NEEDS OF THE BEREAVED IN A HOSPICE SETTING:
IMPLICATIONS FOR NURSING

by

Carol Lee

A thesis submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Master of Science

College of Nursing

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SUPERVISORY COMMITTEE APPROVAL

of a thesis submitted by

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An abstract of a thesis submitted to the faculty of
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ABSTRACT

Nursing care given patients on an inpatient hospice unit is intrinsically different from nursing care delivery in an acute care setting. Hospice units are specifically designed to help the dying and their families. This study was conducted to gain further understanding of the needs of the bereaved and how consistently those needs are met by the nurse on an inpatient hospice unit.

The sample consisted of 100 bereaved family members (78% return rate) who answered a mailed questionnaire. A stratified random sample of 50 spouses and 50 children of the deceased was used from January 1980 through April 1983. The instrument used in this study was a questionnaire designed by the investigator to study the eight needs identified by Hampe's (1973) research.

The results of the study indicated that the bereaved associated with an inpatient hospice unit did experience the same needs as spouses whose mates were terminally ill. After the bereaved had identified their needs, they felt these needs were met all or nearly all the time by the hospice nurse. An additional need identified by the bereaved was being able to stay with the dying patient day and night in the home-like atmosphere provided on the hospice unit.

Although generalizations cannot be made, several important clinical nursing implications are apparent. Nurses must be free to care for the emotional and physical needs of the dying patient as well as the family. The hospice nurse must develop special skills in being able to communicate with the dying and their family members. There is no specific, optimal time to communicate about death and dying. The fact that the nurse is there to provide care and comfort can communicate a sense of security and acceptance of the impending death. Recommendations for future studies were made, based on the findings of this study.

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CHAPTER I

INTRODUCTION AND REVIEW OF LITERATURE

Hospice care for the dying patient is a relatively new concept in the United States, and one that is receiving a great deal of attention. The word, hospice, in medieval times, referred to a place where the weary pilgrim could find lodging, sustenance, and spiritual enlightenment of his travels. Today the word has been adapted to describe a philosophic concept for the care of the terminally ill patient on his journey from life into death. Hospice is a program of palliative and supportive services which provides physical, psychological, social, and spiritual care for dying persons and their families. Hospice services are available in both the home and in inpatient settings.

Craven and Wald (1975) indicate that what people need most when they are dying is relief from the distressing symptoms of their disease, the security of a caring environment, sustained expert care, and the assurance they and their families will not be abandoned. Caring for the physical, emotional and family needs of the patient is the professional ideal of nursing practice. Fulton and Langton (1964) noted that the nurse is often the person who is confronted with the task of making the act of dying as smooth as possible; however, the nurse's role in meeting the needs of the dying patient and of his or her relatives is seldom clearly defined.

As the new concept of hospice developed, nurses have begun to use personal philosophy, scientific knowledge, and creativity to find more effective ways of meeting the needs of dying patients and their families. The role of the nurse on an inpatient hospice unit is an important, but neglected, area of research in nursing. There is little in the nursing literature relative to the nurse's role in a hospice setting for the care of dying patients and their families even though the critical importance of nursing care is obvious. It is the responsibility of the nurse to assist individuals and families to find meaning in illness, suffering and death.

Improving care of the dying and reducing the conflict that surrounds this care are challenges for nursing education and research. Of the nurses who have contributed to the field of death education and care of the dying, a few can be considered "pioneers." In 1959, Saunders wrote a series of articles about dying people, euthanasia, the care of the dying, and nursing approaches to these and related problems. Quint (1967), in writing about nurses and dying patients, drew attention to the importance of nurses acknowledging that nursing care of dying patients is distinctly different from care of other patients. Her work and the writings of Folta (1965) influenced the approach to caring for dying persons and the education of nurses regarding the process of dying. Argondizzo (1976) addressed the need for nursing care to be focused on helping the dying patient cope with fears of death and dying. She states that, because of the nurse's accessibility fo families, the nurse is in a position to offer preventive, supportive, and therapeutic intervention during periods of family grief.

Problem Statement

To what extent does the hospice nurse consistently meet specific needs identified by the bereaved and are those needs being met by the current nursing practice on an inpatient hospice unit?

Purpose

The purpose of this study was to identify the needs recognized by bereaved family members and to determine if the current nursing practice on an inpatient hospice unit consistently met these needs.

Significance

The nursing literature is replete with opinions and anecdotal reports of nursing practices and behaviors believed to be helpful to the dying and their families. The primary concern of hospice care is not with disease, but rather with the needs of a terminally ill person and his family. Therefore, by identifying nursing care practices that the bereaved recognize as having helped them to cope with the death of a family member, the body of nursing knowledge can be expanded to include specifics of nursing care which may provide support, comfort and ease of suffering.

Review of Literature

The twentieth century has seen medical attention focused on the cure of disease. Advances in knowledge and biotechnology have increased the medical profession's ability to control disease and prolong life. An undesirable side effect of emphasis on technological medicine is the potential danger of dehumanization of the dying person and the neglect of the family unit at a time of great stress.

Hospice care provides the patient an opportunity to maintain control over one's life until death occurs. Walborn (1980) talks about hospice as being a philosophy of care as well as providing a setting in which individuals who are dying can live with health care assistance as free from pain and as normally as possible.

In the middle of the nineteenth century, the Irish Sisters of Charity opened the first hospice in Dublin, Ireland, dedicated to caring for people who were dying. Hospice was the name chosen by Mary Aikenhead, the founder of the order. She considered death to be the beginning of a journey and her nursing home to be a resting place similar to those used by medieval pilgrims when traveling to the Holy Land (Lamerton, 1975).

The philosophy of Aikenhead persists in the hospice movement today. Hospice is an idea, a way of caring for the terminally ill, those weary travelers who are nearing the end of their earthly pilgrimage (Wentzel, 1980). Cicely Saunders was a pioneer who challenged the care for the terminally ill in the 1960s. She recognized that the physical and social environment was as important a therapeutic tool as expert medical management and was convinced that pain for the dying was unnecessary (Kohn, 1976). She founded St. Christopher's Hospice in London, England, which was dedicated to the care of the dying, research on pain and symptom management, and the design of a new approach to the more humane care for dying patients and the families. From the development of her seminal ideas, a whole system of terminal care emerged. The patient was treated as a total person who had spiritual, emotional and social needs in addition to the needs for physical comfort. The patient and the family constituted the unit of care. The needs of family members as they anticipate a death and during their bereavement were part of the comprehensive model of St. Christopher's (McIntosh & MacElveen-Hoehn, 1981).

The hospice movement reached America in the 1970s and today there are some 200 hospices in operation. The first hospice in the United States was Hospice, Inc., New Haven, Connecticut, which began as a home care program in March, 1974 (Craven & Wald, 1975). A 44 bed inpatient unit was added later, providing what was considered an ideal hospice program--a home care program, outpatient facilities, and an inpatient unit. Inclusion of all three components provides an open system in which continuity of care is possible. In such a system patients may remain at home, or they may be hospitalized in a hospice unit, or alternate between the two, depending on the patients' and families' needs (Kohn, 1976).

Today, hospice is broadly conceived as referring to a kind of care for the terminally ill and their families that can be given in a variety of ways and under different kinds of auspices. Five forms of hospice care have now evolved: a) home care services, b) hospice teams in hospitals, c) palliative care units in hospitals, d) hospices with hospital affiliations, and e) free-standing facilities (Wald, Foster & Wald, 1980). This diversity of approaches in providing care would be determined in various communities according to particular needs, resources, and objectives. The home care program is involved with terminal care and does not provide home care to other kinds of patients. This type of program usually provides skilled nursing care along with supportive and counseling services. Another approach to hospice care is the hospital-based program, which has a defined unit for hospice beds. The multidisciplinary team provides continuity of care for the patient and their family from the terminal phase through the bereavement period. The program allows a person to meet death with dignity, surrounded by family members. The interdisciplinary hospice team is another approach to care which provides consultation for terminally ill patients and their families on all units in the hospital.

Hospice care is not based on a particular type of organizational structure or setting but rather on a philosophy. MacElveen-Hoehn and McIntosh (1981) identified the major aspects of hospice care that set it apart from other terminal care programs:

1. The patient and the family together are considered the unit of care.
2. Comfort is actively pursued through the control of physical, emotional, psychological and spiritual distress. Effective management of most pain has been developed.
3. An interdisciplinary team is involved in planning and implementing of care. Patients and family members are considered integral members of the team.
4. Support is always available: day or night, every day of the week.
5. Trained volunteers are an essential component of the hospice program.
6. Bereavement care and followup are provided

for the family.

7. Support for care providers is provided for both staff and volunteers to avert emotional exhaustion (1981, p. 32).

The bulk of inpatient hospice care currently being provided is nursing care. Nurses work directly with the physician in the medical aspect of the patient's needs, yet the nurse's role in meeting the nursing needs of the dying patient and the family is seldom clearly defined.

Few nursing studies have focused on specific nursing care practices considered helpful to assist individuals during the time of fatal illness or death of a loved one. Irwin and Meier (1973) demonstrated that some nursing behaviors were more desirable than others in assisting individuals during a loved one's fatal illness. They did not specifically outline what the bereaved need or want from nurses either before or after the death.

Freihofer and Felton (1976) identified nursing behaviors that are considered helpful to both patients and relatives. Their findings revealed that the bereaved believed that nursing behaviors should be directed toward support, comfort and ease of suffering of the ill patient rather than toward themselves.

In summary, no studies were found to show how consistently the nurse met or failed to meet the identified needs of the bereaved in an inpatient hospice setting.

Theoretical Framework

The hospice philosophy is characterized by the acceptance of death as a natural conclusion to life; hope can be offered so that patients will not feel isolated and abandoned. To improve the care provided the dying and the bereaved, nursing care practices that are considered helpful need to be delineated.

Schoenberg, Carr, Peretz, and Kutscher (1970) discussed loss as the deprivation of an object, person, possession or ideal that was considered valuable and had an investment of self. The authors described loss as an integral part of human experience with profound consequences from birth to death. Loss is a universal part of human experience, with the loss of a significant other or loved one being the most profound experience of this kind.

Grief is experienced by a person following a loss, while mourning is the process involved in grief (Dracup & Breu, 1978). Engel (1962) described the grief process as occurring in three separate stages: shock and disbelief, developing awareness, and restitution.

Shock and disbelief occur when a person is informed of an unexpected loss of a loved one. The total reality of the death cannot be accepted. Feelings experienced during this time may be a painful emptiness, anger, hostility, a need to cry, acute anxiety, frustration and guilt. In the final phase, restitution the person realizes he must cope with the loss, and then there is a beginning of renewed interest in objects and relationships (Dracup & Breu, 1978).

Grief and bereavement are ordinarily characterized by intense mental suffering and distress. That bereavement is associated with increased mortality is supported by various studies. Rees and Lutkins (1967) surveyed deaths occurring during a six-year period in a semirural area to determine if bereavement produced an increasing mortality among close relatives (spouse, child, parent, or sibling). Bereaved relatives were found to have a much higher mortality rate during the first year of bereavement. Maddison and Viola (1968) studied a group of 72 widowed people in London. They reported a 40% rise in mortality rate during the first six months following the death of a spouse. Parkes (1964), in studying the general effects of bereavement on both physical and mental health, found a 63% increase in morbidity during the first six months after bereavement.

The impact of bereavement has been viewed as an illness (Peretz, 1970), as a crisis (Maddison & Viola, 1968; Raphael, 1971), and as a psychosocial transition (Parkes, 1970). Other authors have studied the effects of bereavement by using such indicators as physical and mental illness and death, including suicide (Glaser & Strauss, 1972; Kraus & Lilienfield, 1959; Parkes, 1964). It is known that the incidence of somatic and emotional problems and mortality rates in the bereaved are much higher than in the normal population.

That the bereaved need help in meeting the practical problems of bereavement and achieving optimal outcomes is not simply a theoretical concept, but a stern reality. The family cannot give the patient necessary support and companionship if they, themselves, are experiencing overwhelming emotions. Much support for the family of the hospitalized patient can be rendered by the hospice nurse.

Hampe's (1975) research on grieving spouses showed that the spouses had eight needs which were classified under two broad headings. First, there are needs which center on his/her relations with the dying person:

to be with the dying person, to feel helpful to the dying person, to be assured of the comfort of the dying person, to be kept informed of the dying person's condition, and to be aware of the dying person's impending death. Second are personal needs of the grieving person: to ventilate his/her emotions, to receive comfort and support from family members, and to receive acceptance, support and comfort from the health professionals.

Kubler-Ross (1969) wrote of her belief that one cannot help the terminally ill patient in a really meaningful way if one does not include the family. An atmosphere of security and support is necessary to help the family cope with the reality of death. It is the philosophy of hospice to help to provide this support for the bereaved.

Engel (1964) stated that the news of the death or impending death is best communicated to the family group rather than an individual member and should be done in a setting of privacy where the family can behave naturally, without the restraint of public display. Ideally, the bereaved individual should feel that someone has a personal interest in his or her well-being, that there is someone to whom the individual can talk who will not consider it an imposition.

Conceptual Definition of Variables

Hospice

Hospice was defined as a program of palliative and supportive care which provides physical, psychological, social and spiritual care for dying persons and their families within a general hospital setting.

Terminally Ill Patient

A terminally ill patient was considered a dying patient who has been diagnosed as having a disease, injury, or a combination thereof perceived to be incompatible with life. Symptoms of the illness are irreversible and treatment is palliative (Freihofer & Felton, 1976).

Loss

A state of being deprived of or being without something of value that one has had was defined as loss (Peretz, 1970).

Need

A requirement of the person which, if supplied, relieves or diminishes his immediate distress or improves his immediate sense of adequacy or well-being was considered a need (Orlando, 1961).

Bereaved

The bereaved was defined as the significant other individual who has lost a loved one through death. The reference may be to parents, spouse, sibling, or other relatives.

Research Questions

This study was designed to discover:

1. Were the eight needs identified by Hampe's (1975) research also identified by the bereaved in this study?
2. Did the hospice nurse consistently meet the identified needs of the bereaved?
3. What additional needs were identified by the bereaved in a hospice setting that were not identified in Hampe's (1975) research?

Assumptions and Limitations

The following assumptions were made. The respondents were frank and honest when describing their needs in response to the questionnaire. The death of a significant other caused family members some degree of distress. The relationship between the bereaved and the deceased significant other were perceived as a significant loss by the bereaved.

The conclusions drawn from this study referred only to the stated groups, hospitalized at the stated locality, at the time of the study.

CHAPTER II

DESIGN OF THE STUDY

The study was designed to identify needs recognized by the bereaved, after the death of a family member on an inpatient hospice unit. It was also designed to determine if the current nursing practices consistently met these identified needs. The design was a retrospective descriptive study. A questionnaire mailed to 100 subjects was employed.

The study was an ex post facto investigation for the following reasons:

1. Family members of a dying patient may not wish to discuss their needs, for fear that present health care delivery might be adversely affected.
2. During hospitalization, the family may not be able to perceive their own needs because of total involvement with the patient.

Study Population

The study population was the bereaved families of individuals who died while hospitalized on the hospice unit at Holy Cross Hospital in Salt Lake City, during 1981, 1982 and 1983. A stratified random sample of 100 families was used for this study. The subjects were chosen on the basis of the following characteristics:

1. They had experienced the death of a family member on the hospice unit during the years 1981, 1982 or 1983.
2. They had English as their first language, and therefore, were able to complete the questionnaire.

Setting of the Study

The inpatient hospice unit at Holy Cross Hospital is a seven bed unit which provides care to the terminally ill person by a multidisciplinary team of professionals. Holy Cross Hospital is a 343-bed community hospital, founded and operated by the Sisters of the Holy Cross. The Hospice Unit was opened in December, 1979. At the time of this study, the inpatient hospice program provided continuity of care for the patient and family from the terminal phase through the bereavement period. The bereavement period is generally regarded as the period of time during which a person experiences the death of another person, responds emotionally to the experience and adjusts to the loss. Hospice care is attendant to the acute phase of the bereavement process, usually occurring within the first year after the loss.

The nursing staff on the unit consisted primarily of registered nurses (R.N.), with one full time licensed practical nurse (L.P.N.). At the time of the study, there were five full-time R.N.s, four with baccalaureate degrees in nursing. There were six part-time R.N.s, five with baccalaureate degrees in nursing. A team approach was used to provide daily care to the patients. This allowed relationships to develop and enabled the nurse to provide care and support to both patient and family. This relationship of care and concern continued through the bereavement period. Bereavement support services included attendance at funeral services, telephone calls and personal visits by the nurses. Grieving family members were encouraged to visit the inpatient hospice unit and share their feelings and experiences with staff members.

Instrument

The instrument was a questionnaire (Appendix B) developed by the investigator to study the eight needs identified by Hampe's (1975) research. Hampe's data analysis showed that the identified needs of the spouse were not consistently met by nurses. For the purpose of this study, a questionnaire was developed to determine the degree to which hospice nurses consistently met the needs of the bereaved. The questionnaire was reviewed for face validity and clarity by two research faculty members and by three nurses who were involved in the hospice program.

CHAPTER III

ANALYSIS OF DATA

Study Population

A total of 100 bereaved families of individuals who had died on the inpatient hospice unit at Holy Cross Hospital was included in the study. A stratified random sample was obtained, consisting of 50 spouses and 50 children of deceased patients.

Questionnaire Return

The three week data collection period yielded 75 responses that met the criteria for inclusion. Undelivered questionnaires totaled four (4). There was no attempt to contact the 25 individuals who failed to return the questionnaire. A total of 75 questionnaires was returned at a 75% return rate.

Data Analysis

The data were analyzed with computer assistance using the Statistical Package for Social Sciences. Descriptive analysis was accomplished through frequency distributions, means and standard deviations. The responses to the open-ended questions were analyzed for common comments and frequency. Data were analyzed under the following subheadings:

1. Demographic data
2. Needs expressed by the bereaved and consistency with which each need was met by the hospice nurse
3. Responses to open-ended questions.

Demographic Data

Respondents' sex and age, length of time since the relevant death, length of hospital stay, and relationship to the deceased were the demographic variables assessed from the questionnaire.

As presented in Table 1, the sample population ranged from 22 to 82 years of age, with a mean age of 56.5 years. The respondents consisted of 46 females (61.3%) and 29 males (38.7%). This was further subdivided into the respondents' relationship to the deceased. There were 18 husbands (24.0%), 21 wives (28.0%), 11 sons (14.7%) and 25 daughters (33.3%).

Number of months since the death of the family member ranged from 1 to 39 months, with a mean of 14.9 months. Age of the family members at the time of death ranged from 38 to 93 years, with a mean of 69.7 years.

Table 1

Demographic Description of the Sample

		(N)	%
Age of Respondent			
Range:	22 years to 82 years		
Mean:	56.5		
Sex of Respondent			
Female		(46)	61.3
Male		(29)	38.7
		(75)	100.0
Relationship to Deceased			
Husband		(18)	24.0
Wife		(21)	28.0
Son		(11)	14.7
Daughter		(25)	33.3
		(75)	100.0
Months Since Death			
Range:	1 Month to 39 Months		
Mean:	14.9 Months		
Age of Deceased Family Member at Death			
Range:	38 Years to 93 Years		
Mean:	69.7 Years		
Days on Hospice Unit Before Death			
Range:	1 Day to 120 Days		
Mean:	13.8 Days		

Length of stay on the hospice unit before death ranged from 1 day to 120 days, with a mean of 13.8 days. Only 2 of the patients had remained on the hospice unit for a total of 120 days and, since this was considered an exception by the investigator, the data were withdrawn to determine if there would be a significant decrease in the mean length of hospice stay. Withdrawing the data previously mentioned changed the range to 1 day to 51 days, with a mean of 10.5 days for the length of stay on the hospice unit before death.

The questionnaire was composed of 14 two-part questions, the second part requiring an answer only if a "yes" response was given to the first part. The first seven items assessed the needs that centered on the families' relations with the dying person (Table 2). Needs that centered on the grieving families themselves was the focus of the last seven questions (Table 3). The bereaved were instructed to state yes or no for each statement identifying a perceived need. The second part of the question asked how consistently the respondent felt the need had been met by the hospice nurse.

Item 1. Did you want to visit your family member any time of the day or night?

Table 2

Results of Questionnaire on Bereaveds' Identification of Needs and on Perception of Nurses' Response in Meeting that Need on an Inpatient Hospice Unit (N = 75)

Item	Yes (N)	Yes %	No (N)	No %	Perception of Nurses' Responses[a] All the Time	Nearly all the Time	Some of the Time	N/A
1. Did you want to visit your family member any time of the day or night?	(74)	98.7	(1)	1.3	(68) 90.7%	(6) 8.0%	–	(1) 1.3%
2. Did you want to help with the physical care of your family member?	(43)	57.3	(32)	42.7	(32) 42.7%	(8) 10.7%	(3) 4.0%	(32) 42. %
3. Did the hospice nurse give prompt attention to the physical needs of your family member?	(100.0)	75	-		(59) 78.7%	(16) 21.3%	-	-

Table 2 Continued

Item	Yes		No		Perception of Nurses' Responses[a]			
	(N)	%	(N)	%	All the Time	Nearly all the Time	Some of the Time	N/A
4. Did the hospice nurse give prompt attention to the emotional needs of your family member?	(73)	97.3	(2)	2.7	(61) 81.3%	(12) 16.0%	-	(2) 2.7%
5. Did you want to be informed of changes in your family member's general medical condition?	(73)	97.3	(2)	2.7	(56) 74.7%	(13) 17.3%	(14) 18.7%	(2) 2.7%
6. Did the hospice nurse allow you time to talk about your feelings concerning the death of your family member?	(72)	96.0	(3)	4.0	(54) 72%	(16) 21.3%	(2) 2.7%	(3) 4.0%

Table 2 Continued

Item	Yes (N)	 %	No (N)	 %	Perception of Nurses' Responses[a] All the Time	 Nearly all the Time	 Some of the Time	 N/A
7. Did you want to talk about the care given your family member?	(58)	77.3	(17)	22.7	(44) 58.7%	(14) 18.7%	-	(17) 22.7%

Note. [a] Perception of nurses' responses to need was contingent on identification of need as being present.

Table 3

Results of Questionnaire on Identification of Needs by Bereaved and Perceptions of Nurses' Meeting Those Needs

Item	Yes (N)	Yes %	No (N)	No %	Perception of Nurses' Responses						
					All the Time	Nearly all the Time	Some of the Time	N/A			
8. Did you want acceptance, comfort and support from the hospice nurse?	(63)	84.0	(12)	16.0	(56) 74.7%	(5) 6.7%	(2) 2.7%	(12) 16.0%			
					Helpful 7	6	5	4	3	2	Not Helpful 1
9. Did the hospice nurse come to the funeral or mortuary?	(19)	65.3	(26)	34.7	(39) 52%	(5) 6.7%	(1) 1.3%	(2) 2.7%	-	-	(2) 2.7%
10. Has the hospice nurse called or written you?	(41)	54.7	(34)	45.3	(29) 38.7%	(5) 6.7%	(3) 4.0%	(3) 4.0%	(1) 1.3%	-	-
11. Have you attended the monthly bereavement group meeting?	(7)	9.3	(68)	90.7	(7) 9.3%	-	-	-	-	-	-

Table 3 Continued

Item	Yes (N)	%	No (N)	%	Helpful 7	6	5	4	3	Not Helpful 2	1
2. Have you attended the open house held annually?	(10)	13.3	(65)	86.7	(9) 12.0%	(1) 1.3%	-	-	-	-	-
					Excellent 7	6	5	4	3	2	Poor 1
3. Overall, describe your satisfaction with the care received by your family member.					(5) 86.7%	(7) 9.3%	(2) 2.7%	(1) 1.3%	-	-	-
4. Overall, describe how <u>you</u> were treated.					(67) 89.3%	(7) 9.3%	-	(1) 1.3%	-	-	-

Seventy-four (98.7%) respondents stated this was a need experienced while their family member was on the hospice unit, while only one respondent gave a negative response to the item. According to the data, 68 (90.7%) of the respondents reported that this need was met by the hospice nurse "all the time," while 6 (8.0%) of the respondents reported this need was met "nearly all the time" by the hospice nurse.

Item 2. Did you want to help with the physical care of your family member?

Forty-three (57.3%) respondents stated they wanted to help with the physical care of their family members, while 32 (42.7%) did not want to help with the physical care. Of those 43 who wanted to help with the physical care, 32 (42.7%) stated they were allowed to do so "all the time," while 8 (10.7%) reported they were allowed to assist "nearly all the time."

Item 3. Did the hospice nurse give prompt attention to the physical needs of your family members?

All 75 (100%) respondents stated their family member's physical needs were met by the hospice nurse. Fifty-nine (78.7%) said this need was met "all the time," while 16 (21.3%) reported the need was met "nearly all the time."

Item 4. Did the hospice nurse give prompt attention to the emotional needs of your family member?

Seventy-three (97.3%) respondents stated their family member's emotional needs were met by the hospice nurse. Sixty-one (81.3%) said this need was met "all the time," while 12 (16.0%) reported the need was met "nearly all the time."

Item 5. Did you want to be informed of changes in your family member's general medical condition?

Seventy-three (97.3%) respondents acknowledged a need to be informed of any changes in their family member's general medical condition, while 2 (2.7%) did not want to be informed of any condition changes. Of the 73 respondents who wanted to be informed of condition changes, 56 (74.7%) stated the hospice nurse provided this information "all the time," 13 (17.3%) "nearly all the time," 4 (8.0%) "some of the time."

Item 6. Did the hospice nurse allow you time to talk about your feelings concerning the death of your family member?

Asked if the hospice nurse allowed them time to talk about their feelings concerning the death of a family member, 72 (96.0%) stated they were allowed this time, while 3 (4.0%) said they were not. Of those who were allowed time to talk, 54 (72.0%) reported the hospice nurse was available to them "all the time," 16 (21.3%) "nearly all the time," and 2 (2.7%) said the nurse was available "some of the time."

Item 7. Did you want to talk about the care given your family member?

Fifty-eight (77.3%) respondents reported a need to talk about the care their family member received, while 17 (22.7%) stated no need to talk about their concerns. Of those who wanted to talk about the care given, 44 (58.7%) stated the hospice nurse was available "all the time" to allow them to talk while 14 (18.7%) said the hospice nurse was available "nearly all the time."

Item 8. Did you want acceptance, comfort and support from the hospice nurse?

Sixty-three (84.0%) stated they wanted acceptance, comfort and support from the hospice nurses, while 12 (16.0%) did not. Of those who responded affirmatively, 56 (74.7%) said this need was met "all the time" by the hospice nurse, 5 (6.7%) "nearly all the time," and 2 (2.7%) respondents said this need was met "some of the time."

Item 9. Did the hospice nurse come to the funeral or mortuary?

Forty-nine (65.3%) of the respondents reported that the hospice nurse attended the funeral or mortuary, while 26 (34.7%) responded that the hospice nurse had not attended.

A 7-point Likert scale was used to determine the helpfulness of the hospice nurse's intervention. The respondents were asked to indicate the degree of helpfulness or nonhelpfulness in the hospice nurse's attendance at the funeral or mortuary. Of the 49 who recalled the nurse being present, 39 (52.0%) found it helpful, while 2 (2.7%) responded that it was not helpful.

<u>Item 10</u>. Has the hospice nurse called or written you?

Forty-one (54.7%) respondents received a phone call or written note from the hospice nurse, while 32 (45.3%) did not. Twenty-nine (38.7%) responded that this call or note had been helpful, while 1 (1.3%) had found it to be less helpful.

<u>Item 11</u>. Have you attended the monthly bereavement group meeting?

Seven (9.3%) responded that they attended the bereavement group meetings held on a monthly basis, while 68 (90.7%) did not attend any of the meetings. The 7 (9.3%) who attended the bereavement group meetings found them to be helpful.

Item 12. Have you attended the open house held annually?

Ten (13.3%) responded that they attended the open house held annually on the hospice unit, while 65 (86.7%) did not attend. Nine (12.0%) reported the open house to have been helpful, while 1 (1.3%) found it to be "slightly less helpful."

Item 13. Overall, describe your satisfaction with the care received by your family member.

Sixty-five (86.7%) rated their satisfaction as excellent.

Item 14. Overall, describe how you were treated.

In describing how family members were treated, 67 (89.3%) responded their overall satisfaction was excellent.

The responses from the open-ended questions are discussed in the next chapter.

CHAPTER IV

DISCUSSION

To develop an effective approach to nursing care for dying persons and their families on an inpatient hospice unit, it is necessary to learn more about how members of the family experience the care given, not only to the patient, but to themselves. One way to determine which aspects of care are helpful is to have the bereaved describe common needs and to identify whether these needs were consistently met by the hospice nurse during terminal hospitalization of a family member. The investigator was interested in this topic because of experience as a staff nurse on an inpatient hospice unit.

Over the past few years, public interest has brought about open discussion of how death touches everyone, the treatment and care of the terminally ill, and how patients and their families can be helped. Such concern and interest have led to the development of the health care reform called the hospice movement. The movement stemmed from increasing dissatisfaction with so much technological care and so little concern for human beings during a life threatening illness. An exploratory study of the needs of the bereaved on an inpatient hospice unit was considered an appropriate area of research, one which would expand understanding of the more humanistic aspects of nursing care of terminally ill patients and their families.

The purpose of this study was to identify the needs recognized by bereaved family members and to determine if current nursing practice on an inpatient hospice unit consistently met those needs.

Research Question One

Research question one stated:

> Were the eight needs identified by Hampe's (1975) research also identified by the bereaved in this study?

Responses from the bereaved who participated in this study indicated that they did experience the same needs, along with some additional needs (see Table 3).

The most frequently expressed need was that the hospice nurse give prompt attention to the physical needs of the patient. This supports Saunders' (1959) recognization that the physical care of the dying patient was as important a therapeutic tool as expert medical management. It further supports one of the identified major aspects of hospice nursing care that sets it apart from other terminal care programs, which is that comfort is actively pursued through the control of physical, emotional, psychological and spiritual distress (MacElveen-Hoehn & McIntosh, 1981).

The actual touch involved in providing this physical care is crucial. Patients often need the direct expression of human contact. Dying people may feel unclean or repulsive, or that there is an unpleasant odor about them that will keep people away. Therefore, how nurses touch patients in providing physical care can convey caring, acceptance, and respect. According to Lewis (1961), one of the primary requirements of the dying patient is maintenance of body image through good grooming, attractive surroundings, good light and ventilation.

Another need overwhelmingly identified by the bereaved (98.7%) was that of wanting to visit their family member any time of the day or night. Throughout the patient's illness, it is important for the nurse to remember that the family and patient need each other. The response to this item confirms that terminal illness is not the time to curtail visiting hours. The integrity of the family unit should be preserved so that the dying person does not feel alienated.

The need to visit was the one need most consistently met by the hospice nurse in this study, supporting Kubler-Ross's (1969) belief that, in order to help the terminally ill patient in a meaningful way, the family must be available to provide an atmosphere of security and support to the patient.

Other needs identified by the bereaved in this study were the nurse giving prompt attention to the emotional needs of the patient (97.3%), need for information about patient's condition (97.3%), wanting to talk with the nurse about the impending death (96.0%), time to talk with the hospice nurse about family members' feelings concerning the death (96.0%), and time to talk about the care given the dying patient (77.3%). These needs were reported as always or nearly always being met by the hospice nurse.

To help with the physical care of the dying family member was identified as a need by only slightly more than half of the bereaved (57.3%). The reasons for this result are not clear. In some instances, it may be the result of exhaustion from caring for the patient at home prior to admission to the hospice unit. Another reason for not wanting to be involved in the physical care of the patient is fear of complicated-looking equipment or of "doing something wrong." The family may simply need help from the hospice nurse to overcome their fears.

For those family members who expressed a desire to help with the physical care, involvement in some of the patient's personal care may serve to decrease some of the sense of powerlessness which family members feel. Such comforting tasks as helping with a backrub or turning the patient may partly relieve the family's anxiety and lessen feelings of regret and guilt.

Research Question Two

Research question two stated:

> Did the hospice nurse consistently meet the identified needs of the bereaved?

This research question was based on the assumption that the family cannot give the patient necessary support and companionship if they, themselves, are experiencing overwhelming emotions, and that considerable support for the family of the hospice patient can be rendered by the hospice nurse. Analysis of the data led to the conclusion that most needs identified by the bereaved in this study were perceived as being met all or nearly all the time by the hospice nurse. For example, the hospice nurses consistently met the need to visit the patient at any hour of the day or night. Only one respondent reported not being given the information wanted regarding changes in the general medical condition of the dying family member. According to the 75% returned questionnaires, the nurses on the hospice unit studied did, indeed, respond effectively to the needs of the bereaved family members.

Though no similar studies were found with which to compare these findings, Irwin and Meier (1973) did research designed to operationalize the concept of "support" for relatives of fatally ill persons. The results of this study support their findings which suggested that nurses are in a unique position to assess a family's need for support and to render support directly or indirectly in conjunction with their care of the patient.

Research Question Three

Research question three stated:

> What additional needs were identified by the bereaved in a hospice setting that were not identified in Hampe's research?

Generally, the hospice philosophy is characterized by the acceptance of death as a natural conclusion to life: hope can be offered so that neither patients nor their families will feel isolated and abandoned.

Two additional needs identified by the bereaved in this study which support this philosophy were being able to stay with the dying patient day and night and the positive response to the home-like atmosphere provided on the hospice unit. This home-like atmosphere included kitchen facilities which were mentioned by six respondents. Two respondents identified the need to know that the personal belongings of patients would be taken care of after the death and this need was met by the hospice nurse. Family members frequently are not concerned with personal items immediately after a death, but weeks later may want something that was left behind. In this instance, the bereaved were reassured to know that they could come to the hospice unit and pick up the item at a later date.

Over half of the respondents (65.3%) replied that someone from the inpatient hospice unit attended the funeral and all but two individuals said this was helpful. Sometimes it was not possible for the nurse to attend because the funeral was out of town or was restricted to family members. Two respondents reported that they did not find it helpful to have the nurse come to the funeral.

A bereavement group was initiated five months prior to collection of data for this study. The newness of the program may account for only seven respondents having attended the monthly meetings. All seven felt the group had been helpful. This may indicate a need for continuation of the group; however, data from this study are minimal in this area.

Upon completion of the questionnaire, each respondent was invited to add personal comments about how the hospice nurse had been the most helpful and the least helpful, and to identify other needs that were or were not met by the hospice nurse (Tables 4 and 5).

During hospitalization, the patient is the focus of care and family needs often remain unmet; however, it is the philosophy of hospice nursing care to focus on family support as well as support of the patient. Hospice nurses regard it as a responsibility to provide families with the knowledge that they care about them. This humanistic approach is a complement to the dying patient's need to feel valued for being who and what he is. Wentzel (1976) states that the patient and his family "need people around who look as if they are trying to understand." Such involvement is not considered an overstepping of professional boundaries, but rather, because of the nature of hospice, it is a necessary and predominant aspect of the work of the hospice nurse.

Table 4

Most Helpful Responses

Concept	(N)
1. Caring	10
2. Available	8
3. Offered comfort	6
4. Anticipated physical needs	6
5. Anticipated emotional needs	6
6. Kind	4
7. Understanding	4
8. Loving	4
9. Concerned	3
10. Considerate	2
11. Attentive	2
12. Friendly	2
13. Compassionate	2
14. Thoughtful	1
15. Patient	1
16. Listened	1
17. Shared family concerns	1
18. Knowledgeable	1

Table 5

Least Helpful Responses

Response	(_N_)
1. Wanted to have known within a few minutes that my husband was dying.	1
2. Nurse was not available when I needed one _sometimes_.	1
Other Needs Met by the Hospice Nurse	
1. Personal belongings taken care of after the death.	2
2. Being able to stay with the dying family member day and/or night.	2
3. Home-like atmosphere provided on the hospice unit.	2
4. Given food and drink by the hospice nurse.	2

Humanistic nursing encompasses an appreciation of psychosocial aspects of care while extending the concept to meet the needs of the individual as a unique human being with rights and with dignity. Humanistic care assumes a less reductionistic, more holistic approach.

The responses from the open-ended questions were divided into four categories from a humanistic nursing perspective, recognizing that the artificial categories comprise a whole or unified experience. The four categories were: a) physical factors, b) emotional factors, c) cognitive factors, and d) caring factors (Watson, 1979).

Physical factors involved any actual "hands-on" activity or demonstration done for the patient or a family member. One lady described this very well when she stated, "The nurse stayed with me at the bedside and held my hand until my husband had died." Eight subjects responded that the patient received good physical care, which included baths, back-rubs and adequate pain medication.

Two subjects mentioned that they were given food and drink, which they considered helpful. Eight subjects mentioned that the physical needs of their family member had been anticipated and met by the hospice nurse, without being specific in regard to the exact activities of the nurse.

Cognitive factors may be described as one's awareness with reasoning, intuition and memory: the mental process by which knowledge is acquired. Two subjects described the nurses as being very knowledgeable about what to do in any given situation. This made the respondents and their dying family member more comfortable. One man expressed his satisfaction with the care given his wife by stating, "The nurses were so good in explaining everything to me, and even what to expect in her last few minutes of life."

The term, anticipatory grief, refers to grieving that occurs prior to the actual loss. When a death occurs with some forewarning, the potential survivor can begin the task of mourning. The term, anticipatory grief, was coined some years ago by Lindemann (1944) to refer to the absence of overt manifestations of grief at the actual time of death in survivors who had already experienced the phases of normal grief and who had freed themselves from their emotional ties with the deceased.

One of the questions that comes to mind when one thinks about anticipatory grief is, "Does it help postdeath bereavement?" There does seem to be some evidence, particularly from the studies of Parkes, that people who had some advance warning of an impending death did better when assessed at 13 months postdeath than did people who did not have this advanced warning (Parkes, 1975). According to Watson (1975), anticipation of a loss gives a mourner a chance to carry out grief work and express the pain in an appropriate manner. The hospice nurse can facilitate the grief work that accompanies loss by helping patients and families recognize the universal nature of loss as a normal process. The hospice nurse who understands the problems faced by the patient and his or her family is responsive to health issues and can raise the quality of the patient's life.

Emotional factors can be described as overlapping factors. Emotions can be described as any specific feeling, as love, hate, fear, or anger. One daughter's response may explain this more clearly, "Even though all we could do for my mother was make her comfortable, knowing that she was dying, mother was finally at peace on the hospice unit and expressed this to me."

An overwhelming number of responses to the open-ended question of what was the most helpful thing the hospice nurse did were simple one word phrases or concepts that can stand alone. Examples are:

attentive, caring, friendly, kind, compassionate, loving and concerned. This investigator chose to categorize these concepts under the heading, caring factors.

Caring factors (Watson, 1979) aim at the caring process that helps the person attain health or die a peaceful death. The day-to-day practice of professional nursing requires a grounding in a humanistic value system that the nurse continues to cultivate. The humanistic value system must be combined with the scientific knowledge base that guides the nurse's actions. The caring factors described by the subjects present nursing care as a deeply human activity. One lady described the hospice nurse as "being available to give me support and comfort." Existentialists make much of the quality of "being there." Presence is the quality of being in a situation in which one intends to be as aware and as participative as one is able to be at that time and in those circumstances. Presence is immensely more than just being totally inn the situation (Bugental, 1978).

According to the position taken by the subjects in this study, many of their one-word phrases or concepts may be described by the term, "humanistic nursing." According to Paterson and Zderad (1976), humanistic nursing means more than humaneness since, at its very base, nursing is an interhuman event. As an intersubjective transaction, its meaning is found in the human situation in which it occurs. As an existential act, it involves all the participants' capacities and aims at the development of human potential.

In conclusion, the needs of the bereaved in a hospice setting were identified and reported as having been met consistently by the hospice nurse, according to this retrospective, descriptive study. Hospice nurses were perceived as helpful and concerned about the bereaved as well as the care they gave the patient. The results suggest that nurses must be freed to care for the emotional and physical needs of the patient as well as the family. Nurses must accept the human involvement that is required with the care of a dying patient and the family. Nurses must recognize that, when a patient is dying, the family members also are her patients.

Implications for Nursing

The dying do not press their needs. Their families do not ask for much either. For a variety of reasons ranging from ignorance to insensitivity, most health care providers are doing little or nothing to improve the lot of dying patients.

The void exists partly because acute care hospitals are ill-suited to meet the physical and emotional needs of the dying and their families. There is one alternative available for the dying -- hospice care. Hospice goals differ markedly from those of acute care facilities. A major aim of a hospice program is palliation of symptoms so that patients can live out their lives as comfortably and meaningfully as possible.

The findings of this study show that needs of the bereaved who had a dying family member on an inpatient hospice unit were consistently met by the nurse. The hospice nurses have developed special skills in being able to communicate with the dying and their family members. Communication in relationship to death occurs verbally, nonverbally and symbolically. There is no set time to communicate about death and dying. Discussion tends to flow at unexpected times and is intertwined with the physical care.

Nonverbal communication is often more meaningful than verbal. The fact that the nurse is there caring and comforting can communicate a sense of security and acceptance of the impending death.

Further research should be undertaken by nurses in other settings. The sample in this study included bereaved families of 100 deceased patients, randomly selected from the records of an inpatient hospice unit. There was a 75% return of a mailed questionnaires, leaving in question the remaining 25.

An interview may have resulted in more specific information about other needs that were or were not met by the hospice nurse. This study asked the respondents to list any and very few were received. Use of a personal interview might result in more discriminating data.

Identifying the needs of the grieving in a hospice setting, as indicated by the grieving themselves, is a first step in planning meaningful nursing approaches to comfort, support and ease the suffering of the dying and their family members.

APPENDIX A

LETTER OF INTRODUCTION

Dear :

I am asking you to participate in a study to identify needs you may have had while your family member was a patient on the hospice unit at Holy Cross Hospital. Your name was obtained from the records at Holy Cross Hospital. My relationship to this agency is that of a staff nurse on the hospice unit, and as the investigator for this study while a graduate student at the College of Nursing, University of Utah.

For the past three years, the hospice unit has been giving specialized care to dying patients and members of their family. This study will help identify some needs you may have had and how consistently those needs were met by the hospice nurse. Hopefully, by identifying these needs and the ones the nurses met, the hospice nurse can provide additional support and comfort to family members.

Your participation in this study is voluntary. If you wish to participate, please complete the questionnaire and return it in the enclosed addressed envelope within the next two weeks. All information will be handled in a confidential manner and full anonymity will be maintained. The information you give will help improve nursing care for patients and families in the future when on the hospice unit.

Please do not sign your name to the questionnaire so your anonymity can be maintained. No names will be used when presenting the data.

Sincerely,

Carol Lee

APPENDIX B

QUESTIONNAIRE

Below are different needs you may have experienced while your family member was on the Hospice Unit at Holy Cross Hospital. After each statement, please mark "No" if the need did not pertain to your situation and "Yes" if it did. If you mark "Yes," please check <u>one</u> box to explain as closely as possible how often that need was met by the hospice nurse.

What is your sex? Male___ Female___

What is your age? _______

How long ago was the death of your family member? (number of <u>months</u>) _______

How long was your family member on the hospice unit before death? (number of <u>days</u>) _______

How old was your family member at the time of death? _______

What was your relationship to the deceased? __________

1. Did you want to visit your family member any hour of the day or night for unlimited periods of time? No ______ Yes______

   If yes, did the hospice nurses make it possible for you to visit whenever you wanted?

   ( ) All the time ( ) Some of the time
   ( ) Nearly all the time ( ) None of the time

2. Did you want to help with the physical care of your family member? No ______ Yes ______

   If yes, did the hospice nurses allow you to help with the care?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

3. Did the hospice nurses give prompt attention to the physical needs of your family member? No _____ Yes _____

If yes, did the hospice nurses meet these needs?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

4. Did the hospice nurses give prompt attention to the emotional needs of your family member?
No _____ Yes _____

If yes, did the hospice nurses meet these needs?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

5. Did you want to be informed of changes in your family member's general medical condition?
No _____ Yes _____

If yes, did the hospice nurses provide time for you to discuss your family member's condition?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

6. After you were aware of the impending death of your family member, did the hospice nurses allow you time to talk about your feelings concerning the death? No _____ Yes _____

If yes, were the hospice nurses available to you when you wanted to talk?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

7. Did you want to talk about your concerns regarding the care given your family member? No _____ Yes _____

If yes, did the hospice nurses allow you time to talk about these concerns?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

8. Did you want acceptance, comfort and support from the hospice nurses? No _____ Yes _____

If yes, did the hospice nurses meet your needs for acceptance, support and comfort?

( ) All the time ( ) Some of the time
( ) Nearly all the time ( ) None of the time

9. Did one of the hospice nurses come to the mortuary and/or funeral? No _____ Yes _____

If yes, did you and other family members find this helpful? (Circle your answer)

Not helpful Helpful
1 2 3 4 5 6 7

10. Has one of the hospice nurses contacted you by phone or letter since the death of your family member? No _____ Yes _____

If yes, was the contact helpful? (Circle your answer)

Not helpful Helpful
1 2 3 4 5 6 7

How many times have you been contacted by the hospice nurse? (Number of times you can remember)

____

11. Have you attended any of the monthly bereavement group meetings? No _____ Yes _____

If yes, did you find this helpful? (Circle your answer)

Not helpful Helpful
1 2 3 4 5 6 7

12. Have you attended the open house held annually on the hospice inpatient unit? No _____ Yes _____

If yes, was the contact helpful? (Circle your answer)

Not helpful Helpful
1 2 3 4 5 6 7

13. Overall, how would you describe your satisfaction with the care that your family member received from the hospice nurses? (Circle your answer)

Poor   Excellent
1   2   3   4   5   6   7

14. Overall, how would you describe the way you were treated by the hospice nurses? (Circle your answer)

Poor   Excellent
1   2   3   4   5   6   7

In your opinion, what ways was the hospice nurse most helpful to you?

In your opinion, what ways was the hospice nurse least helpful to you?

Did you or your family have any other needs that were met by the hospice nurses? No _____ Yes _____

If yes, please explain them below.

Did you or your family have any other needs that were not met by the hospice nurses? No _____ Yes _____

If yes, please explain them below.

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