

Caregiver Satisfaction

with Hospice Care

by

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Abstract

The purpose of this study was to evaluate caregiver satisfaction with hospice care in one Medicare-Certified, nonprofit hospice agency. This study evaluated the effectiveness of hospice services and the needs of caregivers in order to try to improve existing services provided by the agency. The study population consisted of a convenience sample of 46 Coastal Hospice caregivers.

A descriptive research design was used for this study. A modified version of the Home Caregiver Needs Survey (HCNS) was used to obtain caregiver satisfaction with hospice services. In addition, demographic information was obtained from the Coastal Hospice discharge summaries. Mean values were computed to analyze caregiver satisfaction.

This study found that caregivers are overwhelmingly satisfied with hospice services. The caregivers identified many needs as being important to them. Caregivers were more interested in informational needs, household needs, and personal needs than in psychological and spiritual needs.

Hospices need to continue to do research and to evaluate the effectiveness of the services provided in order to better serve patients and their families. This information is also becoming more valuable to hospices in order to validate themselves to third party payors.

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Chapter I

Introduction

The origin of the contemporary hospice movement is credited to Dame Cicely Saunders. In the 1960's she founded what would become the model for the modern hospice, St. Christopher's in suburban London. Her concept of hospice was to combine the most modern medical techniques in terminal care with the spiritual commitment of the medieval religious orders that had once created hospices as way stations for people on pilgrimages (Beresford, 1989).

In 1974, Hospice, Inc., located in Connecticut was the first hospice to open in the United States. In the next few years volunteers opened hospices in cities across the country. It became apparent that a national organization was needed to assist hospices during this period of growth. Responding to this need, the first National Hospice Organization Board of Directors was elected and its office was established in the nation's capital in 1978.

The Medicare Hospice Benefit enacted in August 1983, was another milestone in the development of the hospice movement in the United States. Many private insurers, recognizing not only the compassion of hospice care, but also its cost-effectiveness, began offering hospice benefits. Additionally, many states now offer hospice benefits under their Medicaid programs.

The availability of reimbursement for hospice care has had a dramatic impact on the growth of hospice programs. As a result, there has been a steady increase in the number of hospices and the number of patients cared for by existing hospices. National Hospice Organization (NHO) statistics indicate that there are now greater than 2620 hospice programs in the United States and Puerto Rico with an annual growth rate in existing programs of 8% (D. Shipp, NHO, personal communication, February 13, 1997).

The concept of hospice care is based on the hospice philosophy. In 1993, the National Hospice Organization (NHO) set forth the hospice philosophy as follows:

Hospice provides support and care for persons in the last phases of incurable disease so that they may live as fully and as comfortable as possible. Hospice recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life. Hospice affirms life and neither hastens nor postpones death. Hospice exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them. Hospice offers palliative care to terminally ill people and their families without regard for age, gender, nationality, race, creed, sexual orientation,

disability, diagnosis, availability of a primary caregiver, or ability to pay. (NHO, 1993, p. 3)

Hospice utilizes an interdisciplinary approach to care in order to focus on the patient's physical symptoms as well as the emotional and/or spiritual concerns of the patient and family. The hospice team works together to develop a plan of care which will enhance the quality of life of the patient and provide support for the patient and family throughout the stages of the terminal illness. The hospice team includes the patient, family, volunteers, a physician, nurses, social workers, clergy, and a bereavement counselor all working together to address the needs of the terminally ill patient.

Hospice believes that death is an integral part of the life cycle and that intensive palliative care which focuses on pain relief and comfort, is an appropriate treatment for the terminally ill. Terminal illness is frequently defined as a point where "nothing more can be done" to cure someone (National Hospice Organization [NHO], 1993).

According to Franco (1985), hospice is characterized by (a) care for the individual rather than treatment of the disease, (b) palliative rather than curative care, (c) pain control and symptom management as high priorities, (d) equality between the patient/family and health care professionals, and (e) concern for interpersonal over

technical aspects of medical care. The hospice considers the patient and family as the "unit" of care (Smith, 1984), implying that the needs of the patient and family are equally important. Hospice professionals evaluate family members to ensure that their psychosocial needs are met.

Hospice care emerged as an alternative means of treatment because of dissatisfaction with traditional medical care for the dying patient (Paradis, 1984). In view of the strong interest in the philosophy of patient care and the therapeutic potential, any evaluation of terminal care, whether hospice or traditional medical care, needs to examine the satisfaction of patients and their families with that care (Hays and Arnold, 1986). For hospice programs, the satisfaction of the patient and the patient's family with their care seems to be particularly salient and appropriate as an outcome measure. According to Locker and Dunt (1978), "quality of care can become synonymous with quality of life and satisfaction with care an important component of life satisfaction (p. 283)." The demand for hospice care has grown not only because of its emphasis on the satisfaction of the patient and the family, but also because evidence suggests that hospice care may be less expensive than conventional care, especially in the last month of life (Hannan and O'Donnell, 1984).

Concomitant with the rapid growth of hospice care in

the United States has been a growing interest in accountability, particularly with the advent of government and third party reimbursement. The Medicare reimbursement legislation attaches a sunset clause contingent upon evaluation of hospice effectiveness (Dush and Cassileth, 1985). Thus, there has been great interest in the appropriate focus of assessment of the outcomes of hospice care.

The issue of patient satisfaction with health care is receiving increasing attention from administrators, practitioners, consumers, and evaluators of health care. One reason for this attention is that patient satisfaction is believed to be one goal of health care delivery. As a consequence of the consumer movement, the satisfaction of the consumer is seen as a necessary outcome of any transaction irrespective of the efficacy of that transaction (Linder-Pelz, 1982).

The purpose of this study was to evaluate caregiver satisfaction with hospice care in one Medicare-certified, nonprofit hospice agency. The results of this study will be useful in evaluating the effectiveness of hospice services and in improving existing services provided by the agency. It may also be useful in identifying needs that are not currently met by the hospice agency. It is hoped that utilization of the knowledge obtained in this study, will

improve nursing services and thereby increase patient and family satisfaction with hospice care..

Chapter II

Review of the Literature

Introduction

Patient satisfaction, a remarkably difficult notion to define, is related to quality of care. It reflects the values and goals current in the health care system and in the larger society of which it is a part (Donabedian, 1969). It is with the purpose of understanding the dimensions of satisfaction with health care, that this literature review was completed. The review will be divided into five sections: satisfaction with hospice care; patient satisfaction with nursing care; satisfaction with home health care; comparison of a telephone survey with a mail survey, and identifying the needs of home caregivers.

Satisfaction with Hospice Care

Barzelai (1981) evaluated a home-based hospice program in Minneapolis by means of questionnaires completed by surviving relatives of patients who had participated in the hospice program prior to the patient's death. Study subjects consisted of the significant others of patients who had participated in the hospice program for greater than two weeks prior to death and who had died between one month and one year prior to the onset of the study. Significant others were defined as the people closest to the dying person, who cared for them and acted as a liaison between

the patient and hospice. The sample size was 20 people and consisted of 13 spouses, 4 children, 2 mothers, and 1 girlfriend.

A letter of introduction to the study was sent to the significant others by the hospice, explaining the study. The subjects were then contacted by telephone and an appointment was made to deliver the questionnaire. Approximately two days later, the questionnaire was picked up by a resident physician.

The questionnaire consisted of 21 questions concerning various aspects of hospice care. There was space available after each question for the subject to add comments. The questionnaire included questions regarding alleviation of physical symptoms, anxiety, spiritual concerns of the dying patient, knowledge about the patient's illness, caregivers wishes regarding place of death, and bereavement support.

Pain was found to be a significant problem, at least occasionally, to most of the dying patients. Of these patients, pain was relieved most or all of the time in 82% due to the intervention of their physician and/or hospice. Other physical symptoms such as vomiting, shortness of breath, and constipation were at least occasionally major problems for 85% of the dying patients. Of these patients, 88% gained some relief. Anxiety was identified as a major problem in 70% of the dying patients and in 95% of the

significant others. The hospice team helped alleviate symptoms in 64% of dying patients and in 89% of significant others.

Fifty percent of the significant others reported that the patient did not have any special spiritual concerns and the rest of the respondents were divided between "yes", "occasionally", and "not sure." The significant others who had spiritual concerns used their own resources and did not utilize the hospice to address these concerns.

Eighty percent of respondents indicated they derived sufficient information about the patient's illness. The physician was a good source of information in 45% of the cases and the hospice in 60% of the cases.

Eighty-five percent of respondents said that it was desirable for the dying person to be at home as much as possible. Reasons given for this included: the person was more comfortable; it enabled the family to grow closer together; it enabled the patient to have some control over his life; and it enhanced the patient's will to live.

Surprisingly, few people in this study identified a need for hospice-centered bereavement work. Bereavement is generally seen as a vital function of the hospice, but this study fails to give it an important place. The sample size for this study was very small and therefore may have not been representative of the total population served.

Creek (1982) studied satisfaction with hospice care by asking caregivers of hospice patients to report on satisfaction with care. At the end of one year of service, the Hospice of Columbus (HOC), mailed an evaluation form requesting an anonymous response to the caregivers of the seventy patients who they served that year. Forty-five caregivers responded to the questionnaire for a response rate of 64%. The evaluation gathered feedback concerning the caregivers' level of satisfaction with the physician while the family member was a patient of HOC, the effectiveness of pain control, satisfaction with the nursing skills, with the supportiveness of the nurses, with the social worker, and with the volunteers. The caregiver responded by placing an "X" on two undifferentiated 16-mm lines placed under each item. The first line was designated to reflect the caregiver's level of satisfaction and the second to reflect the satisfaction of the family as the caregiver understood it. The left end of the line was marked 100% dissatisfied and the right end was marked 100% satisfied. An "X" at the 16-mm point equaled 100% satisfied.

Average satisfaction scores for caregivers and family exceeded 90% for nursing care, the social worker, and effectiveness of pain medication. Mean satisfaction with the physician was 75% for caregivers and 78% for the patient

(as reported by the caregiver). The data indicate that the hospice program was urgently sought by the public and that this hospice will be able to provide homecare services at a cost which is competitive with skilled nursing home care.

In response to a New York State legislative directive, Hannan and O'Donnell (1994) evaluated the use of hospice care within the state's Hospice Demonstration Program. Twelve hospice programs, each providing one of three different models of hospice care were studied. The three models were: 1) community based, 2) hospital based, scattered bed, and 3) hospital based, autonomous unit. The evaluation included an assessment of hospice utilization and charges, a comparison of the costs of hospice care and conventional (nonhospice) care for the terminally ill, an assessment of the satisfaction with hospice care, and an estimation of the impact of volunteers. In addition to assessing the demonstration hospice as a group, the study also sought to compare the three models with respect to cost, utilization, and satisfaction with care.

Each hospice submitted two program profile reports, with each report covering a six-month period from July 1981 through June 1982. These reports contained summary operational statistics on admissions, discharges, sources of patient referral, and sources of payment for all patients under care during the reporting period. A tabulation of

both inpatient and home care services rendered was also supplied. Each program was also asked to submit a budget for the calendar year 1982. In addition to information pertaining to staff patterns and salary levels, they were also asked to include tabulations for the volume and type of volunteer activity during the first six months of 1982.

In January 1982, the hospice programs began submitting patient history reports for each patient discharged. At the time of the evaluation, this set of information was complete for all patients discharged through August 31, 1982. These patient history forms contained detailed patient specific characteristics such as age, sex, diagnosis, place of death, length of enrollment, number of inpatient days, number of home care days, and discharge status. A complete history of the scope and cost of services rendered to each patient by the hospice was also obtained.

To assess the effectiveness of the hospice care provided, a questionnaire was administered to the primary care person (PCP) of each patient who died between February 1982 and June 1982. The PCP questionnaire requested information on the PCP's experience with specific hospice services and the PCP's perception of the care received by the patient. Among the questions asked were those relating to the PCP's relationship to the patient, the PCP's satisfaction with the emotional support and the services

provided to the PCP, the PCP's estimation of the effects of hospice care on the patient's physical and emotional quality of life, the PCP's estimation of hospital care and of specific home care services provided to the patient, and the PCP's satisfaction with bereavement services. Respondents used a 5-point Likert-scale ranging from (1) very dissatisfied to (5) very satisfied or rated the item inapplicable.

The results of the PCP questionnaire demonstrated that there was very high satisfaction with the provision of services and emotional support to the PCP, with the effect on the patient's physical and emotional quality of life, with the variety of home care services provided by the hospice programs, with the characteristics of those home care services, and with bereavement services. Satisfaction levels were exceptionally high.

Analysis of variance tests were used to examine the differences among the hospice models and differences among programs in a model. There were statistically significant differences within the programs in the community-based model and within the program in the hospital-based scattered-bed models. The differences among the three models were not statistically significant at the .05 level but were significant at the .10 level.

The percentage of patients who died at home varied tremendously among programs in each of the three models. Again, differences among models were not significant at the .05 level but were significant at the .10 level. Considerably more patients died at home in the community-based programs (66.1%) than in either the hospital-based scattered-bed programs (31.2%) or the hospital based autonomous-unit programs (21.3%).

Another major finding was that the cost of hospice care for all three models was less than the estimated cost of conventional care for enrollment lengths of up to 120 days. Also, the overall savings resulting from hospice care generally increased for longer enrollments.

The average hospice charge per patient per day varied widely. Among the community-based programs the average was \$76.35/day, whereas the hospital-based autonomous-unit scattered-bed programs averaged \$89.36/day and hospital-based scattered-bed averaged \$115.67/day. The overall average was \$95.10 per patient per day. These differences among models were not statistically significant, however, because of the even larger differences in programs within each model.

A significant finding was that the average length of enrollment varied tremendously between the twelve hospice programs. There were large but not statistically

significant differences among the three models (community-based, 38.7 days; hospital-based autonomous-unit, 59.4 days; and hospital-based scattered-bed, 76.2 days). There were statistically significant differences within the community-based programs, where the average length of enrollment ranged from 18.6 days to 72.9 days.

With regard to volunteers, utilization varied greatly among models and among programs in each of the models. In general, however, volunteers were heavily relied on, and there were indications of substantial cost savings from the use of volunteers.

These results clearly indicate that the care provided by hospices in the New York State Hospice Demonstration Program has met with a high level of satisfaction and is generally less expensive than conventional care for the terminally ill. The data also indicate that although there are large differences among models in the ability to coordinate inpatient and home care services and in the cost of providing hospice care, there are huge differences within models. This suggests that the explanation for these differences probably lies more in the referral and operating policies of individual programs than in the inherent differences among hospice models themselves.

Brescia, Sadof, and Barstow (1984-85) conducted a retrospective analysis of a home care hospice program to see

if they could determine the patient population who would die at home. They also sought to define quality palliative care. A retrospective study of patients in the Overlook Hospice Home Care Program was performed. Records of patients who died in the program between September 17, 1979 and March 17, 1980 were reviewed. Only those patients seen more than once by a hospice nurse were included in the study. Fifty patients died during this period, 36 at home, and 14 in an acute care setting. Parameters to define and document quality palliative care were measured and differences between the patient populations who died at home and those who died in the hospital setting were recorded. Pain was the single most important symptom complex that required hospitalization.

In an attempt to find a difference between the patient population that died at home and that which died in the hospital, several factors were examined. The researchers found that all 5 noncancer-related deaths occurred at home. Medical oriented problems such as pain, vomiting, or incontinence had little effect on where the death occurred. There were no significant differences between the two groups in primary physician speciality, active treatment, sex, marital status, or sex of the primary caregiver. There was a tendency for the patient who was in denial and the younger patient to die in the hospital setting.

The researchers identified that it was important to the caregiver to have help at home by a home health aide or private duty nurse. Visits to the patient by the hospice staff increased in the last week of life and also physician contact increased.

Among the patients who died at home, there was no symptom complex which was perceived as unmanageable by the patient's family, nurse, or physician. The researchers were unable to predict who would die at home in this study. The only variable that may have had some importance was the patient's age and whether he or she had accepted the illness.

Wilkinson (1986) conducted an exploratory study of satisfaction with the care provided by Hospice of Schenectady, a small, community-based, home-care program in New York. Between January 1981 and January 1985, questionnaires were sent to surviving members of 266 hospice patients' families. The sample consisted of all the patients served by Hospice during this period who were discharged due to death. Questionnaires were sent to families of 145 males (54.5%) and 121 females (45.5%) ranging in age from 6 months to 91 years, with a median age of 65 years and a median length of stay in the hospice program of 25 days.

The data were collected for this study using the Evaluation Questionnaire, an 8-item tool using a Likert Scale ranging from (1) indicating a very negative response and (5) indicating a very positive response. Four questions related to concerns of the patient and four questions dealing with concerns of the family were included. The questionnaire also provided a number of opportunities for respondents to write in qualitative responses and comments. Responses were tallied separately by item, and an average satisfaction score was calculated for each respondent.

Patients' family members were sent the questionnaire approximately 3 to 6 months after the death of the patient, requesting their evaluation of the hospice services received and their perception of the patient's evaluation of the hospice care and services. A letter explaining the study was also sent with the questionnaire.

Of the 266 questionnaires mailed out, 118 were returned, a response rate of 44%. The sample of patients for whom the questionnaires were returned consisted of 61 men and 57 women. The gender distribution for respondents was different from that of non-respondents, a difference which was highly significant (Chi square = 12.60, $p < .001$). Husbands were more likely to return the questionnaire than wives (Chi square = 3.52, $p < .06$) and spouses were

significantly more likely to return the questionnaire than were children of the patient.

No significant relationships between the responses for each question and the patients' gender, age, and length of stay in the hospice were found. No significant differences in the average satisfaction were found across gender or age. Family satisfaction was closely related to whether or not responders felt that their initial expectations of hospice care were met. In general, a high degree of satisfaction was reported by questionnaire respondents. Control of pain was a major component of satisfaction in this study.

Dawson (1991) conducted a study which compared the ability of hospice and conventional care settings to meet the basic emotional needs of families during a member's dying and death from cancer. In addition, the relationship of basic needs satisfaction, perceptions about the nurse, and overall satisfaction with the program of care were explored.

The sample consisted of 100 bereaved familial caregivers who completed a mailed questionnaire concerning their perceptions of care at the site of a family member's death. The sites were (1) the home, with care provided by a Medicare certified, community-based hospice program; (2) a hospital affiliated with a Medicare certified, community-

based hospice program; (3) a hospital with its own hospice program; and (4) a conventional (non-hospice) hospital.

Criteria for sample selection were as follows:

- (1) The terminally ill patient who died in the hospital had been admitted at least 24 hours prior to death.
- (2) The terminally ill patient who died at home was served by the hospice program of care for at least one week prior to death.
- (3) The patient's death occurred at least one month prior, but not more than twelve months before, the researcher's contact.
- (4) The patients, whose deaths were a result of a tissue cancer, and the familial caregivers were twenty-years of age or older.

This protocol achieved a return rate of 73% for Group 1; 71% for Group 2; 50% for Group 3; and 39% for Group 4.

The instrument used in this study consisted of a demographic data form and three five-point, Likert type scales. The first scale was the Need Satisfaction Scale which consists of eighteen items necessary to emotional health of the family of a terminally ill patient. The items are the need to be (1) kept informed of the patient's condition, (2) able to do things to help the patient, (3) able to talk about fears and concerns with the people caring

for the patient, (4) aware that the patient was free from pain and comfortable, (5) aware that the staff cared about them and were there to help them, (6) informed when the patient was dying, (7) present when the patient died, (8) able to have the time to say good-bye and (9) able to talk with the staff after the patient's death about events surrounding the terminal illness.

Responses to the Need Satisfaction Scale were scored from 5 (strongly agree) to 1 (strongly disagree). Because subjects were asked to respond to each need both from the standpoint of how intensely the need was felt and how well the program of care met the need, the total Need Satisfaction Scale consisted of eighteen items.

Cronbach's alpha reliabilities were 0.84 for the 18 items of the Need Satisfaction Scale, 0.74 for the Felt Need Subscale, and 0.84 for the Met Need Subscale.

The second scale used was the Nurse Satisfaction Scale which is designed to measure client's satisfaction with the psycho-social support of the nurse. Responses were scored from 5 (strongly agree) to 1 (strong disagree). Total satisfaction with the nurse is indicated by a score of 55, total dissatisfaction by a score of 1. A Cronbach's alpha of 0.96 was obtained for this scale.

The third scale used was the Overall Satisfaction Scale which consisted of a single statement used to evaluate

overall satisfaction with the agency providing care: "If you think about your needs or the needs of your family during the final hospitalization, how satisfied are you with the care and support you received from the hospital or home care agency?" Responses were scored from 5 (very satisfied) to 1 (very dissatisfied).

Of the total sample of familial caregivers (n=100), most were Caucasian (95%), female (66%), and either the patient's husband (28%) or wife (38%). The mean age of the familial caregiver was 59.5 years. Chi square analyses revealed no significant differences among the four groups in gender, income, education, or relationship to the patient.

Hospice groups scored more favorably on all measures compared to the conventional care group. The conventional care group had a greater need satisfaction deficit ($F=11.96$, $P=0.0001$), demonstrated the lowest degree of satisfaction with the psychosocial support received from nurses ($F=11.83$, $P=0.0001$), and reported the lowest level of overall satisfaction with their program of care ($F=6.13$, $P=0.0001$). The differences in scores were greatest between the home hospice group (Group 1) and the conventional care group (Group 4).

A series of t-tests were carried out and indicated that while overall satisfaction with programs of care was comparable, significant differences existed between

hospice groups on some measures. The mean differences in nurse satisfaction scores between Groups 1 and 2 and between Groups 1 and 3 were significant at the $p < 0.05$ level. Nurses in Group 1 were more satisfied than nurses in Groups 2 or 3. Also, significant differences were apparent in the extent of unmet needs between Groups 1 and 3 ($p < 0.01$). In each instance, home hospice care is viewed more favorably than inpatient hospice care.

Pearson correlations revealed a significant negative correlation between overall satisfaction with one's program of care and unmet need scores ($r = -0.69$, $p = 0.0001$), as well as a positive correlation between overall satisfaction and the level of satisfaction with the psychosocial support of the nurse ($r = 0.73$, $p = 0.0001$).

The results of this study emphasize the importance of the nurse in the familial caregivers' feelings of satisfaction with a program of care. In addition, the results indicate that families experiencing a grief reaction are more likely to have basic needs met at home or when inpatient care is within a hospice rather than a conventional hospital.

A study was conducted by Keizer, Kozak, and Scott (1992) to determine how satisfied patients and families were with the service provided on the Regional Palliative Care Unit in Ottawa. Sixty primary care providers of patients

who had died on the Regional Palliative Care Unit (PCU) during a six-month period were randomly selected for survey, using a table of random numbers. Forty-five telephone interviews were completed six to twelve months following the death, representing a response rate of 94% of available eligible candidates.

The 64-item questionnaire consisted of 59 closed-ended questions and five open ended questions. Questionnaire items were organized into ten categories, three concerning background information and seven dealing with levels of client satisfaction. The majority of the items measuring satisfaction levels were rated on a 5-point Likert scale. Responses to the five open-ended questions were recorded verbatim and categorized later. Interviews ranged from fifteen to forty minutes, the mean being twenty minutes. Data were analyzed by the Statistical Package for the Social Sciences 4.0.

Seventy-five percent of respondents were women, 42% were spouses, 33% offspring, 9% siblings and 16% had another relationship to the patient. Seventy percent of the patient admissions to the PCU had lasted between one week and two months.

The major finding was that care was perceived to be highly satisfactory. Unanticipated benefits of this study were that the primary care providers emphasized the

importance to the family of having had the patient cared for on the Palliative Care Unit, and they clearly identified their personal criteria for a "good death."

Primary care providers concurred that a "good death" occurs when the patient is allowed to die peacefully, naturally, without prolongation of the dying process, and surrounded by family whenever possible.

Many families affirmed that their loved ones had enjoyed a high quality of life during their last weeks, and that their family's hope and goal of a "good death" for their relative had become a reality.

Patient Satisfaction with Nursing Care

Risser (1975) developed an instrument to measure patient satisfaction with nurses and nursing care in primary health care settings. To ascertain patient satisfaction with nurses and nursing care, attitude methodology was applied. For this, the Likert method was selected because of its relative ease of administration and scoring, relative simplicity of construction, potential reliability with relatively few items, and relationship to behavioral criteria.

Content area and dimension were defined before constructing the scale. The dimensions and definitions which guided item development were:

- 1) Technical - professional behavior of the nurse which fulfills instrument or goal achievement function.
- 2) Intra-interpersonal - the expressive function of the nurse.
Intrapersonal - the nurse's personality characteristics
Interpersonal - Social aspects of nursing care.
- 3) Trusting Relationship - verbal and nonverbal communication measures.
- 4) Educational Relationship - information exchange between patient and nurse.

Questionnaire items were developed from interviews with patients, literature reviews, and other similar scales. These items were then subjected to two sequential trials and to application of criteria such as variability, representativeness of content definition, ability to discriminate between respondents, and internal consistency. The tool consisted of twenty-five items subdivided into three subscales: 1) technical-professional area, 2) interpersonal educational relationship and 3) interpersonal trusting relationship to which respondents indicated agreement to disagreement in five Likert-type steps.

Respondents for the two sequential trials were 78 and 60 patients of internists or general practitioners at a group health cooperative. Data for the first trial were collected on seven days between June 2 and 19, 1972. Of the patients invited by the investigator to complete the questionnaire, approximately 10% refused. Of the 78 participants in the first trial approximately one-third were male and two-thirds female. Data for the second trial were collected on six days between July 21 and August 7, 1972. Of the sixty participants in the second trial, half were male and half female. In both trials approximately three-fourths of the respondents had been patients at the health cooperative more than five years.

Average scores were obtained for each respondent on each subscale and on the total scale. A marked variance was noted between respondents in their ability to discriminate between content areas. Some respondents obtained satisfaction scores nearly identical in all subareas, while others evidenced significant discrimination between subscales in their scores. Actual ranges of individual subscale mean scores for Trial II were: 1) technical-professional subscale from 1.0 to 2.83; 2) educational relationship subscale from 1.0 to 3.71; and 3) trusting relationship from 1.0 to 3.71. In both trials, patients were most satisfied with the nurse's function in the

technical-professional area and least satisfied with the nurse's behavior in the educational relationship dimension. In both trials, subscale 1, dealing with the technical-professional area, showed considerably less variability than the other subscales in the same trial.

Reliability coefficients, using Cronbach's formula, were obtained for the three subscales of both trials and for the total item cluster. Cronbach's alpha for subscale I was .637, for subscale II was .825, for subscale III was .819, and for the total scale was .912.

Discriminate validation was tested when intersubscale correlation coefficients were obtained for each trial to identify whether the subscales as defined were truly separate dimensions of the domain of attitude toward nurses and nursing care. There was a high correlation between subscales in both trials which indicates a significant common factor between all subscales.

Further refinement of the scale and several additional trial administrations will be necessary to provide information on content validity and to begin accumulation of construct validity data. Use of this tool in settings where the nursing role is broadening and nurses are accepting more responsibility for delivery of primary health would require expansion and redefinition of the current content dimensions.

A study was conducted by Lucas, Morris and Alexander (1988) to investigate the relationship between the patient's exercise of self-care agency prior to hospitalization and subsequent satisfaction with nursing care during hospitalization. The conceptual framework used was Chang's Model for evaluation of health care professionals in facilitating self-care (Chang, 1980).

The sample consisted of 68 subjects who were newly admitted adult medical-surgical patients and had been admitted at least 48 hours. The study was performed during a two-week period in January 1987 in a 495 bed private, community hospital which was located in a southeastern metropolitan area. Subjects were volunteers who met the criteria of being 18 years of age or older, oriented, and in no acute distress as determined by the charge or head nurse.

Within 24 hours of admission, patients completed questions regarding their self-care agency prior to hospitalization and the demographic items of age, race, sex, level of education, marital status, previous hospitalizations, and reason for present hospitalization. As the patients were discharged, they were asked to complete the questionnaire relating to satisfaction with nursing care.

This was a descriptive, correlational study. The Kearney and Feisher Exercise of Self-Care Agency instrument

(Kearney and Feisher, 1979) was used to measure self-care. This instrument consists of 43-items with responses measured on a 5-point Likert scale with 172 being the maximum score. A coefficient alpha of .88 was obtained from the sample. The Hinshaw and Atwood Patient Satisfaction Instrument (Hinshaw and Atwood, 1982), a 25-item, 5-point Likert Scale was used to measure patient satisfaction with nursing care. This instrument measures the degree of satisfaction with technical-professional care, trust, and patient education. The total alpha coefficient was .95 for the current sample.

The self-care agency scores ranged from 93 to 162 with a mean of 126 and standard deviation of 20, indicating a relatively high degree of self-care agency among the subjects. Overall patient scores ranged from 56 to 125, with a mean of 97, reflecting a favorable perception of the nursing care received by the subjects. The relationship between the exercise of self-care agency and overall patient satisfaction was not statistically significant ($r = .2311$, $p = 0.58$) when using Pearson's product moment correlation. When these data were analyzed using the patient characteristics, there were significant relationships according to sex and marital status. For females and married patients, there was a significant positive relationship between self-care agency and overall

satisfaction with nursing care (females, $r = .3329$, $p = .03$; married patients, $r = .3022$, $p = .03$). This study validated portions of Chang's framework by identifying relationships between exercise of self-care agency and patient satisfaction with nursing care in females and married patients.

The practice implication from these findings may be that nurses need to plan nursing care for men with high self-care agency differently than for women and married patients with high self-care agency. Administering a questionnaire such as the Kearney and Feisher Exercise of Self-Care Agency (Kearney and Pleischer, 1979) instrument to patients on admission would give the nurse a base line on which to build patients' knowledge of self-care behaviors.

Satisfaction with Home Health Care

McNeese (1988) used a sample of 300 patients who were discharged by a large government hospital in Houston, Texas and referred to home health agencies in the previous year to study satisfaction with home health services. These patients were referred to home health agencies throughout urban and rural areas in the states of Texas and Louisiana. The instrument used was an adaptation of the Quality of Nursing Care Questionnaire – Patient which consists of three sections. This questionnaire includes demographic data such as: the patient's age, the name of the home health agency,

patient location, and the frequency of visits and length of service. The second section of the questionnaire was grouped logically into three major categories: (1) nurse-client communication, (2) patient teaching, and (3) nurse-client interpersonal relationship and trust. This portion of the questionnaire consisted of 19 items to be ranked on a five-point Likert scale in order of importance as "always," "usually," "sometimes," "seldom," and "never." The last section of the questionnaire consists of open-ended statements.

Fifty-seven percent of the patients responded to the mailed survey. The average length of service by all disciplines was one to six months, and the frequency of visits was one to three times per week. The terms that best describe the health care the patient had received were reported generally by the respondent as excellent or very good.

Ninety-five percent of the respondents felt that nurses or other health care team members were considerate and interested in their welfare. Ninety-three percent indicated confidence in the health care team members and 93% felt that team members were almost always patient and understanding. Eighty-two percent of respondents felt that the home health care staff was knowledgeable and capable of teaching. Seventy-four percent always received written information

about the agency and 87% knew how to contact staff daily. These findings indicate that most patients had been affected significantly by home health care services, and that the respondents expressed appreciation for the services provided and for the staff's concern for their well-being.

Laferriere (1993) measured the level of client satisfaction in a sample of home care clients and also described the dimensions of the domain of client satisfaction in order to define client satisfaction of the home care client.

This was an exploratory descriptive study conducted at a nonprofit Medicare-certified home health agency in Northeastern Vermont. Ninety-seven clients were randomly selected to participate in this study.

The data were collected using the Client Satisfaction Survey (CSS) with revisions which was originally developed by Reeder and Chen in 1990. This scale instrument assesses client satisfaction with home care nursing, incorporating the concepts of patient-client satisfaction and the nursing process. The CSS is a 35-item tool using a Likert Scale ranging from (1) Strongly Agree to (5) Strongly Disagree. The response rate to this survey was 75%.

The overall mean response to the total CSS for the surveyed clients was 1.6966. The low mean value indicated a high degree of patient satisfaction. The most satisfaction

was reported with the following: a) nursing time spent talking with patients, b) the efficiency of the nurse's work, and c) the degree of patience exhibited by the nurse. Less satisfaction was noted with the following: a) the knowledge of what one needs to do to stay healthy, b) the nurse's effort to discuss changes in the client's health since the last visit, and c) withholding of information about test results and procedures.

Cronbach's alpha coefficient for the sample was .99 with individual item correlations ranging from .6963-.9613. Through factor analysis, the following four domains of client satisfaction were identified: (a) technical quality of care, (b) communication, (c) personal relationship between the client and the provider, and (d) delivery of services. Factor analysis did not support the organizational framework of the nursing process for the CSS instrument.

Comparison of a Telephone Survey with a Mail Survey

A study was conducted by Walker and Restuccia (1984) regarding obtaining information on patient care satisfaction with hospital care using mailed questionnaires versus telephone surveys. The purposes of the study were to develop a questionnaire useful in eliciting the perceptions of patients regarding their hospital care and to compare the methodologic and substantive differences between a mail and

a telephone survey of patients done approximately a week past discharge.

It was hypothesized that the telephone method would yield responses indicating more satisfaction than would the mail method, as a result of more patient-interviewer interaction. According to the authors, as the degree of interaction increases (from none in a mail survey to the most in a face-to-face personal interview situation, with a telephone interview considered intermediate), the respondent shows more of a tendency to give an "acquiescent response" — or what may be considered to be the socially acceptable response. Also for this particular survey the "very satisfied" response was always the first category read to the patient over the telephone and may have been chosen for that reason alone.

The results of this study show that telephone respondents were more likely to be very satisfied or to give the highest rating to care received than were the mail respondents. The telephone surveys were found to be more expensive, \$16.22 per respondent compared to \$12.62 per respondent for the mail survey. The response rates for the telephone survey were 67% and 58.1% for the mail survey.

Identifying the Needs of Home Caregivers

In 1992, Hileman, Lackey and Hassanein studied 492 home caregivers of patients with cancer. The primary purpose of this methodologic, correlational study was to identify, categorize, and assess the importance of needs expressed by home caregivers and to determine how well these needs were satisfied. Caregivers surveyed for this study were selected from the records of this nonprofit community cancer agencies and two hospital outpatient oncology clinics in the Midwest.

Three survey instruments were used for this study. They were 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. This tool has two seven-point, modified Likert-type scales following each item that allow respondents to rate the importance and the satisfaction of each need statement. The short version of the Karnofsky Performance Status Scale was used to measure the level of activity of the cancer patient. This is a five-item tool designed to measure a patient's activity level. It has reported reliability ranging from 0.69 - 0.89. The last instrument used was the patient and caregiver information sheet which was developed to gather selected information on both the caregiver subjects and the patients.

Subjects were home caregivers for at least one month, were 18 years or older, and were able to read, write, and understand English. A convenience sample of 492 caregivers were selected from four settings which included a metropolitan nonprofit cancer agency, county units of a state division of a national nonprofit cancer agency, an inpatient oncology clinic, and a radiation oncology clinic in a large metropolitan teaching hospital.

Patients were contacted by telephone or in person by a trained volunteer or the investigator. The purpose of the study and definition of the caregiver were described to the patient and then the patient identified their caregiver. The caregivers were then contacted in person or by phone and explained the purpose of the study, the definition of caregiver, and the admission criteria. The caregivers were then asked to complete the three survey instruments and return in person or by mail. The participation rate varied by site from 70-100%, with an overall response rate of 89%.

Most caregivers in this study were women (66%) but there was a trend toward an increasing number of male caregivers (33%). The racial mixture was representative of the area in which data were collected: 95% white, 4% black, 0.5% Hispanic, and 0.5% other. Most caregivers were married and almost half had education beyond high school. Almost half of the caregivers worked part-time or full-time. More

than 80% described their health as good or excellent. Most caregivers had been in the role of caregiver for 1-12 months and lived with their patients. More than 50% of the caregivers had an annual income of \$20,000 or less. Subjects ranged in age from 20-89 years, with more than 75% of the patients 50 or older.

The greatest needs of the caregiver were informational and psychological. Items often seen among the top ten needs were: 1) information about community resources, 2) information about what to expect in the future, 3) information about the underlying reasons for symptoms, 4) ways to reduce stress, and 5) honest and updated information.

Significant correlations indicated that when the patient's activity level decreased, a caregiver's psychological, patient care, personal, and household needs increased. Caregivers who lived with their patients identified more personal needs than caregivers who were not living with their patients. Low-income caregivers had more household needs and fewer informational needs than caregivers with higher incomes. Also, younger caregivers reported more psychological and personal needs than older caregivers. Most needs changed over time, spiritual needs changed the least, followed by informational, patient care, psychological, personal, and household needs.

Further reliability of the HCNS was also validated by this study. Cronbach's alpha coefficients were calculated to analyze the internal consistency of each factor and each item. The overall reliability of all items in the six factors was calculated as 0.98.

Summary

The literature indicates that caregivers are quite satisfied with hospice care services. There were significant similarities in satisfaction levels in many of the research articles. Several of the studies indicated the importance of the nurse when measuring caregiver satisfaction with hospice or home health care services. It also appears from the literature that it is desirable for the dying person to be at home.

Although the degree of satisfaction with hospice care in the articles reviewed was quite high, there has been limited research in this area. Also there are a limited number of instruments reported in the literature which are available for measuring satisfaction with hospice care.

As a result of the increased cost to insurers for hospice services due to the increased utilization, there is an increasing demand from these insurers for quality outcome measures. Many third party insurance companies are now requesting satisfaction data from hospices with whom they contract. Hospices need to focus more on these areas in

order to have concrete data related to patient and caregiver satisfaction.

The intent of this study was to measure caregiver satisfaction with hospice care and factors which may affect the level of satisfaction in one hospice agency. Hopefully the results of this study will prove valuable for this agency in the development of outcome measures related to satisfaction.

Chapter III

Methodology

Problem Statement

The purpose of this study was to evaluate caregiver satisfaction with hospice services, to identify the variables that are the most indicative in predicting caregiver satisfaction with hospice care, and to identify the most important needs as identified by the caregiver. 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 hospice services.

Theoretical Basis of the Study

Traditionally, nursing practice focused on the actions of nurses. These actions were based mostly on custom and common sense. Nurses provide systematic, scientific, and effective nursing care. The nursing process provides a framework for collecting and analyzing information, planning care, implementing care, and evaluating care. The nursing process will offer the framework for this study.

The nursing process is a set of actions used to determine, plan, implement, and evaluate nursing care (Wolff, Weitzel, Zornow, and Zsohar, 1983, p. 201). The nursing process is a form of problem solving that has been adapted to nursing. The primary purpose is to help the

nurse manage the patient's care intelligently, scientifically, and judiciously. When used properly, the nursing process helps attain the ultimate goals of nursing care, which are to help the patient maintain health, prevent illness, promote recovery from illness, and promote return to a state of maximal functioning, or, when terminal illness is present, to help the patient to a peaceful death (Wolff et al., 1983, p. 201).

There are four components in the nursing process: assessment, planning nursing care, nursing intervention or implementation, and evaluating the results of nursing care. This study focuses on evaluating hospice care and the investigator has used the nursing process as a basis for this evaluation.

Study Design

This was an exploratory descriptive study which is defined by Polit and Hungler (1991, p. 144) as research that aims predominately at describing phenomena rather than explaining them and is common in the emerging field of nursing research.

This study involved quantitative data collection (Likert type questionnaire) and qualitative data, consisting of comments provided by the caregiver. Quantitative data designs are important in order to describe phenomena or assess magnitude and reliability of relationships among

them. Qualitative designs are important in discovering underlying dimensions and patterns of relationships (Polit and Hungler, 1991, p. 652-653).

Research Questions

The following research questions were addressed:

1. How satisfied are caregivers with hospice care?
2. What variables are the most important in explaining caregiver satisfaction with hospice care?
3. What are the most important needs as defined by the caregiver?

Hypotheses

1. There is a relationship between the patient's age and the caregiver's satisfaction with hospice care.
2. There is a relationship between the sex of the caregiver and satisfaction with hospice care.
3. There is a relationship between the patient's length of stay on the hospice program and the caregiver's satisfaction with hospice care.
4. There is a relationship between the patient's insurance class and the caregiver's satisfaction with hospice care.
5. There is a relationship between the number of home health aide visits and the caregiver's satisfaction with hospice care.

6. There is a relationship between the number of pastoral counselor visits and the caregiver's satisfaction with hospice care.
7. There is a relationship between the number of social work visits and the caregiver's satisfaction with hospice care.
8. There is a relationship between the number of volunteer visits and the caregiver's satisfaction with hospice care.
9. There is a relationship between the number of registered nurse visits and the caregiver's satisfaction with hospice care.
10. There is a relationship between the place of death and the caregiver's satisfaction with hospice care.
11. There is a relationship between the diagnosis of the patient and the caregiver's satisfaction with hospice care.
12. There is a relationship between the ethnicity of the patient and the caregiver's satisfaction with hospice care.

Study Population

The population for this research project was caregivers of patients who died while in a hospice program. Coastal Hospice is a Medicare certified hospice licensed in the State of Maryland. Services are provided to four counties

on the Eastern Shore of Maryland with an office in two of the counties.

Study Sample

A convenience sample of caregivers of patients who died while in a hospice program was used. According to Polit and Hungler (1991), a convenience sample entails the use of the most conveniently available persons or objects for use as objects in a study. All primary caregivers of patients who died in the hospice program while the research project was being conducted were included in the study.

Study Variables

The variables essential to this study are defined as follows:

1. Satisfaction - Measured by a 47 item questionnaire which used a 4-point Likert Scale ranging from 1 meaning from very dissatisfied to 4 meaning very satisfied. The questionnaire consisted of five subscales.
2. Caregiver - the person listed on the hospice record as primarily responsible for assisting with the patient's self-care deficits without receiving remuneration.
3. Terminally ill - any diagnosis that warrants a life expectancy of six months or less as defined by the patient's attending physician.

4. Hospice - a program through which home care services are provided to the terminally ill by an interdisciplinary group (IDG) composed of a physician, registered nurse, social worker, pastor, and volunteers.
5. Length of Stay (LOS) - the number of days the patient was in the hospice program as determined by the computer program.
6. Insurance Class - party listed on the patient computer record as the party responsible for paying the hospice services rendered to the patient.
7. Age of the patient - Number of years since the patient's birth as reported on the patient computer record.
8. Gender of patient - Whether the patient was male or female as reported on the patient computer record.
9. Gender of caregiver - whether the caregiver is male or female as reported on the patient computer record.
10. Diagnosis of patient - Medical condition for which the patient was admitted to the hospice program as identified on the patient computer record.

11. Place of death - place where the patient died which is reported on the patient computer record.
12. Number of visits - Number of visits provided by each discipline (to include home health aide visits) involved in the care of the patient. This is determined by the computer program.

Instrumentation

The instrument used in this study to measure satisfaction was a modified version of the Home Caregiver Need Survey developed by Judy Willis Hileman in 1990. The original instrument consisted of 90 closed-ended items gathered from 531 needs statements which 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. Through the process of item development, initial content and face validity for the instrument were obtained.

In order to establish interrater reliability among three nurse researchers and three English experts, the percent of agreement was calculated for each need item. Overall agreement was ninety percent on all items.

Construct validity for the instrument was examined by using Principal Factor Analysis with Promax Rotation.

The instrument was found to be internally consistent with category coefficient alphas ranging from .85 to .97.

For the purpose of this study some of the original 90 questions were eliminated and additional questions were added by the researcher. The questions added were related to the Standards of a Hospice Program of Care (NHO, 1993) and were felt to be pertinent to caregiver satisfaction.

For the purpose of this study, satisfaction was ranked on a four-point Likert-type scale. The scale ranges from 1 meaning very dissatisfied to 4 meaning very satisfied. The researcher believed that simplifying the instrument by minimizing the degrees of choice would give a more valid and accurate assessment of caregiver satisfaction.

After the researcher completed the initial survey, it was reviewed by the President of the Hospice and all of the supervisors for the different disciplines. Several questions which were felt to be redundant were deleted. The survey was piloted with two former caregivers of hospice patients to determine clarity of questions, time needed to complete the questionnaire, and any other information felt to be pertinent. The former caregivers reported that the survey was easy to understand and took them approximately twenty to thirty minutes to complete. Both former

caregivers reported that by completing the survey they learned about hospice services which they did not know were available when their loved one was in the hospice program.

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 services to the family regardless of participation in the study. Demographic information collected included: length of stay in the hospice program, pay source, age of the patient, gender of the patient, gender of the caregiver, diagnosis of the patient, place of death of patient, and the number of visits provided by each discipline.

Research Methods

Data were collected between July 1, 1996 and November 5, 1996. A computer list of hospice patients who had died in the previous three to six weeks and their caregivers was generated weekly by the Hospice's Office Manager. This list was then given to the researcher who assigned a number to each survey and mailed the disclosure letter and survey to the caregiver in a self-addressed, postage paid return envelope. Once the surveys were returned, the Office Manager then matched the number on the survey with the patient's name and generated a discharge summary for the patient. All identifying information was removed from the

discharge summary and it was then attached to the completed survey and given to the researcher. Demographic variables were obtained from the discharge summary. Confidentiality was maintained at all times. The list of caregivers who participated in this study was maintained in a locked file cabinet in the Hospice President's Office.

Ethical Implications

Consent for this study was obtained from the Human Subjects Committee at Salisbury State University and the President of the Hospice. Informed consent was obtained from the subjects. Participation in the study was completely voluntary.

Assumptions and Limitations

The assumption of this research was that the caregivers would answer the questions honestly.

The limitations of this research included that the sample size was small and convenience sampling is the weakest form of sampling. All participants were voluntary, thus causing the sample to be biased and not generalizable.

This study also included a questionnaire which allowed for self-report by the participants. This can often be an area of bias due to the participants' reluctance to report feelings of dissatisfaction. Also the study was conducted by a novice researcher.

Chapter IV

Data Analysis

Introduction

The demographic characteristics of the study sample will be described and the data collected will be analyzed in this chapter. The research questions presented in Chapter III will be addressed. 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 primary caregivers of hospice patients who died between June 9, 1996 and October 19, 1996. The first surveys were mailed the week of July 1, 1996 and the last surveys were mailed the week of November 5, 1996. A total of eighty-eight surveys were mailed and forty-six surveys returned. The response rate for this survey was 52%. Persons listed on the Coastal Hospice record as the primary caregiver were requested to participate in the study. Participation was totally voluntary and did not affect any bereavement services received by the primary caregiver.

Most of the caregivers in this study were female (82.6%). The majority of the patients were male (60.9%) and were white (91.3%). The average age of the patient was 72 years old. The average length of stay (LOS) on the hospice

program was 101 days with a median LOS of 28 days. There were two patients who died during the survey period who had length of stay greater than 1095 days. These patients therefore made the average length of stay longer. The median length of stay is more indicative of the average hospice patient. Most of the patients were on a hospice benefit (82.6%) and died at home (93.5%) (Table 1).

Demographics of the study population are comparable to the statistics from the Hospice Program for 1996. Eighty-one percent of the patients in 1996 were Caucasian and 18.75% African American. The average LOS for 1996 was 80.7 days with a median LOS of 35 days. Sixty-eight percent of hospice patients in 1996 were over the age of 65. Sixty-five percent of the patients in 1996 were on a per diem benefit. Forty-eight percent of patients in 1996 were male.

The median number of nursing visits received was 13 with an average of 31; for home health aide visits, the median was 4 and the average 21; for pastoral care visits, the median was 1 with the average 4; for social work, the median was 1 with an average of 5; and the median for volunteer visits was 0 with an average of 6 visits (Table 2). As one would expect patients received more visits from registered nurses than any other discipline.

Table 1

<u>Demographic Characteristics</u>		
<u>Characteristic</u>	<u>Number</u>	<u>Valid Percent</u>
<u>Gender of Patient</u>		
Male	28	60.9
Female	18	39.1
TOTAL	46	100.0
<u>Gender of Primary Caregiver</u>		
Male	8	17.4
Female	38	82.6
TOTAL	46	100.0
<u>Ethnicity</u>		
White	42	91.3
African American	4	8.7
TOTAL	46	100.0
<u>Age of Patient</u>		
Median Age	72	N/A
Mean Age	72	N/A
<u>Length of Stay (Days)</u>		
Median	28	N/A
Mean	101	N/A
<u>Insurance Class</u>		
Benefit	38	82.6
Other	8	17.4
TOTAL	46	100.0
<u>Place of Death</u>		
Home	43	93.5
Other	3	6.5
TOTAL	46	100.0

Table 2

Number of Visits by Discipline

<u>Discipline</u>	<u>Mean # Visits</u>	<u>Median # Visits</u>
Home Health Aide	21.6522	4
Pastoral Counselor	4.3043	1
Registered Nurse	31.0217	13
Social Worker	5.7391	1
Volunteer	6.1957	0

In order to participate in hospice services patients must receive nursing visits whereas visits by other disciplines are elected by the patient and his or her family. The median number of volunteer visits was much lower than one would expect. It seems that there are many patients and families who do not accept the services of a volunteer.

Instruments

The instrument used in this study was a modified version of the Home Caregiver Needs Survey (HCNS) developed by Judy Willis Hileman in 1990. The original instrument consisted of 90 closed-ended statements incorporated from previous research to be ranked by the caregiver in importance on a scale of 1-7, where 1 is not important and 7 is very important. The original instrument was found to be internally consistent with category coefficient alphas ranging from .85 to .97.

Some of the questions were deleted and additions made by the researcher. The survey used for this study consisted of 47 questions; twenty questions which pertained to informational needs, six questions pertaining to household needs, four questions pertaining to personal needs, twelve questions pertaining to psychological needs, and five questions pertaining to spiritual needs.

Caregiver Needs and Satisfaction

The caregivers were requested to answer "yes" or "no" as to whether it was important to them that information be provided regarding the 47 needs identified in the survey. If the caregiver answered "yes" they were then required to rate their satisfaction with the Hospice staff's response to that need. Satisfaction was ranked on a 4-point Likert scale with 1 as very dissatisfied and 4 as very satisfied.

In general the satisfaction ratings for this survey were quite high. Table 3 shows the data for the needs involving information. Many caregivers rated the need to know how to combat pain and obtain equipment, supplies and medication as the most important needs for this category. It was also very important to caregivers that information be provided about hospice services; medication effects, schedules, and how to give; what symptoms to expect; ways to manage breathing problems; information on nutritional needs; signs and symptoms of approaching death; the physical needs of the loved one; and how to reach the hospice staff after business hours. The caregivers were the least concerned that information be provided regarding possible side effects of treatment, available community resources, and professional counseling. The caregivers were the most satisfied with information regarding hospice services,

Table 3

Needs Involving Information			
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
Hospice Services	97.8%	3.9091	4
Medication effects, schedules, and how to give	97.7%	3.8837	4
What symptoms to expect	97.8%	3.8837	4
Ways to control pain	100%	3.8605	4
Possible side effects of pain medication	88.1%	3.8974	4
Addiction to pain medication	75%	3.8276	4
Control of constipation or diarrhea	87.5%	3.8095	4
Control of nausea and/ or vomiting	86%	3.8889	4
Ways to manage breathing problems	97.6%	3.8537	4
Nutritional needs	95.1%	3.7895	4
Signs and symptoms of approaching death	95.5%	3.8095	4
The physical needs of your loved one	97.8%	3.8636	4
Possible side effects of treatment (such as Radiation or Chemotherapy)	50%	3.9333	4
The type and seriousness of your loved ones illness	90.2%	3.8158	4

Table 3 (continued)

Needs Involving Information			
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
Available community resources such as Meals on Wheels	20%	3.600	4
Professional Counseling	55.9%	3.8421	4
How to reach hospice staff after business hours	95.7%	3.9302	4
How to get equipment, supplies and medication	100%	3.9070	4
Financial coverage of hospice services	90%	3.8889	4
Patient rights such as a Living Will or Durable Power of Attorney for Health Care	82.9%	3.9310	4
MEAN SUBSCORE FOR THE CATEGORY		3.8562	
POSSIBLE RANGE		1-4	

possible side effects of treatment, how to reach hospice staff after business hours and with information provided regarding patients rights such as a Living will or Durable Power of Attorney for Health Care. Caregivers were the least satisfied with information regarding nutritional needs of the patient and available community resources such as Meals on Wheels. Caregivers also did not seem to think that information regarding available community resources such as Meals on Wheels was very important.

Table 4 shows the importance, mean satisfaction, and median satisfaction of needs involving the household. There were six items on this subscale and 100% of the respondents ranked the following as important: to know how to reach the hospice staff 24 hours a day, seven days a week; that the oncall staff respond to phone calls in a timely manner, and that the oncall staff make visits and call the physician for new orders when needed. The respondents were also very satisfied with the hospice staff's response to these items. The least important need identified for this subscale was that a volunteer be available to run errands (51.5%, 3.8125). It seems that caregivers wanted to know that volunteers would be available if they were needed but they were seldom utilized.

Table 5 shows the importance, mean satisfaction, and median satisfaction of personal needs. All four of these

Table 4

Needs Involving Your Household			
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
To know how to reach the hospice staff 24 hours a day, seven days a week	100%	3.8636	4
That the on call staff respond to your phone call in a timely manner	100%	3.8864	4
That the on call staff make visits and call the physician for new orders when needed	100%	3.8864	4
That hospice volunteer services be made available	85.7%	3.7941	4
For hospice to provide a volunteer to stay with your loved one so you could get out of the house	61.8%	3.8421	4
That a volunteer was available to run errands	51.5%	3.8125	4
MEAN SUBSCORE FOR THE CATEGORY		3.8475	
POSSIBLE RANGE		1-4	

Table 5

	Personal Needs		
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
That the hospice staff be caring and concerned	100	3.9111	4
That the hospice staff encourage you to get adequate sleep and maintain your health	97.7	3.8537	4
That you have someone to talk with about your concerns and fears	95.2	3.8974	4
That the hospice staff encourage you to seek support from family and friends	92.7	3.8649	4
MEAN SUBSCORE FOR THE CATEGORY		3.8817	
POSSIBLE RANGE		1-4	

needs were ranked as being important. The most important need identified in this subscale was that the hospice staff be caring and concerned and caregivers were also the most satisfied with this need.

Table 6 shows the importance, mean satisfaction and median satisfaction of psychological needs. There were twelve items on this subscale. These needs were ranked by the caregivers as less important than needs involving information, needs involving the household and personal needs. The most important three needs for this category were: that information be provided about the loved one's emotional needs, that counseling be provided to help the loved one prepare for his/her death, and that information be provided about ways to decrease stress as a caregiver. The least important need identified was that help with accessing community resources such as Meals on Wheels be made available. Caregivers were the most satisfied in this subscale that counseling was provided to them about ways to maintain a normal family life.

Table 7 shows the importance, mean satisfaction, and median satisfaction with spiritual needs. The most important need identified in this subscale was that spiritual counseling be consistent with the loved one's beliefs. The least important need identified was that the hospice clergy provide assistance with the loved one's

Table 6

	Psychological Needs		
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
That counseling be available to help you and your family cope with the future loss of your loved one	77.8%	3.7692	4
That counseling be provided to help your loved one prepare for his/her death	80.6%	3.8148	4
That information be provided to you about your loved one's emotional needs	82.5%	3.8387	4
That the hospice staff suggest ways to talk about death with your loved one	75.7%	3.8148	4
That information be provided about ways to decrease your stress as a caregiver	80.%	3.8710	4
That information be provided to you on how to remain tolerant and patient with your loved one	69.4%	3.8000	4
That counseling be provided to you about ways to maintain a normal family life	54.8%	4.0000	4
That counseling be provided about ways to combat fatigue	57.6%	3.8947	4

Table 6 (continued)

Psychological Needs			
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
That counseling be provided about ways to cope with your loneliness	57.6%	3.8500	4
That counseling be provided to you about ways to cope with the loss of your loved one	69.7%	3.7826	4
That counseling be provided related to your future plans upon the death of your loved one	58.8%	3.7143	4
That help with accessing community resources such as Meals on Wheels be made available	19.2%	3.6250	4
MEAN SUBSCORE FOR THE CATEGORY		3.8146	
POSSIBLE RANGE		1-4	

Table 7

Spiritual Needs			
	<u>Importance</u> % Yes	<u>Satisfaction</u> Mean	<u>Satisfaction</u> Median
That spiritual counseling be consistent with your loved one's beliefs	82.4%	3.7200	4
That the hospice clergy provide support to your loved one	67.7%	3.5714	4
That the hospice clergy be nondemoninational	53.1%	3.7647	4
That the hospice clergy provide assistance with your loved one's funeral or memorial service	22.2%	4.0000	4
That the hospice clergy provide support to you and your family	54.5%	3.6500	4
MEAN SUBSCORE FOR THE CATEGORY		3.7412	
POSSIBLE RANGE		1-4	

funeral or memorial service but this need was also the one that caregivers were the most satisfied with in this category.

More caregivers rated needs involving information, household needs, and personal needs as more important to them than psychological and spiritual needs. Caregivers were slightly more satisfied with personal needs (3.8%) than the other four subgroups.

Variables Affecting Satisfaction with Hospice Care

It was thought that the age of the patient, gender of the patient and of the primary caregiver, ethnicity of the patient, length of stay on the hospice program, type of insurance, place of death, and/or number of visits by each hospice discipline may affect the caregiver's satisfaction with hospice care. Each of these characteristics except volunteers were examined by doing a t-test for independent samples. The disciplines were split into subgroups by median number of visits. A t-test was not run for volunteers because the median number of visits was 0. After each characteristic was reduced to two categories, the statistical analysis was completed. The 0.05 level was used to measure significance.

Relationship Between Age of the Patient and Satisfaction

Table 8 shows the relationship between the age of the patient and satisfaction. The median age of the patient was used to identify if there was a relationship between the the patient's age and satisfaction. In this study, the age did not have an affect on the caregiver's satisfaction with hospice care but the mean satisfaction for caregivers of patients between the age of 1 - 72 years was higher than that for caregivers of patients who were 73 years old or older.

Relationship Between Gender of Patient and Satisfaction

Table 9 shows the relationship between the gender of the patient and the caregiver's satisfaction with hospice care. The gender of the patient was not found to be an indicator of the caregiver's satisfaction with hospice care but there does seem to be a trend toward caregivers of male patients being more satisfied than caregivers of female patients. Perhaps if the sample size would have been larger a significant relationship between the patient's gender and the caregiver's satisfaction with hospice services may have been evident.

Table 8

Relationship Between Age of Patient and Satisfaction

<u>Age</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
1 - 72 years	129.6087	44	.851	NS
<u>≥</u> 73 years	120.9130			

Table 9

Relationship Between Gender of Patient and Satisfaction

<u>Gender</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
Male (n=28)	132.7143	44	1.876	.067
Female (n=18)	113.6667			

Relationship Between Gender of Primary Caregiver and Satisfaction

Table 10 shows the relationship between the gender of the primary caregiver and satisfaction with hospice care. In this study, the gender of the primary caregiver was not found to have a significant impact on the primary caregiver's satisfaction with hospice services. The mean score of male caregivers was higher than the mean score of female caregivers.

Relationship Between Length of Stay (LOS) and Satisfaction

Table 11 describes the relationship between the patient's length of stay on the hospice program and caregiver satisfaction with hospice services. LOS was broken into two subgroups, 1 = 1-28 days and 2 = \geq 29 days. The researcher felt that the caregivers of patients with a long LOS would be more satisfied than those of patients with a short LOS. It was felt that patients with a long LOS had probably utilized more services and therefore would be more satisfied. There was not a significant relationship between the patient's length of stay on the hospice program and the caregiver's satisfaction with hospice care. The mean satisfaction for caregivers of patient's who had a LOS greater than or equal to 29 days was higher than that of caregivers of patient's with a LOS less than twenty-nine days. This is what one would expect to find because the

Table 10

Relationship Between Gender of Primary Caregiver
and Satisfaction

<u>Gender</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
Male (n=8)	131.8750	44	.592	NS
Female (n=38)	123.8684			

Table 11

Relationship Between Length of Stay
and Satisfaction

<u>Length of Stay</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
1 - 28 days	121.1304	44	.808	NS
<u>≥ 29 days</u>	129.3913			

longer a patient is in the hospice program the more services he/she and the family will receive therefore leading to a higher degree of satisfaction.

Relationship Between Patient's Insurance Class and Satisfaction

Table 12 describes the relationship between the patient's insurance class and the caregiver's satisfaction with hospice services. The insurance classes were divided into two groups. Group 1 were those patients who were on a hospice per diem benefit and Group 2 were other insurance, which included commercial insurance policies and one uncompensated patient. It was felt that caregivers of patients on a hospice per diem benefit would be more satisfied than those of patients who were not on a hospice per diem benefit. The hospice per diem benefit covers visits by all of the team members, medications and equipment related to the terminal illness, inpatient respite, continuous care, and general inpatient care which is related to the terminal illness. It was a positive outcome to find that the type of insurance did not affect the caregiver's satisfaction. One would hope that the care provided by the hospice to patients without a per diem benefit is just as good as that provided to those who have one. In this study it was found that the patient's insurance class did not affect caregiver satisfaction with hospice services.

Table 12

Relationship Between Patient's Insurance
Class and Satisfaction

<u>INS</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>	
Hospice Benefit (n=38)	124.8684	44		.166	NS
Other (n=8)	127.1250				

Relationship Between the Number of Home Health Aide Visits and Satisfaction

The researcher felt that caregivers of patients who had more home health aide visits would be more satisfied than caregivers of patients with fewer home health aide visits because caregivers would have to provide less physical care for the patient. In this study, the number of home health aide visits were not found to have a significant effect on the caregiver's satisfaction. Even though there was no significant relationship between the two variables, the means were reverse of what you would expect to find. The mean satisfaction was higher for caregivers of patients who received 0-4 home health aide visits than caregivers of patients who received ≥ 5 home health aide visits.

The relationship between the number of home health aide visits and caregiver satisfaction with hospice care are shown in Table 13. The median number of home health aide visits was used to divide the data into two groups. Group 1 were the patients who received 0-4 home health aide visits and Group 2 those who received ≥ 5 home health aide visits.

Relationship Between the Number of Pastoral Counselor Visits and Satisfaction

The relationship between the number of pastoral counselor visits and satisfaction with hospice care is shown

Table 13

Relationship Between the Number of Home Health Aide
Visits and Satisfaction

<u>#Home Health Aide Visits</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
0 - 4	130.2083	44	1.015	NS
<u>≥ 5</u>	119.8636			

in Table 14. The median number of pastoral counselor visits was used to divide the data into two subgroups. Group 1 were the patients who received 0-1 visits from a pastoral counselor and Group 2 were those patients who received ≥ 2 visits from a pastoral counselor. It was found that the number of visits had no significant effect on the caregiver's satisfaction with hospice care. The mean satisfaction for caregivers of patients who received ≥ 2 pastoral counselor visits was higher than for the caregivers of patients who received < 2 pastoral counselor visits. This is consistent with what one would expect to find.

Relationship Between the Number of Social Work Visits and Satisfaction

Table 15 demonstrates that there is not a significant relationship between the number of social work visits and the caregiver's satisfaction with hospice services. The median number of social work visits was used to divide the data into subgroups to compare whether the number of visits effected satisfaction. Group 1 were those patients who had 0-1 visits and group 2 those with ≥ 2 visits. The mean

Table 14

Relationship Between the Number of Pastoral Counselor
Visits and Satisfaction

<u># Chaplain Visits</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
0 - 1	122.0357	44	-.787	NS
<u>≥ 2</u>	130.2778			

Table 15

Relationship Between the Number of Social Work Visits
and Satisfaction

<u># Social Work Visits</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
0 - 1	123.4167	44	-.375	NS
<u>≥ 2</u>	127.2727			

satisfaction was higher for Group 2 than Group 1 which is what one would expect to find.

Relationship Between the Number of Nursing Visits and Satisfaction

It was felt that the caregivers of patients who received many nursing visits would be more satisfied than the caregivers of patients who received few nursing visits. Table 16 demonstrates that there is not a significant relationship between the number of nursing visits received by the patient and the caregiver's satisfaction with hospice services. The median number of nursing visits was used to divide the data into two groups to compare whether the number of visits affected satisfaction. Group 1 were those patients who received 1-13 nursing visits and Group 2 were those patients who received ≥ 14 nursing visits. The mean satisfaction was higher for Group 2 than for Group 1 which is what one would expect to find.

Relationship Between Place of Death and Satisfaction

The researcher felt that the caregivers of patients who died at home would be more satisfied than the caregivers of patients who died in a facility. Table 17 demonstrates that there was no significant relationship found between the patient's place of death and the satisfaction of the caregiver with hospice services. The place of death was divided into those patients who died at home and those who

Table 16

Relationship Between the Number of Nursing Visits
and Satisfaction

<u># Nursing Visits</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
1 - 13	121.335	44	.375	NS
<u>≥ 14</u>	129.5455		-.802	

Table 17

Relationship Between Place of Death and Satisfaction

<u>Place of Death</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>	
Home (n=43)	125.4419	44		.133	NS
Other (n=3)	122.6667				

died in another setting. Forty-three patients died at home and three patients died somewhere other than home.

Relationship Between Diagnosis of Patient and Satisfaction

The researcher felt that caregivers of patients with a cancer diagnosis would be more satisfied than caregivers of patients with other diagnoses. Historically, the majority of hospice patients have had a diagnosis of cancer, therefore most hospices have more experience in caring for these patients than patients with other diagnoses. Table 18 shows the relationship between the diagnosis of the patient and the caregivers' satisfaction. There was not a significant relationship between the diagnosis of the patient and the caregivers' satisfaction with hospice care. The mean satisfaction for caregivers of patients with a diagnosis other than cancer was slightly higher than that of caregivers with a cancer diagnosis. This is the reverse of what one would expect to find.

Relationship Between Ethnicity of Patient and Satisfaction

Table 19 shows that there is not a significant relationship between the ethnicity of the patient and the caregiver's satisfaction with hospice services. The mean satisfaction for caregivers of Caucasian patients was higher than for that of caregivers of African American patients.

Table 18

Relationship Between Diagnosis of Patient
and Satisfaction

<u>Diagnosis</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
Cancer (n=34)	124.8788	44	-.118	NS
Other (n=14)	126.2308			

Table 19

Relationship Between Ethnicity of Patient
and Satisfaction

<u>Ethnicity</u>	<u>Mean</u>	<u>df</u>	<u>t</u>	<u>p</u>
Caucasian (n=34)	126.4524	44	.755	NS
African American (n=14)	112.7500			

This may be because the majority of the hospice staff are Caucasian. The only two ethnic groups who participated in this study were Caucasians and African Americans.

Comments from Caregivers

Introduction

At the end of each of the five subscales there was a space for comments from the caregiver. Over half of the respondents wrote comments. The comments are included here just as they appeared on the survey, neither grammar nor misspelled words were corrected.

Needs involving Information

- "I am very satisfied with all the hospice staff did for my wife and I."
- "I was very satisfied with the hospice help, but toward the end of my husbands death, I was so tired and give out that I just did not get to talk things out with him. I gave him the best care I could, but I feel like there was something I did not get done. I think that when the hospice nurse sees death so close she should sit down and have both parties talk about how they feel and always the well party should let the sick one know that you love them, especially if there is something that the sick one wants all the family to know before he or she dies. Like his or her wishes for the one that is left alone."

- "Without the Hospice staff my brother would have to have gone to a home. I do not know how I would have managed without them."
- "My husband had heart disease after so many encounters with death, I felt better not looking for special symptoms. He did not take radiation. I was unable to get any other help from other resources until my assets dwindled to nothing. This seems unfair when you can't work because you are tending to someone to keep them out of a nursing home. There should be some resources there for the caregivers especially when days linger into years. Hospice did all they could to help me but it just wasn't there."
- "All the staff at Hospice were great my husband was taken care of in a very efficient caring way by all. I'm so glad you all played a part in his life."
- "The Hospice staff I met were very important here in our home, it was like a second family and it helped my husband."
- "The hospice help was outstanding. There wasn't a stone left unturned. They are very sufficient and gave excellent care. More than I expected."
- "Our RN was very thorough and professional in giving us the information that we needed."

- "The nurses were great, and feeling people. I thank them. The day my husband passed away, the nurse stayed with me 'till my family came."
- "I was disappointed in that, I thought the nurse who came here would attend the funeral and give me some moral support. If she came to the funeral she didn't make herself known to me. She called one afternoon and left a message on answering machine and said she would call later but I haven't heard from her."
- "I knew all about my husband's illness during the last three years."

Household Needs

- "Didn't need volunteers but I am sure the service was there if I had needed it."
- "Didn't receive much help from volunteers."
- "Our family and support system is extensive. For others the volunteer service could be valuable. The only area of concern is the length of time it took to have a hospice on call staff reach our home after the death. It took 1-1/2 hours with knowledge of impending death 1/2 hour prior. This may be due to the large area covered or insufficient oncall staff."
- "I did not have volunteers do anything for me, but I wish I had gotten a volunteer to come in at least once a week."

It would have given me time to think and know more about what I should do and say to him."

- "My brother only lived three days after he got home so I did not get to use any volunteers. I am sure they would be very good."
- "Five minutes is like five hours, especially with a heart patient. I never called oncall staff unless was absolutely necessary. If a caregiver just says, "Hurry and come" then don't ask a hundred questions on the phone. When patient is in bad shape. Also, a suggestion, there should be oncall nurse for each county. A Salisbury patient should not have to wait for oncall staff in Ocean City when there is an emergency. Those times are when you need someone the quickest and the most. It also helps relieve the caregiver of responsibility of what to do. Hundreds of times I had to play that role and went through them by myself."
- "Thankful for a caring staff and helping me to be able to keep going through the sickness and death and follow up afterward. Words aren't enough to say how grateful I am."
- "They were there oncall when I needed them to advise, talk, and support. This I will be ever grateful, an answer to my prayers."

- "To know you could call at any time, day or night meant so much to me."
- "The oncall nurse is fantastic! Each time I talked to the oncall nurse I was treated warmly and professionally, I was encouraged to call with questions and never made to feel that my worries were unreasonable. I was helped each and every time."
- "On one occasion, we were unable to get through to the answering service when we need help. Phone was according to operator out of working order. Maybe need a back-up phone for emergencies."
- "Didn't know about volunteer services."
- "I only used hospice for six days and I was very, very tired."

Personal Needs

- "The hospice staff were exemplary in providing support and comfort to our loved one and the family."
- "My husband's nurse was very caring and I appreciated her very much. I did not really have any family support from the ones closest to us but my family came during the week and on weekend. There were some friends I could call late at night when I needed to talk."
- "I have never expected to be a user of hospice. I had heard what wonderful people they are and now I can say

the nurses were great and they did not talk down to me, everything was explained so I could understand it."

- "In the beginning, I felt I needed none of the above but as time went by all those things helped me survive. The hospice nurses and aides are the core of the organization. Their caring and attitude toward both the patient and caregiver becomes part of your life. Here I will make another suggestion. Help the patient keep the same aide and nurse as much as possible because to someone confined when they don't come it's a great disappointment. Also dignity is the last thing you have to give up. Always put yourself in that patient's place. All aides and nurses were wonderful to me and my husband but some should belong to Hospice and some shouldn't.
- "My opinion of Hospice is impossible to put into words you have the most wonderful staff I have ever had the pleasure to meet."
- "The Hospice makes it much easier to get through and I didn't feel all alone when things were hard to get through, they gave us strength."
- "They knew before I ever asked how to help and what to expect. This really helped."
- "Everyone was very helpful and caring. You have loving caring people on your staff."
- "Our nurse and aide were great, very helpful."

- "Without the help and caring for my husband and counseling me, I couldn't have made it. It made my husband's days more bearable and peaceful. He was so thankful I had the help of a wonderful staff of caring people."
- "They were and have been faithful with calls, letters, and visits since my loss. This was very much appreciated."
- "My family and I did not need counseling to be able to cope with our situation. We knew what to expect and had long ago faced this."
- "The social worker was extremely helpful to us in the initial stage of my husband's cancer. She helped open up the communication between us concerning our fears and feelings."
- "Death happened so fast and quickly. We had a lot of support."

Spiritual Needs

- "We were very pleased with the hospice staff. You are great, I can't say enough."
- "The family's spiritual roots go very deep and clergy of family members were easily accessible and available."
- "I wish now that I had let someone come to our house. I could have used someone especially near the end and I needed to help prepare for my husband's funeral. I did

the best I could with help of the funeral director but there are things I did not do. I will always remember the Hospice that came to our home and the ones that I talked to on the phone. You are a wonderful family. I will remember you all forever."

- "I never talked with hospice clergy until my brother died."
- "Most of our spiritual support comes from our church family but it was also nice to know you had an outsider stop by and it might be a day when you need it. Also it was another visitor for someone who is bed confined."
- "I have nothing but praise for Coastal Hospice. They are one great organization."
- "In my situation assistance with funeral wasn't necessary but I am sure a lot of people would truly appreciate assistance. It did not matter what religion that the chaplain is what really matters is the wonderful job she did helping my father find the Lord."
- "Our community has its own pastor. He was very supportive and helpful."
- "The hospice clergy visited us but we told her that all appreciated visit but had our own pastor who visited often and would come any time if we needed or wanted him."
- "We had our own pastor who helped so very much."

- "I was very pleased with the service I received in this brief period of my husband's illness.
- "I would like to say I could not have asked for a better staff than the Hospice staff. Everything that I needed was provided. I thank everyone that I met on the Hospice staff. I also thank our Lord and Saviour Jesus Christ for letting me meet such beautiful people."
- "I discussed with his primary nurse and we agreed to follow what my husband believed or didn't believe in. No attempt was made to change my husband's mind about what his beliefs were and we appreciate that."

Summary of Comments

The comments listed by caregivers were overwhelmingly positive especially in-regard to the hospice staff. There were several comments addressing oncall services and the amount of time which it took for a nurse to reach the patient's home. This is a very important part of hospice services and an area that has to be evaluated on an ongoing basis. There were also some valuable comments regarding volunteer services. The hospice may want to consider providing increased education on an ongoing basis to patients and families regarding the services that are available to them.

Summary

The population has been described in this study. Statistical analysis regarding the affects of different variables on satisfaction with hospice care has been completed. Comments made by family members were included. Frequencies were completed to define whether the needs were important then a mean and median score was assigned to each need.

Chapter V

Summary

Introduction

The purpose of this study has been to measure the primary caregiver's satisfaction with hospice care. This study further examined variables which may affect satisfaction with hospice care and helped to identify the needs which are the most important to the caregiver. In this chapter the results of the research will be discussed and the implications of the study will be presented. The limitations of the study and suggestions for further research will also be discussed.

Discussion of the Study Findings

Satisfaction with Hospice Care. The results of this study show that the participants were overwhelmingly satisfied with hospice services. There is much in the literature to support satisfaction with hospice care. The high level of satisfaction found by this study corresponds to the work completed by Creek (1982), Hannon and O'Donnell (1994), Brescia, Sadof, and Barstow (1984-85), Wilkinson (1986), Dawson (1991), and Keizer, Kozak, and Scott (1992).

The high level of satisfaction found in this study corresponds to the results found by Creek (1982). Creek (1982) found that average satisfaction scores for caregivers and family exceeded 90% for nursing care, the social worker,

and effectiveness of pain medication. In Creek's study the hospice program was urgently sought by the public which is what this researcher finds with the hospice program evaluated in the current study.

Hannan and O'Donnell (1994) evaluated twelve hospice programs, each providing one of three different models of hospice care. The results of their study demonstrated that there was a very high satisfaction with the provision of services by the hospice program. This also corresponds to what this researcher found in the current study. Caregivers were very satisfied with services and made many favorable comments in regards to the hospice staff and services provided.

Hannan and O'Donnell (1994) also found that the utilization of volunteers varied greatly among the three hospice models. They found that volunteers were heavily relied on and provided substantial cost savings. The results of the current study demonstrate that caregivers would like volunteer services offered but do not always utilize these services. There may be many reasons why the services are underutilized. Many caregivers may be hesitant to accept extra help because they feel that they should be able to handle all of the patient's needs by themselves. Volunteers may also be underutilized due to the short length of stay of some patients. It is difficult to establish

volunteer services when a patient is on a hospice program for a short period of time. Sometimes it is also difficult to find volunteers that will serve in very rural areas. Another problem may be the lack of education provided to the caregivers about volunteer services. Also some hospice staff members access volunteer services for their patients and families on a more regular basis than other hospice staff.

Brescia, Sadolf, and Barstow (1984-85) conducted a retrospective analysis of a hospice program to see if they could determine which patients would die at home. During their study 50 patients died, 36 at home and 14 in a acute-care setting. For the current study, out of the 46 respondents only 3 of the patients died somewhere other than home. The researcher hypothesizes that the hospice staff provides the support needed to enable the caregiver to keep their loved one at home. Many caregivers responded that without the support provided by the hospice team their loved one may not have been able to die at home. It is the philosophy of hospice that patients die at home in familiar surroundings and that is what the hospice staff in this study encourages for their patients.

Wilkinson (1986) conducted a study of satisfaction with the care provided by Hospice of Schenectady, a small, community-based, homecare program in New York. No

significant relationships between the response for each question and the patients' gender, age, and length of stay in the hospice were found. Also no significant differences in the average satisfaction were found across age or gender. This corresponds with the research results in the current study. The researcher for the current study predicted that caregivers of patients with a long length of stay would be more satisfied than those of patients with a short length of stay. It may be hypothesized that the longer the patient is in a hospice program, the more services they will receive and therefore the greater the satisfaction of the caregiver. This was not found to be the case in the current study, and is probably a positive outcome since the length of stay in hospice programs is decreasing. It is very comforting to find that the services that are provided in a short period of time may be just as good as those provided over a long period of time. Patients who do have a short length of stay usually have very staff intensive services which can be very costly for the hospice program. The hospice staff works very hard to see that the hospice philosophy is carried out in the short length of time.

Keizer, Kozak, and Scott (1992) conducted a study to determine how satisfied patients and families were with the services provided on the Regional Palliative Care Unit (PCU) in Ottawa. The major finding was that the care was

perceived to be highly satisfactory. This study found that primary care providers felt it was important that the patient had been cared for on the PCU. This varies drastically from the comments the researcher received in the current study. The comments from caregivers in the current study were overwhelmingly positive that the patient had been able to die at home. Dawson (1991) also found that home hospice care was viewed more favorably by caregivers than inpatient care.

Variables that May Predict Satisfaction with Hospice Care

Satisfaction with hospice care is probably more highly rated than any other aspect of health care. There may be many reasons for this. One could be the type of patient and family who choose hospice services. They may exhibit more needs than the average consumer of health care and may be more vulnerable due to the fact that they are dealing with death. One can hypothesize that the relationship that the hospice staff develops with the patient and caregiver is much closer and more emotional than that of traditional health care. This may be because the hospice staff is actually going into the patient's home and because the death of a loved one is a very emotional time for families. The comments on this survey demonstrated that hospice patients and families often view the hospice staff as a member of their family.

Another reason caregivers may rate satisfaction with hospice care so highly is because they may be too emotionally involved with the care of the patient and the hospice staff to be able to make an objective evaluation. Probably nowhere in health care are families more involved in the care of the patient than with hospice care. The families often become very close emotionally to the hospice staff and may feel that if they evaluate the services negatively, it may impact on the hospice staff.

Hospice staff often view their work as a mission. They feel that it is their responsibility for patients to experience a good death. The researcher hypothesizes that the healthcare worker who chooses hospice work does so because he/she believes in the philosophy of hospice. Often the worker will also have experienced the death of a loved one. This may enable the worker to have the empathy needed to work with dying patients and their families. These workers also often have an overwhelming need to please and many times go beyond their job description in caring for hospice patients. This may also help to explain why families are so satisfied.

Nursing Process.

The nursing process was used in this study to help evaluate the outcome of hospice services. Wolff et al (1983) describes the nursing process as helping to attain

the ultimate goal of nursing care, which when a terminal illness is present, is to help the patient to a peaceful death. The evaluation process is needed to measure the effectiveness of care provided. The high level of satisfaction obtained by this study is evidence of the effectiveness of hospice care.

Most Important Needs as Identified by the Caregiver.

The caregivers identified many needs as being important to them. They seemed to be more interested in informational needs, household needs, and personal needs than with psychological and spiritual needs. Of the twenty items regarding informational needs, $\geq 90\%$ of the respondents rated twelve of these as being important. These twelve items were 1) hospice services, 2) medication effects, schedule, and how to give, 3) what symptoms to expect, 4) ways to control pain, 5) ways to manage breathing problems, 6) nutritional needs, 7) signs and symptoms of approaching death, 8) physical needs of loved one, 9) type and seriousness of illness, 10) how to reach staff after hours, 11) how to get equipment after hours, and 12) financial coverage of hospice.

There were three household needs that 100% of the respondents rated as being important. They were: 1) how to reach the staff 24 hours/day, 7 days/week, 2) timely response to telephone calls, and 3) oncall staff willing to

make visits. All four personal needs were identified by \geq 92% of the respondents as important.

In a study of caregiver needs conducted by Hileman, Lackey, and Hassanein (1992) the greatest needs of the caregiver were found to be informational and psychological. The informational needs were also viewed as being very important to the caregivers in this study. Psychological needs were seen as less important. There seemed to be more of a focus on taking care of the needs of the patient than the needs of the caregiver.

Tulak (1994) conducted a study to identify and compare the caregiving needs of hospice caregivers during and after the terminal care experience. The six most important needs identified by the caregivers during caregiving were: home visits by professionals; ways to keep the patient comfortable; methods of pain control; information regarding physical needs of patient; honest and updated information; and information on type and extent of the patient's illness. These top six needs were in the categories of Needs Involving Information and Patient Care Needs. Rank ordering of categories of needs from the most important to the least important were: patient care; informational; spiritual; personal; psychological; and household needs. 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; and ways to keep the patient comfortable. These needs were contained within the same two categories. The need categories identified as being the most important in Tulak's (1994) study correspond with the categories this researcher found as the most important except for household needs. Household needs were found to be important in this researcher's study but not in Tulak's (1994) study.

Limitations of the Study

Sample Size. The sample size for this study was small, therefore, the general validity of the results should be viewed with caution. The results have limited generalizability beyond the sample studied.

Sample of Convenience. The subjects were non-randomly selected therefore this may have resulted in sample bias. All caregivers of hospice patients who died during the time period outlined in the study were included.

Self-report. When data is gathered by self-report questions of validity and accuracy usually arise. The major drawback with this method is the potential for deliberate or unconscious distortions on the part of the respondents.

Mailed Questionnaire. The main problem with mailed questionnaires is that many people fail to respond to them, leading to the risk of a biased sample. The use of follow-up

reminders can be helpful to reduce this bias. The researcher for this study did not utilize follow-up reminders for the caregivers who did not respond.

Response Rate. The response rate for this survey was 52%. The people who returned the survey may have been representative of the people who were happy. The 48% who did not return the survey may have been unhappy with hospice services.

Survey Instrument. The survey instrument used was based on previous research with questions added and deleted by this researcher. The tool was changed in order to try to make it more sensitive and a better predictor of satisfaction with hospice care. Changing the survey tool did not seem to help in making the tool more effective in gathering information related to caregiver satisfaction. The researcher found that caregivers still indicated a very high level of satisfaction even though the tool was changed. Also the length of the survey may have been a limitation because some caregivers may have not completed it because it was so long.

Implications for Hospice Care

The results of this study support the literature that caregivers are satisfied with hospice care. This study also shows what the most important needs are as identified by the caregiver. This information is helpful in planning and

evaluating hospice services. We should focus more on the areas that the caregivers define as most important and try to ensure that their needs are met. Informational needs were identified as being very important. The hospice staff may need to provide more explicit teaching to the caregivers regarding available services. The hospice staff also needs to evaluate the caregivers' response to the teaching. The initiation of hospice services is usually a stressful time for patients and their families and often they do not retain all the information presented to them, so hospice personnel need to provide ongoing education.

The results of this study support the research that caregivers are generally satisfied with hospice care. Hospices need to continue to do research and to evaluate the effectiveness of the services provided in order to better serve patients and their families. This information is becoming more valuable to hospices in order to validate themselves to third party payors.

Suggestions for Further Study

Evaluation of the effectiveness of hospice care and caregiver satisfaction with hospice care is essential to the survival of hospice care. Managed care is dictating an effective cost-saving approach to health care. Hospice programs have to be able to demonstrate the effectiveness of the services provided and the caregivers satisfaction with

services. In order to do so hospices must be able to identify the needs of the patient and his/her caregiver. Hospices also must take the information gained in the evaluation process and use it to improve services in order to better meet the needs of patients and their families.

Appendix 1

Disclosure Form

I am currently conducting a study on Caregiver Satisfaction with Hospice Care. I am seeking the assistance of former caregivers of hospice patients in completing a survey related to satisfaction with hospice care.

The questionnaire is brief and should take about twenty minutes of your time to complete. The information provided will be kept confidential as consistent with Coastal Hospice policy. The researcher will not receive any surveys with the patient's name or address on them. Only an identification number will be affixed. A list matching identification numbers with patient names will be kept in a locked file with the signed consent forms until the study is completed.

Your cooperation and participation are strictly voluntary and your choice to participate or not to participate will not affect future services provided to you by Coastal Hospice. You may leave any particular questions unanswered or may choose not to complete the survey. However, your participation is very valuable to us and will help us increase the quality of care that we provide hospice patients and families.

If you have any questions about this study or would be interested in the results, please contact Ann Heidt, Coastal Hospice, P.O. Box 1733, Salisbury, MD 21802-1733. Telephone (work) 410-742-8732. You may also contact Karin Johnson, RN, Dr. PH by calling 410-548-5395. Thank you for your assistance.

I have read this form and consent to participate in this study.

Caregiver

Date

Appendix 2

NEEDS INVOLVING INFORMATION

Was this important to you? If you checked yes, the need was important to you, how satisfied were you with the Hospice staff's response to that need:
 (Please check only one)

Was it important to you that information be provided about	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
1) hospice services.	YES NO				
2) medication effects, schedules, and how to give.	YES NO				
3) what symptoms to expect.	YES NO				
4) ways to control pain.	YES NO				
5) possible side effects of pain medication.	YES NO				
6) addiction to pain medication.	YES NO				
7) control of constipation or diarrhea.	YES NO				
8) control of nausea and/or vomiting.	YES NO				
9) ways to manage breathing problems.	YES NO				
10) nutritional needs.	YES NO				
11) signs and symptoms of approaching death.	YES NO				
12) the physical needs of your loved one.	YES NO				

NEEDS INVOLVING INFORMATION
(continued)

Was this important to you?

If you checked yes, the need was important to you, how satisfied were you with the Hospice staff's response to that need
(Please check only one)

Was it important to you that information be provided about	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
13) possible side effects of treatment (such as Radiation or Chemotherapy).	YES NO				
14) the type and seriousness of your loved one's illness.	YES NO				
15) available community resources such as Meals on Wheels.	YES NO				
16) professional counseling.	YES NO				
17) how to reach hospice staff after business hours.	YES NO				
18) how to get equipment, supplies and medication.	YES NO				
19) financial coverage of hospice services.	YES NO				
20) patient rights such as a Living Will or Durable Power of Attorney for Health Care.	YES NO				

COMMENTS: _____

HOUSEHOLD NEEDS

Was this important to you?

If you checked yes, the need was important to you, how satisfied were you with the Hospice staff's response to that need:
(Please check only one)

Was it important to you:	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
1) to know how to reach the hospice staff 24 hours a day, seven days a week.	YES NO				
2) that the on call staff respond to your phone call in a timely manner.	YES NO				
3) that the on call staff make visits and call the physician for new orders when needed.	YES NO				
4) that hospice volunteer services be made available.	YES NO				
5) for hospice to provide a volunteer to stay with your loved one so you could get out of the house.	YES NO				
6) that a volunteer was available to run errands.	YES NO				

COMMENTS: _____

PERSONAL NEEDS

Was this important to you?

If you checked yes, the need was important to you, how satisfied were you with the Hospice staff's response to that need:
(Please check only one)

Was it important to you:	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
1) that the hospice staff be caring and concerned.	YES NO				
2) that the hospice staff encourage you to get adequate sleep and maintain your health.	YES NO				
3) that you have someone to talk with about your concerns and fears.	YES NO				
4) that the hospice staff encourage you to seek support from family and friends.	YES NO				

COMMENTS: _____

PSYCHOLOGICAL NEEDS

**Was this
important
to you?**

**If you checked yes, that the need was important to you, how satisfied were you with the
Hospice staff's response to that need?**
(Please check only one)

Was it important to you :	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
1) that counseling be available to help you and your family cope with the future loss of your loved one.	YES NO				
2) that counseling be provided to help your loved one prepare for his/her death.	YES NO				
3) that information be provided to you about your loved one's emotional needs.	YES NO				
4) That the hospice staff suggest ways to talk about death with your loved one.	YES NO				
5) that information be provided about ways to decrease your stress as a caregiver.	YES NO				
6) that information be provided to you on how to remain tolerant and patient with your loved one.	YES NO				

PSYCHOLOGICAL NEEDS
(continued)

Was this important to you?

If you checked yes, that the need was important to you, how satisfied were you with the Hospice staff's response to that need?
(Please check only one)

Was it important to you:	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT DISSATISFIED	SATISFIED	VERY SATISFIED
7) that counseling be provided to you about ways to maintain a normal family life.	YES NO				
8) that counseling be provided about ways to combat fatigue.	YES NO				
9) that counseling be provided about ways to cope with your loneliness.	YES NO				
10) that counseling be provided to you about ways to cope with the loss of loved one.	YES NO				
11) that counseling be provided related to your future plans upon the death of your loved one.	YES NO				
12) that help with accessing community resources such as Meals on Wheels be made available.	YES NO				

COMMENTS: _____

SPIRITUAL NEEDS

Was this important to you?

If you checked yes, that the need was important to you, how satisfied were you with The Hospice staff's response to that need:
(Please check only one)

Was it important to you:	(Circle one) YES NO	VERY DISSATISFIED	SOMEWHAT SATISFIED	SATISFIED	VERY SATISFIED
1) that spiritual counseling be consistent with your loved one's beliefs.	YES NO				
2) that the hospice clergy provide support to your loved one.	YES NO				
3) that the hospice clergy be non-denominational.	YES NO				
4) that the hospice clergy provide assistance with your loved one's funeral or memorial service.	YES NO				
5) that the hospice clergy provide support to you and your family.	YES NO				

COMMENTS: _____

Appendix 3

STATEMENT OF APPROVAL
COMMITTEE ON HUMAN VOLUNTEERS
SALISBURY STATE UNIVERSITY

Date June 17, 1996

MEMO TO: Dr. Karin Johnson

FROM: Chairman, Committee on Human Volunteers

SUBJECT: Caregiver Satisfaction With Hospice Care

Title of Study

Grant Application No.
Sponsoring Agency

Dr. Karin Johnson
Principal Investigator or Program Director

Ann Heidt
Student Investigator

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 adequately 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.

Stephen Schurich
Chairman

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Psychological Needs

- "All of the psychological services are essential in the death process. Again, our support system is extensive (including a mental health professional in the family) and familiarity (unfortunately) with the death process."
- "All of these things were important to me. Because of in-depth counseling years ago and God's daily help I did not use Hospice very much in this area but know they were there if needed."
- "There was counseling. The nurse and Social Worker gave us the best they knew how. My husband did not want anyone coming in unless he knew about it. He was always in control but it was all of a sudden that I had to take control. It was very hard to care for someone so sick and try to think about what one is going to do when the one she loves is gone forever I thank the Lord everyday for Hospice. I think this study is very important. I think the caregiver should know about No. 1-11 before a loss."
- "We just didn't have time to do all this but I do have booklets on this that I have read."
- "As far as death itself, our faith helps us face that with peace but as far as fatigue, stress, financial, and physical pain it becomes absolutely necessary to have after a long length of time."