1993

An analysis of stressors of hospice home care nurses caring for AIDS patients

Marieann Slone
San Jose State University

Recommended Citation

Slone, Marieann, "An analysis of stressors of hospice home care nurses caring for AIDS patients" (1993). *Master's Theses*. 649.
DOI: https://doi.org/10.31979/etd.d3kh-x9t5
https://scholarworks.sjsu.edu/etd_theses/649

INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps. Each original is also photographed in one exposure and is included in reduced form at the back of the book.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

U·M·I

University Microfilms International
A Bell & Howell Information Company
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
313/761-4700 800/521-0600

An analysis of stressors of hospice home care nurses caring for AIDS patients

Slone, Marieann, M.S.

San Jose State University, 1993

U·M·I
300 N. Zeeb Rd.
Ann Arbor, MI 48106

AN ANALYSIS OF STRESSORS OF HOSPICE HOME CARE NURSES CARING FOR AIDS PATIENTS

A Thesis
Presented to
The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By
Marieann Slone
August, 1993

APPROVED FOR THE DEPARTMENT OF NURSING

Virgil Parsons

Virgil Parsons, DNSc, RN

Emilie Musci

Emilie Musci, DNSc, RN

Nada I. Ferris

Nada Ferris, RNCS, MS, ANP/GNP

APPROVED FOR THE UNIVERSITY

Serena W. Stanford

ABSTRACT

STRESSORS OF HOSPICE HOME CARE NURSES CARING FOR AIDS PATIENTS

by Marieann Slone

This exploratory study identifies the stressors of home care nurses caring for hospice patients with the diagnosis of AIDS. Five hospice home care nurses provided data obtained from demographic questionnaires and semistructured interviews. Four questions were developed to identify the difference in caring for AIDS patients in hospice as compared to other hospice patients, the differences and specific problems, and the role changes the nurse may have experienced.

The data confirmed that there is a difference caring for AIDS patients, and that the nurses caring for these patients are experiencing increased stress due to both physical and psychological problems. Further research is needed to provide better care for the hospice patient with AIDS, and to acknowledge the increased demands on the nurses managing the care.

ACKNOWLEDGEMENTS

Warm and sincere thanks to all of the faculty members, participants of the study, and family members who have helped me in some way to create this thesis. Most importantly, I sincerely thank my husband, Chuck, for his unselfish time, patience, and enduring support during this process.

TABLE OF CONTENTS

Page

Chapter Page

APPENDIXES

LIST OF TABLES

Table Page

Chapter 1

INTRODUCTION

The HIV epidemic has been described as an iceberg, with the diagnosed AIDS cases representing the tip and the reservoir of human immunodeficiency virus (HIV) cases representing the ice below (Chang, Katz & Hernandez, 1992). This population is impacting hospices internationally. The purpose of this study is to ascertain whether home health nurses working in a hospice setting experience increased demands dealing with the increased number of AIDS patients in the population of hospice patients. This research project targeted stressors experienced by hospice home care nurses specific to caring for AIDS patients and managing their symptoms.

Problem

Acquired immune deficiency syndrome (AIDS) is a fatal disease that has caused revolution in the health care system internationally. The recognition of this global problem and its pandemic effects have stimulated the health care industry to organize and become innovative. Since 1981, when the first case of AIDS was diagnosed, until present, there have been changes in the definition of AIDS, as well as standards of care for AIDS patients. During the past decade, health care has revolutionized standards and methodology of care. Home health care has become the fastest growing segment of the industry (Firshein, 1986), and this includes hospice home care.

Statistics confirm that there are over 1,700 hospice programs providing home care for dying patients and their families (National Hospice Association, 1989). According to Stoddard (1990), hospice care in America is varied in practical ways as different as the communities in which it has arisen. The hospice grassroots movement is broadly based and has vastly improved the physical, emotional, and spiritual health for dying patients in this country.

Current statistics from the HIV/AIDS Surveillance Report (Santa Clara County, 1992) document 206,678 diagnosed AIDS cases in the United States, 39,807 cases in California and 906 cases in Santa Clara County. This population is impacting hospice agencies everywhere.

Purpose and Need

Recent literature supports the belief that once a patient is diagnosed with a terminal illness, the burden of care shifts to the nurses. The physician medically manages the patient's disease, while the nurse provides both physical and psychological care (Bram & Katz, 1989). Professionals are expressing frustrations, fears, and concerns for the unmet needs of hospice patients with AIDS. Based on this information and the frustrations and concerns expressed by caregivers, it is necessary that these issues be investigated.

The research objectives were to define the stressors hospice home care nurses are experiencing caring for AIDS patients, define the specific problems causing concern, and note if nurses are experiencing any role changes in their professional and personal lives. The AIDS hospice patient places increased demands on the nurse case manager. These demands and multiple losses set the nurse up for burnout, and it is imperative that health care agencies do not lose any concerned, caring, qualified nurses because the increased demands of their jobs have not been investigated and documented.

Research Questions

In order to identify and clarify these concerns, the following questions were developed:

1. Do you think there is a difference in caring for hospice patients diagnosed with AIDS compared to other hospice patients?
2. Will you identify the differences if any?
3. What are the specific problems you have experienced?
4. As a result of caring for hospice AIDS patients, have you experienced any role changes in your professional or private life?

This study was being conducted because the author assumed that nurses caring for AIDS hospice patients are experiencing increased stress, and the problems related to caring for hospice AIDS patients were both physical and psychological. The care of hospice patients with AIDS has caused role changes for the nurse caregiver, and many of the hospice home care nurses caring for AIDS patients exhibit characteristics of the expert nurse by Benner's (1984) definition.

Definitions

For the purpose of this study, the following definitions applied:

1. Caring: (a) sets up what matters to a person; it also sets up what counts as stressful, and what options are available, (b) sets up the condition that something or someone outside the person matters and creates personal concerns, (c) sets up the possibility of giving help and receiving help (Benner, 1989).

2. Coping includes actions people take when personal meanings are disrupted and smooth functioning breaks down (Benner & Wrubel, 1989).

3. Hospice is a program of care that establishes caring interventions to achieve palliation of the accompanying concerns and distressful symptoms of the process of dying.

4. Hospice home care nurse is a professional nurse with Public Health Certification who case manages the care of dying patients.

5. Stressors are conceptions causing the disruption of meanings, understanding, and smooth functioning so that harm, loss, or challenge are experienced, and sorrow, interpretation, or new skill acquisition is required.

Research Design

Sample and Setting

The sample consisted of hospice home care nurses who serve as case managers for AIDS patients. Five nurses were interviewed from one hospice home care department. A preliminary questionnaire was given prior to the interview to identify the demographic variables of age, level of education, amount of experience in nursing, and the amount of experience in hospice home care.

Methods

The study was designed as an exploratory study to examine the stressful demands made of hospice home care nurses caring for the AIDS patient and their families. Semistructured interviews with a nonrandom, convenience sample of hospice home care nurses were conducted. The data were categorized and problems identified. The demographic data were included in tables.

Limitations

The sample size was small, nonrandom, and drawn only from an area where there is a very large population of people with AIDS. Only female nurses were selected for the study. Generalization of the results to other populations is very limited.

Conclusion

Issues dealing with the management of AIDS patients in the hospice program are surfacing daily. Therefore, this pilot study of hospice home care nurses is needed to formulate hypotheses for further study.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF THE RELATED LITERATURE

Conceptual Framework

The conceptual framework for this study is based upon the work of Patricia Benner (1984; Benner & Wrubel, 1989). Benner's research thesis, developed in From Novice to Expert and expanded in The Primacy of Caring, is that caring is central to human expertise, to curing, and to healing.

Since 1982, Benner has studied clinical nursing practice in order to discover and describe the knowledge that occurs over time in a nurse's practice. According to Alexander (1990), Benner's explanation of nursing practice goes beyond rules and theories and is instead based upon reasonable behavior that responds to the demands of a given situation. As the nurse gains expertise, clinical knowledge becomes a blend of practical and theoretical knowledge. Expertise develops as the clinician tests and modifies principle-based expectations in the actual situation.

Benner was a research assistant for Richard S. Lazarus, who is known for his stress and coping theory. Lazarus and Folkman (1984) describe stress as the appraisal of meanings, and coping is what the person does about the disruption of meaning. Both doing something and refraining from doing anything about the situation causing stress are ways of coping. "The way the person is in the situation sets up different possibilities" (Benner & Wrubel, 1989, p. 63). This is the key concept Benner uses to describe clinical nursing practice in terms of nurses making a positive difference by being in the situation in a caring way. Benner and Wrubel, in their book, The Primacy of Caring: Stress and Coping in Health and Illness (1989), describes the primacy of caring as three-pronged: "the producer of both stress and coping in the lived experience of health and illness . . . . as the enabling condition of nursing practice, and the ways that nursing practice based on such caring, can positively affect the outcome of an illness" (p. 7).

Related Literature

The literature review revealed a lack of research specific to the problem of this study. Current literature discusses the following areas: (a) whether the AIDS patient fits the hospice concept, (b) stress and burnout for hospice nurses, (c) multiple loss phenomenon, and (d) attitudes of health care professionals caring for AIDS patients. All of these are pertinent to this study. For clarity, the review is divided into four sections.

AIDS and Hospice

A recent article by Stephany (1990) describes AIDS as a complex disease with many types of victims, including hospice nurses, unless they realize that hospice for persons with AIDS is different. Stephany describes a declining course usually predictable for victims of cancer, while those with AIDS exhibit an unpredictable course not responding to usual treatment. This is why hospice nurses are at risk for burnout. This emotional toll on caregivers needs to be discussed. In a later article, Stephany (1992) reiterates that AIDS does not fit the cancer model of hospice care and predicts that hospice nurses will face burnout at a much higher rate unless new models are developed for caring for AIDS patients in hospice, and practical knowledge is shared among caregivers.

According to Wallace (1990), hospice programs and AIDS patients are both asking for help. Wallace recommends five guidelines for hospice programs. Caregivers should: (a) clarify for persons with AIDS and their loved ones what hospice cannot do for them, before specifying what it can do; (b) keep a professional footing; (c) learn to listen to personal anger and frustration when dealing with the person with AIDS and the family when they are demanding and difficult, and the nurse cannot make them feel better and she/he is angry; (d) speak the unspeakable to disengage components of the patient-family unit that are enmeshed and often conflicted; (e) understand one's own fears about AIDS: fear of contagion, death at a young age, homosexuality and the drug culture. Caregivers need to remember that the patient is the leader of the team.

Other writers (von Gunten, Martinez, Weitzman, & Von Roenn, 1991) recommend a framework for hospice agencies to serve AIDS patients. The patient must understand he is joining a program for care of the dying and that death is foreseeable in the near future, but the statement of a specific time is not necessary. Care is focused outside the hospital and includes the family, while symptomatic and supportive care are broadly defined. Resolution of the AIDS dilemma might serve the broader purpose, because the result will be the maturation of hospice philosophy, by maintaining its integrity while caring for all dying patients.

Stress and Burnout

When dying patients are young or have a contagious disease, nursing staff may feel acutely uncomfortable, and the patients may become isolated and alone. Larson (1985) conducted a study of 200 hospice workers who anonymously disclosed secret feelings. A reasonable and empirically verifiable hypothesis from the survey was that when helpers' self-expectations are not realized, they experience guilt and anxiety, then resentment, anger, and burnout. Every hospice worker must find a way to be emotionally involved with patients and families that is helpful, congruent with one's unique helping style and not so draining or overwhelming that unmanageable stress results. Difficult feelings need to be shared, worked through, and normalized so one's energies can be directed toward developing better coping skills and strategies.

Cotton (1988) states the effect of having so many young people dying of the same disease could be very depressing to health care workers. In addition, the burden of prejudice and barriers in treating AIDS patients throughout the health care system exists. Current research in the prevention of HIV infection is necessary for prevention, but study into the issues of dealing with those already infected and their caregiver's response to the illness are of utmost importance. Results of these studies would enable health care providers in the provision of optimum care and potentially decrease burnout.

Hospice nurses include both the patient as well as the family in their unit of care. A study done by Bowers and Dickson (1991) notes the fact that the AIDS diagnosis causes many stresses on the family. Many families discover their loved one is homosexual, bisexual, or a drug user at the same time the AIDS diagnosis is disclosed. Families struggle with one or more of the following: (a) fear and panic, (b) stigma and the fear of social rejection, (c) isolation and secrecy, (d) anger, (e) guilt, (f) helplessness, (g) hate, (h) depression, (i) economic hardship, and (j) exhaustion. Social negation of the loss and social isolation from support are primary social reasons for failure to resolve grief. A recommendation for family support suggested by Bowers and Dickson (1991) is an informal drop-in group where people can share commonalities.

According to Hurley, Grossman, and McGriff (1990), grieving and a sense of loss are constant companions when nurses work with people with AIDS. Caring for people with AIDS brings unique opportunities and rewards, but even the most dedicated nurse sometimes finds this work overwhelmingly tiring, lonely, sad, and frustrating. The authors recommend support groups, frequent inservice education, and stress reduction techniques. The intensity of working with AIDS patients requires nurses to take special notice of personal needs and to develop coping skills.

The fact that hospice nurses are reinforced by their work, rather than stressed by it, was a finding in a study done by Bram and Katz (1989) when they compared hospice nurses and oncology nurses. Hospice nurses scored significantly lower on the measure of burnout than did hospital oncology nurses. Demographic data revealed that hospice nurses tended to be older, married, more experienced, and had more academic training. The hospice nurses valued congruence between their professional ideals and the goals, philosophy, and environment of hospice.

Bene' and Foxall (1991) report a comparative study of death anxiety with frequency and severity of job stress in 30 hospice staff nurses and 40 medical surgical staff nurses. The results showed that a significant number of hospice nurses had received death education and had over 8 years of nursing experience. The results suggested that exclusive involvement with the terminally ill does not increase or decrease nurses' death anxiety.

According to Pepler and Lynch (1991), nurses who work in palliative care units (PCU) develop special interactive skills that are generally acknowledged but not clearly defined or understood. This would be an expert nurse by Benner's (1984) definition:

> Expert nurses seem to be able to identify patterns of coping among patients with particular medical problems as well as to discern idiosyncracies. Furthermore, they seem to be able to translate these patterns into effective ways of working with particular types of patients, ways that will minimize anxiety and maximize recovery. (p. 105)

A pilot study was designed to analyze nurse-patient verbal interactions in a PCU. The major themes were control, well-being, humor, uncertainty, and routines. The findings revealed that the most frequent behavior observed was nurses offering control. The interpersonal, cognitive, and behavioral skills of the nurse played a significant role in the realization of nursing goals developed through the process of the nurse-patient interaction. This would be an expert nurse, as defined by Benner (1984).

Multiple Loss Phenomenon

Although there is considerable literature on grief and grief resolution, the relevance of this information has not been adequately applied to nursing. A study by Eakes (1990) focused on how nurses coped with the cumulative effect of dealing on an ongoing basis with dying patients. A number of recurring themes surfaced during the interviews. First, the nature of the relationship established with the dying patient and family appeared to be central to the nurse's ability to achieve resolution of grief. The nurse set limits on the level of involvement and fostered independence. Second, all the hospice nurses focused on "comfort" goals rather than "cure" goals. Third, all of the nurses interviewed spoke of both attachment to their patients and open expression of their feelings with patients and families. Next, the nurses maintained and used solid support systems to ventilate their feelings. Another major factor in the grief resolution was achieving a sense of closure to the relationships with the dying patient and family. All of the hospice nurses verbalized positive attitudes toward the elderly. Viewing these strategies in concert with one another provides a comprehensive, holistic perspective on methods that assist nurses to effectively resolve the deaths of their patients. These are expert nurses by Benner's (1984) definition.

Adams, Hershatter, and Moritz (1991) researched normal grief, catastrophic loss, and burnout. A questionnaire was sent to 157 caregivers, and the data revealed five basic characteristics of accumulated loss: (a) lack of closure, (b) dying and death concerns, (c) ideals versus reality incongruity, (d) identification-distancing, and (e) diminished boundaries. The authors concluded with two recommendations, one for the manager and one for staff. The primary role of the manager was defined as recognizing the impact accumulated loss phenomenon has on staff. The recommendations for staff included examination of personal feelings related to death, utilization of support systems, and employing stress reduction techniques. This study had several limitations including the small sample size, the lack of a standardized tool, and inadequate demographic data, but the recommendations certainly allude to future study.

Carmack (1992) researched multiple loss phenomenon by interviewing well members of the gay community. The findings revealed that balancing engagement and detachment was the basic social process emerging from the data that explained how participants coped with multiple AIDS-related losses. The experience of multiple losses from the AIDS epidemic includes not only the loss of persons but also the loss of a previous lifestyle. The findings were congruent with Lazarus and Folkman's (1989) perception of coping as contextual, temporary, and a process occurring over time. Individuals appraise the meaning of an event for themselves and the degree to which their resources are able to meet the challenge. The process goes through continual shifts within the same person. The findings can serve as the basis for an intervention model for nurses working with persons experiencing AIDS-related losses and cumulative grief by assisting them to achieve and maintain a functional level of involvement in the needs of individuals and the community.

Attitudes of Nurses Caring for AIDS Patients

Multiple research studies are cited in the literature relating to nurses' knowledge and attitudes of caring for AIDS patients. Armstrong-Esther and Hewitt (1989) surveyed baccalaureate prepared registered nurses and baccalaureate nursing students in Canada. The findings indicated that the nurses' basic knowledge of AIDS was incomplete. Burnard (1989) states that many people react to AIDS with fear and prejudice. This attitude may ostracize AIDS patients. The situation can be remedied if people explore their fears and doubts and develop further self-awareness and empathy. Recommendations were made for counseling and self-awareness workshops for nursing staff.

The findings of a survey of nurses from rural communities in Pennsylvania and New York, by Preston, Koch, and Young (1991), suggest many negative attitudes towards AIDS and homosexuality. The nurses had specific educational needs, including the technical aspects of AIDS care and needs in the psychosocial domain. The nurses believed health care facilities were not well prepared to care for persons with AIDS and voiced a need for help for themselves and their families in dealing with negative feelings.

A recent study by Scherer, Haughey, and Wu (1989) indicates that many nurses surveyed are fearful of contracting AIDS and do not have confidence in their ability to meet the intense physical and psychological needs of patients with this illness. The results are also complicated by the large number of homosexuals who are terminally ill. The findings state the need for designing intervention strategies for nurses, including the opportunity to explore attitudes toward death and homosexuality and to provide avenues to increase self-insight and coping skills. Intense education and staff development are needed.

According to Willis (1990), nurses studied in New Zealand expressed strong support for AIDS Public Health measures, but 4% of those responding felt persons with AIDS are not entitled to the same care as other patients. Nursing care requirements for AIDS patients are estimated to be approximately 40% greater than for terminally ill cancer patients (Cotton, 1988). Siminoff, Erlen, and Lidz (1990) found from their survey that intense involvement with patients causes nurses to react with discomfort as they watch the rapid deterioration and death of mostly young patients. The ramifications of these stressors on the quality of nursing care provided to AIDS patients are largely unknown.

In summary, the literature review supports the importance of the need for study of health care professionals caring for AIDS patients. The AIDS hospice patient in the out-patient setting places increased demands on the nurse case manager. These demands and multiple losses increase the nurse's risk for burnout. It is imperative that we do not lose any concerned, caring, qualified nurses because stressors have not been identified, and role changes have not been explored.

Chapter 3

RESEARCH DESIGN AND METHODOLOGY

This chapter describes the methodology used to examine stressors of hospice home care nurses caring for patients with AIDS and their families. The methodology includes: (a) research design, (b) sampling method, (c) data collection procedures for gathering information, and (d) data analysis.

Research Design

An exploratory, descriptive approach was used for this study. Semistructured interviews and a demographic questionnaire were employed to obtain information about the hospice home care nurses caring for patients with AIDS. The instrument used to obtain demographic information was a questionnaire developed by the investigator (Appendix A). The demographic data obtained are summarized in tables.

Sampling Method

The sample population of this pilot study was five hospice home care nurses who have managed care for hospice patients, including patients with the diagnosis of AIDS. Semistructured interviews were conducted with a purposive sample of hospice nurses. Generalization of the results to other populations will be very limited because: (a) the sample size was small and purposive, (b) the survey was done in an area where there was a very large population of people with AIDS, and (c) only female nurses were interviewed.

Data Collection

Prior to initiating the research, approval was secured from the Committee for Protection of Human Subjects at San Jose State University (Appendix B). The investigator also received authorization (Appendix C) from the director of the hospice where the nurses worked. The investigator also indicated to the subjects that participation in the study was strictly voluntary, the material was anonymous and confidential, the nurse was free not to participate after examining the material, and the nurse could withdraw from the study at any time without repercussions (Appendix D).

Five hospice home care nurses volunteered to be interviewed. At the time of the interview, a packet was given to the nurse which included a cover letter (Appendix E), consent form, demographics questionnaire, and interview questions.

Data Analysis

The data obtained from the questionnaire containing demographic information were tabulated and summarized in tables. The taped interviews were transcribed, and the information was clustered for collation and comparison.

The purpose of data analysis was to answer the following questions:

1. Do the nurses think that there is a difference in caring for hospice patients diagnosed with AIDS as compared to other hospice patients?

2. What are the differences, if any?

3. What are the specific problems the nurses have experienced?

4. What are the role changes the nurses may have experienced in either their professional or private lives, as a result of caring for hospice patients with the diagnosis of AIDS?

The results of the data analysis are presented in Chapter 4.

Chapter 4

ANALYSIS AND INTERPRETATION OF THE DATA

This chapter contains the data regarding: (a) demographic characteristics of the sample population according to age, level of education, number of years in the nursing field, and the number of years caring for hospice patients; and (b) a descriptive analysis of the hospice home care nurses' responses to the four questions about hospice patients with the diagnosis of AIDS.

Description of the Sample Population

The sample population of this pilot study was comprised of five hospice home care nurses who have managed care for hospice patients, including patients with the diagnosis of AIDS. The demographic data collected for the study were analyzed from the responses to the questionnaire (Appendix A).

Table 1 reflects the age distribution of the hospice home care nurses participating in the study. The respondents were 37 to 47 years old. The mean age of the participants was 41.6. Table 2 represents the respondents' highest level of education. All of the nurses interviewed held a Bachelor of Science degree in Nursing, and one held a Master of Science degree in Nursing.

Table 3 indicates the number of years the respondent has worked in the nursing field. The respondents have worked in nursing between 4.5 to 18 years. The mean number of years worked was 11.5. Table 4 represents the

Table 1

Age of Respondents.

Nurse	Age	
#1	37	
#2	42	
#3	47	
#4	44	
#5	38	
Total	208	Mean 41.6

Table 2

Respondents' Highest Level of Education.

Level of Education	N'
Diploma	0
Associate Degree	0
Bachelor of Science in Nursing	4
Master of Science in Nursing	1

number of years the nurses have worked in a hospice setting. Data results ranged from 2 to 10 years, with a mean of 5.7. All of the nurses interviewed were female.

Demographic data from this study are similar to a study by Bram and Katz (1989) which revealed that hospice nurses tend to be older, married, more

Table 3

Number of Years Working in the Field of Nursing.

Nurse	Years	
#1	15	
#2	18	
#3	15	
#4	5	
#5	4.5	
Total	57.5	Mean 11.5

Table 4

Number of Years Caring for Hospice Patients.

Nurse	Years	
#1	4.5	
#2	9	
#3	10	
#4	2	
#5	3	
Total	28.5	Mean 5.7

experienced, and have more academic training. The Bram and Katz (1989) study also revealed that hospice nurses valued congruence between their professional ideals and the goals, philosophy, and environment of hospice.

Responses to the Four Questions

The nurses participating in the study all answered the four questions developed to identify and define the stressors of hospice home care nurses caring for hospice patients with the diagnosis of AIDS. There was a unanimous positive response to the first question: Do you think there is a difference in caring for hospice patients diagnosed with AIDS compared to other hospice patients?

A difference in caring for hospice patients with the diagnosis of AIDS as compared to other hospice patients is documented in the literature by several authors, including Stephany (1990, 1992), who states that hospice for persons with AIDS is different, and AIDS does not fit the cancer model of hospice care. The framework recommended by von Gunten, Martinez, Weitzman, and Von Roenn (1991) for AIDS patients includes: (a) the patient must understand he/she is joining a program of care for the dying, (b) death is foreseeable in the near future, (c) care is focused outside the hospital, (d) symptomatic and supportive care is broadly defined. The researchers conclude that the result will be the maturation of the hospice philosophy by maintaining its integrity while caring for all dying patients.

The nurses' responses to the second question: What are the differences, if any, and the third question: What are the specific problems the nurse has experienced, were so similar that they will be discussed together. All of the respondents believed that AIDS did not fit the cancer model of hospice care. Cancer patients have a predictable decline, but with AIDS, the course is never the same.

The unpredictability of the disease causes the treatment plan and the plan of care to change constantly. The many medications and the multiple problems seem to lead to multiple system decline. Statements describing the symptom management are:

1. "It is a minute-to-minute putting out fires,"
2. "A shotgun effect,"
3. "Miserable distressing symptoms that don't respond to treatments in the same way,"
4. "The wounds do not heal, I see little HIV (viruses) everywhere,"
5. "One symptom seems to aggravate another, a chain effect,"
6. "Each day a new problem,"
7. "Not knowing the state of the art treatment,"
8. "Not knowing the medications," and
9. "At times nothing I do helps."

Four of the five nurses expressed frustration dealing with the unpredictability of symptom management. They believe that their professional pride is at stake. One nurse said she always prided herself with preventing problems and planning ahead, whereas with AIDS patients, she is "putting out fires" from minute-to-minute. Another one said, "It's hard to find the cause of the problems and also to control the problems so I feel pretty ineffective sometimes." Another one said that it was frustrating not being able to predict causes, recommend proper and effective treatment, and just not knowing. Another expressed a desire for the model of palliative care for AIDS patients to change, "with AIDS patients gentle hydration is often appropriate," referring to the practice of infusing a liter of fluids every 24 hours to prevent dehydration.

Two of the nurses note that they regularly read journal articles and the gay newspapers and still believe that they have a knowledge deficit regarding treatments and medications. One nurse noted that the extra reading took a lot of her leisure time, and this was an additional stress.

Stephany (1990) describes the declining course for AIDS patients as unpredictable and not responding to usual treatment. She believes that this puts hospice nurses at risk for burnout. Larson (1985) studied 200 hospice workers and concluded with an empirically verifiable hypothesis that when helpers' self-expectations are not realized, they experience guilt and anxiety.

All of the nurses in the target population cited the age of the AIDS patients as a stressor. The patients are described as being young and not having the opportunity to have lived their life. One nurse said, "It is hard to watch young people die especially if their hearts are strong, and it's never a peaceful death." Another said that "The patients don't want to die and are constantly looking for a cure." A third nurse said, "They just fight so hard to live; they think if they can just hold on, there will be a cure." She also noted, "The activists are always saying a cure is coming, so they want to hold on; they are cure focused."

Cotton (1988) states the effect of having so many young people dying of the same disease could be very depressing to health care workers. Four of the nurses said that they identified with the AIDS patients; they were in the same age group. Cotton (1988) also notes that technological and psychological support is needed for health care workers to continue functioning optimally.

All of the nurses identified problems with caregivers (family members and friends) as a constant cause of stress for the hospice patient with AIDS as well as the nurse caring for the patient. The nurses expressed many problems surrounding the caregiver issue. Four of them discussed the limited financial resources of the patient. The financial restriction often caused the patient with AIDS to be in an unpleasant situation, and many times there was a conflict between the patient/significant other and the family over financial and legal issues.

The nurses described many of the AIDS patients in hospice as not having the traditional support system. Often the patient was estranged from his biological family, and the care was pieced together. People took turns caring for the patient, and sometimes there were people in the role of caregiver with whom the patient had previously had poor relationships. Occasionally, the only people in the role of caregiver were supplied from an AIDS support agency. This situation was usually unstable, and the nurse was constantly dealing with different people.

When the significant other or some of the caregivers were active in the gay community, they usually demanded more aggressive care and treatment. One of the nurses described the caregivers as "better educated, better read, and more aware of innovative treatments." This knowledge added to the stress of the nurse because they asked for a lot and wanted it immediately. Sometimes they knew of new treatments before the medical community.

Often it was the sick caring for the sick. The patient's partner would also be HIV positive, and it was whoever was feeling better at the moment caring for the sicker one. Others were just alone, totally alone.

The nurses also described the biological family as causing stress for the patient and nurse. One nurse described most of the parents of the AIDS patients she had cared for as very supportive and loving of their sons. Another nurse told of a situation where the gay son basically came home to his mother's house to die. He was allowed to live in the house, but his homosexuality was never acknowledged. The mother was ashamed of him; she did nothing for him physically and barely communicated with him. His friends were not allowed to visit, and the nurse met him in a nearby coffee shop until he was too sick to leave the home.

Other stories were told by the nurses of the parents finding out their son was gay and dying of AIDS simultaneously. Bowers and Dickson (1991) note that families struggle with one or more of the following: (a) fear and panic, (b) stigma and fear of social rejection, (c) hate, (d) depression, (e) economic hardship, and (f) exhaustion. This situation again placed the nurse in a difficult situation. The parents may express many negative attitudes toward their son, the caregivers, and homosexuality. They never wanted their son to be gay and certainly did not want him to have AIDS. They were tearful, sad, and angry.

The nurses also described the caregivers who were suffering from the multiple loss of many friends and loved ones. They were frightened and angry. All of the nurses surveyed acknowledged the responsibility they felt to support and care for the caregivers of AIDS patients in the hospice program. The extra responsibility for giving support to the caregivers as well as the patient increased the length of time required for each nursing visit.

Four of the five nurses interviewed mentioned dealing with the "secrets" as being stressful. The secrets resulted from the community not being ready to accept gay men coming home to die. The parents, family, and community were "ashamed." One nurse found society's negative attitude toward the gay lifestyle as well as its insensitivity toward people with AIDS very difficult to deal with, and attributed her increased sensitivity to this issue to her lesbian lifestyle. Other nurses had difficulty understanding the negative feelings of the community toward people with AIDS and attributed it to lack of education and ignorance.

One nurse described a situation where, due to fear of repercussions from coworkers, the lover of an AIDS patient felt the need to remain silent creating a barrier to possible support. There were are also secrets about the diagnosis; some families said he was dying of cancer when he was actually dying of AIDS. Some secrets were about what the parents knew or what the lover knew. One nurse stated she was always aware of the patient's right to confidentiality and was never really sure of what the family and extended family knew, and how they related to the patient and each other.

Anger displayed by the patient with AIDS was identified as a cause of increased stress. One nurse described several of the patients she had cared for who were very angry. They were angry because they were young and dying, because they were emaciated and had lost their body image, and because society treated them as outcasts. The nurse acknowledged that sometimes it was hard to empathize with a patient who was so angry or was so demented that he was swearing or trying to physically hurt you throughout each visit.

Homophobia was identified as another cause of stress. As one of the nurses stated, "I think everyone has to deal with a certain amount of homophobia; we must all have an awareness that this exists. Communities are not ready to accept gay guys coming home to die."

Another nurse described the multiple losses of AIDS patients as devastating. Many times they were going through their own grieving because they have lost their partner and friends, and several friends may also be dying. She described their physical loss; "their physical appearance is diminished, they lose their sight; they suffer mental decline, dementia, paranoia." One nurse said that the bereavement visit to the partner who is HIV positive was extremely difficult, because of the significant loss the partner had just experienced and the fact that the partner knew the reality of his/her future.

Carmack (1992) researched multiple loss phenomenon from the AIDS epidemic and describes multiple loss as including not only the loss of persons but also the loss of a previous lifestyle. Carmack's study revealed that balancing engagement and detachment was the basic social process that explained how participants coped with multiple AIDS-related loss. These findings were congruent with Lazarus and Folkman's (1984) perception of coping as contextual, temporary, and a process occurring over time, a process that goes through continual shifts within the same person.

Three of the nurses described managing the neuropathic pain as being much more difficult than managing tumor pain. "The pain is horrible!" "Morphine does not work." "We try everything to relieve the neuropathic pain. We add tegretol, elavil, pamelor, and they still have the terrible burning in their hands and feet." One nurse said, "We try the morphine, the antidepressants; nothing works, and then suddenly for some unknown reason, the pain goes away." Some of the physicians were described as being reluctant to give "too much" medication. Another nurse said, "We all need more education on the types of therapies in terms of pain control and palliation."

Women with AIDS were described as a cause of stress by the two nurses who had the experience of caring for female patients with AIDS. Both nurses identified with the female AIDS patient. Each nurse described young women who had been diagnosed at a late stage of their disease, infected by their husbands, diagnosed during pregnancy, and the husbands had left them. The women with AIDS were described as mothers having no emotional support from their family or the community. They described women who had the responsibilities as mothers caring for their children and household. The mother was also the family's breadwinner. Because of their responsibilities, the women were unable to get the kind of care they needed as quickly as men diagnosed with AIDS, nor were the opportunities for treatment as available. Caring for women with AIDS caused a lot of emotions to surface in the nurse, and each nurse expressed sadness and some anger at the situation. They described that an additional burden for mothers with AIDS was the worry of what will happen to their children, medically and socially.

The factor identified by each nurse participating in the study causing the greatest concern while caring for hospice patients with AIDS is the risk of infection. One nurse said, "The wounds don't heal; they drip and drain and I see little HIV (viruses) everywhere." The ever present potential for exposure is always there. Invasive procedures, such as blood drawing, disimpaction, wound care, and dressing changes are part of the home care nurse's daily routine. One nurse stated,

> The fear and awareness of protecting yourself is always with you; yet you are acting in the role of patient advocate. You want respect for the patient with AIDS, but you always come to that spot of not wanting to be exposed and making sure that you don't put yourself in jeopardy.

Each nurse acknowledged that there is a hesitation, and even maybe a reluctance, to draw blood or perform other invasive procedures. In spite of the hesitation, each nurse verbalized concern and a responsibility to herself and her patient. One nurse said,

> I think that the precautionary hesitation needs to stay with you. I think we should be vigilant and make sure we do not get overloaded, know what our boundaries are, know where to set limits, and when to ask for help.

Another stated, "It's something that you take a deep breath about; you mentally review the procedure and universal precautions; you are organized, and you eliminate the extraneous distractions." Maintaining good clinical skills and being current with the new procedures and treatments are other ways some of the nurses indicated they decrease their risk of infection.

A study by Eakes (1990) revealed a number of recurring themes, including the fact that all the hospice nurses focused on "comfort" goals rather than "cure" goals, and each one spoke of both attachment to their patients and open expression of their feelings with patients and families. Benner (1984) described an expert nurse caring for a dying patient, and states that it is "engagement and involvement that enable the nurse to draw on the resources in the demanding situation. I call this the participative/affirmative power of caring" (p. 214).

The experiences and feelings described by the nurses in this study document the practice of expert nurses as defined by Benner (1984). The interviews reflected nursing practice that blends practical and theoretical knowledge with the caring that is central to human expertise, to curing, and to healing as described by Benner and Wrubel (1989).

The final question asked of the nurses in the study was: As a result of caring for hospice AIDS patients, have you experienced any role changes in your professional or private life? All of the nurses admitted that their caring for AIDS patients was a concern of their families. Three nurses stated that they had very supportive husbands and that their husbands trusted their professional judgment. One nurse described a situation where she came home exhausted, and her husband expressed anger toward her patients, but this was a one time occurrence.

Two of the nurses have been stuck with a needle contaminated by an HIV positive patient. They admitted to concern by loved ones, but they denied any professional or personal role changes. One nurse described an experience that occurred when she was admitting a new patient to the hospice program. A family member questioned her as to if she had been in the home of an AIDS patient that day. The nurse answered positively, and the family member said she hoped she had cleaned up. In conclusion, all of the nurses denied any personal or professional role changes, in spite of the expressed concerns of some family members, and an occasional question from other patients/families.

Summary

The demographic data collected from the sample demonstrated that the nurses were 37 years of age and older, with the mean age of 41.6. They all had completed a Bachelor of Science in Nursing, and one had completed a Master of Science in Nursing. The average number of years working in the field of nursing was 11.5, with a range from 4.5 to 18 years. The nurses had been working with hospice patients from 2 to 10 years, with the mean of 5.7 years.

Descriptive analysis of the semi-structured interviews revealed that all of the nurses believed that there is a difference in caring for hospice patients with the diagnosis of AIDS compared to other hospice patients. The AIDS hospice patient does not fit the accepted cancer model of hospice care.

The nurses' responses to the question about what the differences were and the third question concerning what the specific problems the nurse had experienced were very similar. Therefore, the discussion was inclusive. The nurses all believed that the unpredictability of the disease AIDS, the treatment plan, and the plan of care were stresses. They all also identified age, caregiver problems, and fear of contagion as ever present problems. Four of the five listed symptom management, financial problems, secrets, neuropathic pain, a threat to their professional pride, and the negative attitude in the community towards people with AIDS as causes of stress. Two nurses acknowledged caring for women with AIDS and also the "multiple loss" phenomenon as causing the nurse increasing concern and stress.

The following problems were only mentioned once during the interviews, but because of the small sample size need to be listed here: anger, homophobia, and dermatology problems. The need for a different palliative care model for patients with AIDS was also discussed by a nurse. She believed the hospice rules needed to be adapted for people with the diagnosis of AIDS to include "gentle hydration," and intravenous medications to prevent blindness.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

Issues dealing with the management of AIDS patients in the hospice program are surfacing daily. Lack of recent research in the area of hospice home care nurses caring for AIDS patients prompted this pilot study to identify stressors and formulate hypotheses for further study. Inferences are suggested, and recommendations are offered for further study.

Conclusions

Descriptive analysis of the semi-structured interviews revealed that all of the nurses believed that there is definitely a difference in caring for hospice patients with the diagnosis of AIDS compared to other hospice patients. They believed that the care of the AIDS hospice patient does not fit the cancer model of hospice care, and a new model of hospice care for patients with AIDS is needed.

The nurses' responses to the second question about the differences and the third question concerning the specific problems the nurse had experienced were very similar. Therefore, the discussion was inclusive. The nurses unanimously identified the disease AIDS, its unpredictability, symptom management, nonspecific treatment plan, the ongoing changes in the plan of care, and the younger age of the majority of people diagnosed as causing stress. The negative attitude in the community toward the gay lifestyle as well as toward people diagnosed with AIDS also was identified as causing the nurses' stress.

They all also identified caregiver problems, whether it be that the patient did not have a caregiver or that there were problems with the significant other, the biological family, or members of the gay community. Because of problems with the caregiver situation, home visit time and frequency of visits are increased to give extra support. The nurses definitely indicated this issue increased their work as well as being a stressor.

The area that overwhelmingly caused the nurses increased stress while caring for patients with AIDS is fear of contagion. The ever present potential for exposure is always there. Invasive procedures are part of the home care nurse's daily routine. Each nurse verbalized concern and a responsibility for herself and her patient. They all indicated that the risk of infection is decreased by maintaining good clinical skills, realizing their limitations, and being current with the new procedures and treatments.

Four of the five nurses described their stress level increasing because of the patient's financial problems, secrets, neuropathic pain, and the unknowns surrounding the treatment of AIDS, threatening their professional pride. Two nurses acknowledged increased stress caring for women with AIDS and indicated that society does not afford women the same opportunities for early diagnosis, treatment, and support as it offers male patients. Also, gay men were described as having the additional burden of dealing with the "multiple loss phenomenon," and the nurse grieved with them.

The following are causes of increased stress, identified in the interviews by only one nurse as a problem but because of the small sample size, these concerns need to be listed here: anger, dementia, homophobia, dermatology problems, and the need for a different model of palliative care for patients with AIDS.

The data collected during this pilot study confirmed that there is a difference in caring for hospice patients diagnosed with AIDS compared to other hospice patients, and nurses caring for AIDS hospice patients are experiencing increased stress due to both physical and psychological problems. The idea that caring for hospice patients with AIDS has caused personal or professional role changes was not identified by any of the sample population. Many of the hospice home care nurses exhibited characteristics of the expert nurse described by Benner (1984); this idea was verified by the interviewer's knowledge of the statements, caring attitudes, and the exemplars discussed in the interviews.

The study was conducted in a hospice in an area where the home care nurses had a great deal of experience taking care of gay AIDS patients. The group was just starting to care for women with AIDS, and none of the nurses had cared for a person who contracted the disease from intravenous drug use. The sample size was small, nonrandom, and only female nurses were included. Generalization of the results is very limited, but the vast majority of the information obtained has been documented in recent literature with different target groups.

Recommendations

As a result of this pilot study, the following recommendations can be made:

1. Hospice administrators and staff nurses need to discuss the cancer model of hospice care and whether this model fits the AIDS patients in their program.

2. If the cancer model of hospice care does not work well for patients with AIDS, another model should be developed targeting AIDS patients.

3. The study should be replicated using the outcomes of this pilot to develop a questionnaire, using a 5-point Likert scale, to quantify the data.

4. Hospice administrators and staff need to recognize the need for ongoing education and training for hospice nurses caring for patients with AIDS.

5. Hospice administrators and staff need to recognize that caring for hospice patients with AIDS increases the nurses' stress. Support, recognition, and mechanisms to relieve stress need to be part of the hospice program.

6. The fourth research question concerning role changes should be revised to clarify if caring for patients with AIDS has had any impact on the nurses' personal or professional relationships.

This pilot study confirms the results of previous studies that a different model of care needs to be developed for the hospice patient with AIDS. The AIDS hospice patient places increased stress on the nurse case manager. Therefore, it is imperative that the nurse be included in this project to provide better care for the hospice AIDS patient, and to acknowledge the increased demands on the nurse case manager.

REFERENCES

References

Adams, J. P., Hershatter, M. J., & Moritz, D. A. (1991). Accumulated loss phenomenon among hospice caregivers. The American Journal of Hospice & Palliative Care, 3, 29-37.

Alexander, J. E. (1988). Patricia Benner: From novice to expert: Excellence and power in clinical nursing practice. In A. Marriner-Tomey (Ed.), Nursing theorists and their work (pp. 187-218). St. Louis: Mosby.

Armstrong-Esther, C., & Hewitt, W. E. (1989). AIDS: The knowledge and attitudes of nurses. The Canadian Nurse, 85(6), 29-31.

Bene', B., & Foxall, M. J. (1991). Death anxiety and job stress in hospice and medical-surgical nurses. The Hospice Journal, 7(3), 25-41.

Benner, P. (1984). From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, CA: Addison-Wesley.

Benner, P., & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, CA: Addison-Wesley.

Bowers, J. G., & Dickson, J. K. (1991). Support groups for those affected by AIDS in the family. The American Journal of Hospice & Palliative Care, 3, 39-45.

Bram, P. J., & Katz, L. F. (1989). A study of burnout in nurses working in hospice and hospital oncology settings. Oncology Nursing Forum, 16(4), 555-560.

Burnard, P. (1989). Exploring nurses' attitudes to AIDS. The Professional Nurse, 11, 84-89.

Carmack, B. J. (1992). Balancing engagement/detachment in AIDS-related multiple losses. Image: Journal of Nursing Scholarship, 24(1), 9-14.

Chang, S. W., Katz, M. H., & Hernandez, S. R. (1992). The new AIDS case definition: Implications for San Francisco. Journal of American Medical Association, 267(7), 973-976.

Cole, R. M. (1991). Medical aspects of care for the person with advanced acquired immunodeficiency syndrome (AIDS): A palliative care perspective. Palliative Medicine, 5, 96-111.

Cotton, D. J. (1988). The impact of AIDS on the medical care system. Journal of the American Medical Association, 260(4), 519-523.

Eakes, G. G. (1990). Grief resolution in hospice nurses: An exploration of effective methods. Nursing & Health Care, 11(5), 243-248.

Firshein, J. (1986). Payment squeezes in home health care. Hospitals, 60(80), 26-28.

Hurley, P. M., Grossman, A. H., & McGriff, E. P. (1990). Who supports the nurse when the patient has AIDS? RN, 7, 39-42.

Larson, D. G. (1985). Helper secrets: Invisible stressors in hospice work. The American Journal of Hospice Care, 6, 35-40.

Lazarus, R. S., & Folkman, S. (1984). Stress appraisals and coping. New York: Springer.

Medoff, E. (1988). Strategies for the retention of hospice home care nurse. The American Journal of Hospice Care, 4, 27-30.

National Hospice Organization. (1989). A guide to the nation's hospices. Arlington, VA: Author.

Pepler, C. J., & Lynch, A. (1991). Relational messages of control in nurse-patient interactions with terminally ill patients with AIDS and cancer. The Journal of Palliative Care, 7(1), 18-29.

Preston, D. B., Koch, P. B., & Young, E. W. (1991). AIDS: Experience and attitudes of nurses from rural communities in Pennsylvania and New York. Hospice Journal, 7(1-2), 109-125.

Santa Clara County. (1992). AIDS cases in Santa Clara County. Santa Clara County Surveillance Report.

Scherer, Y. K., Haughey, B. P., & Wu, Y. B. (1989). AIDS: What are nurses' concerns? Clinical Nurse Specialist, 3(1), 48-54.

Siminoff, L. A., Erlen, J. A., & Lidz, C. W. (1990). Stigma, AIDS and quality of nursing care: State of the science. Journal of Advanced Nursing, 16, 262-269.

Stephany, T. (1990). AIDS and the hospice nurse. Home Healthcare Nurse, 8(2), 11-12.

Stephany, T. (1992). AIDS does not fit the cancer model of hospice care. The American Journal of Hospice and Palliative Care, 1, 13-14.

Stoddard, S. (1990). Hospice: Approaching the 21st century. The American Journal of Hospice & Palliative Care, 2, 27-30.

von Gunten, C. F., Martinez, J., Weitzman, S. A., & Von Roenn, J. (1991). AIDS and hospice. The American Journal of Hospice & Palliative Care, 4, 17-19.

Wallace, W. E. (1990). Hospice and AIDS: Clinical issues which affect care. The American Journal of Hospice & Palliative Care, 3, 13-16.

Willis, D. (1990). A survey of nurses' attitudes to AIDS related issues. New Zealand Nursing Forum, 18(4), 7-9.

APPENDIXES

APPENDIX A

Personal Information Form

Appendix A

PERSONAL INFORMATION FORM

Please answer each of the following items as they apply to you. Please do not omit any item.

1. Age: __________

2. Highest Educational Degree Earned:

   _______ Diploma from Hospital School of Nursing

   _______ Associate Degree in Nursing

   _______ Bachelor of Science in Nursing Degree

   _______ Graduate Degree in Nursing or Other Field

3. Number of Years of Work Experience in Nursing ____________

4. Number of Years of Work Experience in Hospice ____________

Thank you for your assistance with this research project.

APPENDIX B

San Jose State Human Subjects
Institutional Review Board Approval

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San José, California 95192-0025 • 408/924-2480

To: Marieann Sloan
38323 Kimbro St
Fremont, CA 94536

From: Serena W. Stanford Serena W. Stanford
AAVP, Graduate Studies and Research

Date: November 5, 1992

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Stressors of Hospice Home Care Nurses Caring for AIDS Patients"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have questions, please contact me at 408-924-2480.

CC: Virgil Parsons

APPENDIX C

Research Project Authorization Form

From Hospice Home Care Department

Hospital/Health Plan Administrator

Medical Group Administrator

Physician-in-Chief

RESEARCH PROJECT AUTHORIZATION FORM

Marieann Slone, R.N., a graduate student at San Jose State University, has my permission to include registered nurses from Kaiser Hospice Home Care Department in a study designed to identify stressors of hospice home care nurses caring for AIDS patients. It is my understanding that:

> this study has been approved by the Department of Nursing and the Committee for the Protection of Human Subjects at San Jose State University;
>
> no respondent will be asked to identify him/himself or will be asked to provide any demographic information that will enable one to identify him/her;
>
> responses of nurses of any organization will be compared with those of other hospices;
>
> my organization will be provided with a copy of the results of the study.

Richard J. Thelt

Sept. 15, 1992
Date

APPENDIX D

Participant Letter

January 20, 1993

Dear Hospice Home Care Nurse:

Your help is needed. You have been selected to participate in a study concerning hospice care for AIDS patients. This study is being conducted through the Department of Nursing at San Jose State University.

Your Director, Dick Brett, has given permission to contact you and schedule an interview. The interviews will be between 60 to 90 minutes long and take place during a regular working day.

Your participation in this research is strictly voluntary. Anonymity will be assured for all respondents by not identifying individuals or their employing organizations.

I will be contacting you by telephone to discuss your participation in this study. If you have any questions, please contact me at (510) 784-4836. Thank you for your cooperation in this important work.

Sincerely,

Marieann Slone, R.N., P.H.N.

APPENDIX E

Agreement to Participate in Research at San Jose State University

Appendix E

AGREEMENT TO PARTICIPATE IN RESEARCH

AT SAN JOSE STATE UNIVERSITY

Responsible Investigator: Marieann Slone

Title of Protocol: Stressors of Hospice Home Care Nurses Caring for AIDS Patients

I have been asked to participate in a research study. The objectives are to define the stressors hospice home care nurses are experiencing caring for AIDS patients, define the specific problems causing concern, and note the role changes nurses are experiencing in their professional and private lives.

I understand that:

1. I will participate in a 60 to 90 minute confidential interview and complete a short demographic form. The interview will be held privately in the facility where I work and will be audio taped.
2. The possible risks of this study are none.
3. There are no discernible benefits from participation in this study.
4. The results of this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission or as required by law. The audio tapes will be kept in a locked box and destroyed after the study.
5. Any questions about my participation in this study will be answered by Marieann Slone, R.N., (510) 784-4836. Complaints about the procedure may be presented to Dr. Virgil Parsons, Chairman of the Department of Nursing, San Jose State University (408) 924-3131. For questions or complaints about research, subject's rights, or in the event of a research related injury, contact Serena Stanford, Ph.D. at (408) 924-2480.

Initial __________

6. If I choose not to participate in this study, I will not incur any loss of service, or be jeopardized in any way by San Jose State University or Kaiser Hospice.

7. My consent is given voluntarily, without being coerced; I may refuse to participate in this study, or in any part of the study, and I may withdraw at any time, without prejudice to my relations to San Jose State University or the facility where I work.

8. I have received a copy of this consent form for my file.

I have made a decision whether or not to participate. My signature indicates that I have read the information provided above and that I have decided to participate.

Date _______ Signature _______________________________________