A PHENOMENOLOGICAL STUDY OF NURSES' EXPERIENCES
CARING FOR PATIENTS WITH
ACQUIRED IMMUNODEFICIENCY SYNDROME
(AIDS)

BY

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to the required standard

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ABSTRACT

This study describes hospital nurses' experiences caring for patients with AIDS. A modified version of Speigelberg's phenomenological approach was used which explored the nurses' experiences from their perspective. A total of eight nurses who had cared for patients with AIDS were interviewed.

The findings indicated that caring for these patients is stressful. The researcher identified sources of stress as both internal and external. Internal stressors included: (1) fear of contracting AIDS; (2) homophobia; and (3) caring for dying AIDS patients. The two external stressors were patient variables and societal views. Lack of perceived emotional support from nursing administration further increased the stress. These nurses believed this form of support was essential.

In order to cope with these experiences, the nurses utilized their usual coping strategies. Common ones were being physically active, relaxing, and talking with others. Different coping strategies were used to deal with the specific stressors. These were identified by the researcher as: (1) rationalization;
(2) knowledge-seeking; (3) withdrawal; and (4) involvement.

This study's findings emphasize the need for support for all nurses caring for patients with AIDS. Implications for nursing education, practice, and research were identified.
Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>iv</td>
</tr>
<tr>
<td>List of Figures</td>
<td>viii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>ix</td>
</tr>
<tr>
<td><strong>CHAPTER 1: INTRODUCTION</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Background to the Problem</td>
<td>2</td>
</tr>
<tr>
<td>Methodological Approach</td>
<td>8</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>9</td>
</tr>
<tr>
<td>Assumptions</td>
<td>9</td>
</tr>
<tr>
<td>Limitations</td>
<td>9</td>
</tr>
<tr>
<td><strong>CHAPTER 2: REVIEW OF SELECTED LITERATURE</strong></td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td>10</td>
</tr>
<tr>
<td>Issues Related to Health Care Professionals</td>
<td></td>
</tr>
<tr>
<td>Caring for Patients with AIDS</td>
<td>12</td>
</tr>
<tr>
<td>Introduction</td>
<td>12</td>
</tr>
<tr>
<td>Fear of Contagion</td>
<td>12</td>
</tr>
<tr>
<td>Homophobia</td>
<td>15</td>
</tr>
<tr>
<td>Terminal Illness</td>
<td>16</td>
</tr>
<tr>
<td>Summary</td>
<td>17</td>
</tr>
</tbody>
</table>
### CHAPTER 3: METHODOLOGY

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>18</td>
</tr>
<tr>
<td>Phenomenological Method</td>
<td>18</td>
</tr>
<tr>
<td>Historical Foundations of Phenomenology</td>
<td>19</td>
</tr>
<tr>
<td>Phenomenological Sampling Procedure</td>
<td>20</td>
</tr>
<tr>
<td>Validity and Reliability</td>
<td>22</td>
</tr>
<tr>
<td>Selection of Informants</td>
<td>24</td>
</tr>
<tr>
<td>Criteria for Selection</td>
<td>24</td>
</tr>
<tr>
<td>Selection Procedure</td>
<td>24</td>
</tr>
<tr>
<td>Characteristics of Informants</td>
<td>25</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>26</td>
</tr>
<tr>
<td>Data Collection</td>
<td>27</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>28</td>
</tr>
<tr>
<td>Spiegelberg's Phenomenological Method</td>
<td>28</td>
</tr>
<tr>
<td>Investigating Particular Phenomena</td>
<td>29</td>
</tr>
<tr>
<td>Investigating General Essences</td>
<td>30</td>
</tr>
<tr>
<td>Apprehending Essential Relationships Among</td>
<td>30</td>
</tr>
<tr>
<td>Watching Modes of Appearing</td>
<td>31</td>
</tr>
<tr>
<td>Exploring the Constitution of the Phenomenon in Consciousness</td>
<td>31</td>
</tr>
<tr>
<td>Suspending Belief in Existence</td>
<td>31</td>
</tr>
<tr>
<td>Interpreting Concealed Meanings</td>
<td>31</td>
</tr>
<tr>
<td>Content Analysis</td>
<td>32</td>
</tr>
</tbody>
</table>
# CHAPTER 4: PRESENTATION AND DISCUSSION OF THE FINDINGS

<table>
<thead>
<tr>
<th>Introduction</th>
<th>34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content Analysis</td>
<td>36</td>
</tr>
<tr>
<td>Nurses' Experiences As Stressful</td>
<td>36</td>
</tr>
<tr>
<td>Stress</td>
<td>43</td>
</tr>
<tr>
<td>Stress in Nursing</td>
<td>46</td>
</tr>
<tr>
<td>Stresses of caring for patients with AIDS</td>
<td>47</td>
</tr>
<tr>
<td>Sources of Stress</td>
<td>48</td>
</tr>
<tr>
<td>Internal Stressors</td>
<td>48</td>
</tr>
<tr>
<td>Fear of contracting AIDS</td>
<td>48</td>
</tr>
<tr>
<td>Homophobia</td>
<td>60</td>
</tr>
<tr>
<td>Caring for dying AIDS patients</td>
<td>70</td>
</tr>
<tr>
<td>External Stressors</td>
<td>83</td>
</tr>
<tr>
<td>Patient variables</td>
<td>83</td>
</tr>
<tr>
<td>Societal views</td>
<td>91</td>
</tr>
<tr>
<td>Lack of Emotional Support</td>
<td>101</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>111</td>
</tr>
<tr>
<td>Usual Coping Strategies</td>
<td>113</td>
</tr>
<tr>
<td>Physical Activities</td>
<td>113</td>
</tr>
<tr>
<td>Relaxation Activities</td>
<td>114</td>
</tr>
<tr>
<td>Talking with Others</td>
<td>115</td>
</tr>
<tr>
<td>Coping Strategies Related To Internal and External Stressors</td>
<td>116</td>
</tr>
<tr>
<td>Rationalization</td>
<td>116</td>
</tr>
<tr>
<td>Knowledge-Seeking</td>
<td>120</td>
</tr>
<tr>
<td>Withdrawal</td>
<td>122</td>
</tr>
<tr>
<td>Involvement</td>
<td>126</td>
</tr>
<tr>
<td>Summary</td>
<td>129</td>
</tr>
</tbody>
</table>
CHAPTER 5: SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

Summary ................................................................. 137
Conclusions ............................................................... 138
Implications for Nursing .............................................. 140
  Nursing Education ..................................................... 140
  Nursing Practice ....................................................... 141
  Nursing Research ..................................................... 143
Bibliography ............................................................. 146
Appendix A: Informant Information ................................. 162
Appendix B: Subject Consent Form ................................. 163
Appendix C: Sample Questions ...................................... 164
List of Figures

Figure 1  Framework for Nurses' Experiences Caring for Patients with AIDS.........................35
I would like to acknowledge and thank all the nurses who participated in this study for sharing their personal experiences with me. I would also like to acknowledge the members of my thesis committee, Dr. Marilyn Willman and Ms. Donelda Ellis, for their continued support and interest. And a very special thanks to my family for their patience and understanding.
CHAPTER 1
INTRODUCTION

Since acquired immunodeficiency syndrome (AIDS) was first identified in 1981, few people, if any, have not heard about this deadly disease. It is a constant topic in the media. AIDS is now considered to be the world's most crucial health problem and the numbers of people infected are expected to continue to increase at alarming rates (Morgan & Curran, 1986). This increase, combined with the terminal nature of the disease, presents a challenge to which all health care professionals must respond. For nurses, particularly hospital nurses, AIDS is an even greater challenge. Hospital nurses must be knowledgeable about AIDS and be current with the latest research. They must care for and comfort patients with AIDS who can have multiple and severe physical problems, and who face great suffering and early death. They also need to provide support for and help to educate patients' family members and friends. In addition to providing this care, hospital nurses must at the same time cope with their own fears and anxieties.
There is little research which describes hospital nurses' experiences caring for patients with AIDS. Specific concerns related to AIDS patients, such as fear of contagion, homophobia, and caring for the terminally ill, have been well documented in the literature (Barnard, 1987; Baumgartner, 1985; Blumenfield, Smith, Milazzo, Seropian, & Wormser, 1987; Bolding & Goldstone, 1985; Christ & Weiner, 1985; Douglas, Kalman, & Kalman, 1985; Geis & Fuller, 1986; Reed, Wise, & Mann, 1984; Rubinow, 1984; Simmons-Alling, 1984). Caring for patients with AIDS is a monumental challenge for hospital nurses and it is also undeniably stressful. However, little is known about what it is like to care for these patients; therefore, this study was designed to explore the experiences of hospital nurses who have cared for patients with AIDS.

**Background to the Problem**

In order to fully understand the nurses' experiences it is important to first know about the nature of the disease. Thus, the epidemiology of AIDS will be described.

AIDS was first identified in homosexual men, which resulted in its being labelled the "gay disease"
Homosexual/bisexual men are the highest risk group and they have captured most of the media's attention. In Canada, the high risk groups are: (1) homosexual/bisexual men (72%); (2) intravenous drug users (0.3%); (3) hemophiliacs (0.1%); (4) blood transfusion recipients before 1983 (1.0%); (5) people from endemic areas (like Haiti and Zaire) (12.9%); (6) sexual partners of one of the above (2.3%); (7) neonates born to AIDS mothers (6%); and (8) others (3%) (Goldstone, 1985a, p. 13). The 3% figure attributed to the group of "others" is frightening because it is not known why these people are affected. Canadian statistics reveal there were 110 people with AIDS as of February 5, 1990 for whom no risk group could be identified (Canada Diseases Weekly Report [CDWR], February 5, 1990, p. 1). Increasingly, new cases have been identified in heterosexual partners of people in the high risk groups. In New York since 1985, 30% of the AIDS cases were diagnosed in heterosexual men and women (Krim, 1985, p. 6). Recent statistics for Canada indicate a total of 64 women and 43 men in this group as of the beginning of 1990 (CDWR, February 5, 1990, p. 3). At this same time, there were 51 children with AIDS, most
having become infected prenatally.

In July 1986 there were 638 people diagnosed with AIDS in Canada (CDWR, July 26, 1986) and by December 1988 the number had increased to 2,209 (CDWR, December 17, 1988). The number of reported AIDS cases is currently doubling every 21 months. The total number of cases in Canada is now 3,458 with 2,122 deaths (CDWR, February 5, 1990, p. 1). The number of people who are infected with the AIDS virus is not known but estimates have ranged from 50,000 to 75,000, of whom 10% will develop AIDS within two years (Krim, 1985, p. 5).

AIDS has a mortality rate of close to 100% two years after diagnosis (CDWR, July 6, 1985; Fauci & Lane, 1984; Krim, 1985; Williams, 1986). It is characterized by suppression of the immune system causing the person to become susceptible to opportunistic infections and rare tumors. Opportunistic infections are caused by microorganisms which take advantage of the immune system's inability to destroy them and therefore they multiply causing disease. Some common opportunistic infections are: pneumocystis carinii pneumonia (PCP), oral candida, herpes simplex, and shigella (Fauci & Lane, 1984;
Goldstone 1985a; Bennett, 1986; Weber & Pinching, 1986). Rare tumors which can also be indicative of AIDS are: Kaposi's sarcoma (KS), lymphoma of the brain, and non-Hodgkin's lymphoma. Symptoms of AIDS vary from person to person depending upon the specific infection. People with AIDS are very ill and can suffer from severe and debilitating symptoms such as muscle wasting, chronic cough, profuse diarrhea, sweating, generalized pain, and confusion. Treatment at this point is focussed on alleviating the specific symptoms and, if possible, the opportunistic infections. There is no cure for AIDS and it is highly unlikely a vaccine will be developed in the near future due to the characteristics of the causative agent.

AIDS is caused by the human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV); it is more commonly referred to as the human immunodeficiency virus or HIV (Bennett, 1985b; Canada Diseases Weekly Report Supplement, 1986; Fettner & Check, 1984; Goldstone 1985a). Although this virus is not one of the most contagious ones, it has certain characteristics that make it difficult to eradicate (Krim, 1985). One of its characteristics is
its ability to become part of the cell it infects and to rapidly replicate itself and then infect other cells. Once the HIV enters a cell it persists for the lifetime of the infected person and can remain inactive for unknown periods of time. Although this virus may be inactive and not cause any symptoms, all people infected are considered carriers. Periods of inactivity are often referred to as the latency stage or the incubation period. Estimates of the incubation period range from 6 months to 8 years (CDWR, May 30, 1987; Goldstone 1985a; Krim 1985; Institute of Medicine/National Academy of Sciences, 1986; Williams, 1986). Another significant characteristic of this virus is that antibodies are incapable of destroying it. Therefore, they are of limited use in the development of a vaccine. In addition to these characteristics the HIV is like flu viruses and has different strains which vary from person to person. This variability further compounds the difficulty of developing a vaccine since it would need to be effective for everyone.

Risk factors which increase susceptibility to AIDS are: practices which involve the transmission of body fluids particularly semen and blood, multiple
sexual partners, and sharing needles used for intravenous injections (Henderson, 1984; Krim, 1985; Schechter, 1985). The risk of becoming infected with the HIV from casual contact is apparently nonexistent (Adams & Lowy, 1985; Bennett, 1986; Goldstone, 1985c; Haber, 1985; Schaffner, 1985; Valenti 1985; Williams, 1986). For nurses who are intimately involved with caring for AIDS patients, the risk factors are said to be extremely low (Beaufoy & Goldstone, 1985; Bennett, 1986; Dhundale & Hubbard, 1986; Gilmore, 1985; Institute of Medicine/National Academy of Sciences, 1986; Jackson & Goldman, 1986).

AIDS is a unique disease which causes severe and debilitating illnesses and death. It is inevitable that many hospital nurses will encounter patients with AIDS at some time in their careers. There is little literature describing hospital nurses' experiences caring for patients with AIDS. It is therefore imperative that research about the impact of AIDS on hospital nurses be implemented. Thus, this study was designed to describe the experiences of hospital nurses caring for these patients. The research question for this study is: What are hospital nurses' experiences caring for patients with AIDS?
The major purpose of this study was to describe hospital nurses' experiences caring for patients with AIDS. This will help nurses who have not yet cared for AIDS patients to understand what they might expect. Another purpose was to identify coping strategies which might help others to deal with their experiences.

Methodological Approach

The methodological approach selected for this study was phenomenology. Phenomenology is one form of qualitative research which looks at the phenomena being studied, in their totality, from the perspective of the people who are involved. It attempts to describe a comprehensive view of the full meaning of the phenomena being studied (Ray, 1985).

Phenomenology gives direction to describe phenomena as they are lived by the informant (Lynch-Sauer, 1985; Munhall & Oiler, 1986; Oiler, 1982). It can be used when little is known about a particular phenomenon. For these reasons phenomenology was selected for this study in order to understand the nurses' experiences caring for patients with AIDS from their personal perspectives and to identify the meaning these experiences had for these nurses.
Definition of Terms

AIDS: Infection with the human immunodeficiency virus (HIV) which results in one or more opportunistic infections and/or rare tumors.

Experiences caring for patients with AIDS: Personal feelings and perceptions about caring for patients with AIDS.

Nurse: An individual who is a practicing member of the Registered Nurses' Association of British Columbia.

Assumptions

It is assumed that all nurses who have cared for an AIDS patient are qualified to speak about their experiences regarding AIDS patients and that their experiences are valid.

Limitations

The nurses in this study were hospital nurses working on medical wards. Therefore, these experiences cannot be generalized to all nurses working with AIDS patients.
CHAPTER 2
REVIEW OF SELECTED LITERATURE

Introduction

In the last eight years there has been much written about AIDS. The lay press has printed numerous articles on various aspects of the disease (Allan, 1985; Barnes & Hollister, 1985; Bishop, 1982; Clark & Coppola, 1985; Lawren, 1985; McKay, 1983; Wallis, 1985; 1986). The researcher has collected over one hundred articles from a British Columbian newspaper between 1986 and 1988.

Law, education, and social work journals have also published numerous articles discussing how AIDS affects their disciplines. However, the majority of literature has been found in the health care field. Larson (1988, p. 60) reports that, from July 1986 to December 1986, 481 AIDS articles appeared in various medical journals. During the same six month period, 36 AIDS articles appeared in nursing journals. A search of the Cumulative Index to Nursing and Allied Health Literature from January 1983 to April 1987, revealed 169 AIDS articles in 46 different nursing journals which were mainly American (Larson, 1988, p. 61).
There have also been books written about AIDS by health care professionals (Durham & Cohen, 1987; Feldman & Johnson, 1986; Witt, 1986). This abundance of literature discusses many different aspects of AIDS; however, most of it focuses on the epidemiology, treatment modalities, or physical care of AIDS patients (Armstrong, Gold, Dryjanski, Whimbey, Polsky, Hawkins, Brown, Bernard, & Kiehn, 1985; Beaufoy, Goldstone, & Riddell, 1988; Bennett, 1985a; 1985b; 1986; Calliari, 1984; Dhundale & Hubbard, 1986; Gever, 1987; Henderson, 1984; Krim, 1985). There is also some literature which discusses the psychosocial implications for these patients and their families (Cecchi, 1986; Guarda & Peterson, 1986; Rubinow, 1984; Van Devanter et al., 1987). Even with all this literature there is little which discusses the impact of working with AIDS patients on health care professionals, particularly nurses.

In this chapter literature which focuses on issues related to health care professionals caring for patients with AIDS will be discussed with emphasis on hospital nurses.
Issues Related to Health Care Professionals Caring for Patients with AIDS

Introduction

The AIDS epidemic has created mass concern not only for society but also for health care professionals who provide intimate care to patients with AIDS. Health care professionals have met the challenge of treating and caring for these patients in an incredibly short time. The amount of research done on AIDS patients and the HIV is staggering; however, the impact of caring for patients with this disease on the professional and personal lives of people in the health care field is not yet known. How this disease affects health care professionals and how they cope are two unanswered questions.

Fear of Contagion

It is undeniable that caring for patients with AIDS is physically, mentally, and emotionally stressful for the professional caregiver (Bennett, 1987; Christ & Weiner, 1985; Geis & Fuller, 1986; McLeod & Silverthorn, 1988; Steinbrook et al., 1985; Van Servellen, Lewis, & Leake, 1987; Zuger, 1987). Fear of contracting AIDS is one concern which can cause this stress. Despite vast documentation of the
low risk to health care workers (Beaufoy & Goldstone, 1985; Bennett, 1986; Dhundale & Hubbard, 1986; Gilmore, 1985; Institute of Medicine/National Academy of Sciences, 1986; Jackson & Goldman, 1986) there is still fear among health care workers of contracting the HIV. Searle's (1987) study in Britain revealed incidents where environmental health officers and district nurses refused to visit patients who were HIV positive. The researcher also noted that ambulance attendants, anesthetists, pathologists, and some nurses had serious concerns about caring for these patients. Butler & Lynch (1988), in a Canadian study, reported similar findings; hospital nurses, physicians, laboratory staff, maintenance personnel, and cleaners had high anxiety levels due to fear of contracting AIDS. A survey of physicians in training from New York and San Francisco revealed that 9% thought about the risk of contracting AIDS on a daily basis; 40% thought about it weekly; and 50% had examined themselves at one point to check for signs of HIV infection (Nursing 1987, September, p.14).

For hospital nurses the perceived risk is thought to be higher due to frequent exposure to body fluids. These nurses care for intravenous lines, drains and
tubes; they suction oral, nasal and endotracheal airways; and also provide basic hygiene, all of which can expose them to infected body fluids. Literature focusing on nurses indicates that they are also afraid of becoming infected (Barnard, 1987; Berry-Koziel, 1987; Blumenfield et al., 1987; Bolding & Goldstone, 1985; Geis & Fuller, 1986; Haines, 1987; Reed, Wise, & Mann, 1984; Rubinow, 1984; Simmons-Alling, 1984).

Battern & Tabor (1983) stated that some nurses quit their jobs due to this fear and the resulting emotional strain, rather than refuse to care for patients with AIDS. Christ and Weiner (1985) also reported female staff resigning at their husbands' insistence.

Geis and Fuller (1986) researched the response of hospice staff to the fear of AIDS and discovered that many were afraid of contracting it despite educational inservices and an infection control policy. They also found that a number of the administrators did not recognize the fear among the staff and told the researchers it did not exist. McMahon (1987) states:

"Staff understand the risk is minimal. They have been seeing and working with many people with AIDS for years now. The issue is fear. It may
be subliminal, but it is real. And facts do not necessarily dissolve that underlying emotion—especially because we can't say it's 100 percent safe. (p. 903).

Nurses may also be pressured by family and friends to avoid caring for patients with AIDS because of the potential threat to the nurses themselves and the people who come in contact with them (Haines, 1987). AIDS patients often feel like social lepers and this attitude sometimes crosses over to the nurses. Family, friends, and sometimes peers ostracize nurses for caring for patients with AIDS (Butler & Lynch, 1988; Haines, 1987; Kennedy, 1987; McLeod & Silverthorn, 1988; Simmons-Alling, 1984).

Another issue that some health care professionals must face is homophobia.

**Homophobia**

Other studies have indicated that, in addition to fear of AIDS, many health care professionals have concerns about caring for homosexual or bisexual patients (Blumenfield et al., 1987; Bolding & Goldstone, 1985; Douglas, Kalman, & Kalman, 1985; Haines, 1987; Reed, Wise, & Mann, 1984; Rubinow, 1984; Simmons-Alling, 1984). Reed, Wise, and Mann (1984)
researched nurses' attitudes regarding their care of patients with AIDS according to the anxiety they felt. They found homophobia was an ever-present issue but most nurses were generally tolerant of homosexual lifestyles. Another study indicated that 31% of the respondents, nurses and physicians, felt more negatively about homosexuality since AIDS emerged and that 9% agreed that "...homosexuals were getting what they deserve" (Douglas, Kalman, & Kalman, 1985, p. 1311). Homosexual and bisexual men are a high risk group, therefore health care professionals need to acknowledge and deal with their feelings about them.

Terminal Illness

Caring for dying patients requires special emotional stamina, but caring for patients with AIDS who are dying requires even more. AIDS patients are generally in the prime of their life and are deteriorating rapidly till death. Most of these patients are between 20 and 49 years and are at the beginning or the height of their careers (Blumenfield et al., 1987; Bolding & Goldstone, 1985; Christ & Weiner, 1985; Haines, 1987; Rubinow, 1984). Caring for such young patients who are terminally ill can cause feelings of frustration and powerlessness for
all health care professionals. Hospital nurses who must care for these patients 24 hours a day may find themselves becoming anxious and starting to think about their own death (Rubinow, 1984; Simmons-Alling, 1984). Dying AIDS patients are very ill and require constant nursing care. The intensity of these patients' physical and emotional needs can be overwhelming, resulting in nurses becoming overtaxed, fatigued, and "burned out" (Bennett, 1987; Haines, 1987; Reed, Wise, & Mann, 1984; Simmons-Alling, 1984).

Summary

This literature review has presented some issues related to health care professionals caring for patients with AIDS. It emphasizes how stressful it can be to work with them. However, it does not provide a clear understanding of how individual health care groups are affected, especially nurses. The lack of research about nurses caring for patients with AIDS combined with the fact that nurses are frequently the frontline caregivers, has led to the development of this study. Its intent is to increase our understanding about what it is like for nurses who care for these patients.
CHAPTER 3
METHODOLOGY

Introduction

The phenomenological approach was chosen for this study because it enabled the researcher to investigate the phenomenon from the perspective of the informants. This method can be used when one desires to understand a phenomenon about which little is known.

In this chapter, the phenomenological method will be presented with discussion of its historical foundations, sampling procedure, validity and reliability, and selection of informants. This study's criteria for selection, selection procedure, and informants' characteristics will also be presented. In addition, the ethical considerations, data collection and analysis will be discussed. Speigelberg's phenomenological method and direction for content analysis will be outlined indicating how it was implemented for this study.

Phenomenological Method

Phenomenology is one form of qualitative research. Leininger (1985) states that qualitative research refers to "the methods and techniques of observing, documenting, analyzing and interpreting
attributes, patterns, characteristics, and meanings of specific, contextual or gestalt features of phenomena under study" (p. 5). This method attempts to look at the phenomena being studied based on the views of the people being studied. Qualitative methods have traditionally been used in sociology and anthropology when the meanings of a particular phenomenon are to be studied from the perspective of a certain culture or society (Munhall & Oiler, 1986). The importance of these methods for nursing is that they "...are the essential means to know and understand phenomena of nursing" (Leininger, 1985, p. 23). Qualitative methods are congruent with the nature and goals of nursing since they support nursing from a holistic perspective (Leininger, 1985; Sandelowski, 1986).

Phenomenology is one type of qualitative research methodology which enables the researcher to study phenomena holistically. It allows the researcher to understand the experience from the perspective of the informants as they have lived it (Omery, 1983).

**Historical Foundations of Phenomenology**

Phenomenology has been described as a philosophy, an approach, and a research method (Field & Morse, 1985; Knaack, 1984; Lynch-Sauer, 1985; Oiler, 1982;
1986; Reinharz, 1983). The 19th century philosopher Husserl is considered the founder of the phenomenological movement (Spiegelberg, 1970; 1981). Existential philosophers such as Marcel, Sartre, Merleau-Ponty, and Heidegger have also influenced the phenomenological movement with their own views of phenomenology (Spiegelberg, 1960; 1970). This movement grew out of the belief that people's behaviour could not be controlled in the same way as natural phenomena (Field & Morse, 1985). One of the objectives of this movement was to describe concrete experiences by identifying related meanings and values, as perceived by individuals (Spiegelberg, 1960). This objective is the focus of phenomenology as a research method: to describe the experience, identify the essence of the behaviour, and promote understanding of human behaviour (Omery, 1983).

**Phenomenological Sampling Procedure**

The sampling procedure for qualitative research is different from that of quantitative research. Field and Morse (1985) differentiate between quantitative and qualitative research sampling procedures by reviewing the purpose of both methodologies. They state that the purpose of
quantitative research "is to examine the distribution of previously known phenomena in a population" (Field & Morse, 1985, p. 93). Random sampling techniques are then appropriate. For qualitative research, the purpose is to understand phenomena which may not be evenly distributed throughout the population. In order to understand a particular phenomenon, it is necessary to seek out the specific population within which it would be most appropriate to investigate the phenomenon to be studied. For phenomenological research a purposeful sample would be required (Diers, 1979; Field & Morse, 1985). This type of sampling is also known as theoretical sampling (Glaser & Strauss, 1967; Wilson, 1985). The sample of informants would be selected based on their specific knowledge or characteristics which would be essential to the study. The size of the sample cannot be predicted prior to data collection. This means that data are collected until no new information can be obtained (Field & Morse, 1985) or when saturation is reached (Wilson, 1985, p. 419). Saturation occurs when the themes or major categories are repeated. All informants need to have information on the subject under study and be credible representatives of the population (Field &
Morse, 1985, p. 117). Subjects are selected because they can illuminate the phenomenon being studied, but the size of the sample is dependent upon the time it takes to establish typical or atypical behaviours, experiences, or events (Sandelowski, 1986, p. 32).

**Validity and Reliability**

When evaluating the validity and reliability of a qualitative study one must keep in mind that, since this method is essentially different from quantitative methods, the criteria to evaluate it must be different. The internal validity of qualitative research can be evaluated based on the credibility of the study (Sandelowski, 1986). Sandelowski (1986) states that "a qualitative study is credible when it presents such faithful descriptions or interpretations of a human experience that the people having the experience would immediately recognize it from those descriptions or interpretations as their own" (p. 30). Another way to determine the credibility of the study is if other people view the experience in the same manner as described in the study. Reiman (1986) discusses validating themes by referring back to the original descriptions and by asking the informants if the descriptions are accurate.
The external validity of qualitative research is threatened less than with quantitative research because in qualitative research the emphasis is on studying the phenomena in their natural settings and with few controlling conditions.

The elite bias is a problem in qualitative research, because subjects who act as informants are frequently the most articulate, accessible, or high status members of their groups (Sandelowski, 1986, p. 32).

Reliability is a necessary prerequisite for validity. Reliability is the ability of the study to be repeated. Auditability is proposed by Guba and Lincoln (1981) to be the criterion for consistency of qualitative findings. An auditable study is one in which a researcher can clearly follow the decision trail of another researcher (Sandelowski, 1986, p. 33). Also, another researcher could arrive at the same or comparable but not contradictory conclusions given the researcher's data, perspective, and situation. Sandelowski (1986) emphasizes that qualitative researchers need to be aware of ensuring validity within their research.
Selection of Informants

In phenomenological research, informants are selected based on their having certain knowledge or characteristics essential to the study.

Criteria for Selection

The nurses for this study were selected based on the following criteria: (1) they were hospital nurses; (2) they had cared for one or more patients with AIDS within the last year; and (3) they were willing to be interviewed and audio-taped on two to three separate occasions.

Selection Procedure

For this study, nurses from two major teaching hospitals in B.C. were recruited. The researcher presented her proposal to the nursing administration at the first hospital. This information was then passed on to nurses working on medical wards who were then asked to contact the researcher by telephone if they were interested in participating. At the second hospital, the researcher made presentations to the nursing administration and also to staff nurses who had cared for patients with AIDS. Again, interested nurses were asked to contact the researcher.

Information letters (see Appendix A) were also posted
on bulletin boards near nursing stations in these two hospitals. Initially, five nurses contacted the researcher for more information. Four of them were interested in participating and the fifth nurse declined stating there was nothing positive she could say about her experiences. Another three nurses were recruited from the second hospital after the researcher had made presentations to them. An eighth nurse contacted the researcher after reading the information letter and asked to participate.

**Characteristics of Informants**

All 8 informants were registered nurses; 3 of them were males. The ages of the informants ranged from 23 to 39 years. Of the 5 female informants, 3 were married and one had a child. None of the men were married or had children.

The informants' education included one with a baccalaureate degree and 7 graduates from a diploma school of nursing, 3 of whom also had psychiatric nursing diplomas. All of them had 2 or more years of hospital nursing experience. The number of patients with AIDS they had cared for ranged from 1 to 50. Five of the informants had cared for 25 or more AIDS patients.
Ethical Considerations

The researcher submitted her research for ethics approval to the UBC Behavioural Sciences Screening Committee for Research, then sent copies of the proposal to both hospitals' research committees. After hospital approval was obtained the researcher presented her proposal to the nursing administration at both hospitals and to staff nurses at the second one.

The study was initially explained to each nurse when s/he contacted the researcher. It was again reviewed at the beginning of the first interview and information letters (see Appendix A) were given to each informant. A written consent (see Appendix B) was then obtained from all informants which outlined their rights to refuse to participate, to withdraw from the study at any time, and to refuse to answer any questions.

Confidentiality was ensured by keeping the names and personal information about the informants in a locked drawer. Interviews took place mainly in the informants' homes at their request, one informant was interviewed in a local community agency and another in the employing hospital. Audiotapes of interviews were
not available to anyone other than the researcher and members of her thesis committee with informants' approval. Transcripts were numerically coded so informants were not identifiable and names mentioned during the interviews were deleted. Four nurses requested numerical coding of the transcript excerpts to be left off the finished research in order to ensure their confidentiality. All informants had the right to be present when audiotapes were being erased; however, when asked, all declined.

Data Collection

Data collection for phenomenological research is usually done by participant-observation or interviews (Oiler, 1982). For this study, data were collected by interviews which were audiotaped and then transcribed verbatim as soon as possible after the interview. A total of 14 interviews were done, each one lasting from 45 to 100 minutes. Initial interviews were unstructured (see Appendix C for sample questions) in order to generate broad concepts and ideas (Field & Morse, 1985). Clarification and validation of these concepts and ideas took place in the second interviews. Six informants were available for second interviews; personal reasons prevented 2 of the
informants from being interviewed a second time. Data collection then ceased after the 14th interview as no new information was provided, thus saturation had occurred. Time required to complete data collection was three and one half months.

Data Analysis

Phenomenological data analysis according to Spiegelberg (1960; 1970; 1981) involves a systematic process of looking at the phenomenon with open eyes. For this study, interviews were transcribed verbatim with the researcher writing comments about nonverbal behaviour in the columns. Data analysis was an ongoing process simultaneous with data collection.

Spiegelberg's Phenomenological Method

The researcher used Spiegelberg's (1960) phenomenological approach which consists of seven steps: (1) investigating particular phenomena; (2) investigating general essences; (3) apprehending essential relationships among essences; (4) watching modes of appearing; (5) exploring the constitution of the phenomenon in consciousness; (6) suspending belief in existence; and (7) interpreting concealed meanings. His first three steps are considered to be essential elements which have been accepted and practiced by phenomenologists.
Investigating Particular Phenomena

The first step is often referred to as descriptive phenomenology. It consists of three operations: intuiting the phenomenon, analyzing the phenomenon, and describing the phenomenon. These operations are intimately connected and usually are not clearly distinguishable. In phenomenological intuiting one concentrates on the phenomenon and becomes familiar with it. One must forget preconceived ideas and view the phenomenon with "open eyes." Elements of the phenomenon are then compared and contrasted and recurring ones are identified. From these recurring elements, the "ingredients" of the phenomenon and their relationships are identified. The comparing and contrasting process is the analyzing operation. The last operation for this stage is the phenomenological description where the phenomenon is described and its nature, problems, and limitations are stated. The phenomenon is then compared with an existing framework. In cases where a new phenomenon or new aspects of an old phenomenon are discovered, Spiegelberg suggests describing it by negation, metaphors, or analogies (1960, p. 673). He emphasizes that the main function of phenomenological description
is to provide guideposts to direct the reader to his/her own actual or potential experience of the phenomenon.

**Investigating General Essences**

Spiegelberg's second step is closely linked to his first. For this step one must take the elements of the phenomenon and look at them as examples or instances that represent the general essence. The general essence is the common pattern shared by the grouping of similar elements. The grouping of elements results in identifying themes or categories. A procedure similar to step one would then be used.

**Apprehending Essential Relationships Among Essences**

The third step involves identifying the essential relationships among the categories. One uses experience, knowledge, and intuition to choose those which are essential to the phenomenon.

These three steps are common to all phenomenological research. According to Spiegelberg (1960), his remaining four steps are not crucial to the phenomenological method but they assist one to critically analyze the phenomenon.
Watching Modes of Appearing

To watch modes of appearing, one identifies what kinds of categories appear and the way in which they appear.

Exploring the Constitution of the Phenomenon in Consciousness

Exploring the constitution of the phenomenon in consciousness is to form a mental orientation or picture of the phenomenon in one's mind.

Suspending Belief in Existence

Suspending belief in existence is known as phenomenological reduction where the technique of bracketing is used. Bracketing is the detachment of personal experiences while at the same time preserving the content. This detachment allows one to suspend judgement about the existence or non-existence of this content. One views the content from a neutral perspective.

Interpreting Concealed Meanings

The last step is to interpret concealed meanings within the phenomenon. Meanings which are not immediately apparent to one's intuiting, analyzing, and describing are discovered. One has to go beyond the obvious and unveil hidden meanings.
Content Analysis

Content analysis for this study was done following Spiegelberg's approach. However, some modifications were made in order to make the process logical to the researcher.

Intuiting the phenomenon (step one) involved reading all the transcripts without preconceived ideas. All transcripts were read numerous times which allowed the researcher to become familiar with the content. Phenomenological analyzing (step one) was done by constant comparing and contrasting of statements. Recurring statements were highlighted and their meanings were written out (step seven). The meanings were identified by reflecting back onto the original statement and constant re-reading (steps five and six). Also, as they were identified they were validated and explored further with other informants. This occurred simultaneously in the first interviews for some informants and the second one for others. These meanings were then organized into themes (step two) and were also compared with the original statements to validate that the themes accurately reflected the original statements (step five and six). The relationships among the themes (steps three and
four) were then examined to identify the essential ones. This analysis was then integrated into an interpretation of the structure and configuration of the phenomenon (step one). The researcher developed a diagram summarizing the analysis and then searched for existing frameworks in the literature with which to compare the newly-defined phenomena. No frameworks were identified as appropriate; however, theory about stress was found to be related to the findings and was therefore used to describe them.
CHAPTER FOUR

PRESENTATION AND DISCUSSION OF THE FINDINGS

Introduction

The study's findings indicate that nurses' experiences caring for patients with AIDS were stressful. There were different sources of stress which the researcher categorized as either internal or external. Internal stressors included: (1) fear of contracting AIDS; (2) homophobia; and (3) caring for dying AIDS patients. External ones were patient variables and societal views. A lack of emotional support was also reported which added to the nurses' stress.

Various coping strategies were described by the informants and categorized by the researcher. Common ones which were used to deal with the nurses' overall experiences were labelled usual coping strategies. These strategies included: (1) physical activities; (2) relaxation activities; and (3) talking with others. Different ones were used to deal with the specific stressors. These were described as: (1) rationalization; (2) knowledge-seeking; (3) withdrawal; and (4) involvement.

A framework describing nurses' experiences caring for patients with AIDS is presented in Figure 1.
<table>
<thead>
<tr>
<th>Experiences As Stressful</th>
<th>Sources of Stress</th>
</tr>
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<tbody>
<tr>
<td>Internal Stressors</td>
<td>External Stressors</td>
</tr>
<tr>
<td>1. Fear of Contracting AIDS</td>
<td>1. Patient Variables</td>
</tr>
<tr>
<td>2. Homophobia</td>
<td>2. Societal Views</td>
</tr>
<tr>
<td>3. Caring for Dying AIDS Patients</td>
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**Lack of Emotional Support**

**Coping Strategies**

<table>
<thead>
<tr>
<th>Usual Coping Strategies</th>
<th>Coping Strategies Related To Internal and External Stressors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical Activities</td>
<td>1. Rationalization</td>
</tr>
<tr>
<td>2. Relaxation Activities</td>
<td>2. Knowledge-Seeking</td>
</tr>
<tr>
<td>3. Talking With Others</td>
<td>3. Withdrawal</td>
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<tr>
<td></td>
<td>4. Involvement</td>
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</tbody>
</table>

*Figure 1. Framework for Nurses' Experiences Caring for AIDS Patients.*
Content Analysis

Nurses' Experiences As Stressful

Stress was identified as the predominant theme in caring for patients with AIDS. The following transcript excerpts illustrate how this theme was identified.

R: What is it like to care for a client with AIDS?
I: Well, when I first started I was very scared, and apprehensive, and anxious, that maybe I could get it. Like, it's so scary to get a disease that doesn't have any hope and if you're exposed you'll get it... and I wasn't quite trusting of the isolation techniques...and I'm still not satisfied that gowning, gloving, and masking will help. I mean look at how long it took to discover it...It originally only affected gays and now just about anyone can get it...For us at work it's really hard to care for these patients, especially when they are really sick and need a lot of physical care, and are dying and need a lot of emotional support, and their families and friends need it and we need

*R: Researcher
*I: Informant
it too. It's scary, it's very nerve wracking, and stressful to have to care for them. There's so much you have to deal with [in] this disease but don't get me wrong I do like the patients...It's just the disease...

In this excerpt, many ideas and concepts were identified such as fear, risk, terminal disease, lack of trust in isolation techniques, new disease, homosexuality, high risk groups, difficulty caring for the very ill AIDS patient, emotional support needed by the patients and their families and friends, the nurse's need for emotional support, liking the patients, and stress. Stress was the predominant theme which overall reflected all informants' experiences. In the previous excerpt the informant stated it was stressful caring for patients with AIDS. Other informants described their experiences in similar ways.

R: What is it like for you to care for clients with AIDS?
I: ...I find that I'm more burned out after work when I have to care for some AIDS patients. I'm more mentally drained and it's tiring. You have to give them a lot [of] time and attention which many
times you don't have... You have other patients you have to care for also... It's a terrible thing. You know we're (the) ones cleaning them up and in contact with the infected fluids so it is stressful. Well, we all know the profession itself is stressful but these guys can be a handful and you know worrying about it.

I: ...caring for them is really different. It's a lot of work 'cause you know taking time to do the isolation... There's no cure, so inevitably they're going to die. And, like, for us to have to care for them when they're at that stage... is hard... I'm not a palliative care nurse. I'm a medical nurse... and yeah, everyone says we see death all the time, well sure, but for older people. You now have to worry about getting it too... Gee if I'm gonna now have to worry about getting it, it's gonna drive me nuts. I don't think that I can last too much longer with these patients... There's so much stress involved thinking about this and that. It's a lot of work...

In these excerpts all the informants stated it was stressful. This theme was validated with other informants to determine whether it accurately
represented their experiences as well.

R: Some of the other nurses have said it's stressful how do you find it?
I: Yeah, I'd agree with that...I find our workload has increased and you know with all the stigma and negative attitudes about it, like, that affects us too. Uhuh, it is stressful.

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R: One theme that keeps appearing is that caring for AIDS clients is stressful. How do you find it?
I: Oh yes, I think so. I mean who says it isn't? Anyone who says it isn't, hasn't cared for them before. I mean really it's a devastating disease. All our patients die from it. It's not one of the more respectable diseases to die from like cancer or some accident. It's not a very pleasant way to die...

Two informants responded to this question by stating that it was not stressful yet as the interviews progressed their descriptions clearly indicated it was.

R: Other nurses have said it's stressful caring for these clients. How do you find it?
I: Well no, I don't find it stressful. Maybe for
them they're scared about getting it or are homophobic. I've seen a lot of that but no, not for me. It's no different than caring for anyone else really.

Later in the interview this informant spoke about caring for dying AIDS patients and stated it was stressful.

I: ...it's such an emotionally laden disease ...It's so intense when they are going to die and it does affect my moods. I mean I have to be caring and intense at work so that when I'm at home it does come out...But it's difficult, it's really difficult. I think that these guys are the same age as me. They are so young to be dying and with such a horrible disease but I have to force myself to keep my own perspective and carry on with life.

R: So do all dying patients affect your moods or is it just these ones?

I: Well no, not all. For some it's a blessing to die. But it's different with them 'cause they have so much to deal with...It is stressful when they're dying, they have to make peace with themselves, their lifestyle and...that's depressing...
R: Some nurses have said it's stressful. One said it was nerve wracking having to nurse them. How do you find it?

I: Hmm no, not really. It's just like caring for any other kind of patient...

This informant then went on to discuss different aspects related to patients with AIDS which were "hard" for her to deal with.

I: ...it's hard to deal with the mental parts, the dementia. You know their behaviour is so psychotic you always have to be on guard...And then trying to explain [to] their families and friends why they're tied down...You see some who may be a lawyer [sic], or something and his mind has gone. It's hard to deal with that...and their sexuality too...

One informant who had only cared for one patient with AIDS did not feel that her experience was "overly stressful."

I: Well, for the one patient that I had it was not overly stressful. But I can see how it would be...mine was still fairly healthy, just in for antibiotic treatment, and then he was able to go home. But I guess if they were worse off then it would be stressful.
For these informants, not only was the overall experience of caring for patients with AIDS stressful but also specific aspects related to their experiences. One informant reported how thinking about AIDS evoked images of "death and destruction."

I: ...it's a really different kind of disease. It's unique and it's interesting to watch what happens to people when you mention it. Everyone gets hysterical, even some nurses at work...that's 'cause it's a new disease. I don't know, it's the worst thing I've ever encountered...You just have to mention it and everyone gets stressed out. Even just thinking about [it], it's like death and destruction.

R: Is that how you imagine it?

I: Uuhh, yeah, and that's 'cause it's a devastating disease...

It was common for the informants to view the disease itself as stressful. Various characteristics about AIDS such as its newness, the lack of a cure, the incidence rate, high risk groups, stigma, and the terminal aspect combined to make this disease devastating. Throughout the interviews these characteristics influenced the informants'
experiences.

Having identified stress as the predominant theme, an examination of the literature related to stress was undertaken.

Stress

Stress has been defined in a variety of ways. It evolved from engineering where external stresses or demands placed on metal result in a deformation or strain (Cox, 1978). From this perspective, stress is viewed as a stimulus which results in a stress reaction. Selye (1974; 1976) describes stress as the response to a stress-inducing agent or stressor. He defines it as the nonspecific response of the body to demands placed upon it. This response is called the General Adaptation Syndrome in which complex physiological processes occur involving metabolic, cardiovascular, neurological, and endocrine functions. Prolonged exposure to stressors and overextension of one's physiological defense responses is thought to cause illness. Selye's theory has been criticized for its over-emphasis on the physiological responses while ignoring the psychological aspects. Cox (1978) suggests that the psychological impact of the stressor on the person determines the physiological responses.
An interactional model of stress incorporates both these ideas however individuals are still viewed as passive, like machines. Cox (1978) and a colleague have described another model where stress occurs due to the relationships individuals have with their environment. Stress is defined as "...part of a complex and dynamic system of transaction between the person and his environment" (Cox, 1978, p. 18). Critical to this theory is the concept that stress is an individual perception. Other theorists also view stress as being individualistic (Antonovsky, 1979; Lazarus, 1977). According to Antonovsky (1979), stress results from exposure to stressors. He defines stressors as "a demand made by the internal or external environment of an organism that upsets its homeostasis, restoration of which depends on a nonautomatic and not readily available energy-expending action (Antonovsky, 1979, p. 72). The converse of stressors are routine stimuli. Individuals respond automatically to routine stimuli or can adapt to them without major problems. Distinguishing routine stimuli from stressors is mainly determined by the meaning the individual attributes to the stimuli. What is stressful for one
person may not be stressful for another. There is a multitude of factors that influences the way a person responds to stress. Paynes (1988, p. 226) summarizes some of these factors as: personality, age, experience, gender, intellectual ability, and cognitive style. Lazarus' (1977) theory includes additional factors such as genetics, nutritional status, and self-esteem. Stress responses or coping strategies are just as variable as the stressors. They are also influenced by similar factors.

Coping can be defined as "problem-solving efforts made by the individual when the demands faced are highly relevant to the individual's welfare, that is, a situation of considerable jeopardy or promise, and when these demands tax that person's adaptive resources" (Lazarus, Averill, & Opton, 1974, p. 60). The purpose of coping strategies is to eliminate, lessen, or withdraw from the stressor. Unresolved stress or ineffective coping results in burnout. Pines and Maslach (1978) define burnout as "a syndrome of physical and emotional exhaustion involving the development of negative self-concept, negative job attitudes and loss of concern and feeling for clients" (p. 233). Individuals perform activities
automatically with no feelings or emotional investment (Storlie, 1979). Stressful occupations like nursing are more prone to burnout (Cherniss, 1980).

**Stress in Nursing**

Stress in nursing has been well documented (Booth, 1988; Calhoun, 1980; Firth, McKeown, McIntee, & Britton, 1987; Lawrence & Lawrence, 1987; Marshall, 1980; Mitchell, 1988; Phillips, 1982; Scully, 1980). A study done by Wolfgang (1988) comparing job stress among nurses, physicians, and pharmacists revealed that nurses had significantly higher mean stress scores on 17 of the 30 items from the Health Professions Stress Inventory (HPSI). Three broad categories of stressors were represented including work overload, on-the-job conflicts, and meeting client needs. The conceptualizations of stress in nursing vary from focusing on the profession itself (Davis & Fricke, 1977; Hott, 1976) to the different stressors inherent in the role (Gentry & Parkes, 1982; Lawrence & Lawrence, 1987; Maloney & Bartz, 1983). Stress related to the profession frequently involves its quest for higher status and recognition (Phillips, 1982). Stressors inherent in the role of nursing include environmental conditions, patients' emotional
problems and those of their families, demands of the patients and supervisors, working conditions, interpersonal and collegial relationships, and contemporary moral and ethical dilemmas (Lawrence & Lawrence, 1987, p. 45).

AIDS is the newest moral and ethical dilemma that nurses will encounter in their careers. Caring for patients with AIDS has increased the stress in an already stressful profession.

Stresses of caring for patients with AIDS.

The appearance of AIDS in society has had an impact not only on the identified risk groups, but on health care professionals (Flaskerud, 1987; Henderson, 1988). Jenner, Levi, and Houghton (1986) state the levels of stress are high for nurses caring for AIDS patients. Nurses are in close contact with these patients and frequently they also experience stressors similar to those of their patients. Specific sources of stress related to caring for patients with AIDS are identified in the literature as fear of contagion, issues in sexuality, death and dying, stigma, exposure to alternate lifestyles, and issues of confidentiality (Bolle, 1988; Christ & Wiener, 1985; Flaskerud, 1987; Simmons-Alling, 1984).
In this study, informants described similar stressors which were categorized by the researcher as either internal or external.

**Sources of Stress**

**Internal Stressors**

Internal stressors were identified as feelings related to caring for AIDS patients. Fear of contracting AIDS, homophobia, and caring for dying AIDS patients were the three internal stressors. These stressors frequently interacted with one another to reinforce or increase the stress.

**Fear of contracting AIDS.**

Fear of contracting AIDS was a common stressor. The risk associated with caring for these patients was stated repeatedly. Although the informants were knowledgeable about AIDS and recognized the risk to be very low, their fear still persisted. The following excerpt illustrates common concerns associated with the fear of contracting AIDS.

I: ...everybody that when you are going to be working with AIDS patients tries to educate you. They tell you all about how it's transmitted and they drum it all into you but there's still that irrational fear that since it's new and you are
there with it all the time that some day you are going to do something careless or there's going to be a way of transmitting [it] that nobody knows about and you're going to get it. Are the gloves thick enough? Are you going to run into an emergency and forget to gown? You know there's that fear, because this is deadly. And I read everything that comes out on it and it says we [nurses] have a miniscule risk, but still. Then you try to push that down with your rational side, the nurse side, that says this and this and this and as long as you follow the precautions you will be safe...

In this excerpt, the informant described her fear as "irrational." She continued with an example.

I: For instance, people will give food, like...boxes of chocolates. Patients that are leaving, and this is going to sound a little peculiar, but if somebody Joe average gives chocolates everybody digs right in. If a BBF [blood and body fluids] patient gives chocolates, there's a few seconds of hesitation. Everybody knows that nobody has just spit all over the chocolates [laughs] to give them to you, but you're
all thinking how long do we leave these chocolates before they're okay. Because the AIDS virus doesn't survive outside the body for so long which is totally irrational, but you're dealing with something that causes panic in the major population and it's the same for us.

Other informants also described their fear in similar ways.

I: ...we all know about this disease. We know how it's transmitted. We know who the high risk people are, so what's the problem? Why are we all afraid and I'll admit it...yes I am scared but it's not that easy...Sometimes this [fear] is so, it's really out of your control. Like, we just don't know what we're up against. It doesn't matter what we know now it's still new. Scientists have made mistakes before with these kinds of diseases...

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I: ...it's the fear of the unknown really. It's irrational yet it exists...There's no guarantee we won't get it...

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I: Most people, like the public, are afraid of it but think of us and how we are the ones caring for
these people. We are the ones in contact and being exposed [voice raised]. It's not rational really but then again what do we know about this disease...

There have been no reported cases of occupationally acquired HIV infection among health care workers in Canada (CDWR, October 29, 1988). The U.S. Centers for Disease Control in Atlanta, coordinate the worldwide reports of occupational exposures. Since 1983, there have been 15 such exposures where the health care workers have seroconverted to HIV antibody, and one worker has developed clinical AIDS (CDWR, August 13, 1988, p. 141). These 15 individuals represent worldwide experience indicating that the occupational risk is low, but not zero. Despite repeated emphasis of this low risk to health care workers, some individuals cannot overcome their fear of infection (Beaufoy & Goldstone, 1985; Bennett, 1986; Dhundale & Hubbard, 1986; Gilmore, 1985; Institute of Medicine/National Academy of Science, 1986). The lack of a guarantee that they could not contract AIDS from their patients was at the center of the informants' fear.

I: ...you know, you don't know who to believe. What should you do. There's no 100% guarantee we
won't get it. We're now listed as a high risk group. They say it's hard to get but you can still get it.

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I: ...there's a low likelihood that I might get it, like an occupational hazard, but who really knows. They can't be completely certain, this is the part that's scary. I wouldn't have this problem if it was curable like I've gotten infections before from them, but gee some antibiotics and you're okay...not with this, it's like whammy and you're gone.

In a survey of nurses' attitudes towards AIDS patients, one half of the respondents reported believing that AIDS can be transmitted to hospital personnel due to patient contact and despite precautions (Blumenfield et al., 1987). Fear is a very strong emotion especially when it involves risks to one's personal safety and well-being.

These informants were aware of the higher risks associated with other infectious diseases like hepatitis; however, they believed no comparison could be made because AIDS is fatal.
I: ...they say it's easier to get hepatitis than AIDS, but at least with hepatitis you don't always die.

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I: ...it's not even like hepatitis where you can or you can't...if you're exposed you are going to get it...

The Blumenfield study indicated that ICU nurses were significantly more afraid to work with patients who had AIDS than with those who had infectious hepatitis (Blumenfield et al., 1987). These researchers hypothesized the ICU nurses are more frequently exposed to body secretions.

Worry about being careless and accidentally stabbing oneself with a contaminated needle or not following the isolation precautions was frequently expressed by nurses in this study.

I: ...there was one time I was exhausted at the end of the day and I didn't wear gloves. I don't know why, tired or lazy and I emptied a bag, you know a foley, and spilled some on me and boy did I wash and scrub...

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I: I know there have been two staff members on my floor, no, three that have been stuck with contaminated needles and it's quite a hysterical moment. I suppose I should list that under my fears nursing them.

R: One of your fears is to stab your finger?

I: Yeah, that's right and it's more likely that this will happen 'cause it's a common occurrence and...also codes that's another one.

Being careless in emergency situations and acting on instinct was another concern expressed.

I: ...sometimes we've had codes happen and your natural instinct is to go to the patient...You don't even think about isolation...You automatically have a reaction...but you now have to stop...You just can't do what your emergency system tells you to do. You have to stop and protect yourself and I worry that maybe I wouldn't do that...

I: ...it's the emergency that really scares me...You don't know how you're gonna react. You're on automatic pilot. You don't have time to think...
At one of the employing agencies there was a policy that all employees would first protect themselves before going into an emergency situation. Although these informants were aware of this policy, they remained worried about how they would react in an emergency situation. The survey done by Blumenfield and others (1987) revealed overwhelmingly that the nurses would be reluctant to perform mouth-to-mouth resuscitation on patients with AIDS.

Fear of contracting AIDS was also related to the belief that other modes of transmission would be discovered which caused some informants to practice more stringent isolation precautions. Batchelor (1984) reported instances where health care professionals have enforced unnecessary and extensive infection control practices to combat fear. Wearing two pairs of gloves was frequently cited as an additional measure since the gloves were of poor quality.

I: ...I don't know if I should tell you this, but I've started to wear double gloves since I had one time where I found a hole in one and so this way it gives me more protection, just in case...It's more expensive, however the alternative is worse.
I: ...I am overcautious. Like, I do gown and glove a lot more than is the policy because I have a feeling that ten years down the line they're going to say gee you know you can get AIDS when it is assimilated through the skin. I think maybe we should've been wearing gloves more often. Well, I'm not going to be the one to say look at me I've got AIDS I should've worn gloves. Well, I wear gloves and I don't care and, like I say, I have been criticized for it [informant was yelling and banging fists].

This informant elaborated on other precautions she took.

I: I went through a stage where I was constantly bleaching all my uniforms everytime I was wearing them and it's not good for the uniforms. [laughs] And my work shoes well, they still don't come into the house they stay out in the carport. But I think sometimes that, in my mind, I won't get it. But it still doesn't stop the extra precautions ...It may not be rational but, like I say, I'm overcautious.

This informant stated the most negative aspect about caring for patients with AIDS was the personal risk
involved. She spoke defiantly about the extra precautions she took and was very forthright in admitting her fear. Other informants were embarrassed talking about the extra precautions they took.

R: You said something earlier about what you did to protect yourself. Can you elaborate on that?
I: Well, I feel sort of funny telling you this stuff. I'm not supposed to be doing it really. I'm embarrassed about it [laughs]. I wear two pairs of gloves at a time and I wear gowns and masks even though I've been told by [name] not to do this. Actually [name] was really annoyed with me and sort of bawled me out but it's not only me. Others do this too but I was seen doing it...I think that it helps. I'm doing everything I can to not get it. I know it seems silly. [laughs]

Fear of contracting AIDS was present not only in the less experienced informants but also in those who had cared for many patients with AIDS.

I: For me, and I work with them all the time...it's the risk, like I say,...that [has] got to be the worst thing about them...
I: I don't think you ever get over it. You're always on guard and the worry of it is still there...

One of the more experienced informants stated she had resolved her fear but it returned when she was working with AIDS patients on a daily basis.

I: Okay, initially I think the first AIDS patient was on this floor and...everybody had sort of a shock reaction and like, oh my God what are we going to do this person has AIDS...We were gowning and gloving everytime we went near him and...I started to get scared again when I thought I had gotten over it, you know.

There were also personal concerns for some informants which increased their fear. One informant wanted to start a family and was afraid of being exposed to the infections patients with AIDS commonly carry.

I: ...I would really like to have a family but I'm afraid to become pregnant and work on [names ward]. I've seen umm nurses become pregnant in the medicine end of the hospital and usually they've been placed working with patients in non-communicable diseases, but it doesn't sway my
fears...You don't know when you get pregnant. I still don't know if my fear is a realistic one or not but to me it is. This is what makes it worse. Another informant who was pregnant was worried about working with AIDS patients.

I: ...well, I had just found out that I was pregnant and I was dealing with three or four who had large herpes ulcers and they weren't sure if they had this toxoplasmosis that a lot of them carry...It was a big worry and I almost became repulsed by them, like, I didn't want to have to deal with them you know.

R: Was this because you were pregnant?

I: Oh no it was beyond the fact I was pregnant...and you know I had been reassured that it was no different than working with anybody else and...I was working night shift one night and reading one of the manuals. Sure enough, there was something right there from Health and Welfare Canada that said pregnant women should not work with them and I was really put off. No one told me this. Now I worry about my baby. I'm really mad...
The risk to pregnant health care workers is usually due to the cytomegalovirus (CMV) that some AIDS patients carry. This virus is known to be teratogenic.

Fear was present for a variety of reasons; informants who stated they were homophobic experienced more fear than the others.

**Homophobia.**

Homophobia was another internal stressor. It can be defined as the pathological or unreasonable fear of homosexuality (Marmor, 1980). In this study, no labels of homophobia were applied to any informant. Individual informants who described themselves as homophobic were included in this category. Homosexuality is a sensitive issue to discuss and initially these informants were hesitant to talk about it. Questions were posed indicating that homophobia was documented in the literature. Also, informants were told others had expressed this feeling. This method resulted in three informants acknowledging they were homophobic. Informants who said they were homophobic believed this was another reason why it was stressful caring for these patients.
R: From what I have read about AIDS there are some people who are uncomfortable with homosexuality. How do you...?  
I: Well, yes, it makes me uncomfortable this gay business. I'm sort of...a little bit homophobic... This is what makes it even harder. You know, having to deal with their sexuality. It's difficult enough to deal with other patients who are not gay, but it's really hard to understand why they are that way...Some people may think I'm anti-gay but I just don't think it's right...Maybe it's not right for me to think that, but that's what I believe.
R: Uhuh.
I: And I just can't accept that kind of lifestyle...It's against God to be homosexual...But here at work I know our religion shouldn't enter it.

This informant described herself as very religious and as having had little exposure to homosexual people. Religion and inexperience in dealing with homosexual clients have been cited as factors affecting the acceptance of AIDS patients (Flaskerud, 1987; Reisman, 1988; Young, 1988). A study by Young (1988) found
that nurses who associated their negative beliefs about homosexuality with their religious beliefs, had other areas of their lives that contradicted their religious teachings. She noted premarital sexual intercourse was also contrary to the nurses' religious beliefs yet they did not feel as negatively towards people who engaged in this forbidden activity as they did toward homosexuals. One possible reason for this variance is that homosexuality may still be viewed as deviant behaviour and against the traditional family. A survey of nurses, general practitioners, and medical specialists who treat sexually transmitted diseases (STDs) reported similar findings (CDWR, Oct. 19, 1985). Two of the predictors of a moralistic attitude were being Catholic and heterosexual. It was also noted that being a professional concerned with STDs does not obliterate the moral attitudes related to one's background.

Negative feelings about homosexuality have been linked with the attitude that those who practice it deserve AIDS (Kelly, St. Lawrence, Hood, Smith, & Cook, 1988). Other informants who did not agree with homosexuality expressed this attitude.
I: ...you know when I found out who the high risk groups were, you know the homosexuals and the drug users, that really bothered me. Because I don't agree with that way of life and in some respects you know it's their own fault.

I: ...and I didn't understand...I was homophobic...And though I had and have friends that are gay males and gay females that I know of from my past, I had the feeling that these patients deserve to be sick...

I: ...I think that at first I was put off and became homophobic because they are so blatant about their homosexuality. Some of them were still talking about picking up people you know what a wonderful time they had in Hawaii...

Blame was not only attached to the patients with AIDS but to the whole homosexual community. Anger was expressed towards this group for having "passed AIDS onto the heterosexuals".

I: If we look now...we can see the spread of AIDS into us because of them, their habits.

R: Us being the non-gays? Is that what you're saying?
I: Uhuh, it was first discovered in the gays... It makes me so mad, like, look at us now. It's all over the place, it's rampant.

R: So do you believe that they are responsible for it?

I: Well, who else? It's their just dessert. It's not me! I know it's just a virus and it just so happened to get a gay guy first, but if you think about it, would it ever have happened if not for them being good reservoirs?

The anger expressed by this informant was related to her overwhelming fear of contracting AIDS from her patients. She stated her feelings about homosexuality were only related to those who had AIDS and she had no difficulty caring for other homosexual patients with different diseases.

R: You said something earlier about other gay patients not bothering you or you didn't have problems caring for them...

I: Uhuh, yeah, it's like if they don't have it, it's not really gonna affect me right?

R: So, is it more the fear of getting AIDS than caring for this type of patient?
I: Yeah, that's it. It's the patients themselves the ones with AIDS. There's the...fear.
The survey by Blumenfield and others (1987) revealed that about one quarter to one half of the nurses were afraid to care for homosexuals because of AIDS. However, one must take into account that 67% of the AIDS patients these nurses cared for were prisoners and had histories of IV drug abuse. The same survey was done six months later and revealed a decrease in this concern on the medical/surgical units which was attributed to experience and education. In this study, it was more the fear of AIDS than caring for homosexual patients that caused the most concern.

Another informant who was also very frightened said she did not trust the AIDS patients because they may deliberately try to infect her. This belief was based on an incident she had with an abusive patient.

Feelings of homophobia and blame were intensified when affectionate behaviours were observed between patients with AIDS and their lovers. According to Myers (1985) physical affection between homosexual couples is not considered socially acceptable.

I: ...well, I didn't want to have to deal with them anymore after seeing them hugging and kissing.
That really got to me. It's not normal and they know how it's transmitted they shouldn't do that...

Although there is no research indicating AIDS can be transmitted by kissing, there was the underlying perception that new modes of transmission would be discovered. Therefore, this informant was not only uncomfortable with the behaviour, but was also concerned about the patient's partner becoming infected at a later date. The previous informant clarified her concern.

I: I think I told you last time, when we met, about...my worry that it's new and there's not enough information about it. So, it's thinking that his friend or lover, or whatever they call each other, is going to get it. Maybe two, three, or more years later...there's that too.

Negative feelings were also reinforced when the informants cared for stereotyped homosexual patients. Storms (1978) believes that increased contact with homosexuals may serve to dispel false stereotypes and lessen homophobia in some individuals; it may also heighten anxiety and increase hostility in others. The next excerpt presents an informant who learned to be more accepting of homosexuals due to increased contact.
I: ...when I think about how I've been exposed to them up front, everyday...for three and a half years. And how I've come around to...more acceptance of gays in the community and an understanding of them...

Increased contact with homosexuals had a different effect on other informants who expressed little tolerance for them.

I: I think the first one I had was, you know, the real stereotyped homosexual; the high pitched voice, the whining, and the hands moving around all the time, and he even had his nails painted. Oh brother! So, I did what I was supposed to with him and was quick about it and I thought, you know he could have prevented this if he wasn't that way. Other informants who were not homophobic described these patients as very "meticulous," "intelligent," and "easy to talk to".

I: ...AIDS patients usually are very good to work with...They're [a] very meticulous type of people, very clean, very, you know, bright, very intelligent...They are younger and...very easy to talk to. I enjoy them as patients, except when they have dementia or, yeah, when they're dying. That's hard to deal with...
I: Yeah, like I don't differentiate other than the risk. You know, I quite enjoy looking after these guys you know because they are wonderful guys, you know. I really do...Like I say, other than the emotional part at the end, the dying, and the risk, they're great. They're funny and they're, you know, really neat.

This informant said she had no problems with the issue of homosexuality because she had a very close gay friend.

Baumgartner (1985) believes that suboptimal care can be provided by health care workers who have strong feelings of homophobia. There have also been reports of patients with AIDS being neglected, rejected, and isolated by the very people whose job it is to care for them (Baumgartner, 1985). This lack of care is based on the stigma attached to these patients. Stigma is the mark of disgrace that is attached to those people who have disvalued roles (Goffman, 1963). It is reflected in prejudicial attitudes and discriminatory behaviours. Ehrlich (1973) views prejudice as a form of derogation; the individual is subject to disparaging remarks, generalizations, and
hostility. Although his work focusses on prejudice and ethnocentricity, he describes prejudice as negative attitudes towards a group of people.

Historically, homosexuals have been stigmatized due to prejudicial attitudes about their sexual preference (Marmor, 1980). People who have sexually transmitted diseases are also stigmatized. Since AIDS is a sexually transmissable disease that affects homosexuals, patients with AIDS suffer from double discrimination.

Informants who stated they were homophobic believed this did not interfere with the nursing care they provided. One of the informants was defensive and said:

I: ...I'm still a good nurse. It doesn't make me bad or anything to admit this. You know, I've been told I give good care and I think these guys get good care from me, I mean, I may not accept them or like their lifestyle but I still nurse them...My personal beliefs don't affect my work. It doesn't interfere with it...

There is conflicting documentation about how beliefs and attitudes affect behaviour. Not all subjects act according to what their attitudes imply. Fishbein
(1966) states that "rather than viewing...behavioral intentions as part of attitude, these phenomena must be studied as variables in their own right, that, like attitudes, may or may not function as determinants of a specific behaviour" (p. 213). Other variables related to attitudes and behaviour must be studied before determining their relationship. Reviews of studies on the relationship between prejudice and behaviour also indicate that other factors need to be considered before concluding that prejudicial attitudes lead to discriminatory behaviour (Bray, 1950; Brookover & Holland, 1952; Linn, 1965). Therefore, although there is some evidence to suggest that homophobia is reflected in the care of patients with AIDS, it is beyond the scope of this study to state whether the informants actually did or did not exhibit discriminatory behaviour towards their patients.

Caring for dying AIDS patients.

Unlike the other internal stressors, fear of contracting AIDS and homophobia, caring for dying AIDS patients revealed the most compassion and empathy for these patients. The informants' focus changed from being only concerned about their own feelings to recognizing what these patients must face.
One informant became very close to a patient and disclosed personal information.

I: ...he asked me if I was gay which I am. And it's something I don't like to divulge at work...I don't think it's anybody's business, but the reason I felt I could tell this fellow was because he was so wanting, I felt, someone to understand him. So I felt, why not, he's not going to be around for much longer...So I was going to do whatever I could for him and that night when I finished shift, [this informant was working on another ward] I was going to see him because I was going to have him the next day. But he died that night, so I didn't even get the chance to say good-bye.

R: Oh you must have been very upset.

I: Yes but we got very close in the sense of sharing just his emotions, and what I felt he needed to hear was that he was okay. So what if he had gotten a rotten deal he was still an okay person and that was all I wanted to tell him. It made me upset and really it was quite frustrating that I never got...the opportunity to tell him.

This informant described other frustrations he experienced caring for these dying patients.
I: ...I see our role as nurses caring for AIDS is to lessen their hurt and help them deal with death. To tell them they are okay persons...It is more intense when they are going to die.

R: What do you mean by intense?

I: Everything is so meaningful for these patients when they are dying so your nursing care must be meaningful to them. You must remember that they are dying and to make their last days as comfortable as possible and let them die peacefully and knowing that they are okay and someone cared. But it's also frustrating to not be able to offer them any hope, to say it will be okay, we'll give you some antibiotics and care for you, and you'll be okay in a few days...And their age that too is frustrating. They're young, around my age.

Other informants described this sense of hopelessness and the frustration of caring for such young patients who were dying. When asked about how they felt about caring for patients with AIDS when they are dying, several informants responded as follows.

I: Death is sometimes a blessing. We all know that. But for them, when there is no hope, absolutely none whatsoever, it's terrible.
What can you do for them? What can you do? Just the basics that's all. I feel bad for them when there's nothing to look forward [to] except dying. It's not as if they have led a full life which is what we say to the elderly. Yeah, he lived a full and rich life, not for these guys they're just beginning the best years.

I: ...well a lot of things to deal with all of a sudden...A lot of people have said it's like getting handed a death sentence which I guess you can't really deny, because I forget how long they expect them to live. It's not that long.

I: Let me tell you, it's or it will be the hardest thing you'll ever have to do. They come to you and you pump them full of antibiotics, antifungals, or whatever they need and try to fix them up all the time thinking what's the use? What's the bloody use? They're only going to die shortly...We just provide custodial care when they are near the end...What else is there? There won't be any miracles for them, there's no remission like cancer, there's no real effective treatment at this time...
Believing death was always inevitable caused these informants to feel hopeless and powerless over what they could do. They did not view themselves as being able to help the patients die peacefully or comfortably. Some informants refused to accept death for these young patients.

I: ...It's the fact that they're so young...I know what you're going to say, young people die from leukemia, cancer, accidents, the whole bit. I've heard this before from [name], but at least with the other things you have a chance, maybe a smidgen of a chance but it's there, right? Except for the car accident, but then again if help arrives early they still have a chance. It's a matter of accepting death for these young people.

Informants who could not accept death in people so young found it was more difficult to care for them when they were dying. Some informants who were close in age to their patients identified with them.

I: ...so when they come here, you try to do whatever you can...They're so young, most of them are mine [sic] and your age, very young people. That's another burden to add to the stress on you. You're looking at someone your age die and it's not a pretty sight.
R: What is it about their death that bothers you the most?
I: Why it's their age. They're only twenty, thirty. I'm that age I can't imagine being told my life's over. Could you imagine that?

Caring for them and observing these patients die reinforced the fear of contracting AIDS for some informants. Another informant was reminded of her fear when caring for many dying AIDS patients.

I: ...Jesus Christ, there was a time when I had three of them on their last leg and it seemed like they were all coming in to die and I started to worry again and be extra careful.

R: What worry about...

I: Yeah, I thought again about the risks involved. It seemed like at least every other day one of them was dying and, like I say, I had to watch myself and be careful...

It was more stressful caring for many dying AIDS patients all at once or during a short period of time.

I: Yeah, just once in awhile where you think I'm going to go crazy if I see one more AIDS patient die in front of my face you know I'm going to go crazy!
Fear of death, discomfort with death, and exposure to dying patients are factors which can contribute to stress and burnout among nurses (Bolle, 1988; Pruyser, 1984). Dames' (1983) study indicated the amount of exposure to dying patients is associated with higher levels of burnout. Although some studies do not confirm this finding (Yasko, 1983), these informants experienced more stress caring for many dying AIDS patients.

I: I had an assignment one time that was so bad I had to go home early to get away from these patients...I had two of them who were dying, cheyne-stoking. Well, one was doing that; the other was sick to his stomach and was so feeble and then, get this, they wanted to admit another one with I can't remember what, something terrible. Anyways, it turns out he's ready to die too. We had to move patients around just to get him in a private. We moved someone else and it's about 3 o'clock or so and I was so upset. It was my last set of shifts so I said I was sick and went home early.

R: Was it the additional client that upset you? The increased workload or...?
I: That too, but I had seen too many of them die. There was a period there when they all just upped and died all at once, like they'd made a pact or something to all die just to drive us nuts...

When there were periods of many deaths the informants did not have adequate time to grieve or cope with the first death before being confronted with another.

I: ...I had a week where two guys died a day apart and then a young kid came in with PCP, arrested, was revived, sent to ICU, then returned to us. What a week! There was no time to think, to feel sad, or anything. It was such a horrible time...

I: It burns you out when you care for them all the time. You really need a break, especially when you know them and they're dying left and right...

Frequently, the patients with AIDS were well known to the informants. Usually they had been admitted to hospital a number of times before they reached the palliative stage. These patients were considered to be friends and this made it more difficult to care for them.

I: ...over the last eight weeks I've seen, oh, maybe four repeaters that I've personally had as patients come in to die...
R: Does it make a difference when you know them?
I: Oh gosh yes! They're my friends now. We know a little bit about each other, they're like a part of your family. And we try really hard, if someone has been here before and comes back in, we try to get them back on the same ward you know for consistency and familiarity. So it's nice for them and it's nice for us...Sometimes though it's better if they are dying to go to another ward because you don't like to watch...

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I: ...when they've been in many times and you fix them up and they come back and you fix them up again, and then if they don't have anyone at home they come in to die. And you say, well this is it, they're dying...This is hard to deal with because by this time they are a friend.

Another frustration described was having to care for the "second generation" patients with AIDS.

I: ...Now just in the last four or five months, I'm finding it really hard...because we're getting what I call in my mind second generation AIDS. We're getting the lovers of the people that have died...And it's really frustrating because you've
gone through the grieving process with these people once and then they come in for themselves...

Informants found it was more stressful when they had to care for the partners of their initial patients with AIDS who had died. Also, when friends or co-workers became ill it was especially traumatic.

I: ...If it's a co-worker...It's really devastating, so much more difficult when it's staff. It's even harder trying to deal with your feelings, you know, like why him? Why him for goodness sakes?

Some of the informants expressed concern about their lack of knowledge and skills caring for dying patients in general. They believed these patients required specialized nursing care.

I: It's mainly the emotional support dealing with their feelings about death, how to make peace with themselves. I mean dying really is a specialty area of nursing and I'm not an expert on it, far from it. I find I learn as I go along and I could certainly do with an inservice on it. Actually, I think there was one but I'm not sure. But when you think about the whole area of death and dying like Kubler-Ross' works, it's mind-boggling what you
really should know about dying before you can care for them...the knowledge and skills the things that are different for them.

Other informants also recognized their lack of knowledge and skills caring for dying patients in general. However, they did not believe there were any differences between dying AIDS patients and other dying patients.

I: ...except for the precautions, you do the same thing when they are in that stage [dying]...

Another frustration identified was feeling powerless to act as the patient's advocate. When one informant disagreed with the treatment plan on behalf of her patient she felt she had no power to enforce her patient's wishes.

I: You know the drugs these guys are on is just incredible. I remember reading something about the interactions of this drug with that drug and it causes low platelets and watch out for internal bleeding...This one guy had a constant stomach ache and he was on a morphine drip...I said to the doctor why don't you stop this drug and let's see if his stomach ache will go away and he looked at me and said but he'll probably die without it. And
I said well he's dying anyways why does he have to suffer. And you know he just said he needs it...I know he didn't discontinue it because he was being used as a guinea pig for this drug that was experimental you know...I tried talking to [name] saying all this guy wants is his stomach ache to go away. That was his priority to get this drug stopped.

R: Uhuh, that must have been upsetting...

I: It certainly was...I remember thinking about him on my days off...Thinking please die before I come back. I--I [sic] just couldn't face his suffering any longer...When I did get back nothing had changed...He died about two weeks later still having a constant stomach ache. What a way to go.

And I think what else could I have done? Maybe just not give him it [drug] then get into trouble or something.

It was frustrating when patients' wishes were ignored and added to the stress of caring for them.

I: ...this patient was in the terminal stage and they made him a slow code.

R: A slow code?

I: Yeah, he wanted to be a code but the doctors
made him a slow code. Which I thought was not very nice...And he was depressed about being a no code and he didn't want to be a no code...Ethically it bothered me and I'd never heard of it before...It was explained to me by a nurse who said when he codes walk slowly to the phone and call the doctor. Now he wanted to be a code and he had told me that he was quite shocked when they mentioned code status with him. He said no I want to be a code...It was decided between the doctors and nurses that he would be a slow code...If it had ever gone to court they wouldn't have had a legal leg to stand on...I had already made my mind up that if he did code I wasn't going to walk slowly. I was going to call a code...Also...this guy wanted to be coded so at least go through the motions. I mean come on, we've coded people before who have had one leg in the grave because the doctor didn't want to make that decision...I mean he was still young. Twenty-nine years old and he still had his mind intact.

Increased stress resulted when informants' beliefs about how the AIDS patients should be treated differed from those of the physicians. The use of experimental
drugs and whether or not to resuscitate these patients are controversial topics.

Caring for dying AIDS patients, homophobia and fear of contracting AIDS, were the three internal stressors. The complexity of caring for these patients was not limited to these stressors, there were additional factors that caused stress.

**External Stressors**

External stressors were factors associated with the informants' experiences that caused stress. They were also feelings related to caring for these patients. Patient variables and societal views were identified as the two external stressors.

**Patient variables.**

Patient variables was another stressor that caused the informants' experiences to be stressful. These variables were identified as the patient's high risk group and stage of illness. For example, caring for a homosexual patient with AIDS was stressful, but caring for IV drug abusers and prostitutes was described as even more stressful. Although prostitutes are not considered a high risk group, they are frequently IV drug abusers as are their sexual partners. There was intense animosity expressed towards these patients who
were believed to be directly responsible for contracting AIDS.

I: ....I find it's worse if they're street people.
R: Worse? Meaning what? Harder to care for them is that...?
I: Yeah, well, it's much much worse [sic] to have to care for the druggies. They lie, cheat, will do anything for their dope so I don't particularly like to care for them. We had one who was a criminal...Well, he didn't have full blown AIDS but was HIV positive and he knew this. [He] kept coming in for bloody stab wounds because he was always fighting...He knew how to prevent it. He just didn't care. That's what most of them are like. They have no concern for human life not even their own. They have got to be the worst. And I say tough beans to you. It's your own fault.

R: Have you ever cared for people who are IV drug abusers?
I: Yeah, a few, and I have problems not thinking that they deserved his or her fate. And also the same if it was a prostitute of either sex. These people know how it's being transmitted and can
prevent themselves from getting it if they want. But generally most gay men are not promiscuous and don't deserve this death sentence... But these ones, well...

Little empathy was expressed for these patients.

I: ...it's their own fault. It's really their own fault. They run around doing drugs and they don't care. They steal. If they have to, they'd steal from their own mothers, if they could. It's their anti-social acts, you know. And when we get them it's a nightmare...'cause if you don't drug them into a coma they get vicious and dangerous.

R: Do you mean they're...?

I: Yeah, they're in withdrawal. And...then you have to be extra careful with the isolation... They're the worst of them, these guys really are. Of all the AIDS patients I've had they take the cake. I worked my buns off with this one guy and never again. Next time a drug crazed AIDS guy comes in that's it. I won't take him. It's too hard. Nope, I will refuse the assignment. I don't care.

R: So would you refuse [to care] for every one of these clients even if they didn't have AIDS or...?
I: Well yes, but especially if they had AIDS.

Definitely if they had AIDS and were doing dope. IV drug use is a deviant subculture where there is a unique set of values, roles, and status-allocation rules (Johnson, 1973). Most members of conventional society have great difficulty imagining themselves or anyone else injecting drugs and also doing the illegal activities to get the drugs (Des Jarlais, Friedman, & Strug, 1986). There is also little empathy expressed for these individuals and they are often objects of fear, mistrust, hostility, scorn and, to a limited extent, pity (Des Jarlais, Friedman, & Strug, 1986). One informant expressed his preference to care for homosexual patients rather than IV drug abusers.

I: ...honestly, we've seen patients who haven't had a bath for six months. The street AIDS people I call them. And you know, then you get somebody like this, who's gay with AIDS and, you know, are [sic] very good about their hygiene and things like that...You see the contrast, and say oh these people are so clean! I'd love to work with them! I'd rather work with them!

Prejudicial attitudes were also expressed towards immigrants with AIDS.
I: ...definitely I believe very strongly that all immigrants should be tested...If they're positive, they shouldn't be allowed in because of the expense this government is putting out is ridiculous.

R: Have you had any immigrants with AIDS?

I: I've had a couple, yeah,...and I mean I'm not saying that they are coming here for treatment, they may not know before they emigrated...It causes problems if you don't understand the language.

R: Is it the different culture that...?

I: Yeah that, and they don't speak English so that makes it worse trying to care for them. If you're trying to figure out what they're saying and teaching them about the precautions it's all very time-consuming. You know we have little enough time as it is.

Negative attitudes towards these patients made it more stressful to care for them. Informants expressed little empathy for immigrant patients. They felt compassion for the innocent victims of AIDS such as, those patients who unknowingly became infected by a sexual partner or contaminated blood transfusion.

I: ...there have been a few where it was, much harder for me to deal with it...Her circumstances
were quite cruel. She was exposed to the virus because it was brought home by her husband, who had never confessed his bisexuality, if there is such a thing...Therefore she contracted it. So, that made the difference...

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I: ...for those people I have all the compassion. I really feel sorry for them...and this is not nice to say, but I feel sorrier for them than I do for the IV drug abusers who have brought it upon themselves and the prostitutes.

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I: ...I know cases where the wife wasn't told due to the rights of the patient. To me, that's the biggest sin in the world...The wife was told her husband died of cancer because he didn't want her to know and she has two young children, you know. That's horrible! I'm a firm believer that if you have AIDS, I'm sorry but the world has to know...I cried for that woman. You know, I thought it was such a tragedy to not tell her. My God!...and I really felt for her it could happen to me, to you, we just don't know...
These patients were viewed as not responsible for contracting AIDS and some of the informants identified with the wives who contracted AIDS from their husbands. Informants believed these patients required more emotional support and, therefore, more time.

I: ...this woman got it from a blood transfusion from surgery...It was sad...I felt she needed more of my time, you know, to express her anger and feelings, and give her some support. Not that they all don't need it, but she I think was one of the first women to get it...I found it more upsetting, so I tried to spend more time with her.

Informants also described different stages of the illness when these patients required more of their time. This is the second patient variable that resulted in stress.

The trajectories of diseases are individualized (Strauss et al., 1984). The trajectory of AIDS is also very individualized depending upon the opportunistic infections the patients develop. People who are initially diagnosed as HIV positive vary with respect to the time at which they will develop an opportunistic infection or full-blown AIDS. Patients with AIDS who were still relatively healthy were seen
as less stressful to care for than those who were acutely ill and required constant nursing care.

I: I don't mind if they can do their own am care and are getting better. If they've had PCP and are almost recovered then it's not as bad...

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I: It's easier when they're not really sick...but when they get to the end than it's more tragic...

Patients with AIDS who had chronic diarrhea or dementia were viewed as more stressful to care for because they required more nursing time.

I: ...They can have continuous diarrhea or dementia...and you constantly have to take care of them and watch that they don't disturb anything or pull it out, [sic], especially if they are demented. And sometimes...we used to have quite a few whose lungs would collapse...

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I: The diarrhea and the dementia have got to be the two worst curses. Everything else I can deal with...if people come in with PCP their first time, and this is going to sound very sad, but it can be a positive experience for them. Because they come in and they're extremely sick, in most cases, and
they do better and they feel good when they leave. We feel better too, it's that [diarrhea] and the dementia that make you work.
The informants' belief that these patients required more time and attention conflicted with their feeling that they didn't have enough time to support them.
I: We are, as you are aware of, short staffed. Not all of the time, but often enough and what I'd like to do for these guys I just can't. It's hard enough just doing the basics for your assignment let alone spend time with them...and I'd like to give them the little extras 'cause they need it, especially those whose family has dumped them.
Feeling unable to offer support and provide the "extras" to these patients added to the stress of caring for them. Stress was also increased when co-workers were unsupportive due to their own fears and/or homophobia.

Societal views.
This external stressor describes the views of individuals with whom the informants associate either at work or at home. These views include those of their co-workers, the patients' families and friends, and the informants' families and friends. Media
reporting about AIDS also affected the informants' experiences and were identified as part of this stressor. Informants felt their stress was increased when they had to deal with negative views about patients with AIDS. Co-workers who were afraid and/or homophobic made the work environment more stressful for the informants. Some informants felt it was necessary to help co-workers to ensure these patients received appropriate care, thus increasing their own workload.

I: ...I've seen many (co-workers) who were anti-gay and were mean with the patients, being, like, really rough. You know pulling them here and pulling them there. Being slow giving them their meds, that kind of stuff.

R: Oh no!

I: Yeah, and this one guy I felt sorry for him. He was dying and was incontinent and well, his nurse wasn't too kind with him...So I helped her out whenever I could just to make sure he was being nursed properly...Like, I would tell her when he needed to be changed and if she was too slow or was taking too much time I'd do it myself.
Other informants also indicated their workload increased when co-workers refused to help with the AIDS patients. The next excerpt is from an informant talking about a float nurse who came to help out on the ward.

I: ...She was useless, completely useless. We finally sent her away...The things she could do like...feed a patient she wouldn't do because she was scared and homophobic...We ended up shortening our breaks just to get finished on time.

Another informant described her experience.

I: They gave me two patients, him and a CVA and they ended up caring for the old guy and I ended up giving him [AIDS patient] total care. He needed it! He looked neglected, I felt, by the nurses there.

R: How was he neglected?
I: Basic care. Just basic care. He was all oily and greasy. His hair was a spider's nest and so umm he [had] no little things in his room you know little pictures and stuff. He was getting his medications and stuff, but everytime a nurse went into his room she would put on a gown, gloves, mask, and goggles. You know it got to be a little
ridiculous, because I just went in with my uniform because he wasn't coughing or bleeding or anything like that.

R: So how did that make you feel?

I: I found it upsetting. It's hard enough to care for these patients without having to deal with other nurses. I mean, I think if we have to work with people like that and, I often wonder how much of his care or lack of care was due to his diagnosis, or due to him being gay as well, you often wonder...I think that a lot of that social stigma is present from the nurses. But it's so subtle they aren't aware of it or don't acknowledge it. I mean patients with hepatitis aren't viewed with the same negative attitudes or paranoia. It's just that there is this stigma attached to them, sometimes it's not so subtle. This one I was telling you about was dirty, really dirty, like he hadn't had a good bath in a month and...they didn't acknowledge him. They just went in and at arms lengths hiked him up in bed. I got so pissed off I wanted to scream just get the hell out of here I'll do it myself!

Anger was a common feeling expressed by the informants
towards co-workers who were afraid or homophobic. One informant described how the presence of one nurse made everyone on the ward "uptight and on edge."

I: We have one we avoid like the plague. [laughs] She's an older nurse who only works casual, but she is really old-fashioned and doesn't like gays. She's always preaching about how it's wrong and all that stuff...We don't like it when she comes, we usually either try to find some menial tasks for her to do, something as far away from these guys as possible, or we send her away...We can't stand her. It makes everyone bitchy. Just seeing her makes us all uptight and on edge.

Stigmatization by co-workers was not tolerated as they were expected to care for all patients in the same manner regardless of their disease. It is interesting to note that this behaviour was not acceptable for co-workers, yet at the same time the IV drug abusers, prostitutes, and immigrants with AIDS were stigmatized by the same informants.

Stigmatization by the patients' families and friends was also hard to deal with. It also placed the informants in a compromising position when the family was unaware of the diagnosis.
I: ...trying to help that person cope or just watching them struggle with the stigma of the disease...The rejection from their families and friends, and also the subconscious rejection from some of the nurses, that's one of the hardest things to deal with...

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I: ...It was a weekend and this guy's mother cornered me and said come on what's wrong with him? You're his nurse, no one is telling me anything. And he had told me how they were devout Catholics and preached how the devil was in gays, and how bizarre eh? Anyways, she was a large woman too, it was in the utility room, and in my mind I heard him saying this. So in my most professional voice I said, well I'm sorry but I can not release that information it is confidential and you need to ask your son about it. Well [laughs], she didn't buy that. And so I finally said much louder, I'm sorry I have no authority to tell you. So she knew she'd get nothing out of me, so she went back to his room...It's an awkward position [to] be in...It makes it worse when the family doesn't know, but
sometimes it's just as bad if they do, especially when they reject them. We had one client whose father refused to see him because of it. He didn't even know his son was gay and so I guess when he found out he had AIDS he put two and two together. But, like, that's what I'm saying, it's all hard. Everything about this disease is hard.

Other patients sometimes reacted negatively to the AIDS patients.

I: Oh God, if you get a middle-aged patient that finds out what the pink sticker on the door means you're up the creek. They don't want those people in the hospital and those people in the smoking lounge and they don't want any of those bloody pink stickers anywhere near their room. They can be extremely unreasonable about it.

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R: How do the other patients on the ward feel about them?
I: I think they're afraid.
R: Afraid?
I: Yeah, they're afraid. I think that overall they're afraid because they're also ill and compromised. I don't think they're happy to share
the ward. They think they'll get it and also some of them are older people who aren't very liberal minded, you know.

Informants also discovered that not only were the patients with AIDS stigmatized but they were as well.

I: ...There was this one time we had, oh some kind of thing at [names hospital] where I don't know what its intent was, maybe to get the whole hospital together. Anyways, I'm milling about and chatting here and there with some of the people I know and I stopped and introduced myself to this one nurse and she said where do you work and I said I work on [ward]. She goes up there where all the AIDS patients are [voice raised] and I felt like oh no what was wrong with that floor...

In addition to patients' families and co-workers, informants' family members who did not understand AIDS or were homophobic were a source of stress.

I: ...My mother is quite hysterical. She's worried about it...the finger pricks. She's worried you know. Of course on T.V. you see all the shows and she said what happens if you prick your finger? And I said well, I really hope I don't, but if I do, well, I do. Then I said even
if you prick your finger it's not a 100% chance that you'll get AIDS. Oh, she says, if you pricked your finger don't tell me because I would die. She would because she's hysterical...Yeah, she doesn't like it and wants me to transfer to the babies. I said mother do you realize there are babies with AIDS too? Oh, well, when do you think you can quit?...

I: My husband wants me to leave. He says he can't stand worrying about me. He wants me to either go somewhere else or stop nursing altogether...I might just have to, to keep the peace, you know. He keeps at me about it...

Pressure from nurses' families to stop working with AIDS patients has been reported in the literature (Blumenfield et al., 1987; Bolle, 1988; Haines, 1987; Henderson, 1984; Simmons-Alling, 1984).

Sometimes the informants' friends were unable to understand why they would want to work with AIDS patients.

I: ...And she says, I don't know why you put yourself in that danger. You can work anywhere you want. Why work with them?...Why not work with other people?
Media reporting about AIDS was another stressor identified. Sensationalistic and incomplete stories caused anxiety in the informants.  
I: ...and what they print in the newspaper is sometimes very disturbing. Like, they have the big headlines saying nurse got AIDS from patient now on deathbed. [laughs]...You read it through and think oh, well, that's impossible but then again this is a well known paper that prints this stuff...Think of the public, if it bothers us, I mean, it makes me worry...  
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I: ...You have to know exactly, exactly [sic] every detail. Every part of these stories, the whole. You know more than a layman, you wouldn't realize the difference if you didn't have a nursing background. But a lot of the reporting is very generalized and they leave out a lot of information which gets you going again...  
Reisman (1988, p. 789) states that "the intense publicity of the disease has served more to heighten awareness and fear than to educate." Informants believed the media was irresponsible at times and were causing much of the anxiety about AIDS.
Lack of Emotional Support

In this study, informants reported a lack of emotional support to help them cope with caring for patients with AIDS. This form of support was described as essential. Although other forms were readily available, such as educational, they were not considered as important. The informants expected nursing administration to provide support yet at the same time they did not want to talk to them for fear of repercussions. They were also reluctant to talk with their co-workers because they worried about confidentiality and felt their relationships would change if they spoke freely. Informants did not turn to their family or friends for support unless they were nurses. The ideal support person was described as a nurse who was not associated with their agency.

The following excerpts illustrate the informants' feelings about their need for emotional support.

I: ...I appreciate the binders with all the AIDS information and [name] is very knowledgeable about AIDS so we can ask her about anything. But that's something we can do on our own, it's the understanding that's so crucial, you know. It's being aware of how we're doing and recognizing when we've
had it...Usually people leave by that time 'cause it goes unnoticed...Anyways, it's the support we need, that's the most important thing.

I: Thank you very much for all the books and papers but give me a pat on the back once in awhile. Some support goes a long way.

Informants were satisfied with the way the educational information was handled. They identified resource people they could approach and ask questions. However, they repeatedly stated they needed emotional support while caring for these patients.

Social support as defined by Kahn (1979) is an interpersonal transaction that includes one or more of the following: the expression of positive affect for one person or another (caring, love, respect); the affirmation or endorsement of another's behaviours, perceptions or expressed views (validation of actions or statements); and the giving of symbolic or material aid to another (money, tangible items, information). Cobb (1976) identified it as a "person's belief that he [she] is cared for, esteemed, and belongs to a network" (p. 300). Included in this network would be relatives, friends, neighbours, co-workers, or professionals paid for their services.
Emotional support is viewed as part of social support. It provides a sense of belonging which enhances self-esteem (Davidson, 1987). In this study, informants described it as being understood and knowing that others were concerned for one's well-being.

R: ...You said that not only did your clients need emotional support but so do you. I believe you said we as in nurses. Do you recall that?

I: Uhuh, we give it to everyone else but not ourselves...We don't get it in return...I think with these patients we're getting it's high time we got some in return...And we're not being understood. They don't understand what it's like for us...And we need them to say yes, I understand what you're going through and knowing that they were concerned for our well-being our welfare...I'd say that's the most important thing we need. Make sure you write that down. [laughs]...

Other informants also identified emotional support as being important.

R: You were saying that it's hard to cope, to deal with everything. What did you...?
I: Well, it wouldn't be so bad if they took the time to see how we're doing...Give us some recognition and try to realize how it affects us...

I: I personally feel the support is not adequate. That's one area I'd say we're having a lot of problems. Yes, we get a lot on the disease. We need that too, but I mean as I've said before this is very stressful to deal with and I know I speak for the others too. That's one very important area. It's something that's, I don't know, overlooked and not considered. Maybe they don't want to get personally involved or whatever, but to me it's very important. It's crucial for all of us nurses, or for that matter, all nurses working with them. We need all the support in the world.

Emotional support was not only seen as essential but it was expected from nursing administration. This was considered part of their role.

I: ...They're [nursing administration] the ones who should be supporting us. They're the ones who need to take a good hard look at this...
R: So what kind of support do you need?
I: Well, the pats on the back saying you're doing a fine job or umm do you need any help? How are you doing? Are you having any problems caring for these patients? How are you? You know, just how are you hanging in there? Are these guys getting to you? Just questions like that.
R: Someone said it was the emotional support they needed is this what you mean?
I: Exactly, that's it...
Informants expected their nursing administration to provide emotional support in the form of understanding and acknowledgement of how stressful it is to care for patients with AIDS.
I: ...And they have all these books and this paper work and these meetings every week. The AIDS committee, the blah, blah, blah, and they sort of come back and say you're having trouble? It's all been planned out. You can't have any problems and you know when is the last time you've cleaned his bum?...They don't have any idea what it's like. They're not standing there when they die. They're not there. I mean, I appreciate what they're doing. They're dealing from the book aspect...They
look at you as if to say well it shouldn't be a problem like there's something wrong with you. Well, there are problems you know, these gloves rip. It's stressful! These guys all die. Our co-workers die! We're scared God damn it! [voice raised].

There was anger and hostility directed towards nursing administration.

I: ...you can't talk to them about your feelings... It would be in your file. You'd get a bad evaluation...

Some informants described an example of support which they believed was inappropriate.

I: ...All the nurses are intelligent people. We all know we need to ventilate. It's very stressful, we have to talk about it but yet we feel forced to go and talk to this psychiatrist like there's no choice. We're all sick about it! What does he know about nursing? And then there's the psych thing, the stigma about seeing one.

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I: He's not a nurse to start with so we lose that perspective and he works here or is a consultant or something. You don't want to talk in front of
everyone. I mean if you do you can't get too
personal and sometimes you want complete privacy
from your employer. You don't want them to know
everything about you either. I mean, its really
inappropriate...

Informants were also reluctant to talk with their
coworkers. One experienced informant believed it
would set a bad example if she discussed how she was
having a hard time.

I: ...I wouldn't talk to one of the female nurses
at work and say well, gee I'm having a really hard
time with this mainly because I'm one of the senior
girls on the ward and I figure that they figure,
well, if she can't handle it what am I going to do!
[voice raised]. It sets a bad example...
The informants were concerned about confidentiality
and how their relationships would change if they spoke
freely.

I: ...it could be damaging if they [coworkers]
knew that you've said all this...It would be
difficult to work with them...You'd be labelled.

Feeling there was no emotional support available
made some informants suppress their true feelings
which added to the stress.
I: ...Who can we talk to? I mean really, think about it. Who is there that would understand without being judgemental and doesn't work here?...We just have to ignore it for now...

Few informants received emotional support from their families and friends. Family members who had difficulties with homosexuality or the disease itself were unable to provide this support.

I: ...We're a very Roman Catholic family and I certainly don't tell them I have gay friends or care for gay people, and as a consequence have AIDS...I don't emphasize it here, they feel uncomfortable with it...

I: ...My mother says I'm doing God's work. I think she sort of sees me as Jesus working with the lepers. [laughs] My mother is a devout Catholic...My father doesn't pay any attention. He ignores me when I talk about it or anyone else. When I mention anything about AIDS to them you can see their eyes cloud over and they just don't want to hear about it. They don't like this stuff...

Informants who recognized their families were uncomfortable with this topic did not use them as
support persons. Even those family members who were comfortable discussing AIDS, were not used as support persons because they could not understand what it was like from a nursing perspective.

I: ...My husband doesn't deal with that situation very often. It's really hard to talk to him, you know. He's not homophobic or anything he just doesn't understand. I say, well you know, I'm really upset about this. I have told him that and said this is getting hard for me now. But, like I say, my family and my husband wouldn't, they don't understand. They don't have to deal with that sort of thing...

I: ...They [family] don't mind if I discuss it. They're quite liberal, but I don't talk that much to them about it...Anyways, 'cause they don't understand it. They're not nurses, so they can't understand what I'm talking about...

Informants who usually received emotional support from their families realized they would not receive it in relation to caring for patients with AIDS. Family members who were uncomfortable with AIDS and even those who were not, could not understand what it was
like. Only another nurse could truly understand. Informants who had family members or friends who were nurses turned to them for support.

I: My mom is a nurse and is very open thank God.
R: Is she a support person for you?
I: Yes she is. Even though she lives 100 miles up north we still write to each other...My mom is really great. She does a lot of therapeutic listening. She says don't ask me for help because I don't have anything material wise but...I can talk to her about the AIDS patients because she is a nurse and can understand. Only a nurse can really understand what another nurse is going through...

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I: ...We're both nurses [friend] and can talk to each other about it...

Literature on social support and occupational stress indicate that emotional support can buffer or mediate stress (Davidson, 1987; Dean & Lin, 1977; Kahn, 1979; Riegel, 1989). One study done by Constable and Russell (1986) revealed that supervisory support is the most meaningful to reduce stress at work. Burnout literature also identified it as a
factor to decrease vulnerability to burnout (Hare, Pratt, & Andrews, 1988). Feeling supported helps individuals to cope with stress.

**Coping Strategies**

Coping is interrelated with the concept of stress. Edwards' (1988) review of coping literature revealed deficiencies in the meaning of coping and the mechanisms by which it influences stress and well-being. He states:

> We still know relatively little about the specific coping strategies individuals use in dealing with stress, the process by which individuals select and implement these strategies, or the mechanisms by which coping affects stress and individual well being (p. 233).

There is also limited nursing literature about specific coping strategies nurses use to deal with their stress. A review of literature on stress in ICU and non-ICU settings revealed a lack of research which clearly identified measures of stress and coping according to the nurses' perceptions (Gentry & Parkes, 1982). Lack of research in this area is partly due to problems in defining stress and coping. Dewe (1987)
notes that the traditional definitions of stress emphasize either the stimulus or the response which focuses on the components of the relationship rather than the relationship itself. His study investigated and described the strategies nurses said they used to cope with work stress. His findings revealed six coping strategies; one was identified as a direct action strategy or problem-oriented behaviour and the other five were palliative strategies. Direct action strategies are behaviours that can change the stressful situation itself. Palliative strategies are temporary measures aimed at lessening the impact of the stress. Dewe (1987) believed the greater number of palliative strategies used were due not only to the differences in personalities of the nurses, but also to the nature of nursing where few direct action strategies can be used in hospital settings. Clarke (1984) identified other coping strategies as indirect where techniques and/or activities are learned.

In this study, informants described both indirect and palliative coping strategies.
Usual Coping Strategies

To cope with their overall experiences caring for these patients, the informants relied upon the usual coping strategies which relieved stress for them. These included physical activities; relaxation activities; and talking with others.

Physical activities.

Directing the energy outward has been described as one method to decrease stress (Flaskerud, 1987; Scully, 1980). Most of the informants used some form of physical activity as a coping strategy.

R: You mentioned last time about the emotional drain you feel from these clients. How do you deal with this?

I: Exercise, I paint, I listen to my music. It does affect my moods, I mean, I have to be so caring and intense at work so that when I'm at home it does come out. But as long as I exercise and keep busy I can prevent myself from becoming depressed or burned out, but it's hard. It's really hard...

I: ...You know, I keep my stress levels down by exercising, visiting friends. I guess for me when
it's really bad, say after one of them has died, I'll go hit some balls, go to the gym, and play raquetball with some friends, meditate, things like that. Just try not to think about work.

Other less strenuous activities were also used to cope with stress.

**Relaxation activities.**

Some informants used relaxation activities to decrease their stress.

I: ...well stress relieving things for me are well, I'll snooze, or just sit, I used to do yoga, calming type of things.

I: ...I enjoy taking hot baths or just finding a good book to read, things like [that]. Or else I can phone my mom and talk to her, well, not really talk to her about these patients [laughs]. My goodness she'd have a heart attack...but I can talk to her and just say I had a bad day at work. So she's good for that.

For this informant, she also used talking as a usual coping strategy. This was the most common one.
Talking with others was seen as an easy and effective coping strategy.

R: ...What do you usually do to cope with this stress?
I: Oh I can talk to anyone in my family, like my sister or my mother. They're really great, you can talk to them about just about anything. So, they're the people I go to first if I need a shoulder to cry on...There was one time though, I was talking about these guys and got them so depressed it didn't help me much.
R: Can you explain why they...?
I: ...Like they don't want to hear about all those homosexual men. All those homosexuals afflicted with that that [sic] disease [mimics mother's voice] so, I don't, I just don't talk about these AIDS people. It doesn't do me any good getting them all upset. It makes me more stressed, so we leave that part of my work out. They don't understand it...

Some informants whose usual coping strategy was to talk with their families or friends, realized it might not be effective if they needed to talk about stress
related to caring for AIDS patients. For these times, the informants would seek out other nurses who could understand them.

I: ...I made one good friend at work when I started and we can talk about this. She knows what I mean and I know what she means...We understand each other. That's who I go to...

Developing friendships with understanding co-workers and sharing feelings were considered to be effective in decreasing stress. However, the specific stressors related to caring for patients with AIDS required different coping strategies. These were identified as: (1) rationalization; (2) knowledge-seeking; (3) withdrawal; and (4) involvement.

**Coping Strategies Related To Internal and External Stressors**

**Rationalization.**

Rationalization was described as thinking logically about AIDS. Mentally reviewing the facts about the disease was used to decrease the informants' fear.

I: ...You use your rational side to cope with the fear. What I mean by this is that I think about all the facts about this disease, like the
miniscule risk. I just keep reminding myself about that.

R: Uhuh, I see, so you think of the facts about AIDS?

I: Yeah, just concentrate on what you know about it...It doesn't completely rid me of fear but it helps to lessen the anxiety. I can at least get through my shifts without looking panic stricken. [laughs]

The rational side was considered the nursing part of the informants where logic ruled over their emotions. For this informant, rationalization was effective in relieving some of the anxiety but not all the fear. Other informants also used this coping strategy to deal with their fear.

I: ...Yes I am scared, but it's not that easy. Sometimes this [fear] is so...out of your control. Like, we just don't know what we're up against...

R: Uhuh, and so do you feel like you can't control your fear? Is that what you're saying?

I: Yes, and I can sit here and tell you all about it. I can recite everything about it 'cause we are made sure we all know all about it. [sic] But I can hear myself saying all this in my mind...
R: Oh, so for you you think about it?
I: Right, I can hear [name's] voice in my head listing the risk to nurses and saying all this.

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I: ...If I know, say I know the night before that I have one of them the next day, then I'll try to mentally prepare myself. I just think to myself well I can only get it if I'm in contact with blood or body fluids. So, I keep saying that...and of course I do all the precautions too. But more of the mental reminders of...how it's transmitted. I say things like that and so then it keeps me on track...

Informants used rationalization as a way to intellectualize and understand the disease itself. Reviewing documented facts about AIDS was helpful for some informants to alleviate anxiety but not to completely eliminate the fear.

Rationalization was also used by some informants to deal with the frustration of caring for these young patients who were dying. This coping strategy was used to help them accept death for them.

R: What do you do to cope when they do die?
I: Well, I think that if it's going to happen,
it's going to happen, you know. I mean as tragic as it may be, I have to think that this is another thing about the disease and...again I look at it in that way. It's part of the disease...I look at it realistically...You try to accept it you know...

Rationalization was also used to cope with negative societal views. Some informants who encountered people who were prejudiced against patients with AIDS or homosexuals, would rationalize their behaviour as following their religion.

I: ...It's [homophobia] really only a product of their [co-workers] religious upbringing. They've been brainwashed to be this way.

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I: ...My dad is very strict. He's a devout Catholic and goes to church regularly and he won't change. If the Bible says it's wrong, it's wrong. When the Bible says gays are okay, then he'll say they're okay...I guess really he's got a case of homophobia...

Recognizing homophobia in loved ones was difficult. It was easier to attribute this attitude to the person's religion rather than to the individual person. The previous informant continued:
I: ...It's the religion you know he was brought up to believe that it was wrong and it's not him, you know. Really, it's not him. It's what he's been taught...

Not all informants rationalized these behaviours as according to the person's religion. Some informants expressed animosity towards anyone who was homophobic describing them as "insensitive" and "ignorant."

**Knowledge-seeking.**

Knowledge-seeking was described as looking for new information in order to increase one's understanding. One of the informants who was uncomfortable with her homophobia described how she became more accepting towards homosexuals.

R: You said last time how you've come around to be more accepting towards homosexual[s] in general. Can you tell me how you did that?

I: I went to this psychiatrist...and I asked him about it. Like, why are they that way? He talked to me about it and gave me some good articles to read and he wasn't judgemental, not at all...He just told me what he knew about it and that they really don't know why they're this way. It may be genetics, it may be environment, who knows?
It was hard for this informant to make the initial decision to talk with this psychiatrist. She was concerned about the stigma of seeing a psychiatrist and having others think of her as mentally ill. After learning more about homosexuality, she felt more comfortable caring for patients with AIDS.

Knowledge-seeking was also used when informants were concerned about sensationalistic articles.

I: ...These stories they have in the media are enough to drive you to drink. They tell you something that might affect you, but they don't tell the whole story...All these health care workers who were supposed to get it. I read that one, good grief!

R: You found it stressful when you read about the health care workers?

I: Yeah, it was scary. They mention this large number of people who were nurses and lab techs and some other people in the hospital and how they were monitoring them for the AIDS virus. It was only half-truths.

R: What did it say?

I: Oh, they'd all been exposed. I don't remember how, finger stabs I think. Anyways, they were monitoring them to see if they would develop AIDS
and I had to go to the librarian and get him to search it for me so I could, you know, read the whole research on it...And then it turns out most of them were partners of IV drug users or in some other high risk group. So I went phew, thank goodness I found that out...But it wasn't in those cheap supermarket tabloids...It was in a newspaper...But I find you still have to get it checked out to make sure it's correct, or you could misinterpret the information...like in this case where they leave out crucial information. So you have to know, you have to find out...

Informants sought out additional information on articles when they were not sure of their accuracy. Even articles from reputable sources were questioned to make sure the informants had all the facts.

Withdrawal.

Informants described withdrawal as distancing themselves from patients with AIDS or avoiding them. This coping strategy was mainly used by the informants who were homophobic. It was also used to cope with the stress caring for patients with AIDS in other high risk groups. The following excerpts were from informants who described themselves as homophobic.
I: ...So I did what I was supposed to do with him and was quick about it. I didn't want to stay too long...I felt uncomfortable being there...

I: If I can trade my assignment with someone else I'll do that. I prefer not working with them...But if I have no choice I'll do it...

Being quick or trading assignments was one way these informants physically withdrew from the patients with AIDS. The previous informant also described how she psychologically withdraws from these patients.

I: ...I know they sometimes want to talk about it. How they got it and everything, but I can't relate to that kind of stuff...I'm busy and have things to do...One time I was changing some patient's dressing and he was talking and talking, yacking away about something or other, and he said something to me that needed an answer and I didn't hear him. I didn't want to hear him...

R: Uhuh, why was that?

I: I think it was maybe because I was tired, not tired in the sense of physically tired, but I think more about all the hoopla. All the ward ever talks about is the AIDS patients and also because it's
not my thing. AIDS patients are not my forte in nursing. I don't want to specialize in it and so that's why, I guess...

Other informants who did not like patients who were IV drug abusers, described how they coped with them.

I: ...Oh yes, we get a few like that [heroin addict] and it's an experience let me tell you. They're not my favourites...This one was calling all the time sitting on the bell and ringing it and ringing it and I'd go in and he'd want some codeine and I'd say it's not time yet. You have to wait for another whatever till it was the right time and he'd be a ringing some more, so I would just not answer it any more. I'd leave him be then he'd go to sleep...

Informants who did not like these AIDS patients would either ignore them or routinely give them sedatives to keep them quiet. The last informant elaborated on how she coped.

I: Yeah, they're in withdrawal and are easily agitated and so I make sure they get their whatever like clockwork. Even reminding the doctors about that, then they don't get all crazy...it's easier to work with them. They sleep most of the time and
I don't have to see as much of them...if you don't do that then you have to be extra careful...

Some informants who had difficulty caring for dying AIDS patients would also withdraw from them. One informant who was caring for two dying patients and was to admit another one, had to go home before the end of her shift because she couldn't cope any longer. Another informant who was feeling overly stressed described her thoughts about a dying AIDS patient.

I: ...This guy was on his death bed and had to be turned regularly and it was late in the afternoon and I'd washed him twice, plus I had all my other patients. And it was time to turn him again and someone reminded me...and I thought oh so what! He can wait! I didn't want to go back in there...I must have turned white I was so shocked at what I was thinking 'cause someone said something to me about my face being white. It made me realize, yes, my time has come I need a break...

This informant became aware of how much stress she was feeling. In the second interview, she said she was thinking of resigning and was looking for another job.
In contrast to withdrawal, the last coping strategy, involvement, resulted in the informants becoming closer to their AIDS patients.

**Involvement.**

Involvement was described as sharing personal information or seeing the patients in the informants' non-working hours. Informants used this coping strategy to deal with dying patients or those who were still relatively healthy. Frequently, informants who identified with their patients in some way, used this strategy.

I: ...He asked me if I was gay, which I am...It's something I don't like to divulge at work...I don't think it's anybody's business...But we got very close in the sense of sharing, just his emotions...When he died they [family] didn't even come up to the hospital and it hurt me...

This informant continued:

I: I have been tested too and so I understand what they're going through and I think I could be next...

Other informants described how they became involved with their dying AIDS patients.
I: ...this one patient was so young, just in his early twenties...I was so devastated when I first met him. He had just moved here...and had no one. There was no one for him so sometimes I would come in on my days off...

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I: I would spend most of my shift with him, just talking and talking. I'd tell him about my family and things...

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I: ...I do occasionally go into work on my days off to visit some patients, but I really try to limit that, you know. Because you can get sort of a martyr complex or messiah complex and I don't want to get like that. I think there is a wall inside of me and I will care for someone up to that wall and then it doesn't go any farther...I only get so close and then I back off and the wall goes up...

Some informants would visit their patients at home after they had been discharged.

I: I've done volunteer work with them and visited them in their homes...I worry about them when they leave. They're so alone. Many times their
families desert them so I do that...it helps me not to worry...

One informant became involved with a patient who was infected unknowingly by her bisexual husband.

I: I called her at home to see how she was doing and [told her] to drop by and see me...

Bolle (1988) discusses one of the problems associated with nurses becoming too closely involved with their patients, especially gay male nurses. She believes they are at risk for overidentification with them. They may have difficulty maintaining professional boundaries and may perceive themselves as personal friends sharing the same cause. These nurses, therefore, have a higher risk for burnout.

Although the informants used involvement as a coping strategy, it was many times ineffective and caused more stress. Informants would continue to worry about their patients when not at work. One informant described how this caused problems with her family.

I: ...I worried about him and I couldn't eat and I was going to have dinner at my parents but I was thinking he was going to die and so at dinner they said why aren't you eating...I said I was thinking
of one of my AIDS patients who was going to die.

Well, they [parents] just flipped out...

Coping with the stressful experiences of caring for patients with AIDS can be a monumental task. Although informants relied on their usual coping strategies, they discovered they needed others to deal with the specific internal and external stressors.

Summary

Nurses' experiences caring for patients with AIDS were described as stressful. This was the predominant theme that illustrated what it was like, for these nurses, to care for AIDS patients. Sources of stress varied for each nurse, but two major categories were identified by the researcher. Internal and external stressors were feelings associated with caring for these patients. Internal stressors included: (1) fear of contracting AIDS; (2) homophobia; and (3) caring for dying AIDS patients. The two external stressors were patient variables and societal views. In addition to these stressors, a lack of emotional support was reported. Although other means of support, such as educational, were described as available, emotional support was perceived to be essential for all nurses caring for patients with AIDS.
In order to deal with their stressful experiences, the nurses utilized their usual coping strategies. These included physical activities, relaxation activities, and talking with others. To cope with the internal and external stressors, the nurses used rationalization, knowledge-seeking, withdrawal, and involvement.

These findings were supported by the literature. The discovery of AIDS has added a new stressor for nurses. According to Jenner, Levi, and Houghton (1986) nurses who care for patients with AIDS can expect to experience increased levels of stress. Fear of contracting AIDS, issues in sexuality, exposure to alternate lifestyles, and death and dying are some stressors related to caring for patients with AIDS (Bolle, 1988; Christ & Wiener, 1985; Flaskerud, 1987; Simmons-Alling, 1984).

Fear of contracting AIDS is directly related to the fact that the occupational risk to nurses is not zero (Bennett, 1986; Dhundale & Hubbard, 1986; Geis & Fuller, 1986; Gilmore, 1985; Rubinow, 1984; Simmons-Alling, 1984). This concern was stated repeatedly throughout this study. Despite the low risk and being knowledgeable about AIDS, nurses were
still afraid. They described their fear as "irrational" and "out of their control." Rubinow (1984) believes that although educational information is provided, it is not actually heard.

Issues in sexuality and exposure to alternate lifestyles was also evident in this study. Nurses who described themselves as homophobic found it even more difficult to care for patients with AIDS. Nurses may feel uncomfortable with homosexuality if their personal values, cultural backgrounds, and religious ideals are challenged with the psychosocial variables of these patients (Simmons-Alling, 1984). This was true in this study; the nurses who said they were homophobic associated this attitude with their religion. Homophobia was also related to the belief that these patients deserved to have AIDS (Kelly et al., 1988). Some nurses in this study did express this view. One nurse was able to see these patients in a more sympathetic manner after she found out more information about homosexuality and had increased contact with them. According to Storms (1978), increased contact with homosexuals can dispel false stereotypes and lessen homophobia in some individuals, but it may also heighten anxiety and increase
hostility in others. Both behaviours were reported in this study.

Exposure to dying patients has been associated with higher levels of burnout (Dames, 1983). Nurses in this study reported increased stress when they cared for many dying AIDS patients. They found it even more difficult to care for the "second generation" AIDS patients who were the partners of the previous ones who had died. Rubinow (1984) discusses the drain nurses can experience when they encounter these patients dying on a daily basis.

Literature about the external stressors was not as extensive as literature about the internal ones. Some patient variables related to AIDS has been identified as having an impact on nurses who care for these patients (Rubinow, 1984; Simmons-Alling, 1984). The various high risk groups were viewed differently in this study. IV drug abusers, prostitutes and immigrants were viewed with more hostility than homosexual AIDS patients. Des Jarlais and others (1986) describe how society in general has little empathy for this group of people. It seems likely, however unfortunate, that this attitude would cross over into the nursing profession. There was even more
empathy expressed for those patients who unknowingly became infected with AIDS. The nurses in this study believed these patients required more emotional support and, therefore, more time. Feeling this added pressure resulted in these nurses experiencing more stress. Another variable related to these patients was their stage of illness. Those patients who were still relatively healthy were seen as less stressful to care for compared to those who were acutely ill. The rapid deterioration in patients with AIDS health can over-burden already stressed health care workers (Rubinow, 1984).

Societal views towards AIDS can add to the nurses' stress caring for these patients. In this study, nurses reported stigma towards patients with AIDS from other nurses, the patients' families and friends, and other patients. The nurses themselves also felt stigmatized by co-workers. Although there was no evidence of stigma from the nurses' families and friends, they were encouraged to stop caring for these patients. This kind of pressure has been reported in the literature (Blumenfield et al., 1987; Bolle, 1988; Haines, 1987; Henderson, 1984; Simmons-Allings, 1984). Another stressor identified
was media reporting about AIDS. Sensationalistic and incomplete stories caused the nurses to become anxious.

In this study, the nurses reported a lack of emotional support. This form of support was seen as essential and it was expected from nursing administration. It was interesting to note that although the nurses were upset about the lack of support, they were reluctant to talk with their administrators for fear of repercussions. Geis and Fuller (1986) describe how hospice staff, if they spoke freely about their fears, were viewed as a threat to the hospice movement. Conflict with administrators was turned inward with the staff assuming the problem was their personal one. Some nurses in this study suppressed their true feelings because they believed no one was available who would understand. Co-workers were not often used as support persons due to the nurses' concern about confidentiality and how their relationships would change if they spoke freely. The nurses did not turn to their families or friends for support unless they were nurses. They described the ideal support person as a nurse because only another nurse could understand
what it was like to care for these patients. It was also mentioned that the support person should not be connected to the employing agency. Literature related to this topic focusses more on supportive strategies to decrease stress rather than looking at how or if nurses receive emotional support. Many authors cite the need for emotional support for nurses caring for patients with AIDS (Bolle, 1988; Bennett, 1986; 1987; Flaskerud, 1987; Geis & Fuller, 1986). Geis and Fuller (1986) state "when staff members are almost overwhelmed by feelings and fears, they need psychological support as badly as they need instructions about following the medical protocol" (p. 241).

The nurses in this study, described different coping strategies they used to deal with their overall experiences and with their specific stressors. The literature on nurses caring for patients with AIDS, presents general coping strategies which may be effective in reducing stress (Beaufoy, Goldstone, & Riddell, 1988; Bolle, 1988; Flaskerud, 1987; Rubinow, 1984; Simmons-Alling, 1984). Bolle (1988) outlines several strategies which can assist in preventing burnout. These include education, staff support
groups, multidisciplinary team meetings, informal peer support, spiritual support, and nursing administration policies and practices (Bolle, 1988, p. 846).
CHAPTER 5
SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

Summary

The discovery of AIDS has resulted in anxiety and fear throughout society. It has had a major impact on all the health care disciplines, especially nursing. There is limited research which describes what it is like for nurses to care for patients with AIDS. Therefore, this study explored nurses' experiences caring for these patients. A modified version of Spiegelberg's (1960; 1970; 1981) phenomenological approach was used to provide a description according to the perceptions of eight hospital nurses.

The findings indicate that caring for patients with AIDS is complex and multifaceted. The nurses described their experiences as stressful. The sources of stress varied for each nurse but the two major categories, identified by the researcher, were internal and external stressors. These stressors were feelings associated with caring for these patients. Internal ones included: (1) fear of contracting AIDS; (2) homophobia; and (3) caring for dying AIDS patients. External stressors were patient variables and societal views. The nurses also reported a lack
of emotional support which they expected from their nursing administration.

Two major categories of coping strategies were used by these nurses. Their usual coping strategies were used to help them deal with the overall stressful experience. Included in this category were physical activities, relaxation activities, and talking with others. In order to deal with the specific internal and external stressors, the nurses used rationalization, knowledge-seeking, withdrawal, and involvement.

Conclusions

There are two major conclusions arising from this study. First, the arrival of AIDS has resulted in increased stress in an already highly stressful profession. Nurses reported being very close to burnout. The denial that these feelings exist or that patients with AIDS are different from others has resulted in these nurses feeling emotionally unsupported. Continued denial of this kind will only add to the nursing shortage as more nurses burn out and leave the profession.

The second conclusion is that nurses need and expect emotional support. This raises the question of
who cares for the caregiver? These nurses believed it was the responsibility of nursing administration to provide emotional support. Although, they were reluctant to discuss their feelings with them, they wanted nursing administration to understand how stressful it is to care for patients with AIDS. This kind of support would need to be implemented in such a way as to protect the nurses' anonymity. At the same time, the nurses need to be ensured of no reprisals for what they have to say.

Increased communication between staff nurses and administration is necessary. Both groups need to work together to accomplish the primary goal of nursing which is to care for patients. Also, nursing administration needs to become aware of how certain patient groups affect staff nurses.

In addition to these conclusions, there is the issue of nurses' ethical and moral obligations. Although this was not specifically addressed in this study, it is related to the overall topic. Nurses are ethically and morally obligated to care for all patients and patients with AIDS are no exception. According to the International Council of Nurses' Code for Nurses, the nurse's primary responsibility is to
those people who require nursing care. Upon entering the nursing profession a person assumes certain professional obligations, the essential one being to provide nursing care to patients (Curtin, 1986). Nurses who have prejudicial attitudes towards a certain group of people may have great difficulty providing high quality care. In this study, there was some evidence of prejudicial attitudes towards homosexuals, IV drug abusers, prostitutes, and immigrants with AIDS. It is beyond the scope of this study to address the actual nursing care provided; however, it is important to be aware of the potential for negative attitudes to affect the quality of nursing care.

Implications for Nursing

Nursing Education

The introduction of stress theory in nursing curricula or increased emphasis in curricula that already include this content is of increasing significance. Beginning nurse practitioners need to be aware of the realities of nursing which includes recognizing that it is stressful. New graduates need to be prepared to identify manifestations of stress in themselves and their patients. They also need to learn how to cope with stress.
As AIDS becomes an increasingly common health problem, new graduates must be knowledgeable about this disease. They must be educated about the medical, psychosocial, legal, and ethical aspects of AIDS. Detailed and accurate information needs to be provided to help dispel misconceptions. In addition, nursing students need to be sensitized to the issues associated with AIDS. Feelings about homosexuality and different lifestyles of people in the high risk groups need to be explored so these future nurses will have a better understanding of these patients. They need to learn about the process of death and dying so they will become more confident in their care.

Nursing Practice

Caring for patients with AIDS is undeniably stressful. Nurses in practice settings need to be aware of the possible stressors they may be faced with when caring for these patients. Receiving and providing support in the work environment is essential. Nurses in this study were distressed at the lack of emotional support yet on the other hand they did not provide it to their co-workers. It was emphasized that this support could be provided only by a nurse who was preferably not connected with the
agency. Strategies to deal with stress in the workplace need to be implemented. Informal voluntary peer groups in hospitals where members trust each other are one possible solution. Also, hospital chaplains could be used as another source of support which would be confidential.

Nurse administrators need to take a closer look at the nurses caring for patients with AIDS. They need to find out how these patients affect the nurses by talking and listening to them, and actually observing their nursing care. Administrators also need to identify specific strategies that could be implemented to provide support. For example, they should provide breaks in nurses' assignments so they don't care for many dying patients in a short period of time. Also, hiring practices need to be reviewed. Potential employees should be asked about their feelings and previous experiences caring for patients with AIDS.

Since nurses are ethically and morally obligated to care for all patients, assessment and monitoring of possible prejudicial feelings need to be carried out by employers. This could be done by surveys or values clarification research and actual observation of
nursing care. Evaluations from patients with AIDS regarding the care they received would be another method. Any such methods would need to be implemented in a non-judgemental manner. In addition, programs might need to be developed that would assist nurses to overcome prejudicial or negative attitudes.

Nursing Research

There is an overwhelming need for research on the nursing care of patients with AIDS, in particular, research which looks at the psychological and ethical concerns of nurses. In this study, nurses described how stressful it was to care for these patients. Further research is needed to validate if this is true for nurses in other settings. Also, continued research is needed on this topic to identify if over time these findings are still accurate descriptions of hospital nurses' experiences.

Stress was the predominant theme which was repeatedly emphasized. There were also indicators of burnout. Some nurses were so overwhelmed and unable to cope, they mentally and/or physically withdrew from their patients. This indicates the need to explore specific coping strategies which are effective in dealing with stress associated with caring for
patients with AIDS.

Coping and support were two major concepts that emerged from this study. These concepts were fundamental to the nurses' experiences; however, the research available did not clearly operationalize them in clinical practice. Therefore, this points to the need for additional research on how coping and support are operationalized in this area. Research is also needed on the effectiveness of different kinds of support. This could include support from colleagues, clergy, and psychologists.

Nurses who felt uncomfortable with AIDS patients' homosexuality and alternate lifestyles received little, if any, assistance to help them understand their feelings. Research on effective strategies to deal with personal and professional conflicts is necessary. Another issue that could benefit from this kind of research is that of dealing with dying AIDS patients. Nurses reported feeling frustrated caring for such young patients who were dying. Research might lead to the development of strategies to help nurses cope more effectively with this aspect of AIDS care.

Research on nurses' attitudes needs to be
expanded. Although some research does exist about nurses' attitudes towards AIDS patients (Kelly et al., 1988; Reisman, 1988), it lacks descriptions of the nurses' feelings and perceptions. One critical topic is the relationship between nurses' attitudes towards AIDS patients and their nursing care. What effects, if any, do negative attitudes towards these patients have on the quality of their nursing care?

Nursing is meeting the challenge of caring for patients with AIDS. Continued research on this topic will further increase our understanding about what it is like to care for these patients and will provide direction to assist nurses to cope with their experiences.
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Appendix B

Subject Consent Form

A Phenomenological Study of Nurses Experiences Caring For Clients With Acquired Immunodeficiency Syndrome (AIDS)

I understand Linda Pickthall's study is to find out what my experiences are caring for clients with AIDS.

I understand being a subject will involve 2-3 interviews of approximately 1 hour in a mutually agreed upon place. These interviews will be audiotaped and transcribed.

I understand my name and any identifying information will not be used in this study or revealed. My confidentiality will be maintained by coding of the transcripts which will be known only to the researcher.

I UNDERSTAND I AM UNDER NO OBLIGATION TO PARTICIPATE IN THIS STUDY AND REFUSAL TO PARTICIPATE WILL NOT AFFECT MY CAREER. I MAY WITHDRAW AT ANY TIME OR REFUSE TO ANSWER ANY QUESTIONS. I UNDERSTAND THERE ARE NO FINANCIAL BENEFITS IN PARTICIPATING IN THIS STUDY.

I, the undersigned, understand the nature of Linda Pickthall's study and give my consent to participate. I acknowledge receiving a copy of this consent.

Name.................................................................

Phone Number....................................................

Signed..............................................................

Date...............................................................
Appendix C

Sample Questions

1. What is it like to care for clients with AIDS?

2. How do you feel about caring for AIDS clients?