1990

Hospice: a descriptive analysis of the structure and formation of hospice organization in West Virginia

Rebecca Ann Lowery

Recommended Citation

Lowery, Rebecca Ann, "Hospice: a descriptive analysis of the structure and formation of hospice organization in West Virginia" (1990). *Theses, Dissertations and Capstones*. 1538.
https://mds.marshall.edu/etd/1538

HOSPICE: A DESCRIPTIVE ANALYSIS OF THE STRUCTURE AND FORMATION OF HOSPICE ORGANIZATION IN WEST VIRGINIA

A Thesis
Presented to
The Department of Sociology/Anthropology
Marshall University

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts

by
Rebecca Ann Lowery
August 1990

THIS THESIS WAS ACCEPTED ON Aug. 13, 1990
Month Date Year

as meeting the research requirements for the Master's degree.

Graduate Advisor K. P. Ambrose
Department of Sociology

Thesis Advisor K. P. Ambrose
Department of Sociology

Leonard J. Deutsch
Dean of Graduate School

ACKNOWLEDGEMENTS

I would like to express my gratitude to all the people who have contributed to the completion of this goal. My family, especially my mother, has been understanding and supportive. I would like to thank my thesis committee, Dr. William Westbrook, Dr. Steve Winn, and my advisor, Dr. Kenneth Ambrose, for all their advice and support.

I am especially grateful to Dr. Kenneth Ambrose for his guidance and support. All of his time and patience has been greatly appreciated.

TABLE OF CONTENTS

Chapter 1

INTRODUCTION

Hospices represent a new branch of the health care delivery system in the United States. Hospice is a concept of medical, nursing and spiritual care. It is a new attitude toward death and dying. Terminal illness is managed so that patients can live comfortably until they die, cared for by family members and friends. The family members are also supported by hospice. Hospice programs have become an important alternative for the dying patient and family. More people are choosing this approach as opposed to the traditional type of heroic medical care.

The hospice concept represents a return to humanistic medicine--to care within the patient's community, family-centered care, the view of the patient as a person. The victim of a terminal illness is permitted to die with dignity (Buckingham, 1983:3). 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. Hospice

helps relieve symptoms during the distress (physical, psychological, spiritual, social, economic) that may occur during the course of the disease, dying, and bereavement (Buckingham, 1983:4).

Hospice services to the terminally ill emphasize palliative rather than curative treatment. The primary goal is to keep the patient alert, oriented, involved with family and friends, and as free of pain as possible (Vandenbos, Deleon, Pallak, 1982:1245). Patients are encouraged to remain actively involved in family and social activities.

Hospices serve approximately 500,00 person each year, and about 95 per cent of these are cancer patients (Vandenbos, Deleon, Pallak, 1982:1245). The patient's disease has reached the stage where curative measures are no longer encouraged and the patient wishes to spend the last weeks or months as fully as possible with family and friends.

Death in an institution such as a hospital or nursing home can be a traumatic experience for both the patient and family. Studies indicate, however, the patient of a hospice program will not experience the anxiety, helplessness, inadequacy, and guilt compared to a patient in an acute-care facility (Buckingham, 1983:3). According to Cohen, "Death in a hospice program, either at home or in a hospice facility, can be a peaceful, even a welcomed way to end one's days" (Cohen, 1979:9).

Dying is not only a physical process; it is a psychological and emotional process, a spiritual and a social process. The process of dying is part of the process of living (Buckingham, 1983:2). Many people believe the objective of terminal care is to help the patient die. On the contrary, the goal of the hospice staff is to help the patient live fully until the time of death (Lannie, 1984:34). The hospice philosophy brings to the individual and family the feeling that the patient can cope with his environment and handle situations as they arise (Lannie, 1984:34).

The philosophy of hospice is positive. The attitude is different from society's as a whole in that hospice emphasizes the meaning and value of human life, as well as the significance of death. The hospice movement is in essence a humane concern for the dying and their families in a society that appears reluctant to acknowledge that dying is a phase of life (Krant, 1978:548).

The American Perspective on death and dying appears to be paradoxical. On the one hand, the mass media confront the fact of death directly while speaking about death and dying has been a taboo topic in our culture. It has been a taboo because it has been hidden. People hesitate to talk openly about the process of dying.

In the medical subculture, as in the larger American society, dying is regarded as deviant behavior. In the

Medical schools and hospitals, physicians and nurses may exhibit considerable skill in handling the medical mechanics of attending the dying, but rarely do they address the patient as a total person (Buckingham, 1983:3). Too often the young intern or resident learns to be the distant authority (Foster, 1978:21). Nurses, especially those socialized to the profession in hospital schools, reflect the characteristics of the medical and hospital subcultures as well as the death-denying values of the larger society (Germain, 1980:47). Studies indicate nurses tend to respond to patient's talk about dying with avoidance behaviors such as physical withdrawal or denial (Germain, 1980:47).

The medical profession is oriented more toward curing rather than caring for the patient. Technological breakthroughs have perpetuated a phenomenon, referred to a "death denying," among health professionals as well as in the society at large (Ryder & Ross, 1977:21). Thus, death represents failure either of the individual physician or of medicine as a whole.

Hospices have made an important philosophical contribution to health care by helping to remove the stigma attached to death and dying and by emphasizing the importance of treating the whole person rather than just the disease (Holden, 1980:59).

Furthermore, hospice care is a holistic approach to the care of the terminally ill; therefore, it should include considerations of ethnic variables and cultural traditions that influence views of death.

Each society has developed roles, beliefs, values, ceremonies, and rituals to integrate death and the process of dying into the culture. Culture shapes what each individual believes to be the meaning of death and helps individuals cope with the fears of death (Kalish, 1980:3).

Kalish and Reynold found the greatest difference in ideologies of death to be associated with differences in cultural backgrounds rather than differences in sex, age, or education (Kalish & Reynolds, 1976:46).

Kalish also discussed the importance of culture in death and dying. He stated:

> Culture influences death concerns in virtually every way possible: it affects causes of death and the kinds of care that dying people receive; it influences perceptions of health caretakers and the methods used by health caretakers and who is entitled to be a health caretaker; it determines funeral rituals and burial rituals and whether remains are disposed of by earth, water, or fire; it has an effect on where the dying occurs, who is in attendance, and how the body is handled after death. It is impossible to exaggerate the role of culture. (Kalish, 1980:46)

According to Cook and Jenkins, hospice programs have tremendous potential as an alternative to the terminally ill in ethnic communities, because of the National Hospice Organization's policy of providing care regardless of the ability to pay and the flexibility of most hospice structures (Cook & Jenkins, 1982:217). Hospice programs can provide quality care and respect ethnic variables surrounding death simultaneously.

The development of special care programs for the dying can be attributed to the work of Elizabeth Kubler-Ross and Cicely Saunders. In 1967 both were entering critical phases of their life's work. Their work would revolutionize the care of the dying, and it would lead to a reexamination of the purposes and practices of medical care (Torrens, 1985:3).

At the University of Chicago Elizabeth Kubler-Ross, a Swiss-born psychiatrist, interviewed and observed dying patients and their families. She understood a great deal about the psychological process of dying and discovered how little was known about the thoughts and feelings of people facing death. As a result of her observations, she documented the decrease of contacts between doctors and nurses and their patients once a terminal diagnosis was made (Torrens, 1985:3).

In 1969 her book, On Death and Dying, Kubler-Ross emphasized it was possible to communicate with the dying patient about their most personal fears and feelings. She also illustrated it was possible to conduct organized and disciplined research on dying. Furthermore, her book presented a theoretical framework describing the psychological stages of dying which allowed for a more exact understanding of patients and their needs (Torrens, 1985:5).

In addition, the success of her book shattered the taboo against speaking openly about dying. This encouraged doctors, nurses, social workers, clergy, and others to look for better ways to serve patients (Torrens, 1985:5).

Cicely Saunders, M.D., in London, started the St. Chistopher's Hospice in 1967. For many years she had hoped to create a model program of care for the dying in which patients could find relief from their pain and professionals could find guidance in their work (Torrens, 1985:5).

By the early 1970's, a solid foundation had been laid by the works of Kubler-Ross and Saunders. Widespread lecturing and writing by both women stimulated interest in hospice programs and care of the dying across England and the United States.

STATEMENT OF PURPOSE

The purpose of this investigation is to explore the development of the selected hospices. This study will describe how the hospices were originally organized and explore some of their common problems. Areas examined will include problems associated with the development of the organization; problems in the operation of the organization; the problems of staffing of the organization with both paid and volunteer workers; the criteria for the selection of both; finally, the patients and families, who are the target of the organization, will be discussed.

DEFINITION OF TERMS

Hospice Care. A comprehensive program of management that offers palliative care to terminally ill patients. It is multidisciplinary approach designed to relieve the patients symptoms and to provide support to both patient and family (Zimmerman,1986:9).

Terminal Illness. This is a period of weeks or months preceding death when serious attempts to cure have been terminated and treatment is palliative.

National Hospice Organization (NHO). Formed in 1977 and incorporated in Washington, D.C., this organization is composed of various categories of institutional and individual members governed by a Board of Directors. The NHO exchanges information between hospice groups, provides information to the public about hospice care, and establishes and maintains the standards for hospice care (Zimmerman, 1986:13).

Licensure. An attempt by the state to define and enforce minimum requirements of operation for hospices (Torrens, 1985:91).

Certificate of Need (CON). Many states require a CON before a hospice program can be established. The CON is issued by a governmental body to an individual or organization for the provision of a new or different health service, for acquisition of major new equipment, or for construction or modification of a health facility (Paradis, 1985:38).

Joint Commission on Accreditation of Hospitals (JCAH). The JCAH can accredit hospice programs. Since this accreditation is voluntary, it is optional for hospice although it may be required for eligibility for certain types of reimbursements (Paradis, 1985:185).

Medicare Certification. These are organizational standards the government considers necessary to ensure safety and quality care for Medicare beneficiaries (Paradis, 1985:220).

Hospice staff. The composition of a hospice care team will vary from program to program, depending upon local circumstances, program objectives and available personnel. Most members include: physicians, nurses, social workers, volunteers, pharmacists, and chaplains (Zimmerman, 1986:10).

Primary Caregiver (PCG). The person who is responsible for taking care of the hospice patient at home. Generally, this a spouse or family member.

Hospital-Based Hospice. A hospital-based model may take different forms. First, the acute care hospital with a centralized palliative care unit is a separate unit within the hospital. The unit has its own staff and designated beds reserved strictly for hospice patients. Second, the acute care hospital consulting program consists of a specially designated hospice team or an already existing staff which provide services to hospice patients who are dispersed throughout the hospital or assigned to key units (Kohut & Kohut, 1984:8).

Hospital-Affiliated Free Standing Hospice. A totally separate facility from the hospital with all beds and staff committed to the care of the dying. The facility is owned and operated by the hospital.

Free Standing Independent Hospice. An independent economic enterprise governed by its own administration, staff, and/or board of trustees. This is a separate facility with all beds and all staff assigned for providing care to the dying patient (Kohut & Kohut, 1984:9).

Extended Care Facility or Hospice in Nursing Home. In this model a nursing home or extended care facility converts beds or units and establishes its own in-house hospice care program. The staff is trained to provide hospice care. The facility is governed by its own board or administrative staff (Kohut & Kohut, 1984:9).

Community-Based or Home Care Program. This is a community supported program which provides and coordinates all hospice services for clients in their own homes but does centralized palliative care unit is a separate unit within the hospital. The unit has its own staff and designated beds reserved strictly for hospice patients. Second, the acute care hospital consulting program consists of a specially designated hospice team or an already existing staff which provide services to hospice patients who are dispersed throughout the hospital or assigned to key units (Kohut & Kohut, 1984:8).

Hospital-Affiliated Free Standing Hospice. A totally separate facility from the hospital with all beds and staff committed to the care of the dying. The facility is owned and operated by the hospital.

Free Standing Independent Hospice. An independent economic enterprise governed by its own administration, staff, and/or board of trustees. This is a separate facility with all beds and all staff assigned for providing care to the dying patient (Kohut & Kohut, 1984:9).

Extended Care Facility or Hospice in Nursing Home. In this model a nursing home or extended care facility converts beds or units and establishes its own in-house hospice care program. The staff is trained to provide hospice care. The facility is governed by its own board or administrative staff (Kohut & Kohut, 1984:9).

Community-Based or Home Care Program. This is a community supported program which provides and coordinates all hospice services for clients in their own homes but does not own or operate an inpatient complex. The program is administratively and economically autonomous.

Target Population. A specific population needing a hospice.

Feasibility Study. A study to investigate the possibility of implementing a hospice program in the community (Breindel & O'Hare, 1979:52).

Chapter 2

REVIEW OF THE LITERATURE

This chapter presents the literature related to various aspects of organizational structure and formation of hospice programs.

Hospice has been a significant force in the United States health care delivery system. Estimates from the Joint Commission on Accreditation of Hospitals and the National Hospice Organization suggest there are about 1,700 hospices across the United States, serving over 100,00 patients (Mor, 1987:19). Mor points out that despite their prevalence, we are only beginning to learn how hospices operate and what their impact has been on our health care system. (Mor, 1987:19). Analysis of the structure of hospice organizations is therefore important.

Paradis and Cummings focused on the development and structure of hospice organizations in our society. They illustrated that hospice has been characterized as having a "diversity of organizational structure" with the result being the creation of three major organizational models: the freestanding hospice model, the home health agency-based model, and the hospital based model (Paradis and Cummings, 1986:374).

The developmental stages of a hospice organization are crucial to the success of the agency. The program must be organized and planned thoroughly in order for it to a successful hospice. Several steps are involved in the beginning stages of hospice which need to be examined. Most hospice organizations start as volunteer or interest groups. Once such a planning committee is established, a hospice program can become a reality.

A prerequisite for any hospice planning committee is the conducting of a needs assessment to determine exactly what agencies or service currently exist in the community which provide support services to the terminally ill and their families. (Kohut and Kohut, 1984:28)

The core members of the hospice planning committee then need to develop clear-cut and comprehensive goals for the hospices program. Both short and long term goals must be examined.

The next stage involves the selection of hospice staff and recruitment of volunteers. In order to be eligible for Medicare reimbursement, a minimum hospice staff should include a professional core of persons in nursing services, physician service, medical, social services, and counseling (Kohut and Kohut, 1984:33).

Following the selection of hospices staff and volunteers, members of the board of directors are selected.

The developmental stages of a hospice organization are crucial to the success of the agency. The program must be organized and planned thoroughly in order for it to a successful hospice. Several steps are involved in the beginning stages of hospice which need to be examined. Most hospice organizations start as volunteer or interest groups. Once such a planning committee is established, a hospice program can become a reality.

A prerequisite for any hospice planning committee is the conducting of a needs assessment to determine exactly what agencies or service currently exist in the community which provide support services to the terminally ill and their families. (Kohut and Kohut, 1984:28)

The core members of the hospice planning committee then need to develop clear-cut and comprehensive goals for the hospices program. Both short and long term goals must be examined.

The next stage involves the selection of hospice staff and recruitment of volunteers. In order to be eligible for Medicare reimbursement, a minimum hospice staff should include a professional core of persons in nursing services, physician service, medical, social services, and counseling (Kohut and Kohut, 1984:33).

Following the selection of hospices staff and volunteers, members of the board of directors are selected.

The board members usually consist of original and active members of the planning committee and volunteer staff, or well known and highly respected members of the community. The board of directors is required to form a corporation. Since a hospice program is a nonprofit organization, it can obtain tax exempt status by completing a certificate of incorporation. A set of bylaws must be written and approved by the hospice board of directors during this stage. (Kohut and Kohut, 1984:37)

Fund raising is another stage in the formation of a hospice organization. A budget should be prepared and presented to potential corporate and individual donors. Potential sources of funding include the United Way, governmental agencies, Hospital corporations, grants from private foundations, and community civic and charitable groups such as the Rotary, Junior Women's Club, Lions Club. (Kohut and Kohut, 1984:39)

Finally, the hospice organization should emphasize public relations. Community support is important for the survival of the hospice program. The organization should distribute brochures and newsletters, announce hospices events on the radio or television, and occasionally run an article in the local newspaper. (Kohut and Kohut, 1984:40)

Studies of successful hospice organization indicate that success is not only determined by financial stability and community support, but also includes the quality of care the patient receives. Labus and Dambrot emphasize the success of the hospice program is usually based on the goal of extending the period of time in which patients can be safely, comfortably, and inexpensively cared for outside of a hospital or other inpatient facility (Labus and Dambrdot, 1985-86: 225).

DuBois also analyzed how hospice organizations meet the needs of the dying. He believed hospice care is only as good as the services the staff can provide, and that in turn depends upon the quality of personnel, the quality of training they have received, the quality of the interactions among staff members, the support the staff receives from the administration, and the relations the staff enjoys with the surrounding community. (Dubois, 1980:67)

Financial concerns are also a major issue in hospice care and the success of the organization. This includes the finances needed to operate a hospice program as well as the impact of Medicare legislation on the hospice movement. (Corless, 1987-88:319)

The regulations published by HCFA (Health Care Financing Review) as part of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRDA) brought an immediate response by hospice leaders. (Corless, 1987:320). Qualified hospice programs became eligible for reimbursement for services provided to the terminally ill through Medicare. Medicare has provided reimbursement for hospice care since 1983, and with that provision have come standards, criteria, accountability and rigid requirements for certification, accreditation, and licensure as well as for reimbursement by other Third-party payers (Bulkin and Lukasok 1982:376).

According to Bayer and Feldman, the Federal government is interested in supporting hospice care. Clinical reports from individual hospices have shown how such services help dying patients and their families, and studies indicate that savings could be considerable (Bayer and Feldman 1982:5).

Chapter 3

THEORETICAL FRAMEWORK

The Sick Role and Dying Role

According to Parsons, the sick role is a constellation of expectations involving both rights and duties or obligations. First, a patient is exempt from the responsibilities of his normal social life. Social obligations or business may be broken. Second, the patient has the right to be cared for. The duties of the sick person includes the obligation to get well. Society regards illness as an undesirable state, therefore, the patient must wish or want to get well. Moreover, the sick person is obligated to obtain competent help in an effort to regain his health. Also the sick person is expected to cooperate with the treatment prescribed in order to get well (Parsons, 1951:442-44).

Still and Todd insist that the person in a dying role has rights similar to the sick person, but his or her duties differ. First, it is important for the dying person to desire to remain alive. There may be no hope for recovery but the patient is expected do retain the will to live, unless he is experiencing excessive suffering (Noles and Clancy, 1983:14). Second, the dying person transfers his healthy social roles to others. This is done on a more permanent basis than with sick person (Noles and Clancy, 1983:14). Third, the dying person has an obligation to avail himself of the necessary supports of life and to cooperate in their administration. Fourth, the dying person is expected to accept the curtailment of freedom and privileges, Finally, dependency is encouraged in the sick role whereas independence, within the individual's limits, is encouraged in the dying role (Noles and Clancy, 1983:14).

In regard to the physician's role and contribution to these patients' roles, Parsons wrote: "The role of the physician centers on his responsibility for the welfare of the patient in the sense of facilitating his recovery from illness" (Parsons, 1951:447). Therefore, the physician's role is primarily curative and complements the sick role rather than the dying role.

When cure is acknowledged to be impossible, the role of the physician is changed and sometimes may be at a loss for words. This may explain why some physicians are reluctant to inform the patient of the seriousness of their illness or to openly discuss the illness with the patient (Still and Todd, 1986:523).

Todd and Still believe one way the physician could talk openly about impending death without threat to his medical or curative role, would be to expand this role to include counselling (Still and Todd, 1986:523).

Kubler-Ross's Stages of Dying

In 1969, Elizabeth Kubler-Ross presented a model for understanding and dealing with the thoughts and feelings of the dying person. From her experience with over 200 slowly dying patients, she constructed a typology of the dying process (Germain, 1980:48). The psychological stages, as outlined by Kubler-Ross are denial, anger, bargaining, depression, and acceptance.

Denial characterizes the patient's disbelief in the seriousness and nature of the illness. Denial is usually used at the initial stages of the disease or when it has been clearly diagnosed. She characterizes the patient's response of denial as "No, not me" (Germain, 1980:48). In the second stage, anger, Kubler-Ross characterizes the patient's response as "why me." The patient realizes the diagnosis was not a mistake and becomes upset. The patient's anger and feelings of resentment may be displaced on the family and staff. Also, a patient who has been in control may find the situation intolerable, because they are forced into a dependent and demeaning role.

Kubler-Ross's third stage is bargaining. The patient's response is characterized as "if you give me one more year, I'll go to church." The patient attempts to postpone death, often for a specified length of time. Usually bargains are made with God; however, a patient might also bargain with the physician or family as an attempt to control life while dying (Germain, 1980:49).

The fourth stage is depression. She characterizes the patient's response as "yes, it's me." During this stage the physical signs of the illness, such as weight loss, disfigurement or additional surgery, become more visible. The patient is likely to feel remorse and guilt due to the sacrifices the family has had to make.

Acceptance is the last stage, which is a peaceful though neither resigned nor happy stage. The patient no longer feels angry or depressed.

Chapter 4

METHODOLOGY

The current research involves a descriptive assessment of health care delivery to critically and terminally ill patients.

Sample

The sample included the following hospice organizations in West Virginia: Hospice of Huntington, Kanawha Hospice Care, Morgantown Hospice, People's Hospice of Harrison County, Raleigh County Hospice Care, and Hospice of Lincoln County. The Ashland Community Hospice of Ashland, Kentucky was also included in the study. All of the organizations were in full operation except the Hospice of Lincoln County. This program had attempted to organize, but was not successful at the time of this study.

Interview Schedule

The directors of the selected hospice organizations were contacted by telephone to schedule a time for the interview. The interviews were tape recorded and notes were taken in the offices of the directors. The taped interviews were transcribed by the author.

An interview schedule was devised and used with the directors of the hospice agencies. The interview schedule used with the director of the Lincoln County hospice was slightly modified, since it was not an operating hospice. This interview concentrated on the problems or limitations that arise during the developmental stages of the program. The study is not an evaluation of the selected hospices but rather a description of the total organization.

The interview schedule comprised a series of questions which the interviewer asked in a face-to-face situation with the respondent. Essentially, the interview schedule was a questionnaire that is read to the respondent. Compared with the population that is researched through the use of a questionnaire, the population researched with an interview schedule is not as restricted, although the sample must usually be restricted in the sense of being much smaller. Other advantages include the opportunity for the interviewer to probe deeply into any questions and the response rate is usually higher than the response rate of the questionnaire. Also, the interview may be longer which enables the interviewer to gather more information from the respondent. Furthermore, if there is some uncertainty about the meaning of a particular question, this can be explained during the interview.

Some of the problems that may lead to unreliable results when using an interview schedule are faulty memory of the respondents, and respondents sometimes refuse to answer or cannot be located. Other problems include people who respond differently because of the presence of an interviewer or simply because they are being questioned, and people who give responses that they feel the researcher wants. Furthermore, questions sometimes have the tendency to tap opinions, attitudes, or perceived behavior, but seldom actual behavior that may be crucial to certain problems.

The interview schedule used in this study focused primarily on four areas: the developmental stages of the hospice program; the organization and structure of the hospice; patient care; and the financial management of the organization.

Questions dealing with the developmental stages focused on the origin of the program and the people involved in the beginning stages. It is important to examine how and why a hospice starts in a particular area or community. Furthermore, the people involved in the beginning stages and their influence in the community cannot be overlooked.

The organization and structure of the hospice were examined in an attempt to understand the operation and function of the agency. This involved the investigation of the hospice staff and the overall operation of the program. The composition of the hospice team may vary from one program to another depending upon the community and available personnel. Also, the number of full-time and part-time staff was considered.

Chapter 5

FINDINGS AND DISCUSSION

In summarizing the findings, the basic organizational requirements will be used. These organizational requirements are activities which agencies must perform in some manner if they are to survive.

The maintenance of the population through recruitment is essential. The recruitment of hospice staff included both professionals and volunteers. The paid professionals are already trained in their profession, therefore, the training of the volunteers was examined.

All potential volunteers must complete a training program offered by the hospice agency. The training required ranges from 8 to 20 hours, depending on the individual hospice program. For example, the volunteers at Kanawha Hospice Care received twenty hours of formal training while the volunteers at the People's Hospice of Harrison County received eight hours of training. The amount of training varied from one organization to another.

In the training program, many topics may be covered. The Executive Director of the People's Hospice of Harrison County stated "We cover the origin and philosophy of hospice, death and dying, grieving and bereavement. We have a section on AIDS and Hepatitis B" (Bentz, 1989). The Executive Director of Morgantown Hospice pointed out that in their training program that

> They talk about cancer issues because not all the patients are cancer patients but the vast majority are. We talk about the different kinds of cancer and some of the symptoms people might have with that. We talk about nutrition, spiritual concerns and we spend a fair amount of time on communication and listening (Kearney, 1989).

The training may be conducted by the hospice staff and others from the community. The Executive Director of the Hospice of Huntington stated:

> We use community people and people from Marshall University. Dr. Johnson teaches a section on communication, Dr. McDowell teaches a section on death and dying. We have a funeral director that participates. We have a minister talk about spiritual aspects and we use hospice staff" (Farrell, 1989).

The Executive Director of Ashland Community Hospice stated "our staff does all the training" (Saxton, 1989). After the training session, all potential volunteers are then interviewed by the director before being considered for the position.

The criteria used for the selection of volunteers involved an examination of the individual's personal characteristics. According to the Executive Director of Hospice of Huntington,

> Any person over the age of eighteen who has not suffered a recent loss in the last year could potentially be a volunteer. We find that they must be emotionally stable, that they must be good listeners, that they must be nonjudgemental, that they have to be caring and willing to help people, and they cannot have a hidden agenda (Farrell, 1989).

The Executive Director of Ashland Community Hospice stated "There really isn't an age limit, although the youngest that we have had is about twenty. It takes somebody who is going to be mature and able to handle the situations that come up" (Saxton, 1989). In addition, the Director of Morgantown Hospice required that the volunteer should be flexible. They had to be willing to do whatever was required in a variety of circumstances. She also suggested that a commitment to the needs of other was also necessary. She stated "They need to be someone who is very caring and nurturing to do this kind of volunteer work" (Kearney, 1989).

Some reasons an individual could be excluded from being a volunteer included the recent death of a significant other which involved grieving and a hidden agenda. When selecting volunteers, the Director of Morgantown Hospice required that an individual should not have a recent death where they were still grieving. She also stated "...they cannot have a hidden agenda, such as everybody needs to be converted to something before they die or that everybody should take medication" (Kearney, 1989).

Individuals not qualified to work in the patient's home were directed to other areas of need within the organization. For example, the Director of Kanawha Hospice Care stated, "I try to place them elsewhere either clerical or on a special project" (Stevens, 1989).

Other hospice team members, such as nurses and social workers, are selected through the interview process. They are interviewed by the director and other staff members, such as the patient care coordinator or social worker. They compare their evaluations, before selecting the new team members. The Director of Kanawha Hospice Care pointed out that when they interview new team members, such as nurses, "they look for certain types of characteristics such as personal coping skills in addition to proficiency in their own field" (Stevens, 1989).

Communication and interaction among members and parts of the organization must be promoted. On the local level, the individual hospice holds staff support meetings regularly to discuss client problems as well as individual problems. Also, the medical director meets with the hospice staff to discuss and plan patient care.

On the state level, meetings are held by the West Virginia Hospice Council. This involves all hospices within the state, and establishes a networking system among the various organizations, both developing and operating hospices.

A division of labor is established through specialization of duties and responsibilities. The Board of Directors which is made up of various members from the community, is responsible for the fiscal management of the hospice agency. Their occupations and positions in the community are diverse. The positions include physicians, nurses, clergy, social workers, funeral directors, pharmacists, attorneys, administrators, businessmen, and community volunteers.

The executive director manages the program and coordinates activities. The director organizes the volunteer training program. This includes scheduling the time the program will be offered, the material to be covered in the training session, and determining instructors for teaching the material.

The director is involved in the interviewing process for the selection of volunteers and other team members, such as nurses and social workers. The director is also responsible for soliciting and maintaining funding, for planning and promoting change or program evolution, and for recruiting and keeping key personnel.

The structure of the organization was consistent among the various hospice agencies with the exception of Morgantown Hospice. In the others, the director and one of the team members selected the professional team members. However, the Director of Morgantown Hospice stated:

> We do not really have a selection process because we do not have our own nurses. We do not provide the skilled nursing services or the home health aides directly. We work with both Home Health Agencies in Monogalia County. We work with them and they provide the skilled nursing services (Kearney, 1989).

The roles of the various hospice staff involve performing the responsibilities and duties assigned. The nurses are given a great deal of responsibility. They have the most contact with the patient and family; they also help with administering medical care to the patient. The social worker's duties include counseling the patient and family, if necessary. Also the social worker will help the family complete various forms, such as insurance policies and Medicare. The members of the clergy provide spiritual care for the patient and family. Finally, the volunteers include office volunteers and lay volunteers who help with the care of the patient and family.

The teaching role of the hospice is extremely important. By providing information to patients and families, the staff may be able to reduce the fear and anxiety that is often associated with terminal illness. Although hospice does provide twenty-four hour availability, the patient and family spend most of the time alone in the home. Because of this, the family is considered part of the care team, so teaching members selected the professional team members. However, the Director of Morgantown Hospice stated:

> We do not really have a selection process because we do not have our own nurses. We do not provide the skilled nursing services or the home health aides directly. We work with both Home Health Agencies in Monogalia County. We work with them and they provide the skilled nursing services (Kearney, 1989).

The roles of the various hospice staff involve performing the responsibilities and duties assigned. The nurses are given a great deal of responsibility. They have the most contact with the patient and family; they also help with administering medical care to the patient. The social worker's duties include counseling the patient and family, if necessary. Also the social worker will help the family complete various forms, such as insurance policies and Medicare. The members of the clergy provide spiritual care for the patient and family. Finally, the volunteers include office volunteers and lay volunteers who help with the care of the patient and family.

The teaching role of the hospice is extremely important. By providing information to patients and families, the staff may be able to reduce the fear and anxiety that is often associated with terminal illness. Although hospice does provide twenty-four hour availability, the patient and family spend most of the time alone in the home. Because of this, the family is considered part of the care team, so teaching family members to meet the patient's needs when support personnel are not in the home is essential.

All members of the hospice team share common values and organizational goals. They provide a special service to both the dying patient and family members.

Hospice strives to meet all of the patient's needs--physical, emotional, social and spiritual--as well as the needs of the family. Emphasis is placed on symptom relief and the quality of life at the end in order to help the patient live as comfortably as possible during his remaining weeks or months. The Director of Hospice of Huntington stated "The goals and objectives of our program are to make people comfortable in a family setting and to keep them as pain free as possible" (Farrell, 1989).

The procurement of necessary resources from the social environment is also important in the organization. In the community-based model, hospice care attempts to integrate community resources with home care. This involves various members and organizations in the community. For example, attorneys may offer free legal advice to the patient and family, and other resources include Medicare, Medicaid, Meals On Wheels, and Dial-A-Ride. Another example would be the Director of the Hospice of Huntington stated

> We got pharmacies to agree to give us a discount on drugs. We got medical suppliers to agree to give us a discount on supplies. We got hospitals to agree to a fixed flat rate for our patients with pain and symptom

> controls, so that we did not have to pay the going hospital rate" (Farrell, 1989).

The director at Morgantown mention several of the advantages of being located in a University city with access to a Medical School. She listed some of the specific services which they had. She related that:

> Because of West Virginia University, we have access to all kinds of people who will do things as a volunteer. When we have a patient who has problems with his dentures, one of the dentists will go the house and realign the dentures. We have people who are in the dental hygiene department who will go in and clean somebody's teeth. And we have a nutritionist who will go in and talk to them about nutritional concerns" (Kearney, 1989).

Organizational activities must be coordinated to achieve collective goals. The major goal of the organization is to meet the needs of the dying person and their family. This involves providing staff and services which enables the person to die at home with family and friends. There are other goals which involve the coordination of activities by the Board of Directors which govern the total organization and helps establish the goals. Also, the director is involved in managing activities, such as the volunteer training program and other meetings. The patient care coordinator organizes the patient's care and other needs of the patient and family. Fund raising events must be organized to maintain financial stability, and contact with the community must be maintained and emphasized.

The organization must provide for the allocation of benefits to the members. Several benefits are found in working with a hospice agency that may not be available in other agencies. Flexible working hours for the members enables the individual to have time to spend with their families and engage in other activities. The Director of the Hospice of Huntington stated:

> We use mostly part-time people that are paid. We do this because most of the women that are in the workforce in this area have families and children. And its also a very intense type of work. We find that people work best when they meet their family needs and their own needs. Also people seem to be more mentally able to handle stress if they have good balance in their life" (Farrell, 1989).

Another benefit includes salaries; some staff members are full-time and part-time paid staff. Furthermore, the recognition a hospice team member receives from others in the community enhances his social status. Also, this status position gives an individual a personal sense of worth and feelings of achievement.

Organizational unity and cohesion is necessary. It is important for the agency to maintain unity and agreement on goals and objectives in order to function smoothly. Cooperation among all members is necessary in order to achieve this unity in the organization.

Hospice uses a team approach. This means many people with many different skills work together for the good of the patient and family. Each member specializes but there is cooperation among all members in dealing with the patient and family. The team holds meetings to coordinate care and to meet the needs of the terminally ill patient. The Director of Raleigh County Hospice Care stated that, "they hold interdisciplinary meetings every other week with the Medical Director" (McKay, 1989).

Furthermore, the time invested by these individuals and the sacrifices made by volunteers and others builds cohesion. The more time invested builds a stronger commitment to the organization which in turn achieves more unity within the organization.

Finally, the organization must develop procedures for change. As policies change on a higher level, the hospice agency must adapt or change as well. For example, when state licensure became mandatory, the hospice organization had to conform in order to continue operation. Also, those hospices that want to be Medicare Certified must uphold the standards required by the Federal government in order to be reimbursed for hospice care.

Other changes involve the type of patient being served by hospice. Hospice serves anyone with a terminal illness; however, the vast majority are cancer patients. In the future, hospice care will be provided to more and more AIDS patients and children with terminal illnesses. The Director of Raleigh County Hospice Care stated that "ninety-eight to ninety-nine percent of the patients have cancer, and we have not had an AIDS patient yet" (McKay, 1989). However, the

Director of the People's Hospice of Harrison County reported that, "we had our first AIDS patient admitted this year" (Bentz, 1989).

Furthermore, the Director of Ashland Community Hospice pointed out that, "with the AIDS problem more and more hospices are going to be taking care of AIDS patients, and those patients can be maintained at home just like any other dying patient" (Saxton, 1989).

In caring for children with terminal illness, the Director of the People's Hospice of Harrison County stated "A lot of people think that all we work with are elderly people but in fact we take any age including children." He goes on to say "Parents tend to be very reluctant to own up to a child being terminally ill, therefore, we probably could have and should have had some children but for those reasons we have not up to this point" (Bentz, 1989).

The Director of Ashland Community Hospice added that:

> We care for infants in our program and a lot of times parents have taken their children back to the hospital just because they always have, but I think now they want to keep their children close to home and really be the ones to be the caretaker for their dying children" (Saxton, 1989).

The Hospice Organizations have met the basic organizational requirements which enables them to operate as viable organizations. The Hospice Movement has been greeted in all of the communities with open arms, which makes the recruitment and funding better for this organization than some other volunteer organizations. There was a need; Hospice has meet this need.

Chapter 6

SUMMARY AND CONCLUSIONS

It has been recognized that a hospice must move through several stages in order to become an organization. Moving from a volunteer or interest group to an operating hospice requires detailed planning and organizing. Also, community support and financial stability are crucial in the developing stages. The developing hospice also needs support from the medical community, because physicians make most of the patient referrals to the hospice program.

Several reasons may be given to explain why the Hospice of Lincoln County was unsuccessful in developing into an operating organization. First, the board of directors for this developing hospice were the same members on the board of directors for the Lincoln County Primary Care Center. The members did not have the time to serve on both boards. Therefore, this led to problems in trying to organize and plan the hospice program.

Furthermore, this developing hospice did not have adequate community support. It was difficult to find volunteers for the program, as well as trained professional. Since this is a rural area, most people work out of town and do not have the time necessary to put into the planning and organizing of the program.

In conclusion, the acting director of the Hospice of Lincoln County decided to hold a town meeting and turn it over to someone who may be interested in starting a hospice in the community.

Hospice programs have become an important alternative for the dying patient and family. More people are choosing this approach as opposed to the traditional type of health care. However, many hospice programs face problems and resistance either financially or politically, especially in the beginning stages. New hospices face problems with politics and bureaucracy because they are required to obtain approval of a Certificate of Need and a license to provide care. Furthermore, hospice programs face a difficult battle in the coming years because they are viewed as a threat to the traditional network.

Limitations of the Study

A larger population would have provided more conclusive results. If all hospice organizations in West Virginia were interviewed, more information could be gathered on the success or failure of such organizations. This would include both operating and developing hospices in order to gain more insight into the reasons or causes for success and failure.

Furthermore, an attempt was made to interview the director of Boone County Hospice. This hospice is a developing organization. However, due to a serious illness in the family, the director was unable to follow through on with the interview.

Suggestions for Further Study

The study could be extended further by examining the characteristics of the hospice patients and caregivers. Information relating to gender, age, race or ethnic background, income, education, occupation and type of illness could be gathered. This type of information would give a detailed description of the hospice patient and their primary caregivers. Any hospice organization could use this type of information, but it would be especially important for one in the developing stages since it would help in determining who is likely to use hospice services.

Furthermore, other areas or questions that could be examined include: Is there a relationship between autonomy and quality of care? Is the level of care higher in Medicare Certified hospices? Does the size of the population in the county determine whether a developing hospice will progress into an operating program?

REFERENCES

Bayer, Ronald and Eric Feldman. 1982. "Hospice Under the Medicare Wing." The Hastings Center Report (December) 5-6.

Bentz, Gale. Personal interview. 7 July 1989.

Briendel, Charles L., and Timothy O'Hare. 1979. "Analyzing the Hospice Market." Hospital Progress (October) 52-55.

Buckingham, Robert W. 1983. The Complete Hospice Guide. Harper & Row.

Bulkin, Wilma and Herbert Lukashok. 1988. "Rx For Dying: The Case For Hospice." The New England Journal of Medicine 318:376-378.

Cohen, Kenneth P. 1979. Hospice: Prescription For Terminal Care. Aspen Systems Corporation.

Cook, Alicia S., and Lowell E. Jenkins. 1982. "Implications of Ethnicity in the Care of the Terminally Ill." Social Casework: The Journal of Contemporary Social Work (April) 215-219.

Corless, Inge B. 1987-88. "Settings For Terminal Care." Omega 18:319-340.

DuBois, Paul M. 1980. The Hospice Way of Death. Human Sciences Press.

Farrell, Charlene. Personal interview. 2 June 1989.

Foster, Zelda, Florence S. Wald, and Henry J. Wald. 1978. "The Hospice Movement: A Backward Glance at its First Two Decades." The New Physician 27:21-24.

Germain, Carol P. 1980. "Nursing the Dying: Implications of Kubler-Ross' Staging Theory." The Annals of the American Academy 447:46-58.

Holden, Constance. 1980. "The Hospice Movement and Its Implications." The Annals of the American Academy 447:59-63.

Kalish, Richard A. 1980. Death and Dying: Views From Many Cultures. Baywood Publishing Company.

Kalish, Richard A. and David K. Reynolds. 1976. Death and Ethnicity: A Psychocultural Study. University of California Press.

Kearney, Margaret. Personal interview. 6 July 1989.

Krant, Melvin J. 1978. "The Hospice Movement." The New England Journal of Medicine 299:546-549.

Kohut, Jeraldine Marasco and Sylvester Kohut. 1984. Hospice: Caring for the Terminally Ill. Charles C. Thomas.

Labovitz, Sanford and Robert Hagedorn. 1981. Introduction to Social Research. McGraw-Hill.

Labus, Janet G., and Faye H. Dambrot. 1985-86. "A Comparative Study of Terminally Ill Hospice and Hospital Patients." Omega 16:225-232.

Lannie, Victoria J. 1984. "The Positive Aspects of Anguish: A Hospice Philosophy." The American Journal of Hospice Care (Fall) 33-35.

McKay, Rhonda. Personal interview. 24 July 1989.

Miller, Suzie. Personal interview. 2 August 1989.

Mor, Vincent. 1987. Hospice Care Systems: Structure, Process, Costs, and Outcome. Springer Publishing Company.

Noles, R., and J. Clancy. 1983. Hospice Care: Principles and Practice. Faber & Faber.

Paradis, Lenora Finn. 1985. Hospice Handbook: A Guide For Managers and Planners. Aspen Systems Corporation.

Paradis, Lenora Finn and Scott B. Cummings. 1986. "The Evolution of Hospice in America Toward Organizational Homogeneity." Journal of Health and Social Behavior 27:370-386.

Parsons, Talcott. 1951. The Social System. Free Press.

Ryder, Claire F., and Diane M. Ross. 1977. "Terminal Care: Issues and Alternatives." Public Health Reports 92:20-29.

Saxton, Carolyn. Personal interview. 19 July 1989.

Stevens, Linda. Personal interview. 12 July 1989.

Still, A.W., and C.J. Todd. 1986. "Role Ambiguity in General Practice: The Care of Patients Dying at Home." Social Science Medicine. 23:519-525.

Torrens, Paul R. 1985. Hospice Programs and Public Policy. American Hospital Publishing, Inc.

Vandenbos, Gary R., Patrick H. DeLeon, and Michael S. Pallak. 1982. "An Alternative to Traditional Medical Care for the Terminally Ill: Humanitarian, Policy, and Political Issues in Hospice Care." American Psychologist 37:1245-1248.

Zimmerman, Jack M. 1986. Hospice: Complete Care for the Terminally Ill. Urban & Schwarzenberg, Inc.

APPENDIX A

INTERVIEW SCHEDULE--OPERATING HOSPICE

1. DATE FOUNDED?
2. YEARS IN EXISTENCE?
3. TYPE OF MODEL?
4. WHAT ARE THE ADVANTAGES AND DISADVANTAGES OF THE MODEL?
5. HOW DID YOU DETERMINE THAT A HOSPICE WAS NEEDED IN THE COMMUNITY?
6. DESCRIBE THE ORIGIN OF THE HOSPICE PROGRAM AND AFFILIATION IF ANY (i.e. HOSPITAL OR NURSING HOME).
7. HAD THERE BEEN ANY OTHER ATTEMPTS BY GROUPS TO START A HOSPICE? IF SO, WERE THEY SUCCESSFUL OR UNSUCCESSFUL?
8. WHO WAS INVOLVED IN THE PLANNING AND ORGANIZING DURING THE DEVELOPMENTAL STAGES? WHAT WERE THEIR POSITIONS IN THE COMMUNITY?
9. HOW DID YOU GAIN PHYSICIAN'S SUPPORT FOR THE DEVELOPING HOSPICE?
10. HOW DID YOU OBTAIN AND MAINTAIN COMMUNITY SUPPORT?

OR IS IT STRICTLY RESERVED FOR CANCER PATIENTS?

32. WHAT IS THE APPROXIMATE AVERAGE LENGTH OF STAY IN HOSPICE?

33. WHAT IS AVERAGE COST OF HOSPICE PER CASE?

34. IS THE PROGRAM CERTIFIED BY JCAH (JOINT COMMISSION ON ACCREDITATION OF HOSPITALS)?

35. ARE THERE ANY LOCAL REQUIREMENTS?

36. HOW MUCH FUNDING DO YOU RECEIVE FROM FEDERAL, STATE, THIRD PARTY CONTRIBUTIONS AND OTHERS?

37. IS THE PROGRAM MEDICARE CERTIFIED?

38. WHAT PERCENTAGE OF THE HOSPICE PATIENTS ARE MEDICARE/MEDICAID RECIPIENTS?

39. WHAT PERCENTAGE DOES MEDICARE PAY?

40. WHAT PORTIONS OF HOSPICE CARE ARE GENERALLY COVERED BY INSURANCE PLANS?

41. IN YOUR OPINION, WHAT WILL BE THE FUTURE OF HOSPICE?

APPENDIX B

INTERVIEW SCHEDULE--DEVELOPING HOSPICE

1. DATE STARTED ORGANIZING THE HOSPICE?
2. TYPE OF MODEL?
3. WHAT DO YOU THINK ARE THE ADVANTAGES AND DISADVANTAGES OF THIS TYPE OF MODEL?
4. HOW DID YOU DETERMINE THAT A HOSPICE WAS NEEDED IN THE COMMUNITY?
5. DESCRIBE THE ORIGIN OF THE HOSPICE PROGRAM AND AFFILIATION IF ANY (i.e. HOSPITAL OR NURSING HOME).
6. HAD THERE BEEN ANY OTHER ATTEMPTS BY GROUPS TO START A HOSPICE? IF SO, WERE THEY SUCCESSFUL OR UNSUCCESSFUL?
7. WHO WAS INVOLVED IN THE PLANNING AND ORGANIZING DURING THE DEVELOPMENTAL STAGES? WHAT WERE THEIR POSITIONS IN THE COMMUNITY?
8. HOW DID YOU ATTEMPT TO GAIN PHYSICIAN'S SUPPORT FOR THE DEVELOPING HOSPICE?
9. HOW DID YOU ATTEMPT TO OBTAIN COMMUNITY SUPPORT?
10. WHAT WAS THE TARGET POPULATION?

11. HOW DID YOU IDENTIFY THEIR NEEDS?

12. WHAT WERE THE GOALS AND OBJECTIVES OF THE PROGRAM?

13. WHAT AREAS OR COUNTIES WAS THE HOSPICE INTENDED TO SERVE?

14. WERE THERE ANY PROBLEMS OR LIMITATIONS IN THE BEGINNING STAGES?

15. OCCUPATION OF THE HOSPICE DIRECTOR?

16. HOW MANY MEMBERS WERE ON THE GOVERNING BOARD?

17. WHO WERE THE GOVERNING BOARD MEMBERS AND WHAT WERE THEIR POSITIONS IN THE COMMUNITY?

18. WHAT COMMUNITY RESOURCES WERE AVAILABLE TO THE HOSPICE PATIENTS?

19. WHAT WAS HE PATIENT CRITERIA FOR ADMISSION TO HOSPICE?

20. WOULD THE PROGRAM ADMIT ANYONE WITH A TERMINAL ILLNESS OR WAS IT TO BE RESERVED FOR CANCER PATIENTS ONLY?

21. WERE THERE ANY LOCAL REQUIREMENTS?

22. IN YOUR OPINION, WHAT WILL BE THE FUTURE OF HOSPICE?