AN OKLAHOMA HOSPICE PROGRAM: CAREGIVER PERCEPTION AND NEEDS ASSESSMENT

By

STEPHANIE GERTRUD GREEN

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Thesis Approved:

Joseph A. Weber
Thesis Adviser

Carolyn S. Henry

David Fournier

Thomas C. Collins
Dean of the Graduate College

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TABLE OF CONTENTS

Chapter Page

LIST OF TABLES

CHAPTER I

INTRODUCTION

History of Hospice

The death of a spouse or close family member can cause tremendous stress and anxiety within a family (Holmes & Rahe, 1967). Experiencing the death of a loved one can cause depression and physical illnesses that can be either real or imagined. Throughout much of the twentieth century in the United States, the handling of terminal illness and death was usually the responsibility of institutions other than the family (Pine & Phillips, 1970). Terminally ill patients were either placed in a hospital or nursing home to be treated by professionals. Within these institutions the medical profession, along with pressures from society, attempted to sustain life no matter what the costs. This often leads to using aggressive treatments that result in a lower quality of life for the patient and does not consider the psychological needs of the dying patient and his or her family (Vandenbos, DeLeon, & Pallak, 1982; Corless, 1988). As a result, most families have had little or no exposure to the dying patient or are not even present when the death occurs (Goldberg, 1973).

Today, many families are choosing alternative methods of providing care for their dying family members. One of these alternative types of care is the hospice program. In the Middle Ages the term "hospice" denoted a "way station" along the route of the Crusades or a center of religious and medical advice for the critically ill (Levy, 1987). As researched by Buckingham (1982), the National Hospice Organization defines hospice as follows:

> Hospice is a medically directed, multidisciplinary program providing skilled care of an appropriate nature for terminally ill patients and their families to live as fully as possible until the time of death and helps relieve symptoms during the distress (physical, psychological, spiritual, social, economic) that may occur during the course of the disease, dying, and bereavement (p. 160).

Hospice services are available 24 hours a day, seven days a week (Levy, 1987). Levy reports that in order to be eligible to use hospice the patient must have a prognosis of less than six months to live and be willing to give up any curative treatment.

The modern development of hospice care is relatively recent, yet rapidly expanding. In 1974, the first hospice in the United States was established in New Haven, Connecticut as a "free-standing" facility (Paradis & Cummings, 1986; Vandenbos, DeLeon, & Pallak, 1982). Patients were transferred to this facility from other hospitals and health care establishments. However a lack of funding and adequate medical facilities, necessitated the establishment of other models for hospice.

"Home health agency-based" programs began as either free-standing facilities, which later applied for home health certification, or as units of home-health agencies (Paradis & Cummings, 1986). Within this type of hospice, patients are cared for at home by nurses, family members and volunteers. Contact with local hospitals, nursing homes, or other inpatient units is kept open to provide inpatient care as needed.

A third type of hospice facility is "hospital-based." These programs are initiated by hospitals to assist patient and families. These facilities may be separate units, scattered bed units, or units staffed by professionals who render care in the home. By 1981, The Joint Commission on Accreditation of Hospitals identified over 800 hospice program (Vandenbos, DeLeon, & Pallak, 1982).

Although no two hospice programs are alike, all programs focus on the family as the basic unit of care. For the patient, hospice programs offers palliative care and symptom control, the choice to die at home with the support of loved ones, and the chance to be involved with family and friends, in hopes of restoring dignity to the patient (Vandenbos, DeLeon, & Pallak, 1982; Wallston, Burger, Smith, & Baugher, 1988). Individualized care programs and choices about treatment are also part of the hospice philosophy.

For the family, hospice provides emotional support, volunteers to help with errands and other supportive activities and also support for the family, during the dying process and bereavement counseling after death. Staff members serve as mediators between estranged family members and strive to preserve and strengthen family interaction (Levy, 1987). Other services are aimed at reducing stress and easing the transition into bereavement. These services include helping the family plan the funeral, providing counseling and making follow up visits and phone calls.

The goal of hospice is to help the patient live the best life possible until they die and to help the caregiver and other family members cope with the death without extreme disruption to the family structure. This means that an important task of the hospice staff is to determine the family's lifestyle before the terminal illness and assess the needs of the family to help them adjust to new roles.

Problem Statement

Since 1974 hospice has provided the needed service of holistic care for terminally ill patients and support for the patient's family. The hospice services are needed to help alleviate the anxieties and stress commonly experienced by patients and family members. Hospice strives to help the patient live the best life possible until death and to help the caregiver and other family members cope with the death while maintaining family structure. In order to provide maximum service, hospice staff must determine the family's lifestyle before the terminal illness and assess the needs of the family to help them adjust to new roles. Thus the question remains, does the hospice staff sufficiently assess the needs of the family in order to provide the maximum support possible both during the terminal illness and during the bereavement period?

Purpose of Study

The research conducted on the effectiveness of hospice programs has resulted in contradictory results. Empirical studies on the value of hospice care is scarce. The studies that exist tend to support the commitment of hospice programs as an alternative means of dying (Hendon & Epting, 1989). Some studies indicate that hospice provides better service to dying patients and their families than the traditional hospital setting. Other studies have shown that, although hospice programs provide beneficial services, there is not a significant difference between groups who have utilized hospice and groups who have used traditional methods of care, such as hospitals or nursing homes.

Medical professionals have difficulty coping with the fact that they are unable to cure a patient (Vandenbos, DeLeon, & Pallak, 1982). The present medical system attempts to sustain life for as long as possible at all costs, with little regard for the quality of life. Once all efforts to cure a patient have resulted in defeat, hospice tries to restore dignity to the dying individual for the remainder of his or her life and give support to the family to ease the stresses of caregiving. Further research in this area needs to be done to fully determine if hospice is actually benefiting patients and their families. The purpose of this study is to examine the effects of the use of hospice services on the caregiver of a terminally ill patient and to determine whether the needs of the caregiver are being adequately met by hospice staff members.

Theoretical Framework

Systems Theory

Systems theory focuses on the family as a whole unit that is made up of individual parts (Sieburg, 1985). Families function as small social systems organized around the relationships between the members of the family (Levy, 1987). In order to fully understand the relationship of a family system, one must look at the interactions between all members within the family. Therefore, studying each member alone will give an incomplete understanding of the entire functioning of the family.

Because of the interactions between family members, a change in the life events of one family member has an effect on other family members. For example, when a family member becomes terminally ill, all family members are affected to some extent. In treating families with terminally ill patients, hospice philosophy follows the systemic viewpoint.

In accordance with systems theory, all hospice programs target not only the patient, but the entire family as the basic unit of care (Levy, 1987). Hospice staff members encourage the dying patient and family members to become part of a team that assesses the needs and arranges the activities of the family system. Therefore, a major role of the hospice staff is to preserve and strengthen family ties and interaction by serving as a mediator and removing the barriers to interaction.

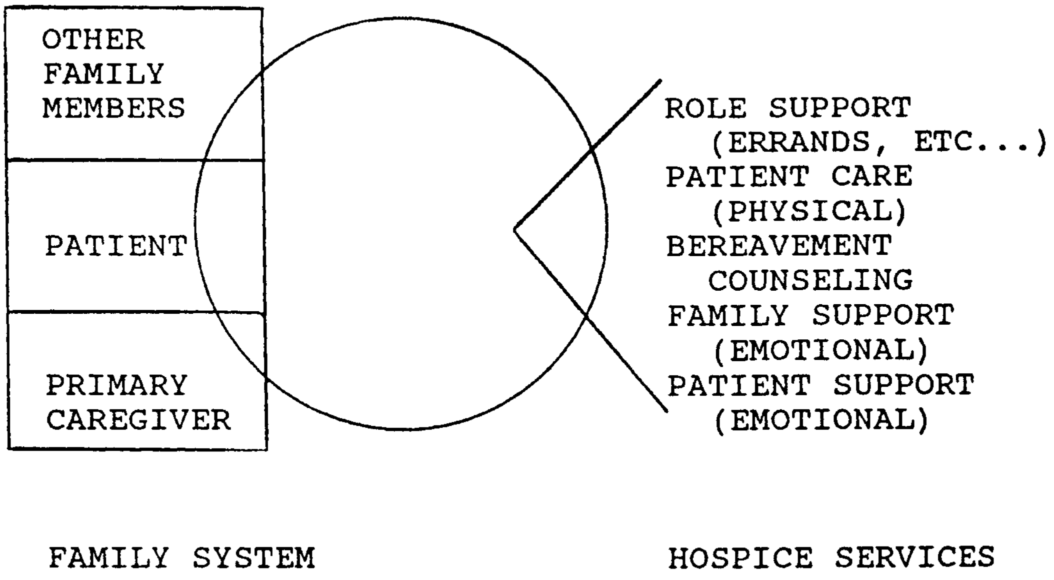

Figure 1. Model to examine the hospice philosophy from a systems perspective.

Looking at hospice through family systems theory, the family can be viewed as a pillar (see Figure 1). The stress that results from the death and illness of a loved one causes a weakness in the family system or pillar. Hospice works to support the family and keep the family from crumbling.

Family Stress Theory

Family stress theory attempts to define the relationships and interactions of family members during times of life changes and crisis (Figley, 1989). This model proposes that the families are in a homeostatic state until a stressor event occurs and creates a state of disorganization or crisis (Walker, 1985). The family remains in this state until, though a period of trial and error, the crisis is resolved and homeostasis is regained.

According to the family stress theory several variables interact to create a crisis (McCubbin & Patterson, 1983). This interaction is represented by the equation ABC=X. The first variable, A, is the stressor event, which is any occurrence that creates change and disruption within the family. This event interacts with two other variables to create a crisis. The second variable, B, is the family's resources. Family resources can either be agencies, such as community service agencies like hospice, that provide social, emotional, and financial support, or simply the support family members give one another. The last interacting variable, C, is the family's perception of the stressing event. The family could view the event as only an inconvenience or as devastating to the entire family structure. All of these variables together equal X, the crisis (see Figure 2).

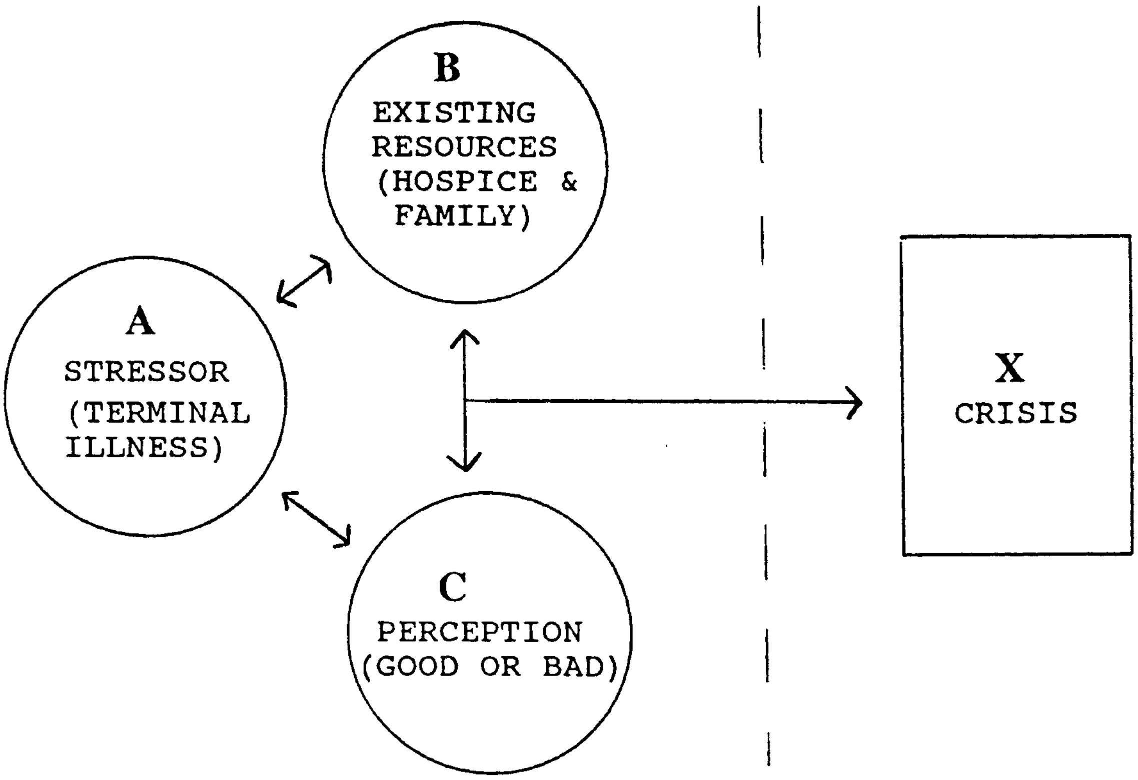

Figure 2. Model to examine the hospice philosophy through Family Stress Theory.

Family stress theory is based on nine assumptions that attempt to explain family life (Figley, 1989). Of these nine assumptions, four can be used to explain the hospice philosophy. The first assumption states that families experience natural hardships and changes throughout the course of the life cycle. Death is a natural part of the life cycle and creates changes in the lives of all those involved. In accordance with this assumption hospice helps those affected by the death to understand that they are not alone in their experiences.

Assumptions two and three are similar. Assumption two states that during times of stress and crisis, families benefit from a network of resources from the community (Figley, 1989). Hospice fits into the family stress theory by acting as a resource during times of crisis. As stated before, a role of hospice programs is to provide support to patients and family members, easing any strain caused by the terminal illness.

The third assumption proposes that family functioning can be enhanced by implementing programs targeted at those areas that are suffering the most. Through several different programs, such as patient care, family counseling, and other services, hospice can help to increase the quality of life for both the patient and family members.

The fourth assumption states that family intervention is enhanced through an assessment process that takes into account the family's strengths and weaknesses (Figley, 1989). In order to fully determine the needs of the family, hospice must first assess the quality of the family system before the crisis to determine the needs of the family both during and after the crisis. Hospice can use the family's coping strengths as a tool in keeping the family structure intact. Once the needs of the family are determined, hospice staff can begin to implement those programs that will best help the family.

By interacting with the family, hospice can also help determine the family's perception of the situation. If the hospice staff is effective, the patient and family will view their situation as difficult but will be able to find the strength to maintain the family function and structure. On the other hand, if hospice is not effective, the patient and family may find that the family system is being destroyed.

There are times during post-crisis, when another crisis producing event is the result of the original crisis producing event. Because of this, McCubbin and Patterson (1983) proposed the Double ABCX model. In this model, McCubbin and Patterson identified a second variable A, which takes into account additional stressors from both family development and from their efforts to cope (Walker, 1985). When a second variable A is introduced, a phenomenon called "pile-up" results. An example of a new stressor, using the hospice example mentioned earlier, would be the primary caregiver having to change jobs in order to accommodate the needs of the patient. Variable B now includes the original resources used plus any new resources needed to help cope. New resources could be the hiring of a health care aid to take over while the primary caregiver is at work. Variable C is the family's perception of the original crisis and the new stressor and resources. Variable X is used to describe the outcome of the family's efforts to return to homeostasis after the crisis.

Research Questions

Families need assistance and support when a family member is diagnosed as terminally ill. The hospice program provides the networks necessary for families to cope successfully with the grieving process. The main research questions this study will address are:

(1) What type of services are offered by hospice and which of these services were utilized most often?

(2) What was the caregiver's overall perception of their hospice experience?

(3) Was communication sufficient between the caregiver and the hospice staff to ensure the caregiver's needs were adequately met?

(4) What other services might have been helpful if they had been available?

It is hypothesized that hospice programs can meet the needs of caregivers with terminally ill patients; resulting in a favorable impressions of hospice programs. Therefore, through the success of hospice many of the stressors that are commonly experienced during the illness and bereavement are alleviated.

Definitions

In order to fully understand the concepts used in this study, the following terms are defined.

Terminal illness is defined as "certification by a physician that the individual has a life expectancy of six months or less" (Schulz & Schlarb, 1988).

Family is defined for this study as an immediate relative of the patient (spouse, parent, or child).

Primary caregiver is defined as an individual, family or friend, who is close to the patient and has willingly taken the responsibility of providing most of the care required by the patient.

Hospice is defined as an agency that is dedicated to providing physical, emotional and spiritual care to the terminally ill and their families.

Summary

Today many families are choosing alternative methods for their terminally ill family member rather than traditional methods of care. One such alternative method is hospice. Hospice has been in existence in the United States for almost 20 years. During this time, hospice staff has been providing palliative care for terminally ill patients and supportive care for families.

Although no two hospices provide the same exact services, the main goal of each one is to help patients live the rest of their life with dignity, and to help the caregiver and other family members cope with the stress of caregiving and the emotional turmoil of bereavement. Since a major task of hospice is to evaluate the needs of patients and their families, it is the purpose of this study to determine whether or not hospice programs are adequately assessing the needs of patients and their family members.

CHAPTER II

REVIEW OF LITERATURE

Introduction

Research on hospice programs and their effect on the caregivers and families of terminally ill patients is not extensive. The physical and psychological effects of caregiving on the family have not been adequately studied by health care professionals (Kirschling, 1986). However, in the last few decades, researchers have focused their studies on family's perception of hospice programs and the impact their services had on the primary caregiver and other family members (de St. Aubin & Lund, 1986).

The first section of this review includes comparative studies that have been conducted on hospice versus non-hospice users. The next three sections discusses primary caregivers, assessment of caregiver's needs, and caregiver's concerns during the patient's illness. The final section shows how hospice has handled the needs of caregivers.

Hospice vs Non-Hospice Caregivers

One of the first studies on hospice programs was conducted at St. Christopher's Hospice in London (de St.

Aubin & Lund, 1986). Researchers compared a group of spouses of patients who had used hospice with a group of spouses of patients who used hospitals. Results showed that the hospice group reported experiencing less anxiety before (but not after) the patient's death and also worried less about revealing their own fears to the patient.

Buckingham (1982) found that families using hospice services felt more independent than families not using hospice. In fact, families not using hospice experienced feelings of personal inadequacy and inferiority. These feelings were not characteristic of hospice primary caregivers. There were also fewer reports of weakened attachments to family, submission, dependence, and anxious dwelling among hospice care persons. Buckingham also notes that hospice patients and their primary caregiver report greater satisfaction in their relationships with relatives, family, spouse, and children than did non-hospice groups. Hospice primary caregivers reported less inhibition in their communication with others than did non-hospice primary caregivers. This increased satisfaction may be attributed to family members who participate in the care of the patient being relieved of some of their feelings of helplessness that is often experienced. Caregivers reported that being able to take care of, providing assistance for, and giving comfort to the dying patient helped to relieve some of the guilt and helplessness that is commonly felt by family members.

In a comparison of caregivers who used hospice services and those who did not, de St. Aubin and Lund (1986) proposed four hypotheses. Hypotheses one and two focus on the experiences caregivers have during the patient's illness. The first hypothesis suggests that hospice family caregivers will perceive greater emotional support from medical staff during and shortly after the death of the patient. The second hypothesis states that hospice caregivers will have higher feelings of involvement in patient care during the terminal illness than non-hospice caregivers.

The last two hypotheses are concerned with the resolutions of grief after the death of their relative. (de St. Aubin and Lund, 1986). Hypothesis three proposes that non-hospice caregivers will have greater amounts of unresolved grief than hospice family caregivers. The last hypothesis states that hospice caregivers will have a more positive bereavement because they experience: (a) lower levels of perceived stress; (b) higher levels of perceived coping; (c) higher levels of perceived health; (d) higher levels of social participation; and (e) higher levels of involvement with friends and relatives.

The findings by de St. Aubin and Lund (1986) were supportive of the first hypothesis; that hospice has a favorable impact on emotional support for caregivers. However, there was not a significant difference between groups to support the other three hypotheses.

Primary Caregiver

In using hospice services, a member of the family is trained as a "primary caregiver." Caregivers are taught how to administer medication and take care of the patient's needs. This training allows someone in the family to become active in the care of the dying patient.

In a study at St. Mary's Hospice in Tucson, Arizona, 97 subjects were asked to complete a questionnaire 13 months after the death of their significant other (Longman, Lindstrom, & Clark, 1989). Subjects were asked to state whether the services provided by the hospice was of assistance. Ninety-six percent thought the hospice was helpful; however, there was some disagreement in when implementation of services should begin. Twenty-one percent thought the services should have began earlier in the illness and only one percent thought hospice became involved too early.

Additional studies have been done concerning de St. Aubin and Lund's third and fourth hypothesis mentioned earlier. One hypothesis suggests that the greater strain during caregiving predicts less difficulty with bereavement (Bass & Bowman, 1990). The second hypothesis suggests that with greater strain during caregiving comes increased difficulty with bereavement.

Support for the first hypothesis can be found in several studies. One study compared pre-death and post-death scores on a measurement of general well-being of bereaved family members. The group showed significant improvement on increased participation in voluntary organizations, increased satisfaction with social and recreational activities, decreased use of psychotropic drugs, and decreased levels of stress-related psychiatric symptoms. Researchers concluded from these findings that the "loss of the caregiver role has resulted in improvements in the quality of life" (George & Gwyther, 1984).

Pre- and post-death physical and psychological well-being for bereaved and non-bereaved older adults were compared in a second study (Norris & Murrell, 1987). Family stress related to normal family functioning was assessed for both pre-death and post-death. Findings showed that bereaved participants who reported high levels of stress before the relative's death showed improved levels of physical health after the death. Researchers interpreted their results to mean that even though a relative's death is emotionally difficult, it signified a relief from a stressful period, resulting in an improved physical well-being. However, it is interesting to note that caregivers did not show an improvement in psychological well-being regardless of the level of pre-death family stress.

Other researchers have found that when hospices services are utilized, although families of terminal patients are under stress, they are more prepared for the death of their loved one and are better able to deal with bereavement (Schulz & Schlarb, 1988). Families feel more in control of the situation and are glad to be actively involved in the care of their loved one.

Craven and Wald (1975) also state that participating in the care of the dying can notably reduce feelings of guilt and helplessness. The active participation is part of the separation process, which includes giving and receiving, coming together and letting go. The separation process, also called "anticipatory grief" or "preparatory grief", is a crucial task that must be resolved if the family is to go on living after the loved one has died.

Support for the second hypotheses comes from the belief that multiple and/or successive stressors have a negative effect on the family (Bass & Bowman, 1990). These successive stressors, referred to as "cascade effect," "overload," or "pile-up of stressors" exhaust a family's capacity for coping, making them more vulnerable to added negative events such as the death of a family member. Results from a study by Bass and Bowman (1990) agree with this hypothesis. They found that the greater strain during caregiving will predict greater strain during bereavement. However, they feel that due to some limitations in their study (small and purposively selected sample, no comparison groups, and method of measuring) more research is needed to determine which of the hypothesis is correct.

A second explanation for this hypothesis stems from studies on anticipatory or preparatory grief. Anticipation of the death of a relative is theorized to allow family members prepare for the death (Bass, & Bowman, 1990). However, evidence supporting the benefits of anticipating or preparing for the death of a loved one are contradictory (Craven & Wald, 1975; Hill, Thompson, & Gallagher, 1988; de St. Aubin & Lund, 1986). Other studies suggest that caregivers are too involved with their responsibilities that preparation for death is actually hindered and an increased commitment and closeness to the loved one is formed. The result may actually be a more difficult adjustment to the death of the relative (Bass & Bowman, 1990).

A third explanation for expecting more difficulty in bereavement is that coping with various types of stressors is influenced by personality traits (Bass & Bowman, 1990). In the context of caregiving, it is thought that caregivers who have personality traits that enable them to cope with the stress of assisting their terminally ill relative with few negative consequences would also be expected to adjust to bereavement with less difficulty. In the same manner, caregivers who found their responsibilities especially stressful would be predisposed to greater stress during bereavement.

Assessment of Caregiver Needs

In a survey, Hampe (1975) interviewed 27 spouses of terminally ill adults in order to determine their needs and whether these needs had been met. The terminally ill adults were hospitalized at the time of the interview. The spouse's needs mentioned were: (1) to be helpful to the dying person; (2) to be with the dying person; (3) to receive assurance of the dying person's comfort; (4) to be informed of the dying person's condition; (5) to be informed of impending death; (6) to ventilate emotions; (7) to receive comfort and support from family members; and (8) to obtain acceptance, support and comfort from health care professionals. Only three of the needs mentioned; the need to be with the dying patient, the need to be helpful to the dying person, and the need to be informed of impending death, were met for at least half of the interviewees. The findings in this study illustrate that families of the terminally ill could identify their needs and that these needs were unmet.

Caregiver Concerns

Barzelai (1981) asked caregivers about particular problems that were experienced before and after the patient's death and if the hospice was able to deal with them effectively. One major problem mentioned was that of anxiety. Eighty-nine percent of the participants in this study felt that hospice was successful in reducing levels of anxiety. The hospice program was also noted as being a means of obtaining emotional support. For several of the participants, hospice served as a liaison in interaction between the caregiver and the medical community and was considered a valuable source of medical information concerning the patient.

Findings at a hospital-based hospice at the University of Massachusetts Medical Center were similar to those of Barzelai's (de St. Aubin & Lund, 1986). Spouses felt more supported and were better able to cope than they felt in prior settings. The study also reported that feelings of loss or grief were perceived as a "major" problem in only half of the hospice participants. Improved family functioning and well-being as well as an increased closeness among family members was also reported.

Hull (1990) conducted a study to formulate a detailed description of the concerns and stresses families encountered while caring for their terminally ill relative in a hospice home care program. The purpose of the study was not to generalize the results to all hospice programs, but to gain information and generate further research on caregivers and how hospice professionals can better assess and meet the needs of their clients.

Concerns related to the patient's mental status (inability to communicate, confusion, and seizures) were mentioned as the most distressing symptoms for families (Hull, 1990). Physical deterioration, bringing on increased dependence on caregivers for basic and personal needs, were also mentioned as very distressing. Examples of this are bowel and bladder elimination, inability to support oneself while being mobile, and administering medications.

Maintaining usual family roles and responsibilities as well as handling family, friends and personal care aids is a second area of major concern for primary caregivers (Hull, 1990). Caregivers experience stress trying to maintain previous roles such as parent, housekeeper, etc. while at the same time adding the new responsibilities of caregiving.

For some caregivers, dealing with the opinions of "well meaning" family and friends was difficult (Hull, 1990). Advice from those not directly involved in the caregiving was often given, though not wanted. Other family and friends were perceived as insensitive to the patient's needs, often visiting too long, not visiting, or discussing the death of others in front of the patient. Stress also came from personal care aids who did not adequately asses or fulfill the needs of the families.

The final major area of concern experienced were personal needs identified by caregivers (Hull, 1990). The five areas of concern identified by primary caregivers were: (1) putting their life on hold, (2) personal health, (3) lack of time for themselves, (4) isolation from family and friends, and (5) feelings of guilt.

By assuming the caregiving role, family members sometimes find it necessary to change or cancel previously made plans (Hull, 1990). Vacations may be canceled or continuing education may be postponed. Some caregivers even make drastic changes in their lifestyle in order to accommodate their new caregiving role. Caregivers have sometimes found it necessary to quit or change jobs or relocate in order to take care of a loved one.

Some caregivers report problems in their own personal health while caring for their loved one (Hull, 1990). This becomes an added stressor. Not following doctor's advice for their own health problems and not getting a good night's sleep are commonly reported problems.

Caregivers also do not have much time for themselves (Hull, 1990). Although other family members and friends helped with errands and other needs, primary caregivers still felt a strong need to be away from caregiving responsibilities to do what they wanted. Caregivers also report experiencing isolation from friends and a need for a normal routine within their social environment.

The final source of stress for primary caregivers was guilt (Hull, 1990). Four circumstances are noted that lead to feelings of guilt: (1) wanting the caregiving experience to be over; (2) not spending enough time with the patient; (3) being less attentive about caregiving responsibilities;

and (4) being impatient with and insensitive to their loved one. Caregivers had set their own expectations on how they should behave and feel toward their dying relative. If they did not live up to their own self expectations, they felt guilty.

The Role of Hospice in Reducing Stress

Kane, Klein, Bernstein, Rothenberg, and Wales (in press) conducted an extensive study of the role of hospice in reducing the emotional stress of terminally ill persons and their families. The caregivers were asked to rate Hampe's (1975) original need statements on the scale of importance. All of the needs were rated very important or extremely important. In addition, caregivers were differentiated into those who were receiving hospice services and those who were not and asked how often the needs were met. Caregivers receiving hospice services reported that their needs for being involved with the terminally ill person were met to a greater extent than those caregivers not receiving hospice services. No differences were found when needs for family support were considered.

Etten and Kosberg (1989) developed the Hospice Caregiver Assessment Inventory and Caregiver Intervention Plan to identify problem areas for the caregivers of dying patients and develop appropriate interventions. Some frequently noted problems were lack of relief, disturbed sleep, and the need for help from others. To aid the families in these areas, hospice staff members arranged for more assistance from family and friends and identified other resources which could provide relief and other forms of assistance. Since some hospice users did not have an extensive family support system nearby, hospice also increased their volunteer support services and in-home assistance.

Another problem that faced caregivers was the relationship between them and the patient (Etten & Kosberg, 1989). Specific problems mentioned included "idealizing the relationship," "anger over the deteriorating relationship," and "the future loss of the relationship." Social workers and psychologists assisted caregivers in understanding the past and present relationship and helped with emotional support in coping with the deterioration and loss of the loved one.

Caregivers also noted difficulty communicating with the patient regarding the different stages of the illness (Etten & Kosberg, 1989). Hospice implemented individual, family, and group counseling to initiate and encourage openness between the caregiver and patient.

Frustration, helplessness, anger, depression, and even physical illness of the caregiver were other common problems (Etten & Kosberg, 1989). Caregivers often set high expectations of their abilities to care for and cope with the patient. Hospice staff members encouraged open discussion of emotions and provided emotional support as well as periodic re-assessment of the family's changing needs.

The information given by Etten and Kosberg illustrates that a primary goal of hospice programs is to help family members cope with caregiving with as little strain as possible. With adequate assessment and communication of needs, hospice can provide families with the needed resources to alleviate the problems associated with caregiving.

Summary

Research in the area of hospice programs is not extensive enough to suggest a significant difference between hospice and non-hospice groups exist. Several researchers have shown that although this difference may or may not exist, the use of a hospice program is not detrimental to the patient's caregiver or his or her family. The findings of studies done on hospice programs is not conclusive enough to safely assume that the utilization of a hospice program is more beneficial than the use of conventional methods of caring for the terminally ill. Therefore, in light of the conflicting evidence concerning hospice services, special focus should be placed on the needs and psychological well-being of caregivers and families to determine whether or not hospice programs are adequately meeting these needs. If these needs are not being met, the services offered by a hospice facility need to be re-evaluated and new programs implemented.

CHAPTER III

METHODOLOGY

The researcher's interest in hospice began several years ago when a close family member had become terminally ill. After several lengthy stays in the hospital the patient and other family members discussed and decided that the best place for the patient to be was at home. Hospice intervention began approximately two months before the death of the patient. The researcher was not the primary caregiver but was very involved with the care of the patient. The primary caregiver, the researcher, and the patient were all very pleased with the support given by the hospice staff member assigned to the family. As a result, the researcher has been interested in determining the needs of hospice clients and how hospice services could best fit these needs.

Design

Previous research has shown hospice services as helpful to families with terminally ill patients. However, the research does not indicate the degree or level of satisfaction of services used by families. The purpose of this study was to determine the services used by families and whether the families were satisfied with those services. This exploratory study focuses on whether hospice staff is successful in relieving caregiver stress and if the caregiver could have managed without the help of hospice. Caregivers were also given the opportunity to offer suggestions on ways hospice could improve their services. It is hoped that through the exploration of these issues, hospice staff members involved in this study will use the results to expand and improve their services.

Sample

Bass, Garland, and Otto (1985) found that, in general, hospice services are used by patients who are diagnosed with some form of cancer. Some of the most common types of cancer mentioned were lung, colon, breast, or prostate. Spouses made up 63% of the primary caregivers with over 43% of patients being cared for by the patient's wife. Husbands were the next most common caregiver. Daughters and sisters were the next most likely caregivers, if the primary caregiver was not a spouse. Caregivers are usually between the ages of 41 and 71 with an average of 61 years. Patients are normally in the same age range as the caregiver, with an average age of 62.3 years. Males comprise of 55.5% of hospice patients, while 44.5% are females. A generalized profile also shows the average hospice patient to be white.

Mercy Hospice in Oklahoma City was contacted and asked to survey their clients. Mercy Hospice (referred to hereafter as "Mercy") is a nonprofit, Medicare certified community service that is affiliated with Mercy Hospital. Mercy currently serves the Oklahoma City metropolitan area and twelve cities outside the metropolitan area. In the spring of 1988 the Mercy Health Center Strategic Plan included plans for a program for terminally ill patients and their families. In 1989 a significant donation was made to this project. As a result of this donation, services for the terminally ill were implemented. Mercy currently serves an average of 60 patients and their families a month.

A copy of the research proposal and questionnaire was given to the director of Mercy. The director was very interested in the study and was sure that the return rate would be high since they have a high return rate on a similar survey. She made a note that the question concerning the hospice staff characteristics would be difficult for many of the clients to answer due to the time passed since hospice was used. The director presented the proposal and questionnaire Mercy Hospital's (Institutional Review Board) IRB. The research was approved and the researcher was requested to share the results with the hospice director.

Subjects in this study were caregivers of a terminally ill patient and were obtained from Mercy Hospice. Most subjects lived within 50 miles of Oklahoma City. Participants were selected by hospice staff on the basis of the following criteria: 1) subjects had used hospice within the past year; and 2) subjects had used hospice for at least two to three weeks. A total of 140 hospice clients met the criteria and were sent a questionnaire. Sixty-five clients returned the survey resulting in a 46% return rate.

Instrumentation

The Caregiver Perceptions of Hospice (CPH) survey used in this study was designed by the researcher to assess the needs of hospice clients and whether the clients felt their needs were met. The CPH was designed to focus on several major areas. The first area was designed to gather demographic information of the subject. The second area focused on patient information and whether other caregivers were involved. The third area of focus included questions concerning the hospice services the subject used and whether they were satisfied with these services. Open-ended questions were asked to give the respondents an opportunity to express services that were the most or least helpful and services they wished had been available. The fourth area focused on information about the hospice staff (see Appendix D).

Hospice staff was concerned with the confidentiality of their clients. A survey was chosen as a means of gathering data because of its ability to keep respondent's identity anonymous. The proposal of this research was presented to the researcher's committee. The committee accepted the proposal with the suggestions to change the format of the survey from open-ended questions to a Likert Scale and to include more questions concerning caregiver and patient characteristics. The proposal and survey was then presented to Oklahoma State University's Institutional Review Board (IRB) and was accepted with no revisions needed. Finally, the proposal and survey was presented to the Mercy Hospital IRB and was accepted with no revisions needed.

Survey Clarification

The initial questionnaire (CPH survey) was reviewed by six volunteers who have an interest in health care related issues. The volunteers ranged from 22-51 years old with an average age of 30. The level of education of the participants ranged from high-school to master's degree. Although the question was not asked on the survey, two males and five females participated in the pilot study. One male and one female were Hispanic. The remaining participants were Caucasian. The participants reviewed the survey for clarity of the questions asked. The participants did not have difficulty understanding the questions. After the pilot study had been conducted several questions were added.

Several questions pertaining to hospice staff characteristics were added. More questions regarding caregiver and patient characteristics were also added. The questions in the survey were also rearranged so that questions of a similar nature were grouped together.

Procedures

The names of hospice clients were obtained from Mercy Hospice files by the researcher. The CPH survey was mailed to the participants by the researcher along with a cover letter and self-addressed, stamped envelope. The cover letter identified the researcher, the purpose of the study and contact information (see Appendix D). The survey included instructions on completing the questions and returning the survey. To ensure confidentiality, the respondents returned the survey directly to the researcher in the self-addressed, stamped envelope. No identifying marks were on the envelope or survey. Data were collected during the last week of February and the first week of March 1994. All questionnaires returned were used in the study, except for two which were returned after statistical analysis was conducted.

Research Questions

The purpose of the CPH survey was to answer several questions. The first question was what type of services are offered by hospice, and of those services offered, which ones were utilized most often? The caregiver's overall perception of their hospice experience was also asked. The communication between hospice staff and clients was also an area of concern. Was communication sufficient between the caregiver and the hospice staff to ensure the caregiver's needs were adequately met? Finally, in an attempt to aid hospice staff in improving their services, caregivers were asked what other services might have been helpful if they had been available? It is hypothesized that hospice staff can determine the needs of their clients and can meet these needs, resulting in a favorable impression of the hospice program. Therefore, through the success of hospice many of the stressors that are commonly experienced during the illness and bereavement are alleviated

Statistical Analysis

Statistics with Finesse was used for the analysis. Frequency measures were obtained to gather descriptive statistics on the hospice clients and generate a client profile. The client profile included information such as the age, gender, educational background and current employment status of the caregiver. Descriptive statistics were also used to obtain a patient profile. This information included patient's age, gender and diagnosed illness.

Group t-tests were used to test the differences in means between gender, education, occupation and income level on the following variables: (1) satisfaction with services; (2) whether the caregivers could have managed without hospice; (3) whether they were able to communicate their needs to hospice staff; (4) the ability of hospice to relieve any psychological stress and (5) their overall perception of hospice. A grouped t-test was chosen because of its ability to compare the differences of means in two independent groups based upon a third variable.

Limitations

The following limitations affect the results of this study:

(1) The participants used in this study were not obtained from randomized sampling procedures. Therefore, it is not possible to generalize the findings of this study to a larger sample.

(2) Only one hospice was used to obtain the sample used. For a more descriptive study, more hospice programs should be used for a better representation of the population being studied. Hospice programs from rural areas should also be studied for a comparison between metropolitan and rural hospice programs.

(3) In order to increase representativeness, more diversity in the types of subjects used is needed. Subjects tended to be white, protestant, middle income

individuals with an average age of 61.

(4) Respondents who used hospice more than six months before the mailing of this survey may have a difficult time remembering the services offered through hospice. For a more accurate response, a survey, such as the one used in this study, should probably be given between 1 and 6 months after the patient's death.

(5) The survey looks at all the hospice services as a group and therefore can not adequately determine the level of satisfaction with particular services used by a particular client. One-on-one interviews could provide more detailed information about the services used and give more qualitative information.

Summary

Previous research has shown hospice as being helpful to families during the terminal illness of a loved one. However; the research does not focus on which services are used by the families or the level of satisfaction of these services. The purpose of this study was to determine the services used by families and whether the families were satisfied with those services.

The sample used in the research was obtained through Mercy Hospice in Oklahoma City, OK on the basis that the client had used hospice within the past year and had used hospice for at least two to three weeks. Participants were mailed the Caregiver Perceptions of Hospice survey and asked to complete the questions and return it in the enclosed self-addressed, stamped envelope.

Descriptive statistics were obtained to gather information concerning hospice client and patient characteristics. Information such as age, gender, education and employment was gathered on caregivers. The patient's age, gender and diagnosed illness was also determined. Group t-tests were used to determine any differences of means in gender, education, occupation and income on satisfaction of services, ability to manage without hospice, ability to communicate with hospice staff, ability of hospice to relieve any psychological stress and overall perception of hospice.

CHAPTER IV

CAREGIVER PERCEPTION AND NEEDS ASSESSMENT OF A HOSPICE PROGRAM

MANUSCRIPT FOR PUBLICATION

Journal Title: The Hospice Journal

Abstract

This study reviewed the satisfaction of services offered by an Oklahoma hospice, the number of services used, the effectiveness of hospice in communicating with caregivers and the overall perception of the program. Patient care was the most used service and the caregiver's perception of hospice was excellent. Through effective communication, caregivers felt their needs were met. Family and demographic characteristics are critical in determining which services are needed and appropriate. It is suggested that hospice staff periodically conduct additional assessments to remind clients of the services available and to determine if the caregivers have additional needs.

In the past, terminal illness and death has largely been the responsibility of institutions, such as hospitals or nursing home facilities (Pine & Phillips, 1970). People who were dying were placed in health care facilities to live their remaining days. The medical profession had the responsibility to use whatever treatments were deemed necessary to sustain life. In 1974, the treatment of terminally ill patients began changing when the first hospice facility was established in the United States in New Haven, Connecticut (Paradis & Cummings, 1986). Patients started being treated with more dignity and respect by the medical profession.

Hospice services provide care for both the terminally ill patient and other family members. Although not all hospice programs are alike, most offer similar types of services. Services such as palliative care, symptom control and volunteer visits offer the patient and family a chance to maintain structure and personal dignity (Vandenbos, DeLeon, & Pallak, 1982; Wallston, Burger, Smith, & Baugher, 1988). Services often provide the family education on caring for the patient, emotional support both during the dying process and after the death of the patient and volunteer help to ease the stress of caregiving (Levy, 1987).

The hospice philosophy is to treat the family as a whole unit (Levy, 1987). This philosophy follows a systems theory perspective, which proposes that families function as small social systems and must be viewed as a whole in order to fully understand the relationships within the family. In other words, the whole is greater than the sum of all its parts. Therefore, hospice not only treats the patient's needs, but the needs of the caregiver and family as well.

Understanding the stress experienced by families as they cope with the events surrounding a death is often difficult for all family members. According to family stress theory, three variables interact to create a crisis. The variables are: 1) A - the stressor event, 2) B - the resources used to help ease the stress of a crisis, and 3) C - the family's perception of the stressor event. Hospice acts as a resource to aid families in coping with a stressor event, the dying of a loved one.

Mercy Hospice: Program Description

Mercy Hospice (referred to hereafter as "Mercy") is a nonprofit, Medicare certified, community service located in Oklahoma City, OK. Mercy currently serves the Oklahoma City metropolitan area and twelve cities outside the metropolitan area. In the Spring of 1988, the goal of establishing a program for terminally ill patients and their families was included in the Mercy Health Center Strategic Plan. This goal was realized in December, 1989 when a significant donation was made which provided services to terminally ill patients. Shortly thereafter, the first family utilized Mercy Hospice. Currently, Mercy serves an average of 60 patients and their families a month.

The hospice team consists of nurses, homecare aides, social workers, clergy and volunteers. These team members provide home care for terminally ill patients and their families. Through palliative care (ie. symptom relief and pain management), the hospice staff focuses on the physical, psychosocial and spiritual needs of the patients. The goal of Mercy is to enable patients and families to make the most of their remaining time together, and help them cope with the process of death and bereavement.

Relevant Literature

Studies conducted on the effects of hospice has resulted in contradictory results. Most studies have shown overwhelming support for hospice care (Hendon & Epting, 1989). However, other studies show that although hospice care provides beneficial services, evidence does not indicate a significant difference between hospice users and users of traditional methods of treatment (de St. Aubin and Lund, 1986). In the last few decades, the research on hospice has been focused on the family's perception of hospice programs and the impact these services had on the caregiver and other family members.

Primary Caregiver

Hospice staff members train a family member, or sometimes a friend, to be the primary caregiver. This training allows someone who is close to the patient to become actively involved in the care of the dying patient. The primary caregiver has the responsibility of providing most of the care required by the patient. Although families of terminally ill patients are under stress, researchers have found that when hospice services are utilized, caregivers feel better prepared for the death of their loved one and are better able to deal with bereavement (Schulz & Schlarb, 1988).

The first study conducted in the United States was conducted at the New Haven Hospice in Connecticut (de St. Aubin & Lund, 1986). Results from this study show that hospice caregivers had lower levels of anxiety, depression, hostility and social maladjustment than non-hospice caregivers.

Buckingham (1982) found that families using hospice services felt more independent than families not using hospice. In fact, families not using hospice experienced feelings of personal inadequacy and inferiority. These feelings were not characteristic of hospice primary caregivers. There were also fewer reports of weakened attachments to family, submission, dependence and anxiety among hospice care persons. Buckingham also notes that hospice patients and their primary caregiver report greater satisfaction in their relationships with relatives, family, spouse and children than did non-hospice groups. Hospice primary caregivers reported less inhibition in their communication with others than did non-hospice primary caregivers. This increased satisfaction may be attributed to family members being relieved of some of their feelings of helplessness often experienced during caregiving. Caregivers reported that being able to take care of, providing assistance for, and giving comfort to the dying patient helped to relieve some of the guilt and loneliness commonly felt by family members.

In a study at St. Mary's Hospice, 97 subjects were asked to complete a questionnaire 13 months after the death of their significant other (Longman, Lindstrom, & Clark, 1989). Subjects were asked to state whether the services provided by the hospice was beneficial. Ninety-six percent thought the hospice was helpful.

Assessment of Caregiver Needs

In an interview with 27 spouses of terminally ill adults, Hampe (1975) categorized the needs most often mentioned and whether the spouse felt these needs had been met. The spouse's needs that were mentioned were: (1) to be helpful to the dying person, (2) to be with the dying person, (3) to receive assurance of the dying person's comfort, (4) to be informed of the dying person's condition, (5) to be informed of impending death, (6) to ventilate emotions, (7) to receive comfort and support from family members, and (8) to obtain acceptance, support and comfort from health care professionals. Only three of the needs mentioned; the need to be with the dying patient, the need to be helpful to the dying person, and the need to be informed of impending death, were met for at least half of the interviewees. The findings in this study illustrate that families of the terminally ill could identify unmet needs.

Another study focusing on the needs of caregivers was conducted by Kane, Klein, Bernstein, Rothenberg, and Wales (in press). Caregivers were asked to rate Hampe's (1975) original need statements on a continuum scale from very important or extremely important to not important. Kane discovered that the needs mentioned in Hampe's original study were rated extremely important in his study. In addition, caregivers were differentiated into those who were receiving hospice services and those who were not and asked how often the needs were met. Caregivers receiving hospice services reported that their needs for being involved with the terminally ill person were met to a greater extent than those caregivers not receiving hospice services. No differences were found when needs for family support were considered.

Caregiver Concerns

Barzelai (1981) asked caregivers about particular problems that were experienced before and after the patient's death and if the hospice was able to deal with them effectively. Anxiety was mentioned as a major problem experienced by caregivers. Eighty-nine percent of the participants in this study felt that hospice was successful in reducing levels of anxiety. The hospice program was also noted as being a means of obtaining emotional support. For several of the participants, hospice served as a liaison in interaction between the caregiver and the medical community and considered hospice a valuable source of medical information concerning the patient.

For some caregivers, dealing with the opinions of "well meaning" family and friends was difficult (Hull, 1990). Advice from those not directly involved in the caregiving was often given, though not wanted. Other family and friends were perceived as insensitive to the patient's needs, often visiting too long, not visiting, or discussing the death of others in front of the patient. Stress also came from personal care aids who did not adequately assess or fulfill the needs of the families.

Five other areas of concern identified by primary caregivers focused on personal needs (Hull, 1990). These areas are: (1) putting their life on hold, (2) personal health, (3) lack of time for themselves, (4) isolation from family and friends, and (5) feelings of guilt.

Four circumstances are noted that lead to feelings of guilt: (1) wanting the caregiving experience to be over; (2) not spending enough time with the patient; (3) being less attentive about caregiving responsibilities; and (4) being impatient with and insensitive to their loved one. Caregivers had set their own expectations on how they should behave and feel toward their dying relative. If they did not live up to their own self expectations, they felt guilty (Hull, 1990).

Research Questions

Families need assistance and support when a family member is diagnosed as terminally ill. The hospice program provides the networks necessary for families to cope successfully with the grieving process. The main research questions this study will address are:

(1) What type of services are offered by hospice and which of these services were utilized most often?

(2) What was the caregiver's overall perception of their hospice experience?

(3) Was communication sufficient between the caregiver and the hospice staff to ensure the caregiver's needs were adequatley met?

(4) What other services might have been helpful if they had been available?

It is hypothesized that hospice programs can meet the needs of caregivers with terminally ill patients; alleviating many of the stressors that are commonly experienced during the illness and bereavement.

Methodology

Sample

The sample used in this study consisted of 65 caregivers who received services from Mercy Hospice in Oklahoma City. Caregivers were identified by hospice staff on the basis of the following criteria: 1) clients had used hospice within the past year and 2) clients had used hospice for at least two to three weeks. A total of 140 caregivers met the criteria and were mailed a questionnaire. Sixty-five (65) caregivers responded, resulting in a 46% return rate. To ensure confidentiality, the respondents returned the survey directly to the researcher in a self-addressed, stamped envelope. No identifying marks were on the envelope or survey.

Instrumentation

The Caregiver Perceptions of Hospice (CPH) survey used in this study was designed by the researcher to assess the satisfaction of hospice clients and whether the clients felt their needs were met. The CPH has four major sections. The first area was designed to gather demographic information on the subject. The second area focused on patient information and whether other caregivers were involved. The third area included questions concerning the services the subject used and whether they were satisfied with these services. The fourth area gathered information on the hospice staff.

Results

Descriptive Characteristics

The descriptive characteristics of the caregiver are presented in Table I. Respondents tended to be white, female and Protestant. Caregiver ages ranged from 25 to 94 years with a mean of 61.1 years. Fifty-three (53) percent of the sample had some form of a college education; with thirty-two percent having a high school education or less. Of the respondents, 41% were retired, and of those still working, 39% had white collar jobs.

Insert Table I about here

A majority of the participants were the sole caregiver for the dying relative. Fifty-eight (58) percent of the caregivers did not have other caregivers living within the home during the patient's illness. The need for additional support was required for almost half of the caregivers. Forty-two percent had several other caregivers living outside the home.

Patient characteristics are presented in Table II. Patients were between the ages of 28 and 97 years with a mean age of 68. Over half of the patients were male. Sixty-nine percent of the patients were the caregiver's spouse. The most common reported illness was some form of cancer (78%). Some of the types of cancer frequently mentioned were lung cancer, breast cancer, colon cancer and liver cancer.

Insert Table II about here

Utilization of Services

Hospice was used for an average of one to two months. The mean number of visits was 3 to 4 times a week, with a mean length of visit of 2 to 3 hours. Visits were made by hospice nurses, home health aids, counselors and volunteers.

The hospice used in this study offered patient care, counseling for the patient and family, bereavement counseling, volunteers and follow-up visits. When asked which services were available it became clear that not all clients were aware of the services offered. The most frequently used services was patient care followed by family counseling (see Table III).

Insert Table III about here

Although hospice clients did not utilize all services available, 88% felt that the services they used were extremely helpful. Although patient care was the most frequently used service, emotional support was mentioned as the means by which hospice helped the most. When asked what other services would have been helpful if they had been available, 83% indicated that hospice did everything possible to help them.

A grouped t-test was used to determine any differences in mean scores on satisfaction of services (see Table IV). Gender, education, occupation and income level showed no differences in their satisfaction with the services used by hospice.

Insert Table IV about here

Communication

Clients were asked to discuss their communication patterns with hospice staff concerning their needs. Eighty-three (83) percent of the participants were able to discuss their specific needs with hospice staff extremely well. Ninety-two (92) percent thought that hospice effectively communicated directions for patient care extremely well.

A grouped t-test was used to determine the difference in communication mean scores (see Table IV). Gender was found to be significant. Females reported that they were able to communicate their needs to hospice staff extremely well; whereas, males were able to communicate their needs moderately well ($p < .01$). Education level, occupation and income level did not indicate any significant differences.

Analysis of Related Hypotheses

Support was listed as the means by which hospice helped the most. Most respondents felt that hospice provided excellent services; however, 9% felt that there was not adequate after care. Eighty-four (84) percent felt that hospice was moderately to extremely helpful in relieving any psychological distress experience during caregiving (see Table V).

Insert Table V about here

Seventy-four (74) percent of the sample felt they would not have managed very well or not at all if it was not for the help of hospice. A grouped t-test was used to determine the difference in mean scores in how well caregivers could manage without hospice. No significant differences were found between gender, education level, occupation and income level of the caregivers. A grouped t-test was also used to determine whether a significant difference in mean scores existed on how helpful hospice was in relieving stress. A significant difference was found. Females thought that hospice was extremely helpful in relieving stress, while males thought hospice was only moderately helpful ($p < .001$, see Table IV). Education level, occupation and income level of the caregiver was not found to be significant.

Eighty-nine (89) percent of the sample's overall perception was excellent, with all respondents stating that they would recommend hospice to someone in a similar situation. A grouped t-test was used to determine the difference in overall perception mean scores. No significant differences were found.

Limitations

Several limitations affect the result of this study. The participants used in this study were not obtained from a randomized sample. Therefore, it is not possible to generalize the findings of this study to a larger sample. Also, only one hospice was used to obtain the sample used. For a more descriptive study, more hospice programs should be used for a better representation of the population being studied. In order to increase representativeness, more diversity of subjects used are needed. Subjects tended to be white, Protestant, middle income individuals over the age of 60 years. Respondents who used hospice more than six months before answering this survey may have had a difficult time remembering the services offered through hospice. For more accurate information, a survey such as the one used in this study should be given between 1 and 6 months after the patient's death. The survey looks at hospice services as a group and therefore can not adequately determine each client's satisfaction with a particular service. In depth interviews would allow all participants the opportunity to discuss in detail their specific hospice experience.

Discussion

The findings in this study are supportive of hospice services and indicate that caregivers are extremely satisfied with the services used. Support for the patient and family was mentioned as the most beneficial service provided by hospice. The support given by hospice staff could be the cause of the effectiveness in relieving the stress commonly experienced by caregivers. By acting as an effective resource in relieving family stress, hospice can influence the caregiver's perception of the situation; resulting in better coping with the death of a loved one.

Not all hospice clients were aware of the services offered. Several factors could influence this discrepancy between caregiver perception and actual services offered. First, caregivers who did not need certain services were possibly unaware of their availability. Second, the time frame between using hospice and answering the questionnaire may have resulted in the client's forgetting what services were offered. Overtime, stressful events are viewed more favorably (Wheaton, 1985). Caregivers having successfully coped with the death of their loved one may look back at the caregiving situation and perceive it as not as stressful as once thought.

It was hypothesized that hospice could meet the needs of caregivers; alleviating many of the stressors that are commonly experienced. Caregivers reported that they were satisfied with the services offered and found hospice to be extremely helpful in alleviating caregiver stress. This success could be attributed to the fact that communication between hospice staff and caregivers remained open. Most respondents stated that they were able to communicate extremely well with hospice in regards to their needs and patient care requirements.

Implications

Although a majority of the caregivers stated that hospice did everything possible to help them, several indicated that there was not adequate "after care." This could be a result of some caregivers not knowing about after-death services such as bereavement counseling, or unable to participate in such services. Expanding bereavement counseling to include in-home visits might be a way of increasing satisfaction in this area.

In order to increase the client's awareness of the services provided by hospice, it would be beneficial for the hospice staff to periodically conduct additional assessment interviews. Assessment interviews would allow for an open dialog between hospice professionals and clients to review services that match specific needs.

The quality of hospice services is rated high. However, there seems to be a discrepancy in the caregiver's perception of the types of services provided. Some respondents mentioned expanding the services already available, such as more volunteer visits. Another respondent mentioned wanting more reading material. A library of death and dying literature would be beneficial to caregivers both during the dying process and bereavement period.

This study indicates that caregivers who use hospice are extremely satisfied with the services offered. Hospice staff are able to adequately assess the needs of their clients and also meet these needs. As a result, hospice is able to help relieve the stress that caregivers experience.

The following recommendations are made for future research:

(1) Studies using more hospice programs in more diverse locations are needed to be able to describe the

services offered and used by hospice clients.

(2) In-depth interviews focusing on hospice services would be beneficial in assessing which services are used most, how services are used, and the satisfaction with the service.

(3) Studying clients and families with ethnically different backgrounds would be beneficial in examining the caregiving experience across cultures.

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TABLE I

DEMOGRAPHIC INFORMATION OF CAREGIVERS

Categories	N	Caregivers %
Gender:		
Male	17	26%
Female	48	74
Age:		
25-45	8	12%
46-65	33	51
66-94	24	37
Education:		
High School	21	32%
College	25	39
Graduate	9	14
Other	10	15
Ethnic Background:		
Caucasian	60	92%
Afro-American	1	2
Hispanic	1	2
American Indian	3	4
Asian	0	0
Other	0	0
Religious Preference:		
Protestant	54	83%
Catholic	8	12
Jewish	0	0
Other	3	5
Occupation:		
Retired	27	42%
Blue Collar	4	6
White Collar	25	38
Homemaker	6	9
Other	3	5
Yearly Income:		
Under $9,999	10	15%
$10,000 - 24,999	20	31
$25,000 - 39,999	17	26
Over $40,000	18	28

TABLE II

PATIENT CHARACTERISTICS

Categories	N	Patient %
Gender		
Male	36	55%
Female	29	45
Age		
28-51	12	18%
52-75	30	46
76-97	23	36
Diagnosed Illness		
Cancer	51	78%
Organ failure	2	3
Multiple problems	5	8
Other	7	11

TABLE III

HOSPICE SERVICES USED

Category	Known Availability %	Used %
Patient care (physical needs)	91%	82%
Counseling for family	80	68
Counseling for patient	65	43
Bereavement counseling	62	35
Volunteers	40	22
Follow-up visits	42	23
Other	6	11

TABLE IV

SATISFACTION OF SERVICES BASED UPON GENDER, EDUCATION, OCCUPATION AND INCOME

Variable	Gender		Education		Occupation		Income	
	Group 1 N=17	Group 2 N=48	Group 1 N=31	Group 2 N=34	Group 1 N=27	Group 2 N=38	Group 1 N=30	Group 2 N=35
Satisfaction of services	1.29	1.10	1.16	1.15	1.15	1.16	1.17	1.14
	t= -1.54		t= -.1289		t= .0871		t= -.2152	
Ability to manage without hospice	3.65	3.88	3.65	3.97	3.74	3.87	3.73	3.89
	t= .897		t= 1.4700		t= .5609		t= .6780	
Ability to communicate needs to hospice	1.53	1.15	1.16	1.32	1.26	1.24	1.20	1.29
	t= -2.107*		t= .9864		t= -.1335		t= .5173	
Hospice helpful in relieving stress	2.00	1.42	1.52	1.62	1.59	1.55	1.43	1.69
	t= -2.83**		t= .5280		t= -.2047		t= 1.3252	
Overall perception of hospice	1.12	1.13	1.13	1.12	1.07	1.16	1.17	1.09
	t= .069		t= -.1212		t= .8858		t= -.8652	

Group 1 = Males Group 3 = < or = High school Group 5 = Retired Group 7 = < or = $24,999
Group 2 = Females Group 4 = 1 year college or > Group 6 = Currently working Group 8 = $25,000 or >
* $p < .01$
**$p < .001$

TABLE V

HELPFULNESS AND COMMUNICATION SATISFACTION

Category		Caregiver
	N	%
Helped most by:		
Patient care/comfort	7	11%
Support	26	40
Providing equipment	3	5
Help with medications	3	4
Multiple areas	11	17
Other	15	23
Helped least by:		
NA-did everything they could	54	83%
Counseling inadequate	1	2
After care not adequate	2	3
Unsure	6	3
Other	2	9
Ability to communicate needs to hospice:		
Extremely well	54	83%
Moderately well	8	12
Somewhat well	2	3
Not very well	1	2
Not at all	0	0
Ability to communicate about patient care:		
Extremely well	60	92%
Moderately well	4	6
Somewhat well	1	2
Not very well	0	0
Not at all	0	0
Helpful in relieving stress:		
Extremely well	35	54%
Moderately well	26	40
Somewhat well	2	3
Not very well	1	2
Not at all	1	1

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APPENDIXES

APPENDIX A

ANALYSIS OF RESEARCH QUESTIONS AND HYPOTHESIS

Research Question One

What type of services are offered by hospice and which of these services were utilized most often?

The hospice used in this study offered patient care, counseling for family and patient, bereavement counseling, volunteers and follow-up visits. However, when asked what services were available, not all clients stated that all the above mentioned services were available. A reason for this discrepancy could be that a client may not have needed a particular service and therefore did not know it was offered. Another explanation could be the amount of time past since the use of hospice and the mailing of the survey is too long to remember what services were offered, especially if a service was not needed.

When asked to identify the services they used it became clear that 82% used patient care, 68% used family counseling, 43% used patient counseling, 35% used bereavement counseling, 22% used volunteers, 23% had follow-up visits, and 11% used other services from hospice (see Table IV). Although hospice clients did not utilize all services available, 88% felt that the services they used were extremely helpful. Support was listed as the means by which hospice helped the most. Most respondents felt that hospice did their best; however, 9% felt that there was not adequate after care. Eighty-five percent of the respondents were very satisfied with the visits.

Research Question Two

What was the caregiver's overall perception of their hospice experience?

Eighty-nine percent of the sample's overall perception of hospice was excellent, with all respondents stating that they would recommend hospice to someone in a similar situation. A grouped t-test was used to determine the difference in overall perception mean scores based upon gender, education level, occupation and income level. No significant differences were found.

Seventy-four percent of the sample felt they would not have managed very well or not at all without the help of hospice. A grouped t-test was used to determine the difference in mean scores in how well caregivers could manage without hospice. No significant differences were found.

For 94% of the clients, hospice was moderately to extremely helpful in alleviating stress for the caregivers. These results could be attributed to the fact that clients were able to effectively communicate their needs to the hospice staff and have these needs met. A grouped t-test was also used to determine whether a significant difference in mean scores existed on how helpful hospice was in relieving stress. A significant difference was found. Females thought that hospice was extremely helpful in helping to relieving stress, while males thought hospice was only moderately helpful ($p < .001$, see Table IV).

Research Question Three

Was communication sufficient between the caregiver and the hospice staff to ensure the caregiver's needs were adequately met?

In response to whether or not communication with hospice staff about needs was sufficient, 83% felt they were able to do this extremely well. Ninety-two percent thought that hospice effectively communicated directions for patient care extremely well.

A grouped t-test was used to determine the difference in communication mean scores (see Table IV). Gender was found to be significant. Females reported that they were able to communicate their needs to hospice staff extremely well; whereas, males were able to communicate their needs moderately well ($p < .01$). Education level, occupation and income level did not indicate any significant differences.

Research Question Four

What other services might have been helpful if they had been available?

When asked what other services would have been helpful if they had been available, 83% indicated that hospice did everything possible to help them.

Hypothesis

Hospice programs can help meet the needs of caregivers with terminally ill patients; alleviating many of the stressors that are commonly experienced during the illness and bereavement. Ninety-four percent felt that hospice was moderately to extremely helpful in relieving any psychological distress experienced during caregiving (see Table IV).

APPENDIX B

HOSPICE STAFF CHARACTERISTICS

Caregivers were asked to describe the hospice staff assigned to their family. Most of the respondents did not remember this information; however, several estimated the information asked for. Many families had several hospice staff. This is partly due to changes in the schedules of the staff members. Nurses and home health aids were frequently mentioned. All nurses were female with a mean age range of 25 to 50. The aid was also female of approximately 26 years old. Other staff members mentioned were counselor, social worker and chaplin. The counselor and social worker were female with an age range of 35 to 50. The chaplin was male approximately 52 years old. The services provided by these staff members include patient care, such as bathing, and counseling.

APPENDIX C

RECOMMENDATIONS FOR FUTURE RESEARCH

The following recommendations are made for future research:

(1) Studies using more hospice programs in more diverse locations are needed to be able to describe the services offered and used by hospice clients.

(2) A more in-depth survey focusing on the services used by each caregiver could give more information regarding which services are used most, in what way they are used, and the satisfaction with the service.

(3) Studying ethnically different backgrounds would be beneficial in examining the caregiving experience across cultures.

APPENDIX D

LETTER AND CAREGIVER PERCEPTIONS OF HOSPICE SURVEY

February 14, 1994

Dear Hospice client:

I am a graduate student at Oklahoma State University and am doing a survey on past hospice clients. Your name was chosen by hospice staff members to complete this survey because you used hospice within the past year for at least two to three weeks. Only the staff members of hospice know your identity.

The research I am doing concerns caregiver's experience and perception of the hospice program. The enclosed survey will take approximately 15-30 minutes to complete. When you have finished the survey, please return it in the enclosed self-addressed stamped envelope.

All of the information you provide in this survey will be confidential and will not be used for any purposes other than this study. The results of this research will be shared with hospice staff members to enable them to better serve their clients.

If you have any questions concerning this study you may contact me, (405) 737-8646, or my academic advisor, Dr. Joseph Weber, (405) 744-5057.

I thank you for your time and cooperation in agreeing to help me complete this research project. I look forward to receiving your survey soon. Thank you again.

Sincerely,

Stephanie Green
Graduate Student

Dr. Joseph Weber
Associate Professor

6201 S.E. 8th
Midwest City, OK 73110

CAREGIVER PERCEPTIONS OF HOSPICE

Please complete the following questions concerning your experience with hospice. Circle the number(s) next to the answer(s) that best describes your situation. If there is more than one primary caregiver, please contact your hospice office for an additional form. In the case of more than one primary caregiver, please complete the survey separately. When you have completed the questionnaire, please return it in the self-addressed stamped envelope.

1. What is the <u>last</u> level of education that you completed?

(1) high school
(2) college: # of years______
(3) graduate school: _____masters _____doctorate
(4) other (please specify__________________________)

2. What is your ethnic background?

(1) Caucasian
(2) Afro-American
(3) Hispanic
(4) American Indian
(5) Asian
(6) Other (Please specify _________________________)

3. What is your religious preference?

(1) Protestant
(2) Catholic
(3) Jewish
(4) Other (Please specify ______________________)

4. What is your occupation?

____ (if retired, please indicate that you are retired and list your past occupation.)

5. What is your current yearly income level?

(1) under $9,999
(2) $10,000 - $24,999
(3) $25,000 - 39,999
(4) over $40,000

6. What is your age? _________

7. Are you:

(1) male
(2) female

8. What is the age of the patient? ________

9. Is the patient:

(1) male
(2) female

10. What was the patient's diagnosed illness?

____

11. What other family members living in the home were involved in the caregiving?

(1) spouse
(2) brother
(3) sister
(4) son
(5) daughter
(6) mother
(7) father
(8) grandmother
(9) grandfather
(10) other (please specify
____________________)
(11) none

12. What other family members living outside the home were involved in the caregiving?

(1) spouse
(2) brother
(3) sister
(4) son
(5) daughter
(6) mother
(7) father
(8) grandmother
(9) grandfather
(10) other (please specify
____________________)
(11) none

13. How many times during one week did a hospice staff member visit your home?

(1-2) (3-4) (5-6) (7 or more)

14. On the average, how long did the visits by the hospice staff last?

(1) less than one hour
(2) one to two hours
(3) two to three hours
(4) more than three hours

15. To what extent were you satisfied with the number of visits?

(1) very satisfied
(2) moderately satisfied
(3) somewhat satisfied
(4) not very satisfied
(5) not at all satisfied

16. If you were not satisfied, how many times do you feel would have been better?

    (1-2) (3-4) (5-6) (7 or more)

17. What services were available from hospice? (Circle as many as apply)

    (1) patient care (physical needs only)
    (2) counseling for the family during the illness
    (3) counseling for the patient
    (4) bereavement counseling for the family
    (5) volunteers for family (companionship, errands)
    (6) follow-up visits after the patient's death
    (7) other (please specify ______________________)

18. What services did the hospice staff perform for you?

    (1) patient care (physical needs only)
    (2) counseling for the family during the illness
    (3) counseling for the patient
    (4) bereavement counseling for the family
    (5) volunteers for family (companionship, errands)
    (6) follow-up visits after the patient's death
    (7) other (please specify ______________________)

19. To what extent were these services helpful to you?

    (1) extremely helpful
    (2) moderately helpful
    (3) somewhat helpful
    (4) not very helpful
    (5) not helpful at all

20. What services would have been helpful if they had been available?

    ____

    ____

    ____

21. What was your relationship to the patient?

    (1) spouse
    (2) brother
    (3) sister
    (4) son
    (5) daughter
    (6) mother
    (7) father
    (8) grandmother
    (9) grandfather
    (10) other (please specify ____________________)

22. Would you recommend hospice to someone in a similar situation as yours?

    (1) yes
    (2) no

23. How long did you use hospice services?

    (1) less than one month
    (2) between one and two months
    (3) between two and three months
    (4) between three and four months
    (5) between five and six months
    (6) more than six months

24. To what extent would you have been able to manage without the use of hospice services?

    (1) extremely well
    (2) moderately well
    (3) somewhat well
    (4) not very well
    (5) not at all

25. In what way do you feel hospice helped you the most?

    ____

    ____

    ____

26. In what way do you feel hospice helped you the least?

    ____

    ____

    ____

27. To what extent were you and the hospice staff able to communicate concerning your needs?

    (1) extremely well
    (2) moderately well
    (3) somewhat well
    (4) not very well
    (5) not at all

28. To what extent did the hospice staff effectively communicate directions for the care of the patient (eg. dosage and frequency of medications)?

    (1) extremely well
    (2) moderately well
    (3) somewhat well
    (4) not very well
    (5) not at all

29. To what extent was hospice helpful in relieving any social or psychological distress (eg. anger, depression, guilt, isolation, etc.)

    (1) extremely helpful
    (2) moderately helpful
    (3) somewhat helpful
    (4) not very helpful
    (5) not helpful at all

30. How might hospice have been more helpful in relieving any social or psychological stress that you experienced?

    ____

    ____

    ____

31. How did you learn about hospice?

    (1) friend
    (2) doctor
    (3) relative
    (4) nurse
    (5) other (please specify ____________________)

32. How many hospice staff members did you have? _______

33. Did the same staff members stay with you throughout the entire illness?

    (1) yes
    (2) no

34. If not, why did the staff members change?

    (1) the staff member no longer worked for hospice
    (2) there was a change in the staff member's schedule
    (3) I requested a change in staff members

35. Please give the duty performed, age, gender and education level (if not known please estimate) of each staff member that helped you and your family. Also indicate how long each staff member helped your family. For education level, please use the following categories: (1) high school; (2) college-# of years; (3) graduate school-masters or doctorate; (4) other-please specify.

	DUTY	AGE	GENDER	EDUCATION	HOW LONG THEY HELPED
staff member #1					
staff member #2					
staff member #3					
staff member #4					
staff member #5					

36. What was your overall perception of the hospice program you used?

(1) excellent
(2) good
(3) average
(4) fair
(5) poor

THANK YOU FOR YOUR TIME IN COMPLETING THIS QUESTIONNAIRE! YOUR TIME AND INFORMATION IS GREATLY APPRECIATED. PLEASE RETURN THIS QUESTIONNAIRE IN THE SELF-ADDRESSED STAMPED ENVELOPE NO LATER THEN MARCH 4, 1994.

APPENDIX E

INSTITUTIONAL REVIEW BOARD FORM

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
FOR HUMAN SUBJECTS RESEARCH

Date: 11-03-93 **IRB#:** HES-94-011

Proposal Title: CAREGIVER PERCEPTION AND NEEDS ASSESSMENT OF HOSPICE PROGRAMS

Principal Investigator(s): Dr. Joseph Weber, Stephanie Green

Reviewed and Processed as: Exempt

Approval Status Recommended by Reviewer(s): Approved

APPROVAL STATUS SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING.
APPROVAL STATUS PERIOD VALID FOR ONE CALENDAR YEAR AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL. ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Reasons for Deferral or Disapproval are as follows:

Y

Signature: ______________________________ Date: November 3, 1993
Chair of Institutional Review Board

VITA

Stephanie G. Green

Candidate for the Degree of

Master of Science

Thesis: AN OKLAHOMA HOSPICE PROGRAM: CAREGIVER PERCEPTION AND NEEDS ASSESSMENT

Major Field: Family Relations

Biographical:

Personal Data: Born in Midwest City, Oklahoma, November 1, 1967, the daughter of Thomas L. and Helga Green.

Education: Graduated from Midwest City High School, Midwest City, Oklahoma, in May, 1986; received Associate of Arts Degree in Psychology from Rose State College in Midwest City in May, 1988; received Bachelor of Arts Degree in Psychology from Oklahoma State University in Stillwater, Oklahoma in December, 1990; completed requirements for the Master of Science Degree at Oklahoma State University in July, 1994.

Professional Experience: Career Counselor, Career Development and Placement Services, University of Central Oklahoma, July, 1993 to Present.