Hospice Nursing Care: Persons with End-Stage Dementia and their Caregivers

By

Mary L. Hazard

A Master's Research Project

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment of
the requirements for the degree of
Master of Science

(April 28, 1997)

APPROVED:

[redacted]

Beverly Hoeffer, R.N., D.N.Sc., FAAN, Professor and Interim Associate Dean for Graduate Studies, Research Advisor

[redacted]

Sheila Kodadek, R.N., Ph.D., Associate Professor, Committee Member

[redacted]

Jane Marie Kirschling, R.N., D.N.Sc., Professor and Associate Dean for Academic Affairs, University of Rochester, School of Nursing, Committee Member

[redacted]

Beverly Hoeffer, R.N., D.N.Sc., FAAN, Interim Associate Dean for Graduate Studies

Acknowledgments

I would like to thank the following people for their guidance and support throughout this research project, Jane Kirschling for her insight in assisting me to focus, Sheila Kodadek for being there, her knowledge and enthusiasm for research and Bev Hoeffer for her knowledge and feedback which helped to stimulate my thinking. I sincerely appreciate each of you.

I would like to thank the hospice nurses who were willing to take time out of their schedules to participate in this project.

Finally, I would like to thank my family who supported me in order to accomplish this project, Siamak for your constant encouragement and never ending faith and Dominique and Patrick, you are my inspiration.

ABSTRACT

TITLE: Hospice Nursing Care: Persons with End-Stage Dementia and their Caregivers

AUTHOR: Mary L. Hazard, R.N., B.S.N.

APPROVED: [redacted]
Beverly Hoeffer, R.N., D.N.Sc., Thesis Advisor

Hospice nurses are increasingly providing care to patients with end-stage dementia in both homes and institutional settings. Although nurses provide the majority of hospice care, little is known about their experience of providing hospice nursing care for persons with end-stage dementia and their caregivers. This descriptive study used intensive interviewing and qualitative analysis to explore and describe current practice of hospice nurses when caring for older adults with end-stage dementia and their caregivers. The sample consisted of eight hospice nurses who were caring for patients with end-stage dementia and their caregivers in an in-home hospice program. Data generated from the interviews were analyzed and emergent themes identified.

The participants described ways the care for patients with end-stage dementia and their caregivers was unique in comparison to care required by hospice patients and caregivers of patients who did not have end-stage dementia. When the patient has end-stage dementia, the focus of care shifts from direct care of the patient to family focused care. Hospice nurses' ability to provide family-focused care varies, in part because they often receive no formal education in this area. Hospice nurses find connecting with the patient who has end-stage dementia to be difficult. They manage to compensate for the loss of knowing they have made a connection with the patient by making a connection with the caregiver. The need that hospice nurses have for information on providing care to patients with end-stage dementia and their caregivers was one of the most significant findings of this study. Participants also raised the issue of needing to obtain the information and tools that will assist them in determining whether the patient with end-stage dementia is appropriate for continued hospice care.

This study suggests that hospice nurses could benefit from additional education in family, gerontological, and mental health nursing in order to provide for the needs of patients with dementia and their caregivers and families. Nurses with advanced preparation in geropsychiatric nursing would be an ideal resource for hospice nurses caring for this vulnerable population.

Table of Contents

List of Tables

Chapter I

Introduction

The aged population of America is growing. As the population grows older the incidence of dementia is increasing. At the same time there has been increasing interest in hospice care as the preference for persons with end-stage dementia. Hence, gaining a clearer understanding of the current practices of hospice nurses in relation to this patient population will add to our knowledge base and understanding of nursing practice. This information can be used to educate and prepare hospice nurses to meet the needs of persons with end-stage dementia and their caregivers.

The Elderly Population and Dementia

In 1989, the number of people aged 65 years or older was 31 million. By the year 2030, it is estimated that the number of elderly will reach 66 million (U.S. Dept. of Health & Human Services, 1991). Four million Americans suffer from Alzheimer's disease for which there is currently no known cure; by the year 2050 this number could increase to 14 million (Alzheimer's Association Alzheimer's Disease Statistics Fact Sheet, 1995). In persons 65 years and older, Alzheimer's disease (AD) is estimated to account for 56% of dementia; vascular causes are estimated to account for 14% of dementia, multiple causes (which are predominantly AD and vascular dementia) for 12%, Parkinson's Disease for 8%, brain injury for 4%, and other causes for up to 6% (Bachman et al., 1992). Finally, 10% of older adults who reside in the community at large are afflicted by AD and other organic mental disorders (U.S. Dept. of Health & Human Services).

Collins and Ogle (1994) surveyed 82 family caregivers who were providing in-home care to a relative with dementia. Their objective was to identify the place of death and pattern of predeath services. The sample consisted mostly of female spousal caregivers who had been caring for the person with dementia for an average of 6 years before death. The site of death for this group was in the home (41%), nursing home (32%), a hospital (26%). Patients with dementia who eventually died at home often had short stays in a hospital or nursing home in the 90 days prior to their death. There was a higher average number of days spent in the hospital in the 90 days before death if the person with dementia had a spousal caregiver. The findings on in-home service use by this sample, who spent at least 45 days of their last 90 days at home, showed that 21% used no in-home services, 48% used no skilled nursing services, and only 27% had received a physician home visit. Collins and Ogle concluded that family caregivers can provide the majority of care for their dying family member with dementia at home. However, the results have raised questions about the extent to which the needs of these families for medical and skilled nursing support are being met.

Hospice Care

Hospice is considered a philosophy of care which is focused on palliative rather than curative treatment. At the center of care is the patient. The unit of care is the family and/or caregivers. The hospice interdisciplinary team provides support to both patient and family/caregiver throughout the dying process. While the majority of care is typically provided in the patient's home, there are hospice programs that are in-patient based (National Hospice Organization, 1995). Regardless of where the patient is residing, the hospice team continues to provide care until death occurs or until the patient chooses to no longer receive services. Individualized care is provided by an interdisciplinary team which consists of the primary physician, hospice medical director, registered nurses, medical social workers, certified nurses aides, pastoral support, occupational therapists, physical therapists, bereavement counselors, speech therapists, nutritional support, and a volunteer program. Kirschling and Luce (1992) found that in Oregon the majority of hospice visits were provided by registered nurses, with an average of 12.1 visits per patient, followed by home health aides, with an average of 2.3 visits per patient.

The National Hospice Organization has developed standards of care for persons with a life threatening illness who have chosen supportive care from a hospice program. Any person who has been determined to have a life threatening illness with a prognosis of 6 months or less and who chooses palliative care is eligible for hospice services. The interdisciplinary team of hospice staff is charged with meeting the physiological, psychological, social, and spiritual needs of the patient and his or her primary caregivers. They are also required to assist the patient and caregivers with obtaining the necessary economic support for the care required. A written plan of care is developed by the attending physician, hospice medical director, registered nurse, and the interdisciplinary team. The assessment of the patient and primary caregivers determines the plan of care and takes into account social, cultural, and religious needs. The plan of care is revised as the needs of the patient, caregivers, and family emerge.

The National Hospice Organization reports that there are 2,544 hospices operating in the United States and Puerto Rico. One out of seven persons who died in the United States in 1994 (from all causes) received care from a hospice program. Payments for hospice services are predominantly from Medicare (67%), followed by private insurance (15%), Medicaid (9%), and other sources (3%). Nonreimbursed care represents 6% of persons served. More than 90% of hospice services are provided in the patient's home (National Hospice Organization, 1995).

Persons with Dementia

Luchins and Hanrahan (1993) surveyed professional and family caregivers regarding what they thought was the appropriate health care for persons with end-stage dementia. The study found that the majority of physicians, gerontology professionals, and families of persons with dementia would choose hospice care for the patient with end-stage dementia. A national survey of hospice programs revealed that less than 1% of the patients in these programs had a primary diagnosis of end-stage dementia and that only 21% of hospices provided services for such persons. The primary reason given for not providing services was the difficulty in predicting a prognosis of 6 months (Hanrahan & Luchins, 1995a).

Volicer, Hurley, Fabiszewski, Montgomery, and Volicer (1993) developed a formula to predict short-term survival in patients with dementia of the Alzheimer's type. Their results provide a formula for use in conjunction with clinical judgment to certify patients with dementia of the Alzheimer's type for hospice services. The National Hospice Organization (1995) has published guidelines for determining prognoses in selected non-cancer diseases. Dementia is one of the three diseases for which medical guidelines were established in order to determine patient eligibility for the Medicare/Medicaid Hospice Benefit (Stuart, et al., 1995). But while there is growing support for persons with end-stage dementia to receive hospice care, few of these persons currently receive this type of care in the last months of their lives.

Statement of Purpose, Research Questions

The purpose of this study was to explore and describe the current practice of hospice nurses when caring for older persons with end-stage dementia. Hospice was defined as in-home care for the purposes of this study. The particular areas explored with these nurses were as follows:

1. The experiences nurses had providing hospice care for persons with end-stage dementia and their caregivers.

2. Similarities and differences between the nursing care provided for

patients and caregivers of patients with end-stage dementia as compared to the nursing care provided to other hospice patients.

3. Resources that facilitate the care provided by hospice nurses for the older adults with end-stage dementia and their caregivers.

The researcher hopes the information gained through this study will be useful in educating hospice nurses who are unfamiliar with the unique needs of persons with end-stage dementia and their caregivers. Hospice program directors may be able to utilize the results to plan for the needs of their staff who are working with these patients and caregivers.

Chapter II

Review of the Literature

Published studies on the utilization of hospice services for persons with end-stage dementia have increased. The literature was reviewed using Medline, CINAHL, and PsychINFO databases for the past 10 years. Keywords used in the search included dementia, hospice, and nursing care. Hand searches were done with the following hospice-focused journals: *The American Journal of Hospice Care* (1993-1996), *The Hospice Journal* (1986-1996), and *Journal of Palliative Care* (1992-1996). Seven research-based articles were found for inclusion in this literature review. The conclusions drawn from these studies indicated that hospice services are appropriate for persons with end-stage dementia.

Six of the 7 articles were authored by two research teams: Volicer, Volicer, Fabiszewski, and Hurley; and Luchins and Hanrahan. In 1986 the need for a hospice approach to treating patients with end-stage dementia was raised by Volicer (1986). The decision to not treat infections could be made early in the dementia process and was often accepted by families of persons with advanced dementia. The practice of providing adequate nutrition and hydration without forced intervention was upheld by the courts if the patient had approximately one year or less to live (Volicer, 1986). The decisions made by patients as part of their advanced directive, or by the family on the patient's behalf, were shown to follow the hospice philosophy of palliative care. The research articles focused on four major areas: the type of health care appropriate for persons with dementia, current hospice utilization, predicting survival time, and programs that provide comfort care and/or hospice care. No studies were found to focus on what is entailed in the hospice nursing care of persons with end-stage dementia.

Health Care Appropriate for End-Stage Dementia

Luchins and Hanrahan (1993) conducted a study to determine what kind of health care family caregivers and professionals thought was appropriate for persons with end-stage dementia. The study sample included a survey of 1,000 randomly selected non-physician members of the Gerontological Society of America (GSA), all 819 physician members of GSA, and 500 family caregivers of persons with dementia contacted through the Alzheimer's Association. The questions on the survey related to five levels of care, from highly aggressive to comfort and pain control only (palliative care). The majority of respondents chose palliative care only (61% physicians, 55% gerontology professionals, and 71% family caregivers). The authors noted that among respondents there was an over representation from GSA members who had direct care responsibilities. This included nurses (23%), who made up the largest number of GSA respondents. Eighty percent of the family caregivers were women, and 67% of the family caregivers provided the majority of care for the family member with dementia. Both family and professional caregivers favored palliative care for persons with end-stage dementia, especially if they had prior experience with terminal care decisions.

Persons with Dementia -- Utilization of Hospice Care

A national survey by Hanrahan and Luchins (1995a) was conducted to determine the extent to which persons with dementia received hospice services. They sampled 1,694 hospice programs, with a 70% return rate. Their findings indicated that less then 1% of persons with a primary diagnosis of end-stage dementia receive hospice services.

Hospices were more likely to provide services for persons with a primary diagnosis of end-stage dementia if they were already providing services for persons with a secondary diagnosis of dementia or if they were a larger hospice program. The diagnosis of dementia did not prevent the provision of hospice care. The reasons cited for not enrolling persons with dementia into hospice programs included difficulty in determining survival time (80%), not having adequate respite services to meet the needs of the caregivers for persons with dementia (70%), staff needing additional training in order to cope with the required care (57%), and the added difficulty of patient behavior problems (54%).

Predicting Survival Time

One of the issues raised for not enrolling persons with end-stage dementia to hospice services is the difficulty in predicting survival time. The following research was done to begin to address this issue. An approach for calculating short-term survival using a statistical model for persons with end-stage AD was tested (Volicer, Hurley, et al., 1993). A prospective cohort study was designed with a sample of 104 patients of whom 90% were white males with advanced AD who were monitored more than 34 months and with 68 patients having had a least one fever episode. An additional sample of 71 persons with AD who had at least one fever episode were used to test the model. The results of the study indicate that older age, more advanced AD at the time of a fever episode in the patient receiving palliative care, and an institutional admission for long-term care within 6 months of a fever episode were associated with the likelihood of death within 6 months of fever onset. When the additional independent sample of 71 patients with AD were tested using the statistical model the prediction of survival was correct. The authors concluded that if the patient is an older Caucasian male with advanced AD who had been receiving palliative care and recently institutionalized, prediction of a six month prognosis following fever onset is possible in conjunction with the clinical decision.

In another study, Volicer, Volicer, and Hurley (1993) utilized the Bedford Alzheimer Nursing Severity Scale to differentiate variability of dressing, sleeping, speech, eating, mobility, muscles, and eye contact between persons with middle and late stage AD. The sample was from their previous study (see above). A form designed to evaluate persons with AD for inclusion in a hospice program was used. Included in the evaluation was the Bedford Alzheimer Nursing Severity Scale, date of admission to long-term care, an onset of fever episode, and demographic information. The results indicated greater age and more severe disease related to shorter survival. It was also found that when all patients were combined, those who had not received antibiotics had a shorter survival time. The use of nomograms to predict the probability of mortality within six months were applied to the sample. Of the patients who were calculated to have a probability of dying $\geq .75$, 91% died within the predicted 6 months. The generalizability of these results was limited by the sample who were mostly white males and younger in age than the average long-term care patient.

Provision of Hospice Services to Persons with Dementia

Additional research efforts have focused on the feasibility of providing hospice services to persons with end-stage dementia. Volicer, Rheaume, Brown, Fabiszewski, and Brady (1986) evaluated a program on a long term care ward that was part of the Alzheimer's Disease Research Program at Bedford, Massachusetts, Division of the Boston Geriatric Research, Education, and Clinical Center. The program was comfort focused and limited the treatment options for persons with advanced AD. The goal of this program was to maximize patient comfort and quality of life through a modified hospice approach. Patients (N=40) were assigned a level of care based on a continuum of aggressive to comfort care only. This was done through a consensus process of the multidisciplinary team and physician who then met with the family to determine an acceptable level of care. Agreement between staff and family members on the level of care was not always resolved. When this occurred, the family's choice determined the level of care provided. The majority of care was intensive nursing and comfort measures, including the use of antipyretics, analgesics, oxygen, and anticholinergics if needed. A total of 62% of the patients were not treated with antibiotics if they developed a urinary tract infection or pneumonia. The results after the first year did not show an increase in mortality even though medical care was limited in this sample of persons with AD.

Brechling and Kuhn (1989) report on establishing a home-based hospice program that specializes in the care of persons with end-stage dementia funded by the Rush Alzheimer's Disease Center and the Chicago Area Chapter of the Alzheimer's Association. This pilot program evolved out of the difficulty encountered by patients with end-stage dementia and their families in accessing hospice services or the availability of sufficient resources. The admission criteria for the program included: dementia as the primary diagnosis, the most advanced stage of dementia determined as a two or less on the Mini-Mental State Exam and a rating of 43 or greater on the Dementia Behavior Scale, a primary caregiver who accepted the hospice philosophy of care, a do-not-resuscitate order, and legal guardianship by the primary caregiver if there was conflict between family members. Eight terminally ill persons with dementia had been enrolled in this program at the time of the study. Six persons were not enrolled because they did not meet the admission criteria; of these, 3 later died suddenly at home. Of the 8 enrolled in this program, the average length of stay for the 3 persons who died was 24 days. The five patients still living had been enrolled in the program an average of 95 days; their median length of stay was 66 days with a range of 19 to 273 days.

The care provided by the interdisciplinary team in the pilot program included education on treatment options and palliative care, managing physical needs of patients, support for primary caregivers, reducing the social isolation of caregivers, intervening when caregivers coping has been dysfunctional, addressing loss and grief, practical support for caregivers, assisting with financial constraints, respite, conflict resolution, assistance with funeral arrangements, and bereavement follow-up. At the time of publication, issues still being addressed are the lack of information on end-stage AD and related dementias, ethical issues in relation to caregiver decision making on behalf of the person with dementia, the financial and psychological needs of the caregivers, cost effectiveness, choice of funding to ensure access, and the need to collaborate with groups to influence policy makers about the needs of this population. The care provided in this pilot program was very labor-intensive. The staff in this program identified that emotional support was the primary need of caregivers in this sample.

A recent pilot study by Hanrahan and Luchins (1995b) was conducted to test the feasibility of providing palliative care for persons with end-stage disease. Criteria for enrollment to their hospice program were based on severity of cognitive decline, seriousness of medical complications, and an interested caregiver. The sample consisted of 11 patients, 64% who were women and 90% who were African American. Their ages ranged from 81 to 102 years old and the majority were confined to bed. Enrollment took place over more than a two year period. The median survival time for this group, using the established criteria, was 5 months; the average was 7 months. The majority of hospice care in this study was provided by nursing staff who consisted of licensed practical nurses and nurses' aides. The average visit frequency was 2 to 3 times per week and averaged 1.5 hours per day. The only source of funding for these patients was the Medicare hospice benefit. The hospice was able to provide care under the Medicare hospice guidelines, the palliative philosophy of care was accepted by the caregivers, and the hospice staff responded in a positive manner. At the conclusion of this pilot study, the hospice continued to enroll persons with end-stage dementia.

In summary, the research to date indicates that palliative care is preferred for persons with end-stage dementia yet few of these persons are currently receiving hospice services. Studies are underway to better predict survival time and pilot programs to test the feasibility of providing hospice services to persons with end-stage dementia. Although nurses provide the majority of hospice care, little is known about their experience of providing hospice nursing care for persons with dementia and their caregivers.

Chapter III

Method

In this descriptive study, intensive interviewing and qualitative analysis were used to explore and describe the experience of hospice nurses caring for patients and the caregivers of patients with end-stage dementia.

Design

Intensive interviewing involves an unstructured interview process which searches to find those things that already exist (Lofland & Lofland, 1995). According to Lofland and Lofland, the aim of intensive interviewing is to "seek to *discover* the informant's *experience* of a particular topic or situation" (p. 18). To this end, participants are guided through the interview process using a conversational style of data gathering and an interview guide (see Appendix A) rather than a structured interview schedule. After the detailed information on the study topic has been gathered, it is then qualitatively analyzed (Lofland & Lofland).

The development of the interview guide for this study was based on the researcher's experience as a hospice nurse and guidance from the research committee. The interview guide was pilot tested with two hospice nurses identified by the hospice director of the program where the researcher is employed. These pilot interviews were done prior to obtaining approval from the Internal Review Board/Committee on Human Research and so were not included in the findings. After obtaining the nurses' verbal consent to participate in the pilot study, the pilot interviews were conducted and transcribed by the researcher. The data were then analyzed and assigned descriptive codes. The questions covered in the interview guide were: (1) the nurse's experience of providing care for hospice patients and their caregivers and (2) the nurse's particular experience when providing hospice care for patients with end-stage dementia and their caregivers (e.g., what facilitates the care or makes it more difficult; what rewards, if any, are there to providing care; how does the nurse prepare for providing hospice care; what kinds of resources or supports would be helpful for providing care to these patients and their caregivers). Upon completion of the interview, the researcher collected demographic data in order to describe the participants (see Appendix B). Upon completion of the pilot interview process, the interview guide questions were determined to be appropriate for the study purpose by the researcher and the research committee members. No changes to the research guide were made.

Procedure for Identifying the Sample

The participants for this study were obtained by mailing a letter to hospice program directors in two northwestern states with a description of the study (see Appendix C). A follow-up phone call was made to the program directors to answer questions and to gain their agreement to distribute the information about the study to 3 nurses from their program. Although the researcher agreed to meet with the hospice director and/or the hospice nurses to further explain the study, this was not found to be necessary.

The directors were asked to identify up to 3 registered nurses currently employed in their hospice program who had provided services to older adults with end-stage dementia during the past year and would be willing to provide written consent to be interviewed. The directors were asked to provide the nurses with an informational letter about the study. A post card was included with the letter for the nurses to return if interested in participating in the study (see Appendix D).

Procedure for Securing Participants and Conducting Interviews

Prior to data collection, this study was examined by the Oregon Health Sciences University Human Subjects Review Committee to assure the protection of all subjects (see Appendix E). The study was approved on December 6, 1996, and met the criteria for exemption (Category #2) from review by the Committee on Human Research.

Upon receipt of a post card, the researcher contacted each registered nurse to discuss the study and establish an interview time and place. The researcher met with each participant on an individual basis and in a private place to conduct the interview. Interviews took place at the convenience of the participants. Prior to beginning the interview the researcher reviewed the purpose of the study. Participants were informed they had a right to stop the interview at any time, to refuse to answer specific questions, or to withdraw from the study if desired. The informed consent form was reviewed with the participant and the participant's signature obtained prior to beginning the interview. After a total of 8 participants had been obtained, no further participants were sought. At that point, data analysis revealed signigicant redundancies in themes, and data collection was stopped.

The interviews lasted anywhere from 1-2 hours and were tape-recorded. The interview tapes were transcribed by the researcher, and any identifying information was removed to ensure the confidentiality of participants. All data, including signed consent forms, interview tapes, data transcripts, summaries and notes, were kept in a separate locked file cabinet when not in use. Consent forms were kept separate from the other data to assure confidentiality of the participants. The only persons with access to the data were the researcher and the members of the research committee.

The Study Sample

Eight hospice nurses working in home-care hospice programs comprised the sample for this study. They all reported having provided nursing care to patients with end-stage dementia and their caregivers within the previous year. Seven of the participants reported they had provided nursing care to an increased number of patients with end-stage dementia within the previous year. The estimated average number of patients with end-stage dementia for whom they had provided care was 15, and the range was 2 to 40.

All 8 participants were female, ranging in age from 32 to 74 years, with an average age of 54. They had been providing nursing care anywhere from 5.5 to 56 years, with an average of 25.5 years. The average number of years working

Table 1

Sample of Eight Hospice Nurse Participants

Sample	M	range	n	%
Age	54	32-74		
Years in nursing	25.5	5.5-56		
Years as a hospice nurse	6	2-12		
Nursing Education:				
diploma			1	12.5
associate			1	12.5
baccalaureate			6	75.0
Estimated number of patients with end-stage dementia the nurse had provided care for over the past year:	15	2-40		
Nurses who had a family member diagnosed with dementia:			6	75.0
Nurses who provided any of the family members care:			1	12.5

as a hospice nurse was 6, with a range of 2 to 12 years. Six participants had baccalaureate degrees in nursing, one had an associate degree in nursing, and one nurse had a diploma in nursing. One participant had provided care for her own family member who had been diagnosed with dementia. The care she provided to the family member was described as direct care.

Participants selected the sites for their interviews. Four chose their work sites, two their own homes, one the interviewer's home, and one chose the researcher's university.

Data Analysis

A qualitative method of data analysis was utilized with the intent of developing an in-depth understanding of the experience that hospice nurses have caring for patients with end-stage dementia and their caregivers. According to Taylor and Bogdan (1984), researchers begin to "make sense out of what they are studying by combining insight and intuition with an intimate familiarity with the data" (p. 130). Data analysis was continuous throughout the data collection process. Contact summaries were written after each interview. The interviews were transcribed by the researcher in order to facilitate an in-depth understanding of the participants.

All data were coded and sorted into categories with the aim of identifying themes. In qualitative research, coding is a organized way of sorting and arranging the data collected into categories in order to arrive at an interpretation (Taylor & Bogdan, 1984).The data were read and reread in order to verify emergent themes in accordance with the purpose of this study, which was to explore hospice nursing care provided to older adults with end-stage dementia and their caregivers.

Trustworthiness of data were met through the criteria of Lincoln and Guba (1984): credibility, transferability, dependability, and confirmability. Credibility was met through the analysis of the interviews by the researcher and research committee. Transferability was met through the participants' rich descriptive responses to the interview questions, thus allowing readers to decide the applicability of such experience to their own situations. Dependability and confirmability were met through the establishment of an audit trail which included the transcribed interview data, data reduction and analysis, data reconstruction and synthesis, and the guidance of a faculty member experienced in qualitative methodology. The research advisor and committee members were closely involved throughout the data analysis phase of the research in order to promote the trustworthiness of the data.

Chapter IV

Results

A qualitative method was used to analyze nurses' experiences in providing hospice care for persons with end-stage dementia and in caring for their caregivers. The participants spoke of caregivers as family members, caregivers as the staff of adult foster homes or long term care facilities, and professional caregivers hired for in-home care. For the purposes of this study, the term caregiver will be used in all cases, except when otherwise qualified in the directly quoted words of a study participant.

Three themes emerged during analysis of the data as described by the participants: the caregiver as the focus of nursing care, "making a connection," and the hospice nurses' need for information. These three themes are described below with examples.

In addition to experiences that fall into the three theme categories, participants reported that providing hospice care became more difficult due to an unreliable prognosis when a patient had end-stage dementia. End-stage dementia was variously described as a primary hospice diagnosis, a secondary diagnosis, and as a result of another disease process. The two areas this highlighted, the definition of end-stage dementia and the issue of prognosis, are described at the end of the chapter.

Theme 1: Caregiver as the Focus of Nursing Care

The participants described the care they provided to patients with end-stage dementia as focused on the patient's caregiver. Patients with end-stage dementia were reported to be unable to reliably participate in the assessment, the establishment of the plan of care, and the ongoing evaluation of that care due to the dementia process. Participants compensated for the patients' inability to participate in their plan of care by obtaining the assessment information and determining a plan of care through each patient's caregiver.

Assessment and care planning. The participants explained that the care for patients with end-stage dementia involved a physical assessment, just as they would do for any hospice patient. The cardiopulmonary system, bowels, bladder, skin integrity, mobility, nutrition, hydration, medications, pain, and safety of the patient were all assessed by the participant. Because patients with end-stage dementia are not able to provide the necessary information, assessment is made via the caregiver and the participants' observations. "It's like caring for a baby," one participant said, "because they can't tell you anything. The only thing you can really know is by observation....[and by] relying on what the caregiver can tell you." Another participant put it succinctly: "We rely an awful lot on the family members."

In addition to time with the patients, much of the participants' time was spent with the caregiver who supplied the assessment facts. In order to identify the patient's needs and the effectiveness of symptom management interventions, participants relied on both the caregiver's report of the patient's condition between visits and what the participant herself observed. The plan of care also was determined from the participant's clinical assessment and the information supplied by the caregiver. As one participant noted, "The interventions I will do for someone who is demented will [involve] connecting with their caregivers and hearing from them the history in order to find out what's going on with this person, besides just my own observations."

When asked to describe how their time is spent caring for patients with end-stage dementia, one participant reported that it, "Seems like it's almost more instruction for the family [than providing physical care for the patient]." Participants reported that patients with end-stage dementia usually require less "hands on" nursing care and so much of their time is spent with the caregiver identifying problem areas and teaching the caregiver how to provide the patient's care. One participant noted that, because of agitation, confusion and other behavioral changes due to dementia, participants "end up doing more family supportive stuff than actual hands on with the Alzheimer patient [and the] dementia patient."

Pain assessment. Participants reported difficulty determining whether the patient with end-stage dementia experienced pain. The patient was not able to tell the participant whether they had pain, where the pain was located, what the intensity of the pain was, nor to provide feedback on the effectiveness of pain medications. For example, one participant said she was doing more guessing. "Pain control is always an issue with a demented patient," she said. "When they're very confused and having a tremendous amount of pain then it's hard to know where the pain is.... I don't want to under treat the pain just because of the confusion." Another participant reported, "You feel really helpless if they are hurting, if the caregiver denotes there is pain somewhere and you're trying to find out specifically where that pain is so you can get appropriate medications."

When the participants were unsure whether the patient with end-stage dementia was experiencing pain, they asked for the caregiver's assessment. The participants reported obtaining much assessment and evaluation about the patient's pain from the caregiver, in addition to their own observations. The caregiver was described by the participants as the person who "knows the patient" and is most likely to know if the patient is experiencing pain. One participant described it this way:

> People with dementia can't give you a definite "Yes, I hurt. This is where it is." They can't tell you if the medication and other pain control measures have helped. So we rely an awful lot on the... wife or children of the patient acting as their caregiver. They can give us an idea as to whether the patient's grimacing or groaning may be from pain.

Provision of care. The participants described the care they provided for patient's with end-stage dementia as "supporting" the patient's caregiver. In fact, because the patient with end-stage dementia was generally unable to comprehend or participate directly in their care decisions, participants described the care they provided as directed toward the caregivers who were providing for the patient's needs. Participants described three ways they provided hospice nursing care to caregivers of patients with end-stage dementia.

First, participants listened to the caregivers' needs and concerns. Participants described caregivers of patients with end-stage dementia as often being the "sole caregiver" who provided 24-hour-a-day care. These caregivers were sometimes described as being, "very needy." As one participant reported, "They need a lot of support. They need a lot of help to try and understand what's going on." This participant continued:

> In some ways [the caregivers for patients with end-stage dementia] require a little more emotional support than people that are caring for a loved one who has cancer. Because [the family of the patient with cancer is] still getting the recognition and feedback of love from the person that they're caring for.

Caregivers of patients with end-stage dementia were described as needing someone to listen to their fears when the patients behavior was unpredictable. Two participants reported that it was important to the caregivers that those coming into the home to provide care for the patient treat him or her as a person.

Second, participants reported that caregivers needed to have the care they were providing to the patient with end-stage dementia validated. One participant gave this example: "What I'm finding is that caregivers don't always want you to come out, but they need reassurance that what they're doing [for the patient] is the right thing." The participants also validated the care provided by the caregivers by teaching caregivers how to assess patient needs, ways to communicate with the patient, and how to provide the care needed by the patient. Participants recognized the caregiver for the important work they did in providing the patient's day-to-day care. In addition to providing psychosocial support and teaching caregivers how to provide care, participants explored issues around dying.

Finally, participants evaluated and encouraged the caregiver to accept any available family or community resources for respite. Participants described making referrals for hospice volunteers, certified nurses aides who could help with the patient's personal care, and medical social workers who could arrange respite for the caregiver. The caregivers of patients with end-stage dementia were often not willing to accept respite, as one participant reported:

> Problematic behaviors of the patient are extremely draining for the caregiver, which places the caregiver in a vulnerable position. We really encourage breaks, volunteer support, or anything that allows the caregiver to get a break from the patient's care. Reality is that [caregivers] are not always able or willing to take a break, but we try to encourage them and walk them through [accepting respite].

Problematic behaviors. Participants described behavior problems in terms of safety issues and the caregiver's ability to manage the patient's care. Safety issues were reported by the participants as particularly relevant to the care provided to the patient with end-stage dementia. Participants dealt with these issues by teaching the caregiver how to provide a safe environment for the patient who was likely to wander off or who had become unaware of potential hazards. Participants also reported the caregiver's safety as an area of concern when the patient had end-stage dementia. For example:

> It depends on how agitated [the patients] are.... is it safe to keep them at home if they're getting more and more confused and the medicines not working? I mean, you don't want them to be non-functional, but on the other hand, they sometimes become combative, hit the caregivers and spouses, and hit the nurses, so that's a real safety issue.

If a patient exhibited aggressive behaviors the caregiver was at risk for injury. According to participants this was particularly relevant if the patient was stronger than the caregiver or the caregiver happened to be aged.

Problematic behaviors described by the participants included wandering, compulsive behaviors, resistance to care, and verbal or physical aggression. For example, one participant described an incident wherein a patient had become physically aggressive. Then she went on to say that she asked herself

> Is there a safety issue? How safe is that person and how safe is the family... and staff going in. In general, the approach would be to check out with the family what their perception was of what's going on... and depending on what that response is, then that's something we'll connect with the team.

This process was described by another participant as "making sure the social workers are involved and trying to get the chaplain in.... so it ends up being more family instruction and safety." The participants targeted their interventions toward managing the behavioral symptoms in order to promote the care recipient and the caregiver's safety.

Rewards of providing care. Participants found working with caregivers of patients with end-stage dementia rewarding. For example, one participant said,

> The real rewarding thing was the help we were able to provide for his wife, the relief she got from us there, the extra help and support... I was able to control the symptoms, and that made life easier for everybody.

When the participants could determine they had made a difference in the patient's situation or had helped through their support of the caregivers, then they felt rewarded. The participants reported being available 24 hours a day to help the caregivers problem solve was one way they made a difference. One participant described this as being, "a listening ear." Another participant noted that, "the 24 hour phone number was "very supportive for families because if something goes wrong they know that help is close by." Even when participants reported there were no rewards when providing care to the patient with end-stage dementia, they did report that there were rewards in observing the caregiver's ability to provide care for the patient.

Theme 2: "Making a Connection"

In particular, participants noted the importance of making a connection. This connection was described in relation to both patients and caregivers.

Connecting with the patient. The participants described that making a connection with a patient who had end-stage dementia was particularly challenging. Participants reported that while they were able to verbally exchange information in order to learn what the patient without dementia needed, this was not possible in the patient with end-stage dementia. For example, one participant reported difficulty "just trying to connect with them. They're so 'gone' is the problem." Another participant noted, "There's not that strong connection with the patient on a personal level and sometimes I even have to struggle."

Not being able to reliably communicate with the patient who had end-stage dementia was described as an issue. One participant put it this way:

> It's nice to be able to ask patients questions and get answers back to gauge how effective you're being. You don't have that with the patient with dementia. Just not making the emotional connection. Although there is a connection you can make... that was really important to his wife.

One participant reported going to the funeral of the patient with end-stage dementia

> because you often see a picture of a live person that you don't see [when you are providing care for the patient with end-stage dementia]. [At the funeral] people share some of [the deceased patient's] past, you can get a little better picture [of who they were]. I feel like I need to be able to relate to them as a real person, that's hard when the person is demented.

When participants found it difficult to connect with the patient, they reported managing to connect with the patient's caregiver, who in turn supplied information needed to manage the patient's care.

Connecting with the caregiver. The majority of participants reported that, while they were uncertain about having made a connection with the patient, they were able to make a connection with the caregiver. One participant noted that "it's very helpful to be able to have a connection to the family. To be able to connect someplace.... connecting with that caregiver, hearing from them what the needs are."

One participant described in some detail the relevance of connecting to the caregiver when the patient had end-stage dementia and then went on to describe how important it is "to build a bond" with the patient, too, in spite of their dementia. One way of connecting with the patient through the caregiver is through personal history. "Very often the family will show pictures," one participant reported, which helped participants to know "what this person was really like." Over half of the participants reported obtaining a family history or as one participant put it, "the patient's life [in] review."

Connection between the patient and caregiver. Participants reported seeing connections made between the patient with dementia and other staff or the patient's caregiver as rewarding. For example, as one participant described it, the patient "would connect with our chaplain who went in and visited and played music.... the response was minimal, but there was a little bit of a response there. That was rewarding." One participant did report not finding any rewards to providing hospice nursing care for patients with end-stage dementia. She went on to say that she did find seeing the connection between the caregiver and patient rewarding: "It's rewarding to see that the caregiver loves that patient regardless." The following participant reported the importance of assisting the caregiver to connect with the patient with end-stage dementia:

> Because you have to offer assistance for setting up ways to manage around communicating, it's a big issue. How do I know when they're having pain? How do I know what they want when they're obviously expressing a need but can't communicate what that is?

Theme 3: Hospice Nurses' Need for Information

The participants reported a range of experience in providing care to patients with end-stage dementia prior to becoming hospice nurses. Three participants reported experience caring for patients with dementia in long-term care prior to caring for patients on hospice. Whether or not the participants had provided previous care to patients with end-stage dementia in other settings, they reported the need for information about dementia. Participants reported obtaining information related to caring for the hospice patient with end-stage dementia from professional journals, National Hospice Organization literature, the Internet, and other hospice staff, with social workers being mentioned most often.

Available information. Overall, the participants did not report an awareness of what information was available about end-stage dementia. For example, one participant reported, "There's just not a lot of written stuff in relation to dementia." Another reported, "There's not a lot of information, and I work well with information." One participant asked during the interview, "I don't think there's much out there, is there?" Participants reported reading hospice related materials yet were not aware what information was available in the area of providing care for the patient with end-stage dementia.

Preparation to provide care. When asked how they prepared to provide nursing care to the patient with end-stage dementia and their caregivers, the participants often replied, "Shoot from the hip a lot." All of the participants described using a variety of resources in preparation for providing hospice nursing care to patients with end-stage dementia. They described reading whatever was available, obtaining information from other team member's experiences providing care to patients with end-stage dementia, obtaining a history and physical from the physician, and obtaining the patient's illness history from the caregiver whenever possible. One participant described it this way, "You just kind of go in and fly by the seat of your pants and just try to do the best you can with the resources you have."

Helpful resources. Participants reported that more information or resources would be helpful in providing care to patients with end-stage dementia and their caregivers. It was suggested that being able to read "articles and things about how to cope with problems" would be "very helpful." Two participants suggested "an inservice on dementia; I can't remember us having one." Other participants responded by requesting information specifically for the caregiver: "You know, for the family. Are there support groups?" The participants reported the need for information on community resources available for nurses caring for patients with dementia and resources available to supply information and support to caregivers.

Participants described the need for information on medications for problematic behaviors. The level of discomfort the participant described related to a lack of knowledge about managing symptoms related to the end-stage dementia. As one participant reported,

> the combativeness, that's the hard one. [It's alright] when you know a patient in pain is usually going to take the pain medicine. [Problems occur] when they're combative and they don't understand why you want them to take something, and they're refusing it... [You're] trying to get something in them so it will take the edge off, [but] they don't understand why you're even picking on them.

For one participant, the pharmacist was the most helpful resource when seeking information on medications related to problematic behaviors. She found it helpful

> discussing with the pharmacist which is the best drug to use, what's the dosage to recommend. I usually try to have some idea what I want before I ask the doctor because often they don't really know what's best.

Another participant formed a relationship with the staff of a geropsychiatric unit. When the participant required information on managing particularly difficult behaviors in the home or had questions about medications related to managing behaviors, she would call the geropsychiatric unit to "check medications, ask for advice about situations, maybe use [the staff] as a sounding board." In general, participants sought guidance from those they perceived to be experts.

All participants reported a need for information on caring for the patient with end-stage dementia and their caregivers. Those areas participants identified as being particularly helpful related to general information, general information on managing problematic behaviors, and information on medications utilized to manage problematic behaviors. Participants reported that the information they would find helpful in relation to the caregiver would be specific to community resources available for the caregiver of the patient with end-stage dementia.

Additional Findings

In addition to the three themes described above, participants touched on the areas of dementia definition and prognosis. Participants noted that end-stage dementia could be defined various ways: as a primary hospice diagnosis, as a secondary diagnosis, or as related to another disease process. Participants reported that providing care to the patient with end-stage dementia was more difficult when the dementia was a primary diagnosis because the prognosis was not reliable.

Definition of end-stage dementia. Participants were sent a letter of introduction explaining that the study was focusing on hospice nursing care for patients with end-stage dementia and their caregivers. The hospice directors were asked to identify nurses who had provided hospice nursing care to patients with end-stage dementia and their caregivers within the past year. During the course of the interview process the participants described hospice nursing care for patients with end-stage dementia in terms of patients with a primary diagnosis of end-stage dementia due to Alzheimer's disease or vascular disease and they talked about end-stage dementia in terms of the dementia as a secondary diagnosis. Half of the participants also discussed dementia related to another disease process, such as cancer metastasis to the brain or to end-stage HIV as end-stage dementia.

Two participants requested a definition of dementia from the researcher.

> When you say dementia, tell me what you mean... or end-stage dementia.... When you're talking end-stage dementia, you're talking people that had a diagnosis of dementia prior to coming into hospice? Are you talking people that could have dementia also related to metastasis to the brain from a diagnosis of cancer or is this strictly like Alzheimer's... or having Parkinson's...or having cancer related problems... is that mainly what you're talking about?

One participant noted that "the patient's diagnosis is CVAs [cerebrovascular accidents] which are responsible for the dementia," and asked the researcher, "do you consider that a primary [hospice diagnosis of end-stage dementia]?"

The participants were able to articulate the differences in the care needed when patients had a primary diagnosis of end-stage dementia or when the end-stage dementia was described as a secondary diagnosis or secondary to another disease process. The participants reported that when the end-stage dementia was a secondary diagnosis or secondary to another disease process, the care just as good as ever." The prognosis when a patient had end-stage dementia, participants said, was unreliable. When describing this difficulty, one participant said, "It's not that normal cancer where you're going to see appetite changes, a lot to do with pain, [and] you can almost count down the line what is going to happen."

Participants described patients with a primary diagnosis of end-stage dementia as "a long-term patient" when compared to other hospice patients. Patients referred to hospice with a primary diagnosis of end-stage dementia were described as either on hospice services for only a few days or for longer than the 6-month time frame established as a criteria for referral to hospice services. One participant noted that, while "cancer patients most of the time are short-term," that is they die within the 6-month prognosis, patients with a primary diagnosis of end-stage dementia "have been more of a long-term patients" in the hospice program for 6 months or longer. Two participants described a feeling of loss due to the length of the relationship they developed with patients with end-stage dementia and with their caregivers.

Participants reported that for patients who had a primary diagnosis of end-stage dementia they were more cautious when managing symptoms which required medications that were sedating. One participant said,

> I would probably be a little more aggressive [if the patient had cancer] than in somebody with Alzheimer's because they may improve. So you don't want to "snow" them.... The disease course [of Alzheimer's], isn't the same [as with

cancer.]

This participant reported that she might have to shift the focus of care for the patient with end-stage dementia from a “terminal care” to a “chronic care” model and that in some cases the patient was found to be no longer hospice appropriate (prognosis over 6 months).

The participants described providing care for a diverse group when the patients had end-stage dementia. The participants reported that their patients and the caregivers of those patients had different specific needs depending on whether the dementia was described as a primary hospice diagnosis, a secondary diagnosis, or related to another disease process.

Chapter V

Discussion

Areas explored with the participants in this study in relation to hospice nursing care provided to older adults and the caregivers of older adults with end-stage dementia include: current hospice nursing practice, comparison with the nursing care needed by other types of hospice patients and their caregivers, and necessary resources, support or education needed. The discussion will cover (a) the meaning of the findings of this study, (b) a comparison with what has previously been reported in the literature, and (c) the implications for hospice nursing pracitice when providing care for patients with end-stage dementia and their caregivers. Following the discussion, a summary, limitations of this study, and suggestions for future research are included.

Meaning of Findings

Participants of this study reported hospice nursing care for patients with end-stage dementia as being focused on the caregiver, noting that while "connecting with the patient" who had end-stage dementia was rarely possible they were able to "connect with the caregiver" of the patient. Participants reported a need for information on caring for persons with dementia and for their caregivers and stated that providing hospice care for the patient with end-stage dementia was made more difficult by the ambiguity inherent in the prognosis for these patients. These findings are examined below.

Shift of care to the family. In a study by Chesla (1996), it was found that nurses providing care in the CCU (coronary care unit) also provided a diverse range of care to the patients' families. Some nurses in that study provided technological care without involving the family while other nurses recognized the significant role of the family to the patient's well-being and were expert at incorporating the family in the care plan. Similarly, participants in this study describe the care they provide to patients with end-stage dementia first in terms of the physical care, and then in terms of the psychosocial or emotional support to the patients' caregivers. It may be that nurses providing hospice care have been trained to focus on the patient's physical care needs yet recognize the important role the family plays in the successful care of the patient. While the majority do not directly identify the care they provide as holistic, family centered care, the descriptions participants made of their nursing during the course of this study included the physical, psychosocial, emotional, and spiritual care of the family caring for the patient with end-stage dementia. When the patient has a disease process like end-stage dementia the nurse is required to shift the focus of care to the caregiver and family in order to meet the patient's needs. As with the Chesla study, hospice nurses vary in their ability to incorporate the family in the assessment and care planning.

Hospice nurses act as advocates for both the patients and families of the patients for whom they provide care. The safety of the patient with end-stage dementia is a priority because their inability to verbalize needs and to be reliably understood makes them vulnerable. The combined stresses of daily physical care of a dying loved one and the emotional issues which surround dying and death leave the caregiver vulnerable as well. For these reasons teaching caregivers to provide safe care is one of the main concerns of hospice nurses. When the caregiver is unable to provide the necessary, safe care for the patient, then the nurse must intervene on the patient's behalf. This was an area the participants found particularly challenging when they perceived that the caregiver of the patient with end-stage dementia could benefit from respite but remained unwilling to accept it. The participants experience provided them an understanding of how much physical and emotional energy was needed to provide care for the patient with end-stage dementia. Preparing the caregiver to recognize when a break from caregiving could help sustain the caregiver for the duration of time that the patient with end-stage dementia would need care helped to avoid caregiver "burn out" or injury to the caregiver directly due to fatigue.

The literature on caregiving cites numerous reasons why caregivers do not accept respite services. Perhaps the caregiver feels a "moral obligation" to provide care to the patient regardless of the cost to the caregiver (Wilson, 1992). It may be that the caregiver is so overwhelmed he or she is unable to make decisions concerning respite (Chenoweth & Spencer, 1986). If respite care requires transferring the patient from home to a nursing facility, a caregiver's reluctance to accept respite may have to do with an understanding of the impact that changing the patient's environment can have on him or her. In this study, participants ascribed caregivers' reluctance to accept respite services to the fact that the patient must be transferred to a nursing facility for the duration of the respite. If in-home respite was possible, many caregivers felt uncomfortable with the idea of having a stranger in the home,

Loss of an aspect of hospice care. One of the rewards of providing hospice care is the opportunity to get to know the patient intimately. This intimacy becomes difficult when a patient has a disease process, such as end-stage dementia that limits the ways the nurse can "connect" with the patient and know that he/she is meeting the patient's needs. "Connecting" has been described in hospice literature as the way the nurse forms a relationship with a patient and family and the way the nurse aides that patient and family in order for caregiving to take place (Rasmussen, Norberg, & Sandman, 1995; Zerwekh, 1995). Nurses make an extra effort to form a connection with patients who have cognitive impairments, but the participants in this study described this as an unreliable source of information about the patient's well-being. Objective ways of knowing whether there was a connection (e.g., the patient's facial expression, the patient's comfort in the nurse's presence, feedback from the caregiver) were also perceived as unreliable.

Participants regularly were able to compensate for the loss of connecting with the end-stage dementia patient by connecting with the patient's caregiver. By connecting with the caregiver the nurse is able to obtain information about the patient that allows him or her to more reliably meet the patient's needs. Much of the care hospice nurses provide is in the form of emotional support for the patient who is dying. With end-stage dementia the specific needs a patient has in this area is less clear. When the patient develops dementia related to another disease process such as cancer or HIV while on the hospice program, the nurse has had an opportunity to connect with the patient prior to the dementia.

In family nursing it has been theorized that by affecting one member of a family the health professional affects the family unit (Shepard & Moriarity, 1996). By connecting with the caregiver of the patient with end-stage dementia, and assessing and meeting the caregiver's psychosocial needs, the hospice nurse provides care indirectly for the patient. The care hospice nurses provide for the caregiver can ultimately lead to that caregiver continuing to provide care for the patient with end-stage dementia.

<u>The need for information and resources.</u> In hospice care, the patient, the caregivers, and the hospice staff are all interested in maintaining the patient at home whenever possible till death occurs. Problematic behaviors can jeopardize a patient's ability to remain at home. In this study, participants were not confident about how to manage those problematic patient behaviors which could jeopardize the caregiver's or patient's safety, and they identified this as an area where they needed more knowledge. Curiously they seemed unaware of information that is currently available in this area. One reason hospice nurses may not be aware of the amount of information related to caring for patients with end-stage dementia as a primary diagnosis is that this group of patients has traditionally had limited

access to hospice services (Hanrahan & Luchins, 1995a). Further, since the majority of patients in hospice care have been cancer patients, the hospice programs have traditionally provided education for staff on caring for persons with cancer. Nurses working in hospice may not have identified a need for information on caring for patients with a primary diagnosis of end-stage dementia due to the limited numbers of these patients who have had access to hospice services. In addition, educational opportunities through the hospice programs employing the nurse may have not identified the need for this information for the same reasons. However, hospice nurses are increasingly providing care for patients with diagnoses other than cancer, such as end-stage heart disease, end-stage pulmonary disease, end-stage HIV, and end-stage dementia. Identifying the hospice nurses educational needs in order to provide care to a diverse group of patients and their caregivers is extremely important. Hospice nurses teach caregivers and families about the patient's disease process and how to manage symptoms related to that disease process while they care for the patient at home. In order to educate the caregivers and family, the nurse must first possess that knowledge.

A majority of participants in this study use other hospice staff as a resource for managing the care of the patient with end-stage dementia. This may not be an effective means of obtaining the information the hospice nurse requires to provide care for the patient with end-stage dementia if the staff member approached has no more education or experience in caring for patients and caregivers of patients with end-stage dementia. Information and training on providing dementia care could benefit hospice nurses and other staff in order to meet the needs of this group of patients and their caregivers.

Ambiguity about the purpose of care. Hospice nurses often find themselves providing chronic care instead of terminal care for the patient with end-stage dementia. In the participant's experience end-stage dementia presents a situation in which the patient referred for hospice care either dies within a few days or remains in hospice for many months. One of the concerns nurses face in the latter case is that, if the patient's medical condition stabilizes, measures may need to be taken to preserve the patient's Medicare hospice benefits. Taking the patient off the hospice program would then diminish the support available to the caregiver. In hospice care the goal generally is to promote the patient's comfort and safety until death occurs. This goal is met through palliative symptom management and the provision of psychosocial support for patients and caregivers within the 6 month prognosis period. Given the above named factors, the model of care for the patient with end-stage dementia is made uncertain due to the variability of the prognosis.

Hospice nurses could be trained to utilize a tool, for example, the National Hospice Organization (NHO) worksheet for determining prognosis of dementia, in order to better predict the patient's prognosis. Stuart et al. (1996) have reported that, when using the NHO guidelines previously published for Alzheimer's disease, Luchins et al. (in preparation) were able to accurately predict mortality within the 6-month hospice criteria in about 85% of patients. Such a tool would assist the nurse when conferring with the primary physician and the patient's family to determine continuation or cessation of hospice services when the patient's condition has stabilized.

Comparison with What is Known

Issues that affect the hospice nurses' ability to provide the appropriate care for the patient with end-stage dementia when the prognosis is uncertain were described. Participants in this study were able to provide hospice care for patients with end-stage dementia; however, they required more education on the needs specific to this group of patients, with problematic behaviors being mentioned most often.

Provision of appropriate hospice care. Hanrahan and Luchins (1995a) reported that 57% of the hospices reported that staff required additional training in order to provide care to patients with end-stage dementia and over half of those surveyed reported behavior problems as an additional difficulty. The participants in this study identified a need for more information in the area of managing behavior problems, especially in relation to the use of psychoactive medications. What they were not sure of was whether any such information was available and where to obtain it if it was.

According to the 1995 Hospice Fact Sheet (National Hospice Organization, 1995), 78% of the patients for whom hospices provide care have cancer, 10% have heart-related diagnoses, 4% have AIDS, 1% have renal disease, 1% have

Alzheimer's, the remaining 6% other miscellaneous diagnoses. Participants report that the majority of the information available to them is related to care for the hospice patient with cancer. Although, the participants report providing care for increasing numbers of patients with end-stage dementia, they had not received information or education on providing care to the patient with end-stage dementia or their caregivers nor had they sought the information. Nurses choosing hospice care generally come from clinical backgrounds of medical/surgical/oncology nursing and are taught primarily to assess and treat physical symptoms. Nurses may have received little if any family-oriented nursing education, limited education in death and dying, and limited training in the psychosocial issues patients and the caregivers of patients with end-stage dementia experience. It may be that nurses providing hospice care have been trained to focus on the patient's physical care needs yet recognize the important role the family plays in the successful care of the patient.

Hanrahan and Luchins (1995a) found that hospices who were providing care to families of patients with end-stage dementia were not always able to meet the needs for caregiver respite. They hypothesized that the reason hospices were not able to meet the needs of caregivers of patients with end-stage dementia for respite was a combination of the length of time the families were enrolled in the hospice program and the limited resources those hospices had available to pay for respite. In this study, participants also reported reluctance on the part of the caregivers to accept respite as a barrier to respite use. Another barrier is that the hospice programs are limited to in-patient respite (the participant's hospice programs provided respite in the nursing home only), and caregivers were not willing to place the patient in the nursing home even for a limited time.

In this study participants reported families were able to accept a palliative plan of care when the patient had end-stage dementia. They found what was needed most from the hospice staff was emotional support for the caregivers and families. This was found to be true as well in the study done by Brechling and Kuhn (1989) where the majority of the work the hospice staff provided to patient's with end-stage dementia and their caregivers was emotional support for the caregiver and respite care.

Determining length of survival. According to Hanrahan and Luchins (1995a) less than 1% of the patients with end-stage dementia are admitted to hospice programs. The major reason cited for patients with end-stage dementia not having access to hospice programs was the difficulty of predicting survival time. Difficulty determining the prognosis of end-stage dementia was also reported by the majority of the participants in this study as making the provision of care more difficult. Studies conducted up to this time do provide some guidance for hospices to evaluate patients with end-stage dementia. According to Volicer et al. (1993), the criteria for determining a person with end-stage dementia to be within the 6-month prognosis period for hospice services were: fever episodes in conjunction with advanced age, more severe Alzheimer's dementia, and the palliative management of care. NHO has published medical guidelines for determining the prognosis of non-cancer diagnoses, in which end-stage dementia is included. In the most recent publication (Stuart et al., 1996) of this guideline, a study done by Luchins et al. (in preparation) has shown that when the NHO guidelines for Alzheimer's disease were used, the prediction of a 6-month mortality was accurate 85% of the time. The participants in this study did not report utilizing the guidelines established by the NHO for determining the appropriateness of the patient with end-stage dementia for hospice care nor did they report any training in the use of this tool. Two participants did mention they were aware of the NHO guidelines.

Participants in this study described their patients with end-stage dementia as remaining in the home and being cared for by the hospice team till death occurred. Those patients who were cared for in an institutional setting were there prior to the hospice nurse's involvement in the patient's care. This lends support to the Collins and Ogle (1994) study, which has found that a hospice approach to care for the patient with end-stage dementia is feasible when there is an available caregiver.

Implications for Hospice Nursing Practice

This study suggests that hospice nurses could benefit from additional education in family, gerontological, and mental health nursing in order to provide for the needs of patients with dementia and their caregivers and families. Hospice agencies could support professional staff in obtaining education through seminars funded by the agency and scholarships for nurses seeking formal education in order to care for the specific needs of patients with end-stage dementia and their caregivers. Nurses with advanced preparation in geropsychiatric nursing, which includes preparation in gerontological, mental-health, psychiatric, community health, and medical-surgical nursing (Hogstel & Nichols, 1995), would be an ideal resource for hospice nurses caring for patients and caregivers of patients with end-stage dementia.

Providing educational support for staff caring for patients with end-stage dementia and their caregivers through inservices or keeping staff informed of seminars available in their area would be another way hospice programs could support nursing staff. Schools of nursing could make available seminars for nurses providing care for patients with dementia in their area. Hospice nurses are in the best position to identify their needs for information when caring for patients with end-stage dementia.

Summary

Hospice nurses are increasingly providing care to patient's with end-stage dementia in both the home and institutional settings. They are providing this care within the hospice palliative model of care. What the participants described in this study were ways the care for the patient with end-stage dementia and their caregiver were unique in comparison to the care required by other hospice patients and their caregivers. When the patient has end-stage dementia, the focus of care shifts from direct care of the patient to family focused care. Hospice nurses' ability to provide family-focused care vary, in part because they receive little to no formal training in this area. Hospice nurses find connecting with the patient when they have end-stage dementia to be difficult. They manage to compensate for the loss of knowing they had made a connection with the patient by making a connection with the caregiver. The need that hospice nurses have for information on providing care to patients with end-stage dementia and their caregivers was one of the most significant finding of this study. Participants also raised the issue of needing to obtain the information and tools that will assist them in determining whether the patient with end-stage dementia is appropriate for continued hospice care.

Limitations

The study was limited by the use of convenience sampling. The researcher's inexperience conducting a qualitative interview and analysis was a further limitation. This was countered by the researcher working with researchers who are experts in qualitative methodology, hospice nursing, and dementia care.

Future Research

The results from this study can be used to generate hypotheses for future research directed at understanding and promoting optimal nursing care for person's with end-stage dementia and their caregivers who elect to receive hospice services. Research that seeks to gain an understanding of the needs of the patient and the caregiver of the patient with end-stage dementia and the impact these needs have on hospice services would assist hospice nurses in the assessment and provision for those needs. Studies of hospice nursing that utilize family systems theory or a family care paradigm to evaluate nursing care would assist hospice nurses in identifying interventions that would assist these patients and their families in the healing process. Programs for educating hospice staff on how to care for patients with end-stage dementia and their families need to be tested in order to determine the most useful and cost effective way of providing this needed support.

References

Alzheimer's Association Alzheimer's Disease Statistics Fact Sheet. (1995). Alzheimer's disease statistics fact sheet [On-line]. Available: http://www.alz.org/dinfo/factsheet/ADS.html?statistics

Bachman, D. L., Wolf, P. A., Linn, R., Knoefel, J. E., Cobb, J., Belanger, A., D'Agostino, R. B., & White, L. R. (1992). Prevalence of dementia and probable senile dementia of the Alzheimer type in the Framingham Study. Neurology, 42, 115-119.

Brechling, B. G. & Kuhn, D. (1989). A specialized hospice for dementia patients and their families. The American Journal of Hospice Care, 6(3), 27-30.

Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of the family caregivers. Gerontologist, 26(3), 267-272.

Chesla, C. A. (1996). Reconciling technologic and family care in critical-care nursing. Image, 28(3), 199-203.

Collins, C. & Ogle, K. (1994). Patterns of predeath service use by dementia patients with a family caregiver. Journal of American Geriatric Society, 42, 719-722.

Hanrahan, P. & Luchins, D. J. (1995a). Access to hospice programs in end-stage dementia: A national survey of hospice programs. Journal of American Geriatric Society, 43, 56-59.

Hanrahan, P. & Luchins, D. J. (1995b). Feasible criteria for enrolling end-stage dementia patients in home hospice care. The Hospice Journal, 10(3), 47-54.

Hogstel, M. O. & Nichols, M. K. (1995). Resources. In M. O. Hogstel (Ed.), Geropsychiatric nursing (pp. 56-72). St. Louis, MO: Mosby Yearbook.

Kirschling, J. & Luce, L. (1992). Oregon Hospice Association: Statewide data set. The Hospice Journal, 8(3), 35-45.

Lincoln, Y. S. & Guba, E. G. (1985). Establishing trustworthiness. In Naturalistic inquiry (pp. 289-331). Beverly Hills, CA: Sage Publications.

Lofland, J. & Lofland, L. H. (1995). Evaluating data sites. In Analyzing social settings: A guide to qualitative observation and analysis (3rd ed., pp. 16-30). Belmont, CA: Wadsworth Publishing.

Luchins, D. J. & Hanrahan, P. (1993). What is appropriate health care for end-stage dementia? Journal of American Geriatric Society, 41, 25-30.

National Hospice Organization. (1995). Hospice fact sheet. (Available from the National Hospice Organization, 1901 N. Moore Street, Suite 901, Arlington, VA 22209).

Rasmussen, B. H., Norberg, A., & Sandman, P. O. (1995). Stories about becoming a hospice nurse: Reasons, expectations, hopes, and concerns. Cancer Nursing, 18(5), 344-354.

Shepard, M. P. & Moriarity, H. J. (1996). Family mental health nursing. In S. M. Hanson & S. T. Boyd (Eds.), Family health care nursing (pp. 302-326). Philadelphia: F. A. Davis.

Stuart, B., Alexander, C., Arenella, C., Connor, S., Herbst, L., Jones, D., Kinzbrunner, B., Rousseau, P., Ryndes, T., Wohlfeiler, M., Cody, C., & Buckley, S. (1996). Medical guidelines for determining prognosis in selected non-cancer diseases (2nd ed.) (Item No. 713008). Arlington, VA: National Hospice.

Stuart, B., Herbst, L., Kinzbrunner, B., Preodor, M., Connor, S., & Ryndes, T. (1995). Medical guidelines for determining prognosis in selected non-cancer diseases. (Item No. 713008). Arlington, VA: National Hospice Organization. Organization.

Taylor, S. J. & Bogdan, R. (1984). Working with data: Data analysis in qualitative research. In Introduction to qualitative research methods: The search for meanings (2nd ed., pp. 123-145). New York, NY: John Wiley & Sons.

U.S. Department of Health and Human Services. (1991). Aging America: Trends and projections (DHHS Publication No. FcoA 91-28001). Washington, DC: U.S. Government Printing Office.

Volicer, L. (1986). Need for hospice approach to treatment of patients with advanced progressive dementia. Journal of American Geriatric Society, 34, 655-658.

Volicer, B. J., Hurley, A., Fabiszewski, K. J., Montgomery, P., & Volicer, L. (1993). Predicting short-term survival for patients with advanced Alzheimer's disease. Journal of American Geriatric Society, 41, 535-540.

Volicer, L., Rheaume, Y., Brown, J., Fabiszewski, K., & Brady, R. (1986). Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. Journal of the American Medical Association, 256, 2210-2213.

Volicer, L., Volicer, B. J., & Hurley, A. C. (1993). Is hospice care appropriate for Alzheimer's patients? Caring Magazine, 12(11), 50-55.

Wilson, S. A. (1992). The family as caregivers: Hospice home care. Family Community Health, 15(2), 71-80.

Zerwekh, J. V. (1995). A family caregiving model for hospice nursing. Hospice Journal. 10(1), 27-44.

Appendices

Appendix A

Interview Guide

Question: Tell me about the nursing care you provide to hospice patients with end-stage dementia (ESD) and their caregivers.

Probe Questions: What is it you do as a hospice nurse for patients with ESD?

What is it you do for their caregivers?

What is providing hospice care for patients with ESD and their caregivers like for you?

What helps you in providing care?

What makes providing care more difficult?

Have you found particular behaviors in the patient with ESD to be problematic?

Are there aspects of the care that make it rewarding?

Are there ways you prepare yourself to provide care?

What kind of resources or support if any would be helpful?

Do the patients with ESD that you provide care for have a primary diagnosis of dementia or another hospice diagnosis?

How does this impact the care you provide?

How does the care you provide to persons with ESD and their caregivers compare to the care you provide to other hospice patients?

Collect identifying information at end of interview.

Appendix B

Demographic Information

Subject identification number ___

Date of interview _________

Place of interview _______________

Age ___

Gender 1. Female 2. Male

Nursing education: (Circle all that apply)

1. Diploma
2. Associate degree
3. Baccalaureate degree
4. Master's degree
5. Doctoral degree

Number of years in nursing: ___

Number of years as a hospice nurse: ___

Estimate the number of patients with end-stage dementia you have provided nursing care for while working in hospice over the past year: ___

Has the number increased (I), decreased (D), or stayed the same (S)? ___

Has a member of your family been diagnosed with dementia?

1. Yes
2. No

If yes, what is your relationship to this person? _____________

Do you currently, or did you, provide any of their care? _____

Appendix C

Letter to the Hospice Program Director

Date:

Hospice Director Name:
Hospice Director Address:

Dear Director Name,

I am a graduate student at Oregon Health Sciences University conducting a study on the care hospice nurses provide to persons with end-stage dementia and their caregivers. I have been working as a hospice nurse in the Portland area for more than ten years. I am asking you to identify up to three nurses who have provided care to patients with end-stage dementia during the past year and to provide those nurses with an informational letter along with a post card to be returned to me if they are interested in participating.

The study has been approved by my faculty research advisors at the School of Nursing and the Institutional Review Board/Committee on Human Research at Oregon Health Sciences University. There are no foreseeable risks to participants. The information will be obtained using an unstructured interview process seeking to discover the experiences of hospice nurses who provide care to patients with dementia. The particular areas to be explored are nurses' experiences in providing care to persons with end-stage dementia and their caregivers, how their nursing care is similar, or different from the care provided to other hospice patients, and what resources the hospice nurse needs in order to provide quality care for these patients and their caregivers.

The interview is expected to take approximately one to two hours and will be tape recorded. The interviewee may elect to answer only specific questions or stop the interview at any time. The criteria for inclusion in this study is that the participant must be a registered nurse who is currently employed in a hospice program that provides services to older adults with end-stage dementia. The participant must be willing to provide written consent agreeing to be interviewed.

Enclosed you will find an informational letter addressed to possible participants along with a post card to be returned by those participants willing to be interviewed who meet the criteria. I will contact the nurses who return a post card to establish an interview time at their convenience.

I would be happy to share the results of this study upon completion. This study may not be of direct benefit to you, however, it will provide information that could be used to plan for staff education and development in providing care to patients and their families. If you have any questions, please feel free to contact me at the address or phone number provided. Thank you for your help.

Sincerely,

Mary Hazard, RN, B.S.N.
14895 SW Gearhart Dr.
Beaverton, Oregon 97007
(503) 641-0250

Appendix D

Letter to the Participant

Date:

Dear Hospice Nurse,

I am a nurse with over ten years of hospice experience and a graduate student at Oregon Health Sciences University, School of Nursing. I am seeking hospice nurses who are willing to be interviewed about their experiences in providing care to patients with end-stage dementia and their caregivers. There is little description of this experience found in the literature. The interview will focus on your experience of providing hospice care to these patients and their caregivers. The knowledge obtained could be used to help prepare future hospice nurses to care for these patients and their caregivers.

To participate in this study you must be a registered nurse who is currently employed in a hospice program that provides services to older adults with end-stage dementia. The interview will be tape recorded and is expected to take approximately one to two hours. A follow-up phone call may be needed in order to clarify information obtained during the interview. Prior to the interview you will be asked to sign a written consent form agreeing to participate. Included with this letter you will find a pre-addressed post card. Please indicate a convenient time of day and a phone number where you can be reached if you are willing to participate. Upon receiving the post card I will call you to discuss the interview and set up a convenient time and place for the interview.

As part of the interview I will need to collect some descriptive information. This information as well as the interview data will be kept in a locked file cabinet to ensure confidentiality. The only persons having access to this information will be myself and the nursing faculty advising me on this project. You may choose to answer only specific questions or stop the interview at any time.

If as hospice nurses we will be expected to provide care for increasing numbers of patients with end-stage dementia and their caregivers, we can all benefit from understanding more fully what that experience entails. If you are interested, at the completion of the study I would be happy to share the results with you. I hope to receive your post card and look forward to meeting with you.

Sincerely,

Mary Hazard, RN, B.S.N.
14895 SW Gearhart Dr.
Beaverton, OR 97007
1-503-641-0250

Appendix E

IRB#: Exempt 2

Approved: December 6, 1996

OREGON HEALTH SCIENCES UNIVERSITY

Consent Form

TITLE. Hospice Nursing Care: Persons with End-Stage Dementia and their Caregivers.

PRINCIPAL INVESTIGATOR. Mary Hazard, BSN, RN Telephone (641-0250)

ADVISOR. Beverly Hoeffer, DNSc, RN Telephone (494-3894)

PURPOSE.

You have been invited to participate in this research study because of your experience in providing nursing care to patients with end-stage dementia and their caregivers. The purpose of this study is to explore and describe the current practice of hospice nurses when providing care to this group of people. Results of this study may be used to help educate and prepare future hospice nurses when providing care to persons with end-stage dementia and their caregivers.

PROCEDURES.

Hospice nurses like yourself who have worked with end-stage dementia patients during the past year will be identified through hospice program directors. Your hospice program director will provide you with an informational letter of the study. If you are willing to participate in the study you will return a pre-addressed post card with a phone number of when and where to be contacted to Mary Hazard, BSN, RN, the principal investigator of the study. Upon receipt of the post card, Mary Hazard, BSN, RN, will call and set up a time to interview you. The interview is expected to last 1-2 hours and will be tape recorded. An interview guide will be used in order to explore your experience when providing care for patients with end-stage dementia and their caregivers. You will be asked questions such as, "Tell me about the nursing care you provide to hospice patients with end-stage dementia and their caregivers." You also will be asked to provide some brief descriptive information about yourself (e.g., number years you have been a nurse, number of years you have been a hospice nurse).

RISKS AND DISCOMFORTS.

There are no foreseeable risks to participating in this study. If at any time you experience discomfort you may choose to not answer specific questions or stop the interview at any time.

BENEFITS.

You may or may not personally benefit from participating in this study. However, you may contribute information that can be used to help educate and prepare hospice nurses to provide quality care to patients with end-stage dementia and their caregivers.

CONFIDENTIALITY.

Your name will not appear on any of the interview responses. Data from the interview will be coded to ensure confidentiality of participants. Identifying information will be kept in a separate locked file cabinet and the only persons with access to this information will be Mary Hazard, BSN, RN, principal investigator or Dr. Beverly Hoeffer, research advisor. Neither your name nor your identity will be used for publication or publicity purposes. According to Oregon law, suspected child or elder abuse must be reported to appropriate authorities.

COSTS.

There will be no cost to you for your participation in this study.

LIABILITY.

The Oregon Health Sciences University, as a public institution, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers, or employees. If you have further questions, please call the Medical Services Director at (503) 494-8014.

PARTICIPATION.

If you have any other questions regarding this study please contact Mary Hazard, RN, BSN at (503) 641-0250. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887.

Participation in this study is strictly voluntary and you may feel free to withdraw at any time.

Your signature below indicates that you have read the foregoing and agree to participate in this study. You will receive a copy of this consent form.

Thank you for your willingness to participate.

Signature of Subject	Date
Signature of Witness	Date
Signature of Principal Investigator	Date