

**A Comparison of the Needs of Hospice  
Caregivers During and After  
the Caregiving Experience**

by

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## ABSTRACT

The purpose of this study was to identify Hospice caregiver needs during and after the caregiving experience and to determine if perceptions of needs change over time. This study also examined certain characteristics as they relate to perception of family needs. The study population consisted of a convenience sample of 52 Delaware Hospice caregivers.

A descriptive research design was used for this investigation. Data on caregiver needs was collected using the Home Caregiver Needs Survey (HCNS). In addition demographic information was obtained from the caregivers. Mean values were computed from the responses of the caregivers both during and after the experience. The top six needs both during and after caregiving were included within the categories of information needs and patient care needs.

The needs identified after caregiving more clearly define the intensity of the caregiving experience. Specific details of caregiving such as: RN or HHA help with care; information on medication effects and schedules; information on what symptoms to expect; and ways to combat fatigue increased in importance. Retrospective caregiver needs reflected a moving away from irrelevant patient care issues and a focusing on those issues that most directly related to patient comfort. They also reflected increased

interaction with people other than the patient. A significant difference was seen in several needs of male caregivers and non-white caregivers.

Further investigation is needed to more clearly define the changes in care needs throughout the caregiving experience. Consistent assessment of the family needs as well as evaluation of success in meeting those needs is vital.

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## CHAPTER 1

### INTRODUCTION

Health care in the United States continues to experience a transition from hospital to home. The demand for home care services for the management of advanced cancer has become an important component of the health care system. It is estimated that in 1994, 526,000 people will die of cancer (Cancer Facts & Figures - 1994). There is a strong incentive today to have patients remain in their own homes where they can be cared for in familiar and comfortable surroundings. This, of course, means that a family member will be functioning in the role of caregiver.

Research has consistently documented that families are the primary providers of service to the frail and disabled living in the community (Horowitz, 1985). The principle caregivers of family members are spouses, followed by adult children (Barnes, Given, & Given, 1992). Women are the predominant caregivers with wives assuming the major caregiving responsibilities for their husbands and daughters assuming the care for their elderly parents (Brody, 1990). Little is known about how family make up and interaction influences the experience of caregiving, but for most caregivers the emotional stresses associated with caregiving are far more difficult to deal with than the physical or financial aspects of care (Horowitz, 1985).

While the caregiving experience may be rewarding for families, it may also be stressful. Within family systems perspective, it is recognized that stress in one family member has an impact on other family members (Friedman, 1992, p. 118). Although nursing personnel provide some direct care, much of the burden of care is on the family. These family members have varying degrees of abilities to fulfill this role of caregiving. A study by Qureski and Walker (1987) found that 45% of the caregivers reported "health problems which made caregiving difficult" and 42% said they "needed more help" (Qureski & Walker, 1987, p. 238). Caregiving responsibilities can become physically and emotionally draining, especially when shortfalls exist in the extended family's abilities to assist with care.

The social isolation of caregivers has been identified as a factor in producing stress and feelings of resentment and guilt. In one study (Alan, 1988), 66% of the caregivers reported less visiting of friends or relatives, 56% reported giving up holidays, and 53% reported giving up entertaining at home. Caregiving has an impact on lives.

Nevertheless, when asked to rate caregiving as rewarding, a burden, or equally balanced, Seale (1990) found that 46% found it rewarding, 7% found it a burden, and 26% reported that it was a balance. These figures would indicate the "mixed blessing" that caregiving provides.

The stress that advanced cancer causes for families and the growing expectation that home care will be provided by families, necessitates that caregiving families seek assistance to supplement their care. In order to serve this group more effectively, health care professionals must examine the experience of caregiving and explore the needs of caregivers. As families become more involved in caregiving, health care is moving from a patient centered focus to a family centered focus. Because much of the success of a home care program depends on the ability of the caregiver to provide care, it is extremely important to strive to meet the needs perceived by the caregiver. Only as caregiver needs are met will patients be provided the quality of life necessary to make the last days as comfortable and meaningful as possible. And thus families will be assisted with the effective resolution of loss and grief.

The purpose of this study is to examine the anticipated and retrospective needs expressed by caregivers of terminally ill cancer patients cared for at home and to determine if perceptions of the demands of caregiving change over time. Because the literature (Wingate & Lackey, 1989) has shown a disparity between needs identified by patients, caregivers, and nurses, it is important to get information from the primary source rather than others who assume they know the needs of the

caregiver. The best source for information about caregiver's needs is the caregiver. Examining needs longitudinally and comparing the anticipated needs with the retrospective needs should give a more complete picture of the total caregiving experience.

Although programs for the caregivers of terminal cancer patients are on the rise, the appropriateness of these programs cannot be evaluated until the needs of home caregivers are identified. Identification of caregiver needs and development of interventions to meet these needs will assist health care professionals in meeting the needs of caregivers.

The findings of this study may be used to give direction to hospice in evaluating the effectiveness of current services and in prioritizing the needs for the development of new services. As health care professionals are able to meet caregiver needs, caregivers in turn will be able to meet patient needs. However, allowing the caregiver to focus too strongly on the personal care demands during caregiving may limit psychosocial supportive interventions that are more helpful to the ultimate outcome of caregiver well being. Using the knowledge obtained in this study, nursing will be able to improve services and to provide total care to families of terminally ill patients.

## Chapter II

### REVIEW OF THE LITERATURE

#### Introduction

Studies on the needs of patients and their families are becoming increasingly common in the literature. As we struggle with health care reform, it will become more important to know how to best use our health care dollars for the most efficient provision of service. It is with the purpose of understanding the needs of caregivers of advanced cancer patients, that the literature review is being completed. The review will be divided into three sections: the perceived needs of the caregivers of hospitalized cancer patients; the perceived needs of caregivers of patients receiving outpatient palliative treatment; and the perceived needs of caregivers of terminally ill patients in a home care setting.

#### Perceived Needs of Caregivers of Hospitalized Cancer

##### Patients

Hampe (1975), in her classic study of the needs of spouses of terminally ill patients, was a pioneer in the study of needs. The purpose of the study was to determine if spouses of the terminally ill could recognize and identify their own needs and if spouses perceived nurses as having helped meet their needs.

Twenty-seven spouses, whose mates were diagnosed with a terminal illness, were interviewed. Taped, semistructured interviews with open-ended questions were administered to discover the needs of the grieving spouses. The initial interview was conducted in the hospital and the second interview was completed in the home 3 to 12 weeks after the death of the spouse. Eighteen mates subsequently died and 14 of the widowed spouses had a second interview. This two phase data collection was chosen by the researcher to understand the needs during anticipatory grieving and to see if the death altered the perception of needs.

Eight needs of grieving spouses were identified and ranked as follows:

- 1) to be with the dying person
- 2) to be helpful to the dying person
- 3) to be informed of the mates condition
- 4) to receive assurance about the comfort of the dying person
- 5) to be informed of impending death
- 6) to ventilate one's emotions
- 7) to receive comfort and support from the family members
- 8) to receive acceptance, support, and comfort from health professionals.

During the initial interview twenty-five spouses identified all 8 of the needs and the other 2 spouses

identified 5 and 7 needs respectively. Identification of the need did not necessarily mean the need was met.

Spouses believed that nurses had been helpful to the mates and 87% of the spouses perceived their needs on the second interview to be the same as their needs on the first interview. Interestingly, "...spouses felt that nurses were too busy to help the families" (Hampe, 1975). Suggestions for further research included a study with a heterogeneous and a critically ill population.

In 1984, Wright and Dyck conducted further research using a descriptive exploratory study of 45 next-of-kin of hospitalized patients throughout the cancer experience. A twelve-item Likert type need scale and a semistructured interview with three equal groups of patients at various stages of illness were completed. The four concerns identified most frequently in the interviews were:

- 1) problems created by the symptoms of the disease
- 2) fear of the future
- 3) waiting
- 4) difficulty with obtaining information

The highest priorities in the need scale were:

- 1) to be informed of patient's condition
- 2) to be assured patient is comfortable
- 3) to be informed of any changes
- 4) to be with the patient as much as possible
- 5) to communicate with the patient

These responses reinforced the comments made during the interview and supported Hampe's (1975) study findings.

**Perceived Needs of Caregivers of Patients Receiving  
Outpatient Palliative Treatment**

Oberst, Gass and Ward (1989) described the caregiving demands on families of ambulatory patients receiving outpatient radiation treatment at a cancer center in the midwest. The study involved 47 family members. The majority of caregivers were women who had been caring for spouses an average of 17 months.

The Appraisal of Caregiving Scale, a 53-item instrument derived from cognitive appraisal theory, was administered to measure the meaning of illness in terms of four appraisal dimensions: harm/loss, threat, challenge, and benign. The Caregiver Load Scale was used to measure caregiving demand. Fifty of the 68 questionnaires distributed were returned.

Caregivers reported the most time and effort spent on providing transportation, emotional support, and managing extra household tasks. Although 40% of the caregivers rated the patients as very or fully dependent, the least effort was reported in personal care, assisting with ambulation and treatment administration. The primary source of help was reported as family and friends.

Results on the Appraisal of Caregiving Scale found that the mean appraisal scores were highest for the

challenge subscale and lowest for harm/loss subscale. Caregivers with the lowest social status and poorest health reported greater perception of harm/loss. Greater threat scores were found with lower caregiver education and lower social status. Older caregivers saw their circumstances as more of a challenge and more benign than younger caregivers. It was also found that greater time spent in caregiving meant a greater perception of harm/loss and threat.

While ambulatory radiation patients are generally seen as functioning somewhat independently, families saw themselves clearly as caregivers. It was further reported that the length of treatment/illness increases the intensity and stress of caregiving. This is an important point to keep in mind, especially when many families go from a treatment modality to a terminal phase quickly. This intensifying of the load over time may mean that, in some cases, caregivers go on to manage terminal care in an exhausted state.

Home care needs of cancer patients receiving outpatient treatment and their caregivers were also studied by Blank, Longman and Atwood (1989). The sample of eight patients and their caregivers were chosen from a cancer center in Arizona. The questions that the study attempted to answer were in relation to the care needs of cancer patients, the care needs of caregivers of cancer patients,

and the difference between the needs of patients and caregivers.

Separate interviews were conducted with patients and with caregivers to answer, among other things, "What do you consider your major problem, stress area, or areas of concern? Content analysis was used to group the data according to intrapersonal stressors, interpersonal stressors, and extrapersonal stressors.

The needs that were identified by caregivers were:  
Intrapersonal - anxiety over the unknown, role conflict and overload, fear of being alone, respite from caregiving, guilt from not being with the patient enough;

Interpersonal - lack of family support, decreased interaction with patient, personal care needs, limited knowledge of patient's condition;

Extrapersonal - transportation and finances.

Several areas were reported by both patient and family. Those areas were: treatment information, support with role change and social needs, transportation, and finances. The authors felt that the needs identified in the study could be used in providing the basic data for future development of needs assessment tools.

In 1992, those same authors expanded their study of home based patients receiving cancer treatment and their caregivers (Longman, 1992). This study was also involved

in developing scales to measure care needs of home based patients.

The sample consisted of 30 patients receiving radiation or immunologically based treatment and 29 caregivers. There was no homogeneity in relation to stage of disease and treatment; however, subjects were relatively independent in their activities of daily living.

The Caregiver Need Scale, under development by the authors, was composed of ninety items in areas of personal care (28 items), activity management (13 items), involvement with health care (19 items), work (2 items), interpersonal interaction (21 items), and finance (7 items). The importance of needs was rated on a scale of 1 to 10 from lowest to highest. The interpersonal interaction category was rated first by caregivers; however, there were great differences among caregivers in the number of perceived needs. Caregivers in this study reported six "very important" needs as defined by greater than 50% of caregivers rating at nine or above on the scale. Those needs were: assurance of patient's comfort, assistance with physician orders, maintaining awareness of patient's condition, inpatient admission if necessary, available emergency help, and awareness of changes.

Caregivers felt that 71% of their needs were met. No patterns were seen in the unmet needs except that caregivers, overall, had more unmet needs in the areas of

personal care, activity management, and interpersonal interaction. This study demonstrated clearly that caregivers can identify their needs and also can identify whether those needs were met or unmet. It further documented that caregivers and patients "had many needs that were important enough to warrant attention".

Also in 1992, Hileman, Lackey and Hassanein studied 492 home caregivers of patients with cancer (Hileman, Lackey, & Hassanein, 1992). The primary purpose of the study was to categorize and assess the importance of needs expressed by home caregivers and to determine how well those needs were satisfied. Caregivers surveyed were selected from two hospital outpatient oncology clinics and two nonprofit community cancer agencies in the Midwest.

The survey instruments used included the Home Caregiver Need Survey (HCNS), the short version of the Karnofsky Performance Status Scale, and a patient and caregiver information sheet. The HCNS is a 90 item, six dimension, self-report survey which allowed the respondents to rate both the importance and the satisfaction of each need statement. The Karnofsky Performance Status Scale was used to measure the level of activity of the cancer patient and the patient and the caregiver information sheet was developed to gather information on the caregiver and the patient.

Patients were contacted by phone or in person by

trained volunteers. Patients identified their caregivers after definitions and purpose were described to them. The caregivers were then contacted by phone, in person, or by mail and asked to complete the three instruments and return them. The surveys were mailed out in three phases with decreasing return at subsequent phases. The decrease in return was explained as being due to the number of caregivers that were no longer in the role of caregiver because they lived out of state and returned home or the patient died.

The study found that 66% of the caregivers were women, showing the upward trend toward male caregivers. Most of the caregivers were married, almost half had education beyond high school and 10% had postgraduate education. Almost half of the caregivers worked part or full time. More than 80% described their health as good or excellent. Most caregivers were in the role for 1-12 months. Almost 75% lived with the patient and more than 50% had incomes of \$20,000.00 or less.

The greatest needs of the caregiver fell mainly in two areas: informational and psychological. Items seen among the top ten needs were:

- 1) information about community resources
- 2) what to expect in the future
- 3) underlying reasons for symptoms
- 4) ways to reduce stress

#### 5) honest and updated information

It was found that when the patient's activity level decreased, a caregivers' psychological, patient care, personal, and household needs increased. Low-income caregivers had more household needs and fewer informational needs. Younger caregivers reported more psychological and personal needs than older caregivers. Most of the caregivers' needs changed over time, however, spiritual needs changed the least.

#### Home Based Terminally Ill Cancer Patients

Holing (1986) described the caregivers' perceptions of the dying trajectory and the identification of periods of greatest intensity. Fourteen caregivers of terminally ill persons were recruited from two home care agencies. They were interviewed within 12 months of the patients' death. The interview guide included open-ended and directed questions evolving from the literature review. Sixty-six critical events identified by the caregivers were categorized, using content analysis, into two major categories and 17 subcategories. The two major categories were: concerns perceived by the caregiver as stressful, and concerns perceived as joyful or positive. Seventy percent of the identified events were perceived as stressful and 30% were perceived as joyful. In the stressful category, 43% of the caregivers reported feelings of inadequacy or

exhaustion in regard to personal care issues. They also reported the difficulty in "watching the patient experience physical problems". Not only is symptom control important, but sensitivity to the effect of the symptoms on the family is an important aspect of care. The emotional energy required for caregiving was reported to be greater overall than the physical energy required. Caregivers identified 64% of the events as requiring an exceptional amount of emotional energy and 25% of the events as requiring exceptional amounts of physical energy. In regard to joyful events, 57% described the closeness they experienced and the satisfaction they received from caregiving. This study once again points to the mixed blessing of caregiving and the importance of helping the caregivers find some joy or meaning during this time.

These mixed blessings were further studied by Foster (1987) in an attempt to discover what services were expected and what information was needed by caregivers and the extent to which caregivers were informed of, and satisfied with, the services provided. The study retrospectively explored the perceptions of 47 caregivers from four community based hospices in urban areas of Michigan. The interview guide consisted of 99 items divided into three sections which included demographic information, orientation and understanding of hospice services, and expectation and satisfaction with hospice

services. The needs for service were reported as:

- 1) emotional support with caring for patient
- 2) someone to talk over care periodically
- 3) home medical monitoring
- 4) assistance with direct nursing care.

Top priorities for caregiver needs were good communication with hospice staff and having someone available to answer questions over the phone anytime, emergency 24 hour home care, and assistance in direct nursing care at regular intervals. Caregivers preferred that staff be on standby to intervene directly on behalf of emotional and medical/physical support needs, as opposed to educational instruction as to how to be more self reliant. Few caregivers expected spiritual guidance, education about funeral arrangements, transportation services, and financial and legal planning assistance. Major findings in this study support the idea that caregivers are as much receivers as they are givers and that as health care professionals are able to meet caregiver needs, caregivers in turn will be able to meet patient needs.

Kathleen Stetz (1987) examined spouses' needs during caregiving of 65 advanced cancer patients recruited from home care agencies in the Northwest. Advanced cancer was divided into advanced stable and advanced progressive. Only 13% of the patients were receiving treatment. Scores on the Zubrod Scale, a determinant of physical disability,

indicated that the patients were generally confined to bed and needed assistance with activities of daily living. The spouse caregivers reported an average of 23.16 hours spent in the home per day, seven days a week. Qualitative data was collected in taped interviews using the Experience of Caregiving Interview Schedule. The content of the data was analyzed and coded into nine mutually exclusive categories of care giving demands. Many of the categories, such as life style changes required to manage personal care, managing the household, constant vigilance, and information about the cancer itself, have been recorded in previous research. One new area of interest was termed, "standing by", and was defined as "observing the spouse's experienced illness". Thirty-nine percent of the caregivers reported this demand. This study also found that male caregivers were more concerned with managing personal care and the household, while female caregivers were more concerned with their inability to control the deterioration in the patient's condition. Concerns about the future were reported by only 9% of the caregivers. This report is in contrast to an earlier study by Krant and Johnston who reported fear of the future more frequently than limitations in patterns of daily living (Krant & Johnston, 1978).

In 1992 Stetz expanded the study to include a longitudinal exploration of perceived alterations in

caregiving demands during and after the caregiving experience (Stetz & Hanson, 1992). Thirty-one of the original sample of caregivers from the 1987 study volunteered to participate in this study. The 31 bereaved spouses were contacted a minimum of six months following the first interview to determine if there were any changes in perceptions of caregiving demands over time. All patients had died two to nine months prior to the second interview. While five of the original eight demand categories remained prominent, some differences were noted in other areas. The greatest demand during caregiving was managing the physical care. After death, standing by and observing the slow deterioration was remembered as most difficult by both sexes. Additional areas of concern in the second interview that were not mentioned in the first interview were challenged judgements, timing of the ill spouse's death, and turning over control. In response to the question, "What, if any, things would you do differently?" 51% of the respondents indicated they would have accepted more help. That help consisted of, for the most part, additional "how to care" information as well as direct personal care.

This study clearly demonstrated that perceived needs of caregivers may change over time. Health care professionals need to be aware of this fact in order to provide the holistic approach required in terminal care.

Allowing the caregiver to focus too strongly on the demands during illness may limit supportive interventions that are more helpful to the ultimate outcome of caregiver well-being. Because 51% of the caregivers, in retrospect, reported that they would have used more help, it is important that the health care professionals encourage assistance during caregiving as a positive step toward retaining the caregiver in his or her role.

Several home care studies identified the needs of caregivers by looking at the issue from the perspective of the patient and/or the nurse, as well as the caregiver. Wingate and Lackey (1989) developed a study with the intention of using naturalistic inquiry to determine actual needs described by the patient and the caregiver. Three groups - 10 home care cancer patients, 14 caregivers, and 9 nurses, were asked to list their perceptions of the needs of cancer patients and their caregivers. Each group was asked to complete an appropriate open ended question related to :

What are cancer patient's needs?

What are caregivers of cancer patients needs?

A total of 622 responses were generated, with 264 of those generated being caregiver needs. The responses were categorized into six patient needs and the same six caregiver needs plus one additional need. The six categories were:

- 1) information needs
- 2) household management needs
- 3) physical needs of patient
- 4) psychological needs
- 5) spiritual needs
- 6) legal or financial needs
- 7) for caregivers - respite needs.

Caregivers rated their respite needs lower than the patient or the nurse. Of the 264 caregiver needs, 30% related to psychological concerns. The study mentioned the disparity between the three groups and stressed the importance of getting information from the primary source rather than others who assume they know the needs.

Margaret Hull (1991) examined caring behaviors of hospice nurses as perceived by family caregivers over the course of the caregiving experience. Fourteen family members from 10 different families were studied. The interviews focused on the needs that families identified as most and least important in caring for the dying relatives, nursing behaviors they found most and least helpful, and their perceptions of the role of the hospice nurse. Discussion centered on four areas of needs:

- 1) 24 hour accessibility and availability
- 2) effective communication skills
- 3) caring and nonjudgmental attitudes
- 4) competence as practitioners

The study stressed that nurses can have an effect on lowering the anxiety levels of patients and caregivers.

Patricia Ryan (1992) also looked at nursing behaviors as perceived by the caregiver and the hospice nurse. The study consisted of 20 caregivers and 5 nurses. A Q-sort methodology was used, consisting of 60 nursing behaviors that were divided by the researcher into three classifications related to patient's physical needs, patient's psychosocial needs, and caregiver's psychosocial needs. The category that related to meeting the psychosocial needs of the patient was seen by both nurse and caregiver as significantly more helpful than the other categories. The most helpful nursing behaviors were:

- 1) Listen to what the patient wants
- 2) Provide the patient with emergency measures
- 3) Assurance that nursing services will be available 24 hours a day, 7 days a week.
- 4) Answer questions honestly.
- 5) Talk to the family to reduce fears.
- 6) Provide information needed when death occurs
- 7) Stay with the patient during difficult times
- 8) Teach family how to keep the patient comfortable

### Summary

The literature indicates that caregivers can identify their needs and can rank them in order of importance. Although priorities of needs changed with the

population studied, there were significant similarities in many of the research articles. Two of the high ranking needs were the need to know about changes in condition and the need to be assured of the patient's comfort. The prognosis of a terminal illness is among the most stressful events that can happen to a family. The high stress of caring for a terminally ill cancer patient must be acknowledged, and interventions must be tailored for these patients with the protection of the caregiver in mind.

Although the literature has proven that families can identify their needs and rank them in order of importance, many of the studies have taken a rather narrow look at needs. Most of the studies conducted to identify the needs of home caregivers have been descriptive. Previous studies have asked open-ended questions with limited number of participants in varying phases of illness. Few studies looked at the changes in perceived needs over time. A thorough search of the literature also revealed limited tools to specifically measure the individual needs of the caregivers. The intent of this study is to look at a broad group of specific caregiver needs during and after the terminal care experience. Most patients admitted to hospice are limited in their activities of daily living, are no longer receiving aggressive treatment, and have chosen to receive only comfort measures.

## Chapter III

### METHODOLOGY

#### Introduction

This chapter will discuss the theoretical basis of the study, the study design, study variables, instrumentation and the study questions. Accounts of the data collection will be given, as well as a short summary of the statistical procedures that were used. The assumptions and limitations of the study will also be discussed.

#### Theoretical Basis of the Study

Nursing's Human Need Theory (Yura & Walsh, 1988) will offer the framework for this study. Originating from international needs research, the theory identifies thirty-five human needs and groups them as survival needs, closeness needs, and freedom needs. Although individual needs are defined and described, the theory views the individual in a holistic approach.

The theory propositions were developed in relation to the four major nursing concepts of human beings, society/environment, health, and nursing. The purpose of nursing, to contribute to the client's quality of life and maximize his/her resources, is inherent in attempting to meet specific needs of the client, family, and community. Only as all the components interact in a concerted effort to arrive at human need fulfillment, can the goal be

reached. The theory further suggests that alterations in human need fulfillment in the extreme are coexistent with illness and death and that human need fulfillment at the other end of the spectrum is synonymous with maximal wellness. "It is believed that the preservation of, the fostering of, the maintenance of, and the facilitation of the integrity of all human needs of person(s) is the territory of nursing" (Yura & Walsh, 1988 p.70).

Families experiencing the stress of a terminal illness have many needs. Assessing the needs of caregivers is a vital component in family needs fulfillment. In order for these needs to be optimally met, the nurse and the family must have congruent perceptions of the unmet needs. Communication and adequate assessment allows for setting mutual goals and ultimate attainment of needs fulfillment.

#### Problem Statement

The purpose of this study was to describe anticipated and retrospective needs expressed by caregivers of terminal cancer patients cared for at home. The study will further determine if perception of the demands of caregiving change over time. Looking at needs longitudinally and comparing the anticipated needs with the retrospective needs should give a more complete picture of the total caregiving experience. The findings of this study may be used to give direction to hospice in evaluating effectiveness of current services and in prioritizing the needs for the development

of new services.

### Study Design

A longitudinal descriptive design was used to complete this project. Descriptive research allows the "phenomena to be described rather than explained" and provides the opportunity for the "human experience to be revealed without preconceived restrictions" (Polit & Hungler, 1991, p.144). Longitudinal studies, such as panel studies, allow data collection using the same subjects at more than one point in time (Polit & Hungler, 1991, p.244). A Likert type questionnaire was used to describe the affective domain.

### Research Questions

The following research questions will be addressed:

1. What are the anticipated needs identified by the caregivers during the initial phase of the hospice caregiving experience?
2. What are the retrospective needs identified by the caregiver after the caregiving experience?
3. Is there a significant difference between the anticipated needs expressed by caregivers and the needs expressed by the same caregivers retrospectively?
4. What is the relationship between the surveyed characteristics of the caregivers and the needs expressed by the caregivers?

### Study Population

As the population is the entire set of individuals that meet a common set of criteria (Polit & Hungler, 1991, p.25), the population for this research project was caregivers of terminally ill cancer patients admitted to Delaware Hospice. Delaware Hospice is a Medicare certified hospice licensed in the state of Delaware. Services are provided statewide with offices located in each of the three counties.

### Study Sample

A convenience sample of those families admitted to Delaware Hospice was used. All persons listed on the Delaware Hospice record as the primary caregivers of a patient diagnosed with cancer were included in the study. After explaining Delaware Hospice services and obtaining consent for admission, the assessment nurse explained the purpose of the study and invited participation of all those meeting the criteria. Only if the caregiver appeared to be having an extremely difficult time dealing with the situation did the assessment nurse not approach the caregiver about participation in the study. If the assessment nurse perceived increased stress when talking to the caregiver about the study, the caregiver was not invited to participate. Participation in the study was completely voluntary.

### Study Variables

The variables essential to this study are defined as follows:

1. Need: An internal tension that results from an alteration in some state of the system (Yura & Walsh, 1988, p.70)

Anticipated need: A requirement identified prior to initiation of hospice services.

Retrospective need: A requirement identified after the caregiving experience is completed.

A 90 item Caregiver Needs Scale developed by Judy Willis Hileman in 1990 was given to caregivers to determine identified need.

2. Caregiver: The person listed on the Delaware Hospice record as primarily responsible for assisting with the patient's self care deficits without receiving remuneration.
3. Terminally ill: A cancer diagnosis with a physician approval of admission to Delaware Hospice because of a probability of metastasis and/or a limited life expectancy of six months or less.
4. Hospice: An agency that provides home care services to the terminally ill through an interdisciplinary team composed of a physician, registered nurse, social worker, pastor, and

volunteer.

5. Health care professional: Any professional member of the hospice interdisciplinary team.

### **Instrumentation**

The instrument to be used in this study is a modified version of the Home Caregiver Need Survey developed by Judy Willis Hileman in 1990. The original instrument had 90 closed-ended items generated from 531 needs statements that were gathered from prior research. The items were ranked on a seven point Likert-type scale ranging from 1 meaning not important to 7 meaning very important. Through content analysis, Hileman sorted the need statements into the seven caregiver need categories developed by Lackey and Wingate (1989). Replications and cross duplications were then identified and omitted. Initial content and face validity for the instrument were obtained throughout the process of item development. To establish interrater reliability among three nurse researchers and three English experts, percent of agreement was calculated for each need item. Overall agreement was 90% on all items. Principal Factor Analysis with Promax Rotation was used to examine construct validity for the instrument. This procedure clearly defined six need categories which represented only a slight revision of the Lackey-Wingate categories. The instrument was found to be internally consistent with

category coefficient alphas ranging from .85 to .97.

As the population being studied was generally older and possibly somewhat confused because of the changes taking place in their lives and because of the emotional stress caused by the terminal illness, it was felt that simplifying the instrument by minimizing degrees of choice would give a more valid and accurate assessment of the perceived need. The importance of the need for this study were thus ranked on a four point Likert-type scale (Appendix). The scale ranged from 1 meaning not important to 4 meaning very important.

The instrument included a disclosure form explaining the purpose of the study, requesting the caregiver's participation, and assuring confidentiality and continued provision of high quality service to the family regardless of participation in the study. Demographic information collected included: gender; age; race; education; household income; work status; health status; county/city of residence; length of time in caregiving; relationship to patient; and timing of referral to hospice in relation to stage of disease. This information was collected to explore the relationships between caregiver characteristics and caregiver needs.

### Research Methods

Data were collected during the fall of 1993 and the

spring and summer of 1994. The assessment nurse in each division of Delaware Hospice was responsible for disseminating the questionnaire during the initial assessment visit. The principle investigator met with each of the assessment nurses to explain the purpose of the study and to give them an opportunity to review the demographic sheet and the questionnaire. Any questions that they had were answered at that time or any time during the research.

After explaining the nature of the research and answering any questions the caregiver may have had, the assessment nurse invited participation of the caregiver. The nurse emphasized that the hospice care team would not be informed as to who agreed to participate in the study and who declined the invitation. Furthermore, the caregiver's decision in regard to participation would in no way affect the services they or their families received from the hospice program. If the caregiver agreed to participate, the assessment nurse gave the questionnaire in a sealed envelope with instructions to complete, place in the self addressed stamped envelope, and mail within five days. The questionnaire was returned by mail to the researcher. Only caregivers of patients diagnosed with cancer were included in the study. Patients' names and caregivers' names and addresses were obtained to prepare for completing the second questionnaire.

One to two months after the death of the patient, the caregiver was sent the same questionnaire to complete. The purpose of the second administration of the questionnaire was to determine if perceptions of needs change over time.

### Data Analysis

Once the data was collected it was coded and cleaned. The researcher performed frequency analysis to determine a mean value for each caregiver response during caregiving as well as after the experience.

Numerical values were assigned according to the degree of importance of the need. The values ranged from 1, meaning not important, to 4, meaning very important. The data were collapsed and the means and standard deviations for the ninety need statements were calculated separately for the first survey (during caregiving) and the second survey (after caregiving). Mean subscores for each need category were also computed. A t-test for paired samples was completed to determine if a significant difference at the 0.05 level existed between the mean value of responses on the two surveys. A Wilcoxon rank sum test was also completed on the data. After reducing each characteristic to two categories, a t-test for independent samples was completed.

### Ethical Implications

Consent for the study was obtained from the Human Subjects Committee at Salisbury State University and the

Research Committee at Delaware Hospice. Informed consent was obtained from the subjects prior to completion of the survey.

Participation in the study was completely voluntary. Although the researcher knew the patient's name, information obtained after that point remained anonymous. The importance and reason for the study was explained and a cover letter was used to reiterate the explanation and what was being asked of the participants. It is acknowledged that dealing with the terminal illness of a family member can be stressful. It is further acknowledged that questioning caregivers about their needs at this time could cause further stress. If the caregiver appeared to be having an extremely difficult time dealing with the situation, the assessment nurse did not approach the caregiver about participation in the study. If the assessment nurse perceived increased stress when talking to the caregiver about the study, the caregiver was not invited to participate. Although an attempt was made at the initial interview to assess and minimize the stress that participation in study might cause, the mailed second survey did not allow for the assessment of increased risk. However, no reports of increased stress were received. No other risks of participation were anticipated.

#### Assumptions and Limitations

The assumptions of this research included the thought

that all caregivers are able to assess their own needs. It further assumed that caregiving creates many physical and psychological stressors and that the role of the health care professional in caring for the terminally ill includes attention to the needs of the caregiver.

The limitations of this research included the idea that the sample of convenience may not be representative of the population. All participants in this study were voluntary, thus causing the sample to be biased and not generalizable.

#### Summary

Chapter Three presented the methodology used in this study. The theoretical framework, instrument, study design, sample, study variables, and study questions were presented. The ethical implications, assumptions and limitations of the study were briefly outlined, and research methods and data collection were discussed.

## CHAPTER IV

### Data Analysis

#### Introduction

In this chapter, the demographic characteristics of the study sample will be described and the data which was collected will be analyzed. The four research questions presented in Chapter Three will be addressed individually. The Statistical Package for Social Sciences (SPSS-X) has been utilized to analyze the results of the data collection.

#### Demographic Description of the Study Sample

Inclusion in this study sample was limited to the families admitted to Delaware Hospice between November 1993 and September 30, 1994. Persons listed on the Delaware Hospice record as the primary caregivers of a patient diagnosed with cancer were requested to participate in the study. Participation remained totally voluntary and did not impact on the care received.

Of the 189 families eligible to complete the survey, 124 families (66 percent) were approached during this time to participate in the study. If the assessment nurse perceived increased stress and/or difficulty dealing with the experience, the survey was not presented to the caregiver. This occurred in 65 (34 percent) cases.

Of the 124 families who received the surveys, 52 (42 percent) families completed both surveys and were eligible

for inclusion in the study. Four of the surveys returned were completed only after the patient's death. Twenty-two of the surveys were completed during the caregiving experience but not completed after the caregiving experience. The remaining 46 families failed to return the first survey. A summary of the demographic characteristics of the sample is given in Table 1.

Most of the caregivers in this study were female (80.8%) and were over the age of 56 (57%). The majority of the caregivers were white (86.5%) and spouses (50%). The next most frequently occurring relationship was that of a child as the caregiver (35%). More than 69% of the caregivers did not work and 77% spent greater than 16 hours a day in caregiving. Most caregivers (84%) described their health as good or excellent. Eighty-six percent of the caregivers said that the referral was soon enough. Just over half (56%) of the caregivers spent less than six months in caregiving. Sixty-seven percent of the caregivers have a high school or less education and 38% of the caregivers have an income of less than \$19,000.00 annually.

### Instrument

The instrument used in this study is a modified version of the Home Caregiver Needs Survey (HCNS) developed by Judy Willis Hileman in 1990. The original instrument had 90 closed-ended statements incorporated from previous

Table 1:

**Demographic Characteristics of Sample Subjects**

<b>Characteristic</b>	<b>Caregivers</b>	<b>Percent</b>
<b><u>GENDER</u></b>		
male	10	19.2
female	42	80.8
TOTAL	52	100.0
<b><u>AGE</u></b>		
under 40	10	19.2
40 - 55	7	13.5
56 - 65	18	34.6
Over 65	17	32.7
TOTAL	52	100.0
<b><u>RACE</u></b>		
white	45	86.5
black	5	9.6
other	1	1.9
Missing	1	1.9
TOTAL	52	100.0
<b><u>RELATIONSHIP</u></b>		
spouse	26	50.0
child	18	34.6
parent	2	3.8
brother/sister	2	3.8
friend	2	3.8
other	2	3.8
TOTAL	52	100.0
<b><u>HOURS OF CAREGIVING</u></b>		
less than 4	3	5.8
4 - 15	8	15.4
greater than 16	40	76.9
Missing	1	1.9
TOTAL	52	100.0
<b><u>COUNTY OF RESIDENCE</u></b>		
City of Wilmington	2	3.8
New Castle County	16	30.8
Kent County	12	23.1
Sussex County	22	42.3
TOTAL	52	100.0

Table 1: (continued)

<b><u>WORK</u></b>		
none	36	69.2
full time	8	15.4
part time	8	15.4
<hr/>		
TOTAL	52	100.0
<b><u>HEALTH</u></b>		
excellent	14	26.9
good	30	57.7
fair	4	7.7
poor	4	7.7
<hr/>		
TOTAL	52	100.0
<b><u>TIME IN CAREGIVING</u></b>		
less than 6 months	29	55.8
6 - 12 months	11	21.2
13 - 24 months	5	9.6
greater than 24 months	5	9.6
Missing	2	3.8
<hr/>		
TOTAL	52	100.0
<b><u>REFERRAL</u></b>		
too soon	1	1.9
soon enough	45	86.5
not soon enough	5	9.6
Missing	1	1.9
<hr/>		
TOTAL	52	100.0
<b><u>EDUCATION</u></b>		
highschool or less	35	67.3
college or above	17	32.7
<hr/>		
TOTAL	52	100.0
<b><u>INCOME</u></b>		
less than 19,000	20	38.5
20,000 - 29,000	5	9.6
30,000 - 49,000	14	26.9
greater than 50,000	4	7.7
Missing	9	17.3
<hr/>		
TOTAL	43	100.0

research to be ranked by the caregiver in importance on a scale of 1-10, where 1 = not important and 10 = very important. Permission for use and a copy of the complete questionnaire was obtained from the author. The instrument was found to be internally consistent with category coefficient alphas ranging from .85 to .97.

Modification of the instrument was completed in order to simplify the completion process. Several of the needs statements were further clarified with direction from a panel of experts. Modification also included the reduction of the scale to 4 choices where 1 = not important and 4 = very important. A reliability analysis was completed on the modified version of the scale. The modified version was found to have category coefficient alphas ranging from .84 to .95.

### Caregiver Needs

The caregivers were asked to rank each of the 90 need statements as not important, slightly important, important, or very important. Caregivers were asked to rate the perceived importance of the need during and after caregiving. Table 2 thru Table 7 show the need statement items categorized according to the Home Caregiver Needs Survey for the period during caregiving as well as the period after caregiving.

The data were collapsed in order to increase the frequencies in each choice category. To accomplish this

the choice categories of not important and slightly important were combined. The frequencies and mean scores were then computed from this data. The computed mean scores, standard deviation and rank for each item appear on the noted Tables. The description of the top needs in each of the following examples was determined by a naturally occurring gap in the statistical information.

Table 2 contains the need items included in the category of Needs Involving Information. The top seven information needs during caregiving identified by caregivers were in order of importance: physical needs of my patient; honest and updated information; type and extent of my patient's illness; how to give medication; information about treatment side effects; what symptoms to expect; and medication effects and schedules. The same seven information needs were identified by the caregiver after caregiving. However, there was a change in the importance. After caregiving the needs identified in order of importance were: medication effects and schedules; what symptoms to expect; physical needs of my patient; honest and updated information; information about treatment side effects; how to give medications; and type and extent of patient's illness. One of the most significant differences in these two lists is that medication effects and schedules moved from 6th place to 1st place. An equally significant difference was seen as the need item, type and extent of

Table 2:  
**NEEDS INVOLVING INFORMATION**

Mean score, standard deviation and rank for Caregiver Needs

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Medications effects and schedules	3.62(.57)	6	3.81(.49)	1
Information about treatment side effects	3.65(.56)	4	3.67(.58)	5
Underlying reasons for symptoms	3.31(.73)	9	3.46(.73)	9
What symptoms to expect	3.63(.60)	5	3.79(.46)	2
How to contact physician	3.56(.64)	7	3.37(.77)	10
Honest and updated information	3.77(.47)	2	3.73(.49)	4
Physical needs of my patient	3.78(.46)	1	3.75(.52)	3
Information about therapies	3.23(.78)	10	3.12(.73)	13
Information about drugs	3.50(.64)	8	3.52(.67)	8
Helping to trust caregiving abilities	3.56(.64)	7	3.27(.84)	11
Type and extent of my patient's illness	3.77(.47)	2	3.58(.64)	7
How to give medications	3.67(.55)	3	3.62(.60)	6
Ways to inform children of illness	3.04(.77)	12	2.96(.86)	14
Ways to cope with role changes	2.98(.80)	13	2.88(.70)	15
Sitters to be with the patient	3.17(.79)	11	3.19(.74)	12
Total Category Subscore	51.92(5.50)		51.71(6.23)	
Mean Category Subscore	3.46		3.44	

patient's illness, moved from second place to 7th place.

The category of Needs Involving Your Household lists the need items included in that category in Table 3. The top six needs identified by caregivers during caregiving were: emergency number available; help with physical care from a neighbor or volunteer; time for self away from house; information about community; help with errands; and professional counseling. Those same need items were identified by the caregivers after caregiving with very little change in order of importance. They were: emergency number available; help with physical care from a neighbor or volunteer; time for self away from house; help with errands; information about community; and professional counseling. The only difference in these two lists were the interchange of need items number 4 and 5.

Table 4 identifies the need items included in the category of Patient Care Needs. The top six needs in order of importance as identified by caregivers during caregiving were: home visits by professionals; ways to keep patient comfortable; methods of pain control; RN or HHA help with patient's physical care; not leaving patient alone; and ways to provide adequate nutrition. Many of the same needs were identified after caregiving. They were: RN or HHA help with patient's physical care; home visits by professionals; ways to keep patient comfortable; ways to improve patient's appearance; not leaving patient alone;

Table 3:

**NEEDS INVOLVING YOUR HOUSEHOLD**

Mean score, standard deviation and rank for Caregiver needs

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Help with errands	2.60(.75)	5	2.71(.72)	4
Help with housework	2.39(.60)	8	2.43(.67)	9
Help with transportation	2.38(.69)	9	2.41(.70)	10
Help with yard work	2.17(.47)	12	2.13(.40)	12
Emergency number available	3.73(.49)	1	3.73(.60)	1
Help with physical care from a neighbor or volunteer	3.02(.78)	2	2.90(.82)	2
Time for self away from house	2.83(.81)	3	2.80(.80)	3
Help continuing children's activities	2.36(.66)	10	2.52(.74)	8
Caregiver Support group	2.46(.64)	7	2.54(.75)	7
Professional counseling	2.56(.80)	6	2.57(.85)	6
Help with baby sitting	2.25(.59)	11	2.26(.56)	11
Information about community	2.63(.71)	4	2.62(.75)	5
Total Subscore for the category	31.21(4.98)		31.21(4.99)	
Mean Subscore for the category	2.60		2.60	

Table 4

**PATIENT CARE NEEDS**

Mean score, standard deviation and rank for Caregiver Needs

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Ways to help patient maintain some independence	3.46(.67)	10	3.50(.61)	7
Ways to keep patient comfortable	3.79(.46)	2	3.79(.54)	3
Information about which liquids are best	3.50(.61)	8	3.37(.74)	11
Ways to provide adequate nutrition	3.60(.60)	6	3.46(.73)	8
Methods of pain control	3.79(.54)	3	3.85(.46)	1
Activities to make patient feel purposeful	3.46(.71)	11	3.19(.82)	14
Ways to deal with decreased energy	3.44(.67)	12	3.25(.82)	13
Information about how to get patient to eat	3.46(.67)	10	3.38(.80)	10
Ways to dress patient comfortably	3.19(.69)	14	3.15(.83)	15
Equipment to help with patient care	3.48(.64)	9	3.44(.67)	9
Ways to reassure patient	3.52(.61)	7	3.52(.67)	6
RN or HHA help with patient's physical care	3.69(.58)	4	3.85(.46)	1
Ways to improve patient's appearance	3.00(.77)	15	2.79(.89)	4
Ways of coping with patient's diagnosis	3.33(.71)	13	3.31(.67)	12
Not leaving patient alone	3.65(.59)	5	3.69(.54)	5

Table 4: (continued)

Home visits by professionals	3.81(.44)	1	3.83(.43)	2
<hr/>				
Total Subscore for the category	55.98(6.06)		55.31(7.24)	
Mean Subscore for the category	3.499		3.457	

and ways to reassure patient. The most significant change in this area was that improving patient's appearance moved from 15th to fourth place after the caregiving experience. Home visits by professionals was also replaced in the first place position by RN or HHA help with patient's physical care.

The need items identified in the category of Personal Needs are listed in Table 5. The top six needs for this item during caregiving in order of importance were: caring and interested professionals; support from family; support from friends; understanding from patient; maintaining health; and adequate sleep. The top six needs after caregiving were: caring and interested professionals; support from family; support from friends; maintaining health; adequate sleep; and someone with whom to talk.

Table 6 reflects the need items in the Spiritual Needs category. The most important need during and after caregiving was: strong faith in God. The most significant difference in the two lists was the increasing importance of personal prayer after caregiving.

The category of Psychological Needs is presented in Table 7. The top seven needs during caregiving in this category were: information on hospice care; way to encourage patient, feedback that giving proper care; information about patient's psychological needs; information about what to expect in the future; information

Table 5:

**PERSONAL NEEDS****Mean score, standard deviation and rank for Caregiver Needs**

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Time for personal needs	2.87(.74)	7	2.85(.78)	8
Time for rest	2.94(.75)	6	3.00(.77)	6
Maintaining health	3.15(.75)	4	3.08(.74)	4
Adequate sleep	3.08(.79)	5	3.08(.76)	4
Someone with whom to talk	2.94(.75)	6	3.04(.79)	5
Understanding from patient	3.19(.77)	3	2.94(.75)	7
Appreciation from patient	2.83(.86)	8	2.65(.74)	9
Continuing social activities	2.44(.73)	9	2.33(.58)	10
Support from family	3.42(.67)	2	3.54(.67)	2
Support from friend	3.19(.66)	3	3.25(.65)	3
Caring and interested professionals	3.44(.64)	1	3.69(.54)	1
Total Subscore for the category	33.50(5.67)		33.38(4.81)	
Mean Subscore for the category	3.045		3.03	

Table 6:

**SPIRITUAL NEEDS****Mean score, standard deviation and rank for Caregiving Needs**

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Personal prayers	3.19(.66)	4	3.39(.72)	2
Prayers from others	3.29(.78)	3	3.37(.74)	3
Help dealing with fears	3.06(.83)	5	3.06(.83)	6
Strong faith in God	3.66(.59)	1	3.60(.60)	1
Clergy with whom to talk	3.04(.77)	6	3.17(.83)	5
Hope for future	3.37(.66)	2	3.33(.76)	4
Total Subscore for the category	19.52(3.73)		19.85(3.68)	
Mean Subscore for the category	3.25		3.31	

Table 7:

**PSYCHOLOGICAL NEEDS**

Mean score, standard deviation and rank for Caregiver Needs

	During Caregiving		After Caregiving	
	Mean(SD)	Rank	Mean(SD)	Rank
Ways to deal with the unpredictability of future	2.98(.83)	9	2.94(.78)	14
Information about death and dying	2.80(.80)	14	2.81(.79)	18
Help dealing with fears	2.80(.80)	14	2.81(.79)	18
Ways to deal with depression	2.77(.81)	16	2.83(.81)	16
Ways to discuss death with patient	3.21(.80)	5	3.13(.84)	7
Information about what to expect in the future	3.23(.76)	4	3.27(.72)	4
Ways to deal with anger	2.77(.83)	16	2.81(.84)	18
Information about funeral planning	2.75(.76)	18	2.81(.74)	18
Ways to deal with guilt feelings	2.57(.81)	20	2.71(.78)	19
Information on Hospice Care	3.57(.61)	1	3.71(.54)	1
Information about legal matters	3.23(.78)	4	3.10(.63)	9
Ways to be more patient and tolerant	3.10(.80)	6	3.08(.79)	10
Ways to resolve unfinished business	2.94(.92)	10	3.04(.84)	12
Ways to maintain normal family life	3.21(.82)	5	3.06(.83)	11
Help with financial matters	2.79(.78)	15	2.52(.70)	23

Table 7: (continued)

Ways to better communicate with patient	3.06(.73)	7	3.10(.85)	9
Ways of coping with loneliness	2.81(.84)	13	3.02(.85)	13
Ways to combat fatigue	2.98(.83)	9	3.19(.79)	6
Ways to decrease stress	3.02(.80)	8	3.12(.81)	8
Ways to encourage patient	3.43(.70)	2	3.44(.73)	2
Feedback that giving proper care	3.27(.77)	3	3.37(.71)	3
Contact after patient's death	3.06(.83)	7	3.10(.80)	9
Ways to inform family of illness	2.90(.85)	11	2.90(.80)	15
Information about patient's psychological needs	3.27(.77)	3	3.20(.80)	5
Classes on giving physical care	2.65(.81)	19	2.82(.82)	17
Patient support group	2.76(.84)	17	2.63(.77)	21
Financial help	2.76(.84)	17	2.58(.76)	22
Ways to deal with sexual needs	2.16(.42)	21	2.20(.49)	24
Information about activities and exercises	2.98(.83)	9	2.69(.79)	20
Help understanding insurance forms	2.85(.92)	12	2.71(.81)	19
Total Subscore for the Category	88.04(15.41)		88.13(12.98)	
Mean Subscore for the Category	2.93		2.94	

about legal matters; and ways to maintain normal life. The top seven needs after caregiving were: information on hospice care; ways to encourage patient; feedback that giving proper care; information about what to expect in the future; information about patient's psychological needs; ways to combat fatigue; and ways to discuss death with patient. The most significant difference in this category was that ways to combat fatigue and ways to discuss death with patient increased in importance and information about legal matters and ways to maintain normal life decreased in importance.

Total subscores and Mean subscores for each category were also computed and appear at the end of each Table. The rank order mean category subscore (from the highest to the lowest) calculation for the experience both during and after caregiving is as follows: Patient Care Needs (3.49 and 3.45); Needs Involving Information (3.46 and 3.44); Spiritual Needs (3.25 and 3.31); Personal Needs (3.04 and 3.03); Psychological Needs (2.93 and 2.94); and Needs Involving Your Household (2.60 and 2.60).

#### **Ranked Caregiver Needs During Caregiving**

Table 8 lists the top six ranked needs of caregivers during the caregiving experience. Three of the top six ranked needs identified by the caregivers during caregiving were listed under the category of Patient Care Needs. They were: home visits by professionals; ways to keep patient

Table 8

**Ranked Needs During Caregiving**

<b>Caregiver Needs</b>	<b>Category</b>	<b>Mean</b>	<b>SD</b>
1. Home visits by professional	(C)	3.81	.44
2. Ways to keep patient comfortable	(C)	3.79	.46
2. Methods of pain control	(C)	3.79	.54
3. Physical needs of patient	(I)	3.78	.46
4. Honest and updated information	(I)	3.77	.47
4. Type and extent of patient's illness	(I)	3.77	.47
Total subscore for the top six needs		22.71	
Mean subscore for the top six needs		3.78	

**\* Category Key**

- (I) - Needs Involving Information  
(C) - Patient Care Needs

comfortable; and method of pain control. These were also the three top ranked needs. Also included in the top six needs identified by the caregivers during caregiving were three items from the category of Needs Involving Information. They were: Information about the physical needs of my patient; Honest and updated information; and Information about the type and extent of patient's illness.

#### Ranked Caregiver Needs After Caregiving

Table 9 lists the six most important needs identified by caregiver's after the caregiving experience. Two of those needs are listed in the category of Needs Involving Information. They were: Information regarding medication effects and schedules and Information about what symptoms to expect. The category of Patient Care Needs included four of the top six needs identified by caregivers after the caregiving experience. Those were: Methods of pain control; RN or HHA help with patient's physical care; Home visits by professionals; and Ways to keep patient comfortable.

#### Differences in Ranked Needs During Caregiving and After Caregiving

When comparing ranked needs of the six most important needs during and after caregiving, the two most important need categories of information and patient care remained consistent (Table 10). However, the items within those

Table 9

Ranked Needs After Caregiving

<u>Caregiver Need</u>	<u>Category</u>	<u>Mean</u>	<u>SD</u>
1. Methods of pain control	(C)	3.85	.46
1. RN or HHA help with patient's physical care	(C)	3.85	.46
2. Home visits by professionals	(C)	3.83	.43
3. Medication effects and schedules	(I)	3.81	.49
4. What symptoms to expect	(I)	3.79	.46
4. Ways to keep patient comfortable	(C)	3.79	.54
Total subscore for the top six needs		22.92	
Mean subscore for the top six needs		3.82	

**\* Category Key**

(I) - Needs Involving Information  
(C) - Patient Care Needs

Table 10:

Comparison of top six ranked needs during and after caregiving

Caregiver Need	Category	Rank	
		During Caregiving	After Caregiving
Home visits by professional	(C)	1 (3.81)	3 (3.83)
Ways to keep patient comfortable	(C)	2 (3.79)	6 (3.79)
Methods of pain control	(C)	3 (3.79)	1 (3.85)
Physical needs of patient	(I)	4 (3.78)	7 (3.75)
Honest and updated information	(I)	5 (3.77)	8 (3.73)
Type and extent of patient's illness	(I)	6 (3.77)	15 (3.58)
RN or HHA help with patient's physical care	(C)	8 (3.69)	2 (3.85)
Medication effects and schedules	(I)	13 (3.62)	4 (3.81)
What symptoms to expect	(I)	12 (3.63)	5 (3.79)

\* Category key

(C) - Patient Care Needs

(I) - Needs Involving Information

categories for the top six needs did change. Four items changed more than four rankings between caregivers needs during caregiving and caregiver needs after caregiving. One of those items, type and extent of patient's illness, decreased from sixth place during caregiving to 15th place after caregiving. Three items significantly increased in importance. RN or HHA help with physical care moved from eighth place during caregiving to second place after caregiving. Information on medication effects and schedules moved from 13th place during caregiving to fourth place after caregiving. And information on what symptoms to expect moved from 12th place during caregiving to fifth place after caregiving. Methods of pain control increased slightly from third place to first place. A slight decrease (2-4 rankings) was also seen in the following need items: home visits by professionals; ways to keep patient comfortable; physical needs of patient; and honest and updated information.

The total subscore for the top six ranked needs during caregiving was 22.71. While the total subscore for the top six ranked needs after caregiving was 22.92. This was an increase of .21. The mean subscore for the top six ranked needs during caregiving was 3.78. The top six ranked needs after caregiving had a mean subscore of 3.82. This represented an increase of .04. In both instances there was a rank increase in needs after caregiving.

Comparison of Significantly Different Caregiver Needs  
During and After the Experience

A t-test for paired samples was computed for all 90 need statements to determine the difference between the caregiver's perception of needs during caregiving and the caregiver's perception of needs after caregiving. The results indicated twelve statistically significant differences (Table 11). The p value for this test was set at the 0.05 level of significance. Five of the need items showed an increase in importance from the perception of needs during caregiving to the perception of needs after caregiving. They were: Caring and interested professionals; Help continuing children's activities; Ways to combat fatigue; RN or HHA help with physical care; and Information about medication effects and schedules. The remaining seven need items showed a decreases in importance from the perception of needs during caregiving to the perception of needs after caregiving. Five of those items were significantly different. They were: Information about exercises for patient; Helping patient to trust caregiving abilities; Purposeful activities for patient; Help with financial matters; and Information about type and extent of illness. Two need items represented a trend toward significance in decreasing perception of needs after caregiving. They were: How to contact physician and Appreciation from patient.

Table 11:

Comparison of Caregiving Needs Where There Was a Significant  
Difference During and After the Experience

<u>Need Statement</u>	<u>*</u>	<u>Mean During</u>	<u>Mean After</u>	<u>t</u>	<u>Sig t</u>
Caring and interested professionals	(N)	3.4423	3.6923	-3.47	.001
Information about exercises for patient	(P)	2.9804	2.6863	2.69	.010
Helping patient to trust caregiving abilities	(I)	3.557	3.2692	2.68	.010
Help continuing children's activities	(H)	2.3673	2.5306	-2.22	.031
Purposeful activities for patient	(C)	3.4600	3.1800	2.19	.033
Help with financial matters	(P)	2.7885	2.5192	2.13	.038
Ways to combat fatigue	(P)	2.9808	3.0192	-2.11	.040
R.N. or HHA help with physical care	(C)	3.6923	3.8462	-2.06	.044
Information about medications effects and schedules	(I)	3.6154	3.8077	-2.02	.049
Information about type and extent of illness	(I)	3.7692	3.5769	2.02	.049
How to contact physician	(I)	3.557	3.3654	1.81	.077
Appreciation from patient	(N)	2.8235	2.6471	1.77	.083

## \* Category Key

N - Personal Needs

P - Psychological Needs

I - Needs Involving Information

H - Needs Involving Your Household

C - Patient Care Needs

A Wilcoxon rank sum test was also completed on the data (Table 12). The results of this test showed that there was no significant difference between the rankings of the items within the subscale. The 2-Tailed P value ranged from .1968 in the category of Spiritual Needs to .9860 in the category of Needs Involving Your Household.

#### Variables Affecting Perception of Needs

It was thought that gender, age, race, relationship, time in caregiving and income may influence the caregiver's perceptions of needs. Each of these characteristics were examined by doing a t-test for independent samples. After each characteristic was reduced to 2 categories, the statistical analysis was completed. The results of the t-test revealed that there was no significant difference in the perceived needs in regard to the following characteristics: age, relationship, time in caregiving, or income. At the 0.05 level of significance, the results indicated statistically significant differences in the perception of needs in relation to two characteristics (Table 13). Those characteristics were gender and race. Males perceived the patient care needs, both during and after caregiving, and information needs after caregiving to be significantly higher than did females. Non-whites perceived the personal needs and psychological needs during caregiving to be significantly higher than whites.

Table 12:

**Comparison of the Ranking of Need Items within Need Categories**

---

<u>Need Category</u>	<u>2-Tailed P</u>
Needs Involving Your Household	.9860
Needs Involving Information	.7597
Psychological Needs	.5451
Patient Care Needs	.4675
Personal Needs	.4666
Spiritual Needs	.1968

**Table 13****Characteristics Affecting Perception of Needs****GENDER**

Category Need Statement	Male Mean	Female Mean	t	Sig t
Patient Care Needs During Caregiving	59.2	55.21	2.23	.040
Need for Information After Caregiving	55.3	50.85	2.63	.016
Patient Care Needs After Caregiving	58.5	54.5	2.18	.039

**RACE**

Category Need Statement	White Mean	Non White Mean	t	Sig t
Personal Needs During Caregiving	32.62	39.80	-3.89	.008
Psychological Needs During Caregiving	86.55	103.00	-2.81	.034

**Summary**

In this chapter, the population has been described and similarities and differences between the samples have been examined. Statistical analysis comparing the perceptions of caregiver's needs during caregiving and after caregiving was completed. Rank ordering of caregiver's needs during and after caregiving was completed and the differences were noted. Significantly different caregiver's needs during and after the experience were also described. Lastly, mean category need scores were compared to determine if any of the sample characteristics related significantly to caregiver's needs.

## CHAPTER V

### SUMMARY

#### Introduction

The purpose of this study has been to identify and compare the caregiving needs during and after the terminal care experience. This study further examined certain characteristics of caregivers, and their relationship to the expressed needs of caregivers. In this chapter the results of the research will be discussed and the implications of the study will be presented. Limitations of this study and suggestions for further research will be addressed.

#### Discussion of the Study Findings

Needs During Caregiving The first research question addressed was "What are the anticipated needs identified by the caregivers during the initial phase of the hospice experience? The six most important needs identified by caregivers during caregiving were:

- Home visits by professionals
- Ways to keep patient comfortable
- Methods of pain control
- Information regarding physical needs of patient
- Honest and updated information
- Information on type and extent of patient's illness

There is much in the literature to support many of the

needs during caregiving that have been identified in this study. These needs correspond closely to those needs identified in the research by Hampe (1975), Wright and Dyck (1984), Longman (1992), Hileman (1992) and Stetz (1992 and 1987) . "To be informed of patient's condition" ranked third in the Hampe study, first in the Wright and Dyck study, and third in the Longman study. "To receive assurance about the comfort of the patient" ranked fourth in the Hampe study, first in the Longman and Stetz studies and second in the Wright and Dyck study. "Honest and updated information" ranked sixth in the Longman study, third in the Wright and Dyck study, and fifth in the Hampe and Hileman study. "Information on type and extent of patient's illness" ranked third in the Hileman study. With both of these statements there could be a question of caregivers trust in health care professionals. Part of this may be due to where they are in the grief process and some of it may be valid distrust.

Although "Home visits by professionals" was not stated in those terms, an item with close association was third in the Hileman study, fifth in the Longman study, and eighth in the Hampe study. "Methods of pain control" was not identified specifically in any of the other studies. However, this item clearly aligns itself with patient comfort measures which is included in the other studies. Stetz (1992) affirms in her study that the primary need of

the caregiver during the experience is help managing the physical care of the patient.

There were several items that appeared as priorities in former studies but do not appear in the current study. One of those items was "to be with the dying patient" (Hampe, 1975), "stay with the patient during difficult times" (Ryan, 1992), and "guilt from not being with patient enough" (Blank, Longman and Atwood, 1989). The philosophy and practice of home care and hospice generally allows the caregiver sufficient time to be with the patient so that this area is not a need. In addition, hospice care has minimized physician contact and inpatient stays through increased coordination of services. Thus "physician orders" and "inpatient if necessary" is not as great a need as in former studies (Longman, 1992).

The top six needs during caregiving identified in this study were in the two categories of Needs Involving Information (3) and Patient care needs (3). Rank ordering of categories of needs from the most important to the least important were: patient care; information; spiritual; personal; psychological; and household needs. This is slightly different from the findings of Hileman and Lackey (1990) and Hileman, Lackey, and Hassanein (1992), who noted that informational and psychological needs always occurred most frequently. The cultural differences in the geographic area (rural versus urban) and the

differences in the administration of the questionnaire (written versus phone or in person) may account for some of the differences in ranking between this study and others.

Needs After Caregiving The second research question addressed, "What are the retrospective needs identified by the caregiver after the caregiving experience?" The six most important needs identified by caregivers after caregiving were:

- Methods of pain control
- RN or HHA help with patient's physical care
- Home visits by professionals
- Medication effects and schedules
- What symptoms to expect
- Ways to keep patient comfortable

The needs expressed after caregiving more clearly define the intensity of the care experience. Caregivers' lives become controlled and regimented by pain and symptom control, physical care, and medication schedules. It is documented in the literature that as the length of illness increases so does the stress of caregiving (Oberst, Gass, and Ward, 1989). This is also supported by Hull's study (1991) that identified 24 hour accessibility and competent practitioners of primary importance to caregivers. However, importance of pain control was not validated in the Hull study. Her study documented that pain control was not discussed by the subjects and that pain control was not

a major concern of hospice families. This may have been a broad generalization.

Once again the top six needs after caregiving were contained within the same two needs categories. Those categories were Information Needs (2) and Patient Care Needs (4). Rank ordering of need categories after caregiving from the most important to the least important were patient care, information, spiritual, personal, psychological, and household needs. The importance of "patient care needs" supports the findings of the study by Stetz (1992) in which 51% of the caregivers stated that they would have accepted more help in response to the question, "What, if any thing, would you do differently?"

#### Comparison of Needs Expressed During Caregiving and Needs Expressed After Caregiving

The third research question addressed was "Is there a significant difference between the anticipated needs expressed by caregivers and the needs expressed by the same caregivers retrospectively?" The top six ranked needs revealed four items in which there were differences from anticipated needs to retrospective needs. One of those items, "type and extent of patient's illness", decreased in importance after caregiving. From the perspective of the grief process this was seen as an understandable priority change.

The three items in the top six needs that increased in

importance after caregiving were: RN or HHA help with patient's physical care; information on medication effects and schedules; and information on what symptoms to expect. It would seem in this case that the caregivers were now able to more clearly define their needs for care. Perhaps as the patient's physical condition declined, these specific care issues became more important. It is unclear from the way the question was stated which discipline was most helpful, the RN or the HHA. However, many families call the HHA the nurse so the distinction may not be important. Regardless, nurses need to understand the effects of anticipatory grief on the caregiving process and develop care plans accordingly.

The study revealed that a significant difference existed between the anticipated needs and the retrospective needs in twelve of the need items. The first five represented an increase in importance of the retrospective needs. Those items were:

- Caring and interested professionals
- Help continuing children's activities
- Ways to combat fatigue
- R.N. or HHA help with physical care
- Information about medications effects and schedules

These needs seem to be centering more on the caregiver rather than on the patient needs and reflect more interaction with people other than the patient. Kubler-

Ross (1970) pointed out that a primary need of spouses of dying patients is to alleviate loneliness and isolation by sharing feelings with another who can offer comfort and support. The grief/loss issue is of paramount importance to caregivers and many times reflects their changing needs. This is also supported in the literature of Hileman, Lackey and Hassanein (1992). These authors found that as the patient's condition deteriorated, a caregivers' psychological, patient care, personal, and household needs increased. Foster (1987) found that "someone to talk over care periodically" ranked second in importance in his study. He also found direct nursing care assistance ("standing by") rather than only educating the caregiver to manage the care to be most helpful.

The remaining seven need items represented a decrease in importance of the retrospective needs. Those items were:

- Information about exercises for patient
- Helping patient to trust caregiving abilities
- Purposeful activities for patient
- Help with financial matters
- Information about type and extent of illness
- How to contact physician
- Appreciation from patient

Once again, there seems to be a normal moving away from especially irrelevant patient care issues and a focusing on

those issues that most directly relate to patient comfort. One thing that seems most important is that change does occur in caregiver needs and evaluation should be done on a consistent basis.

Although the Wilcoxon rank sum test revealed no significant difference between the items within the category subscale, several interesting changes from the first survey to the second survey were noted. Under the category of information, "medications effects and schedules", and "what symptoms to expect" increased in importance. Under the category of patient care needs, "methods of pain control", "RN or HHA help with patient's physical care" and "ways to improve patient's appearance" also increased in importance. It would seem that disease progression may have had a direct correlation with an increase in needs. As caregiving continued, the full effect of the process was more clearly felt, understood, and specific needs identified. Perhaps as a protection, it appeared that caregivers were only able to process a limited amount of stress and needs at a time.

Decrease in ranking was seen in several areas. Under the category of personal needs, the item, "understanding from patient", moved from third place to seventh place. Under the category of spiritual needs, "hope for the future", moved from second place to fourth place. Lastly, under the category of psychological needs, "ways to

maintain normal family life", moved from fifth place to eleventh place and "information about activities and exercises" moved from ninth to 20th place. More realistic expectations of self and understanding of the disease trajectory may explain many of these changes.

Most needs changed only slightly over time. Household needs changed the least, followed by personal, psychological, information, patient care, and spiritual needs. The categorical changes over time are different from the findings of Hileman and Lackey (1990) and Hileman, Lackey, and Hassanein (1992). Those studies found that the category with the least change was spiritual needs, followed by informational, patient care, psychological, personal and household needs.

#### Variables Affecting Needs Perception

The fourth research question examined certain characteristics of the caregivers which may influence perception of needs. The characteristics examined were: gender, age, race, relationship to patient, time in caregiving, and income. Of those characteristics, only two were found to suggest a significant difference. Those two were gender and race.

Males perceived the category of patient care needs, both during and after caregiving, and information needs after caregiving to be significantly more important than females. This finding is consistent with the study done by

Stetz in 1987 which found that male caregivers were more concerned with managing personal care and the household than were females. The typical inexperience of the American male in the role of caregiving can explain the increased need for information.

Non-whites perceived the category of personal needs and psychological needs during caregiving to be significantly more important than did whites. This may be indicative of a cultural difference not merely related to caregiving. Non-whites seem to be more experienced in care giving and may have more extended family and community involvement in their care.

#### Limitations of the Study

Sample Size. Because of the small number of caregivers who participated in the study, the generalizability of the results should be viewed cautiously. Beyond the sample and geographic area studied, the results have limited generalizability.

Sample of Convenience. Self selection of the participants may have resulted in sample bias because the subjects were non-randomly selected. Caregivers perceived to be having the most difficult time, hence probably having the greatest needs, were not encouraged to become a part of the study. Thus the sample obtained for the study may not have been representative of a true picture of caregiver's needs.

Self report. Self-administered questionnaires to gather data present the questions of validity and accuracy. The responses gathered by this method can always be questioned in regard to honesty and understanding. Much effort was taken to assure the caregivers' confidentiality and anonymity. Without providing assistance that could further bias the answers, it is difficult to assess understanding.

Association with Human Needs Theory An attempt was made to group the 90 need items into Human Needs Theory classification of survival, closeness, and freedom needs. The hospice staff was asked to participate in this grouping process. They found this task to be very subjective and in some instances impossible. Because of the difficulty of the process and the inability of the group to come to any consensus, the researcher questioned the validity of any conclusions from this information. Therefore classification in this manner was not completed.

#### Implications for Terminal Care

The numbers of home care oncology patients that rely upon nursing for information and support for patient care will increase in the future. Because the study clearly demonstrated that caregiver needs do change over time, it is important that nurses constantly assess the care needs of families. A tool that quickly and accurately assesses the changing caregiver needs would be very helpful. This

tool could also be expanded to elicit satisfaction with how well these needs were met.

The two most important needs of this community were patient care and information. It would seem that increased importance should be placed on these two areas. Because of shorter hospitalizations and multiplicity of service providers the coordination of services becomes increasingly important. Nurses can provide support for the caregivers to facilitate understanding and ability to provide the needed home care. Families ascribe high priority to symptom control and patient comfort. With the utilization of available knowledge and skill to relieve symptoms, in effect, the nurse is ultimately meeting caregiver needs.

While we know that this is a very stressful time in the lives of these people, we also know that stress limits the cognitive abilities of caregivers. Perhaps the development of more written information (family manuals) or videotaping would be helpful in certain situations. Consistently reviewing the information provided and discussing what to expect will more adequately ensure preparation and awareness of how to handle given situations.

Although 80% of the caregivers in this study were female, the male population expressed definite needs in regard to caregiving that must not be overlooked. The

study by Stetz (1990) and Hileman (1992) reflect more of the upward trend in the number of male caregivers. It is also difficult to know how many male caregivers were so overwhelmed with caregiving that they did not or could not take the time to complete the questionnaire. The male population has special needs that require a sensitivity and perhaps increased resource acquisition.

It is documented in the National Hospice Organization literature that hospice care is traditionally supplied to the white middle class population. Whether this is a utilization issue or an access to care issue is not well understood. Eighty-six percent of the caregivers in this study were white. This is only slightly under the racial mix (79% - white) in Delaware.

The increase in sophistication and complexity of caregiver's lives require ongoing attention. A little over 30% of the caregivers in this study worked. This can cause much stress and anxiety for the caregiver and may require special services that are currently not provided by many organizations. Attention to needs may focus on provision of volunteers or paid sitters/companions to provide care while the caregiver is at work. Increase in respite services may also be needed.

Although many hospices are exploring a pre-hospice program to provide counseling and support services while the patient is still receiving treatment, the study

findings do not greatly support the need for such service. Eighty-six percent of the caregivers said that referral to hospice was soon enough. No matter what the intent of the program, anything with the name of hospice associated with it would send messages to the patient and caregiver that they may not be able/willing to hear.

The fact that 38% (and perhaps much higher if the 9 missing were included) of the caregivers have an income less than \$19,000.00 annually could mean that very little surplus money is available for supportive care. Hospice may need to look at supplementing services well beyond the medically necessary limit of care that is currently provided. The volunteer component is very helpful but still limited in numbers as well as ability to serve this population.

Suggestions for Further Study Prudent and cost effective studies to continue exploration of family needs are essential. Refinement of assessment tools and satisfaction surveys would be extremely valuable to provision of quality customer service and care. Because of the individualized care that is paramount in home care settings, it is important to evaluate the needs of each family as well as identifying common needs. A consistent assessment of the family needs and evaluation of success in meeting those needs is vital. While this study identified needs it did not then rate success. Expansion of the study to other

diagnosis groups would also be most helpful. Follow up interviews at shorter/longer periods may more clearly define the changes in care needs.

**Summary** Increasing numbers of patients with cancer are being cared for at home by family caregivers. At some time in the course of the disease, almost all of the caregivers are afforded the opportunity to provide direct patient care. Caregivers clearly identified that the two most important needs were patient care and information. In order to minimize the stress and allow for energy to be spent in the most important tasks, adequate information concerning patient care responsibilities must be given. It is only as the caregiver is enabled to feel adequate and knowledgeable about the task of caregiving, will they then be provided the opportunity to "be present with" the one requiring care. This will further allow them to realize and experience the privilege of caregiving to its full extent and will enhance grief resolution.

Nursing's Human Need Theory suggests that alterations in human need fulfillment in the extreme are coexistent with illness and death and that human need fulfillment at the other end of the spectrum is synonymous with maximal wellness. Active and ongoing family participation in identification of needs is crucial to effective care planning and need fulfillment. Only as the caregiver's needs are met will they, in turn, meet patient needs.

**APPENDIX 1**

**DISCLOSURE FORM**

I am a Salisbury State University student currently studying the stress that people experience in caring for someone admitted to Delaware Hospice. I am seeking the assistance of family members in completing a survey concerned with needs that they might have as caregivers.

The questionnaire is brief and should take about twenty minutes of your time to complete. You will be asked to complete this questionnaire twice during this survey. The information provided will be kept confidential. The patient's name and caregiver's name and address will appear on the form for identification purposes for completion of the second survey; however no name appears on the questionnaire. You will be contacted after the caregiving experience and be asked to complete the questionnaire again at that time.

Your cooperation and participation are strictly voluntary and your choice to participate or not to participate will not affect the care of your family member. You may leave any particular questions unanswered or may choose not to complete the survey. Your participation is very valuable and will help increase the knowledge that is necessary to provide quality care for Delaware Hospice patients and families.

If you have any questions about this study or would be

interested in the results, please contact Judi Tulak, Delaware Hospice, Suite 107, 600 DuPont Highway, Georgetown, De. 19947. Telephone (home) 410-749-4526 or (work) 302-856-7717. You may also contact Karin Johnson, RN, Dr PH by calling 410-548-5395. Thank you for your assistance.

I have read this form or had it read to me, and consent to participate in this study.

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Caregiver

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Date

**APPENDIX 2**

Please check ( ) how IMPORTANT each of the following needs was to you

Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
-------------------	------------------------	---------------	--------------------

**NEEDS INVOLVING INFORMATION**

1 Information about medications - effects and schedules

_____	_____	_____	_____
-------	-------	-------	-------

2 Information about treatment side effects

_____	_____	_____	_____
-------	-------	-------	-------

3 Information about the underlying reasons for symptoms

_____	_____	_____	_____
-------	-------	-------	-------

4 Information about what symptoms to expect

_____	_____	_____	_____
-------	-------	-------	-------

5 How to contact physician

_____	_____	_____	_____
-------	-------	-------	-------

6 Honest and updated information

_____	_____	_____	_____
-------	-------	-------	-------

7 Information about the physical needs of my patient

_____	_____	_____	_____
-------	-------	-------	-------

8 Information about therapies

_____	_____	_____	_____
-------	-------	-------	-------

9 Information about drugs

_____	_____	_____	_____
-------	-------	-------	-------

10 Helping my patient to trust my caregiving abilities

_____	_____	_____	_____
-------	-------	-------	-------

11 Information about the type and extent of my patient's illness

_____	_____	_____	_____
-------	-------	-------	-------

12 Information on how to give medications

_____	_____	_____	_____
-------	-------	-------	-------

13 Ways to inform children of illness

_____	_____	_____	_____
-------	-------	-------	-------

Please check ( ) how IMPORTANT each of the following needs was to you	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
14 Ways to cope with role changes (eg. child becoming caregiver)	_____	_____	_____	_____
15 Information about sitters to be with the patient	_____	_____	_____	_____
<b>NEEDS INVOLVING YOUR HOUSEHOLD</b>				
1 Help with errands	_____	_____	_____	_____
2 Help with my housework	_____	_____	_____	_____
3 Help with transportation	_____	_____	_____	_____
4 Help with my yard work	_____	_____	_____	_____
5 Emergency number available	_____	_____	_____	_____
6 Help with my patient's physical care from a neighbor or volunteer	_____	_____	_____	_____
7 Time for myself-away from the house	_____	_____	_____	_____
8 Help continuing my children's activities	_____	_____	_____	_____
9 A caregiver support group for me	_____	_____	_____	_____
10 Places to go for professional counseling	_____	_____	_____	_____
11 Help with baby sitting	_____	_____	_____	_____
12 Information about community resources	_____	_____	_____	_____

Please check ( ) how IMPORTANT each of the following needs was to you	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
<b>PATIENT CARE NEEDS</b>				
1 Ways to help my patient maintain some independence	_____	_____	_____	_____
2 Ways to keep my patient comfortable	_____	_____	_____	_____
3 Information about which liquids are best for my patient	_____	_____	_____	_____
4 Ways to provide my patient with adequate nutrition	_____	_____	_____	_____
5 Methods of pain control	_____	_____	_____	_____
6 Activities that will make my patient feel purposeful	_____	_____	_____	_____
7 Ways to deal with my patient's decreased energy	_____	_____	_____	_____
8 Information about how to get my patient to eat	_____	_____	_____	_____
9 Ways to dress my patient comfortably	_____	_____	_____	_____
10 Equipment to help with patient care	_____	_____	_____	_____
11 Ways to reassure my patient	_____	_____	_____	_____
12 R.N. or Home Health Aide help with my patient's physical care	_____	_____	_____	_____
13 Ways to improve my patient's appearance	_____	_____	_____	_____

Please check ( ) how IMPORTANT each of the following needs was to you	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
14 Ways of coping with my patient's diagnosis	_____	_____	_____	_____
15 Not leaving my patient alone	_____	_____	_____	_____
16 Home visits by professionals to check my patient	_____	_____	_____	_____
<b>PERSONAL NEEDS</b>				
1 Time for my personal needs	_____	_____	_____	_____
2 Time to rest	_____	_____	_____	_____
3 Maintaining my own health	_____	_____	_____	_____
4 Adequate sleep	_____	_____	_____	_____
5 Someone with whom to talk	_____	_____	_____	_____
6 Understanding from my patient	_____	_____	_____	_____
7 Appreciation from my patient	_____	_____	_____	_____
8 Continuing my social activities	_____	_____	_____	_____
9 Support from my family	_____	_____	_____	_____
10 Support from my friends	_____	_____	_____	_____
11 Caring and interested professionals	_____	_____	_____	_____

Please check ( ) how IMPORTANT each of the following needs was to you

Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
-------------------------	------------------------------	------------------	--------------------------

**SPIRITUAL NEEDS**

- |                                |       |       |       |       |
|--------------------------------|-------|-------|-------|-------|
| 1 Personal prayer for strength | _____ | _____ | _____ | _____ |
| 2 Prayers from others          | _____ | _____ | _____ | _____ |
| 3 Help dealing with my fears   | _____ | _____ | _____ | _____ |
| 4 A strong faith in God        | _____ | _____ | _____ | _____ |
| 5 Clergy with whom to talk     | _____ | _____ | _____ | _____ |
| 6 Hope for the future          | _____ | _____ | _____ | _____ |

**PSYCHOLOGICAL NEEDS**

- |   |       |       |       |       |
|---|-------|-------|-------|-------|
| 1 Ways to deal with the<br>unpredictability of the future | _____ | _____ | _____ | _____ |
| 2 Information about death and dying                       | _____ | _____ | _____ | _____ |
| 3 Help dealing with my fears                              | _____ | _____ | _____ | _____ |
| 4 Ways to deal with my depression                         | _____ | _____ | _____ | _____ |
| 5 Ways to discuss death with my<br>patient                | _____ | _____ | _____ | _____ |
| 6 Information about what to expect<br>in the future       | _____ | _____ | _____ | _____ |
| 7 Ways to deal with my anger                              | _____ | _____ | _____ | _____ |
| 8 Information about funeral planning                      | _____ | _____ | _____ | _____ |

Please check ( ) how IMPORTANT each of the following needs was to you	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
9 Ways to deal with my guilt feelings	_____	_____	_____	_____
10 Information on hospice care	_____	_____	_____	_____
11 Information about legal matters	_____	_____	_____	_____
12 Ways to be more patient and tolerant	_____	_____	_____	_____
13 Ways to resolve unfinished business with my patient	_____	_____	_____	_____
14 Ways to maintain a normal family life	_____	_____	_____	_____
15 Help with financial matters	_____	_____	_____	_____
16 Ways to better communicate with my patient	_____	_____	_____	_____
17 Ways of coping with my loneliness	_____	_____	_____	_____
18 Ways to combat fatigue	_____	_____	_____	_____
19 Methods to decrease my stress	_____	_____	_____	_____
20 Ways to encourage my patient	_____	_____	_____	_____
21 Feedback that I am giving my patient proper care	_____	_____	_____	_____
22 Contact after patient's death	_____	_____	_____	_____
23 Ways to inform family of illness	_____	_____	_____	_____

Please check ( ) how IMPORTANT each of the following needs was to you	Not Important (1)	Slightly Important (2)	Important (3)	Very Important (4)
24 Information about my patient's psychological needs	_____	_____	_____	_____
25 Classes on giving physical care to my patient	_____	_____	_____	_____
26 A patient support group for my patient	_____	_____	_____	_____
27 Financial help	_____	_____	_____	_____
28 Ways to deal with my sexual needs	_____	_____	_____	_____
29 Information about activities and exercises for my patient	_____	_____	_____	_____
30 Help with understanding insurance forms	_____	_____	_____	_____

**APPENDIX 3**

Statement of Approval  
Committee on Human Volunteers  
Salisbury State College

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Date February 23, 1994

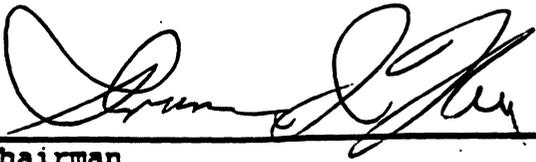
MEMORANDUM TO: Karin Johnson/Judi Tulak  
FROM : Chairman, Committee on Human Volunteers  
SUBJECT : A Comparison of Caregiving Needs During and After the  
Caregiving Experience  
Title of Study

Grant Application No. SSU Department of Nursing  
Sponsoring Agency

Dr. Karin Johnson  
Principal Investigator or Program Director

The Committee on Human Volunteers has considered the above application and, on the basis of available evidence, records its opinion as follows:

- (1) The rights and welfare of individual volunteers are adequately protected.
- (2) The methods to secure informed consent are fully appropriate and adequate; safeguard the rights of the subjects (in the case of minors, consent is obtained from parents or guardians).
- (3) The investigators are responsible individuals, competent to handle any risks which may be involved, and the potential medical benefits of the investigation fully justify these studies.
- (4) The investigators assume the responsibility of notifying the Committee on Human Volunteers if any changes should develop in the methodology or the protocol of the research project involving a risk to the individual volunteers.

  
Chairman

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CURRICULUM VITAE

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Date of Birth: March 31, 1949  
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EDUCATION

- 1963-1967 Monongahela High School - Monongahela,  
Pennsylvania  
High School Diploma
- 1967-1969 Washington Hospital School of Nursing,  
Washington, Pennsylvania  
Registered Nurse Licensure
- 1977 Chesapeake College - Wye Mills, Maryland  
Associate of Arts
- 1977-1979 Salisbury State College - Salisbury, Maryland  
Bachelor of Science in Nursing, 1979
- 1992-1994 Salisbury State University - Salisbury, Maryland  
Graduate Student in Rural Health Nursing Program  
Thesis: A Comparison of the Needs of Hospice  
Caregivers During and After the Caregiving  
Experience.  
Masters of Science in Nursing, December, 1994.

PROFESSIONAL ORGANIZATIONS

Honor Society of Phi Kappa Phi, 1979

Patient Care Service Committee of the American Cancer  
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American Nurses Association

Delaware Nurses Association

Sigma Theta Tau, 1994

**EMPLOYMENT**

- 1969-1970 Monongahela Hospital - Monongahela, Pennsylvania  
Staff Nurse.
- 1970-1978 Eastern Shore Hospital Center - Cambridge,  
Maryland  
Psychiatric Nurse Supervisor.
- 1978-1984 Middletown Health Center - Middletown, Delaware  
Public Health Nurse II.
- 1984- Delaware Hospice, Inc. - Georgetown, Delaware  
Present Program Coordinator.