perception of lacking support to offer, no personal reserve to deal with additional crises, and feeling the burden of living with a person of AIDS is excessive. This feeling of depletion can be related to other recent losses.

Despite the ambivalence of remaining in a relationship with a person with AIDS partners report gains from involvement with a person with AIDS. Partners trust in both the relationship and the person with AIDS. All relationships are perceived as monogamous.
Partners feel that barriers to communication have broken down since the AIDS diagnosis and the couples communicate more freely now. Partners relate that they know and understand the person with AIDS better and relationships are improving over time as more emotions are shared. As relationships improve partners and person with AIDS become more open emotionally. People with AIDS also believe the relationship is improving and their lifestyles are improving by being in a committed relationship. People with AIDS express the wish to be surrounded by caring people and that a committed relationship is important to their health.

Partners feel they learn many things from being involved with a person with AIDS. Living with a person with AIDS is seen as a motivator to acquiring knowledge about AIDS. Even as person with AIDS identify their own issues partners take a proactive stance and learn about AIDS independently. Partners share their knowledge through volunteer work and in the work place. Knowledge adds to the partners sense of control. Involvement with medical issues leads the partners to a greater understanding of their health. Partners learn the importance of asking questions of the person with AIDS and not stifling their emotions. Partners believe they gain from both the positive and negative aspects of being involved with a person with AIDS.

The partners of person with AIDS develop philosophies over the course of their relationship. Developing a philosophy is seen as an outcome of living with a person with AIDS. One philosophy is that life has great meaning and it is wrong to waste time on
trivial matters. Partners experience a review of their own lives and come to see the sanctity of life. Partners attempt to remain positive and seek to discover meaning in experiences. Partners express a deeper appreciation for life. The person with AIDS and the partner seek to enjoy the time that is left engaging in meaningful events. Life is lived one day at a time.

Despite the positive experiences of being involved with a person with AIDS partners experience internal struggles. Partners are ambivalent about their degree of commitment to the person with AIDS with some partners experiencing total commitment and others noting that same sex relationships effect the degree of commitment. There is a feeling that if gays were more accepted by society there would be less promiscuous behavior and gay relationships could gain in depth. One response of a partner is to believe that involvement with a person with AIDS helps evolution as a gay activist and gives feelings of personal growth as a gay male. Conversely other partners feel that involvement with a person with AIDS does not change feelings about being gay and still another partner feels that AIDS is making it more difficult to admit being gay. Some persons with AIDS are not happy being gay, view gays as bad people, and accuse gays of deliberately spreading AIDS. This attitude on the part of the person with AIDS is difficult on the partner.

An internal struggle partners face is feelings about the gay community and social acceptance. Partners may believe that the gay community is segregating gays and
encouraging gays to live a heterophobic and limited lifestyle. The concept of gay community may be perceived as counterproductive to gay goals. There is ambivalence about the meaning of gay and a feeling of being distanced from society because of sexual preference. Some partners do not share their personal lives with others because they perceive older people in society as equating gay with evil. There is belief that the government is stopping the control of AIDS.

Another internal struggle partners are facing is related to their relationships. Partners do not expect long relationships and view commitment as a major step. Commitment is postponed and there is uncertainty if the relationship would last without the issue of AIDS.

Partners acknowledge that they are influenced by the person with AIDS and are unsure if this influence is to their benefit. There is change over the expression of sexuality. Decline in sexual activity may be related to the partners' emotional turmoil or the couple may mutually decide to limit sexual contact.

Lack of communication causes difficulty. Communication is perceived as a lack of caring and partners acknowledge the need to learn communication. Communication is feared and causes anxiety. There is fear that communication may result in being overcome with emotion. Partners feel that lack of communication is a large problem in their relationship with the person with AIDS. Without clear communication expectations go unmet and this causes anxiety to the partner and the person with AIDS.
Along with lack of communication comes a feeling of lack of emotional closeness. When there is little visible emotion between the partner and the person with AIDS this is worrisome to the partners. Some partners feel a lack of emotional sharing and feel this is detrimental to the relationship. Partners believe that lack of emotional sharing may be a residue of how a person is raised. Partners are unsure how to encourage emotional sharing but feel that lack of sharing is negatively impacting the relationship.

Partners feel a myriad of emotions. They feel anxiety when separated from the person with AIDS and an urge to connect when apart. Prior experience with a person with AIDS is viewed as helpful in managing anxiety. Partners worry about the person with AIDS being alone and the difficulties families cause. Partners feel that by being HIV negative they can never totally relate to the person with AIDS.

There is acknowledgment that being involved with a person with AIDS is taxing and emotionally depleting. Partners experience emotional depletion at some point in the relationship. Emotional depletion may occur when partners perceive that involvement with a person with AIDS results in emotions in constant flux, and feelings of being unstable and out of control. If there are communication problems or problems with allowing emotional closeness this adds to the emotional burden.

Preserving the relationship is often painful and fighting is viewed as a strenuous crisis. Other crisis are related health issues and the fact the partner may not know how to deal with certain health issues. Families can precipitate a crisis when they refuse to offer
financial support. Maintaining the relationship may be difficult if partners perceive outside
goals are being negatively impacted. The partner and the person with AIDS may have
diverse backgrounds and differences in educational levels resulting in a lack of mental
stimulation that is disturbing to the partner.

Partners fear the future and fear the unknown. The future feels uncertain and
partners feel that their view of life and their behavior has been changed by involvement
with a person with AIDS. Partners are struggling with life goals that effect their future.
Events are occurring quickly with multiple events such as infection and hospitalization
occurring in a short period of time. Partners have difficulty adjusting to change. The role
of the partner is in flux. Partners experience anxiety over change in the relationship and
believe that knowing your HIV status changes your life. Life with a person with AIDS is
confusing in its' complexity.

Events such as hospitalization, AIDS related illnesses, and disclosure are viewed as
turning points in relationship. Another turning point may be when the partner feels the
ability to speak openly about the AIDS diagnosis. Partners see falling CD4 counts as
milestones especially as the count falls below 200. Adding or subtracting drugs from the
person with AIDS regime is marked as a milestone.

Partners feel that AIDS itself causes internal struggles. AIDS is seen as adversely
effecting the relationship and depleting emotions. Partners feel AIDS is a nightmare and
have difficulty integrating AIDS into the relationship. Thoughts of AIDS are perceived as
increasing over time and thoughts become uncontrollable. AIDS is viewed by the partners as intrusive and leading to a loss of privacy. AIDS spread is viewed as unpredictable and partners feel that AIDS closes people out of society. Partners interaction with others are hampered by the burden of AIDS. AIDS can divide the couple and act as a mood breaker. Partner can feel the financial impact of AIDS as the person with AIDS is less able to work and bills continue to accumulate.

Partners fear loss of the person with AIDS prior to death. Dementia is viewed as a loss before death. Partners may see dementia as the worst outcome imaginable. The person with AIDS is there in body but unable to communicate thoughts to his partner or understand what is being communicated to him. Partner fear losing the person with AIDS to narcotics. There is a wish for the person with AIDS to be comfortable but fear if the person with AIDS is over sedated the couple will not be able to interact. Some partners feel that AIDS does not end with death and the disease of AIDS will become a permanent part of the partners' life as will thoughts of the person with AIDS.

Preparation for death is an issue for the partners. Previously witnessing a person die of AIDS is perceived as helpful preparation for what may occur. Partners involvement with medical treatment is perceived as preparing for death. People with AIDS may take responsibility for the disease, preparations for death, and financial arrangements. One way partners prepare for death is by bargaining with God for the recovery of the person with
AIDS. Some partners believe that certain events must be borne alone and the grieving process is one such event.

Some partners are discussing end-of-life decisions with the person with AIDS although final decisions remain. The person with AIDS may wish no heroics and partners may support this decision. Partners allow the person with AIDS emotional space in which to reach their decisions regarding end-of-life decision. Partners encourage the decision to resolve issues before death. Some partners believe that comfort for the person with AIDS is paramount at the end of life.

Partners see periods of wellness for the person with AIDS. At times there is no physical indication of the disease, especially when no opportunistic infection is present. Partners cherish these periods of good health. People with AIDS remain active and partners feel grateful when activity is maintained.

There is effort on the partners’ part to keep AIDS on hold. Partners may view the person with AIDS as normal and continue previous activities like eating out, going to movies, and socializing with friends. While engaging in activities the partner is able to forget about AIDS. Some partners believe that when AIDS is latent is the time to deal with unresolved issues so energy is not wasted later when there is no energy to spare. Long uncomplicated times between the partner and person with AIDS is when the disease is on hold.
Partners experience fear. There is fear over death of the person with AIDS and fear over grieving alone. Partners can imagine the person with AIDS' fear, knowing that death is approaching. Partners experience increasing fear of the situation.

Partners are aware of the ultimate outcome for the person with AIDS. AIDS symptoms become more visible with passing time and partners acknowledge there is no cure for AIDS. Recovery is remote. Feelings that AIDS is permanent, the person with AIDS will die, life is finite and AIDS is fatal are common thoughts for partners. Partners may see death as an immediate concern and perceive living daily in a life and death situation.

Partners experience death approaching. Partners observe a change in the physical appearance of the person with AIDS and see AIDS-related physical changes as more visible. This serves to remind the partner that death is approaching. Death is felt as a hovering presence and the partners fear it may attack without warning.

Partners feel ambivalence over discussing death with the person with AIDS. Originally talk of death is welcomed and viewed as a lessening of denial. As time passes partners do not want to discuss the death of the person with AIDS. Partners wish to avoid discussion especially when the partner is healthy. Partners also fear their reaction as physical deterioration occurs.

There is uncertainty over how to react to death. Without past experience of death to draw on partners may feel uncertain how to act. Discussing this concern with the
person with AIDS is perceived as an intrusion. Other partners are uncertain over how the
last days should be spent. Partners feel the person with AIDS may wish to accomplish
something and not have the opportunity. Partners experience relief when the person with
AIDS has decided how to spend the final time and also voices satisfaction over life.
REFERENCES


