

COMMUNITY ORGANIZATION PROCESS
IN HOSPICE DEVELOPMENT

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To my wife and children

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PREFACE

Ideas about death and dying have been developing for centuries. A particular interest in caring for the dying has intensified in recent years. The health care professional is at the beginning of this new direction of medical care. Emphasis is on hospice as total care through an interdisciplinary team. This improvement for caring for the dying is answering the physical, psychological, spiritual, and social needs of the terminally ill. These advances are changes in the character of care for the dying.

Community organization is one method for the community's use in developing a hospice program. It is not intended that the principles and strategies of community organization be understood as the only methods of accomplishing the goal of providing care for the dying. It is one means by which the community can obtain this goal. The community organizational process restores a certain amount of control to the local community by identifying their needs, finding resources to deal with these needs, and taking action regarding them.

Many people have made this paper possible. I wish to thank them all. My mother, my friends and colleagues at St. Anthony Center, and Texas Woman's

University Houston Center encouraged, supplied ideas, guidance, and understanding. Without their help I would have faltered.

The support, love, and encouragement of my wife and children deserve a special thanks. Without their constant help, I would never have finished. I dedicate this thesis to them.

CHAPTER I

INTRODUCTION

Not too many years ago, death was regarded as a natural occurrence in which the family observed and participated (Kubler-Ross 1969). Today most family members do not participate in the dying experience. Instead, people die in the hospital and are mourned in the funeral home (Elder 1976). Because of this trend, the physical, social, and emotional needs of the family and patient are being overlooked (Lack and Buckingham 1979). These deficiencies require a systematic approach by a team or caring institution. The team or caring institution must be able to shift its focus to detect whether the patient, the family, or the patient-family unit is momentarily in need of assistance in coping with the patient's state of terminal illness (Worby and Babineau 1974). This constant shift in focus can only be accomplished by tailoring a service to meet each individual's needs (Lack and Buckingham 1979). This service will aim at satisfying the overlooked needs of family and patient by using an approach that is innovative by today's hospital standards, one embraced by the concept "hospice", the caring for the dying (Stoddard 1978).

Hospice represents the filling of a significant gap in our health care system (Cohen 1979). Acute-care institutions are geared to cure patients and send them home (Stoddard 1978). Hospice, on the other hand, treats the symptom regardless of whether it is physical, emotional, or mental, rather than just the disease (Lack and Buckingham 1979).

The community should be part of the development of hospice. The rationale behind this viewpoint is that the consumer involved in the planning and delivery of a health service introduces a wider range of viewpoints and support (Phillips 1968). This developmental process, involving the consumer, is community organization. Community organization is more than just planning for the future. It is a process of intervention at a community level oriented toward influencing the community in solving its problems. The intervention must be by a community organizer who is trained in need identification and problem-solving techniques (Rothman 1974). The needs of the community as the organizer sees them and the felt needs of the people may be quite different. If a program is to be effective, it should be directed basically to needs as seen by the people, rather than the organizer (Dunham 1963).

With this user orientation in mind, the role of the community organizer in the development of hospice will be

more than just that of planner. His role will be to assure those affected by the program that they will have a large part in determining what goes into their hospice plan as needs are identified, objectives are stated, resources are found to deal with needs, and action is taken regarding the objectives.

CHAPTER II

STUDY DESIGN

Statement of the Problem

Certain researchers' (Anderson 1955; Averill 1968; Bowlby 1961; Brown 1972; Bruhn 1973; Engle 1964; Kubler-Ross 1969; Lack and Buckingham 1979; Parks 1967; Rice 1972; Ross 1970; Rothman 1974; Silver 1973) studies indicate three essentials in the development of hospice. These fundamentals are as follows: (1) a solid foundation for action is needed to develop hospice, (2) the people of the community want, and should have, the opportunity to participate in health planning, and (3) the community organizational process is the tool for that planning. Based on the need for these essentials, the problem of the study is: What are the components needed in the construction of a guide for the health care professional that will give him an understanding of hospice, community organization, and the organizational tasks needed in the development of this new community health resource?

Purpose of the Study

The purpose of this paper is to develop a guide which will provide the following:

1. To discuss hospice in a manner that will give the health care professional a

better understanding of the definition, goals, and objectives of this service.

2. To discuss the community organizational process that is needed to develop a hospice program.
3. To discuss assessment in a manner that will give the health care professional an understanding of the factors that will influence the community's needs.

Accordingly, the design classified as the purpose is descriptive.

Background

There are five identifiable types of hospice in this country. The first and least popular type, because of cost of operation, is the free-standing hospice. The second and most expensive to operate is the free-standing hospice with a hospital affiliation. The third type is a hospice unit within a hospital. The fourth is a hospice team within a hospital. The fifth, and most popular because of cost savings in operation, is the home care team (English 1979).

The current level of hospice development in the United States is an estimated 200 in 40 states. In Texas, hospices have been established in Orange, San Antonio,

Dallas, and Austin. While there are no hospices formally recognized as such in Houston, some groups have made efforts toward development. Examples of these efforts are as follows. Four meetings were held gathering interested parties in an effort to unite all concerned into a committee for hospice development (Bonneau 1979). The Visiting Nurse Association of Houston proposed to the United Fund that money be provided for a hospice team (Visiting Nurse Association of Houston 1978). Sen. Chet Brooks of Pasadena told his office staff and the staff of the sub-committee of the Special Committee on the Delivery of Human Services to look into possibilities that the state can finance a hospice (Houston Chronicle 1979). The Houston-Galveston Area Council Health Systems Agency (1979) requested assistance in developing more specific details about hospice.

Obvious local interest is developing in hospice, but substantial work will be required to move from this small perception of need for a hospice to a community resolution and adoption of a hospice project. This work involves steps to gain active support from the rest of the community, persuade community groups and individuals to form and participate in an organization representing

the whole community, and then enlist this representative group to accept the responsibility for the development of hospice (The Primary Care Development Project 1976; Reinke 1972).

For the development of a hospice, certain organizational activities must be carried out to gain active support. This process includes designating or electing members as officers with specific responsibilities, establishing a meeting schedule, following an agenda, recording minutes of meetings, and communicating progress to the community. All are essential activities in allowing the organizational group to keep track of development and progress and to approach systematically the future problems. This effort establishes a basic organizational structure so subsequent activities can be carried out efficiently (The Primary Care Development Project 1976; Reinke 1972).

Much of the first efforts at enlisting support of groups or citizens of the community to support hospice will be unsuccessful because there will not be a great deal of community awareness. An effective method of creating awareness of need for hospice is imperative. This can be done in a number of ways, including the use of case histories of individuals who have had a need for

hospice service and went without help (Libman 1969).

A critical component in the success of hospice is the degree to which the community is made aware of patient needs (English 1979).

Once awareness is established, expansion of membership to a larger base is necessary. Key people who have access to community resources should be included in the group. Then it is essential to persuade community groups, as well as the individuals, to participate in the organization of hospice. It will also be essential that these groups and individuals accept responsibility for the development of hospice (The Primary Care Development Project 1976; Reinke 1972). These steps are necessary so citizens of the community have the opportunity to examine their own situation, to discover unmet needs, to select priorities, and to find solutions to their highest priority problems. Many of today's health care problems have to do with past decisions being made by only a few people without consulting the community to gain acceptance (Rice 1972). The people of the community want, and should have, the opportunity to participate in the development of any new health planning for their area (Anderson 1955; Brown 1972; Rice 1972; Silver 1973). The tool for this development of health planning for individuals who demand to influence

their own destiny is the community organizational process (Bruhn 1973; Rothman 1974).

A foundation in theory for this study is found in Hage (1965) on organization theory. This thesis is justified in that the method of this study concerns community organization. The focus of this process is hospice, an organization.

Methods

Literature pertaining to hospice and community organization, as related to the community-development model and the social-action model, has been searched and examined carefully. First, hospice development has been reported in terms of history, types of hospice, operational needs, criteria for admission, symptom control, and understanding grief. Second, community organizational principles have been developed through explanation of organizational theory, history and background of community organization, community-development principles and strategies, social-action principles and strategies, and those factors which are an integral part of assessment. Finally, an integration of hospice and community organization will be discussed.

Definitions

Assessment: For the purpose of this study, assessment refers to a tool for planning used to evaluate

the needs of the community. The assessor may draw on the past as well as the present to predict the needs of the future (Bruhn 1973; Dunham 1963). The factors used in this study for assessment are as follows: geographic, demographic, and socioeconomic characteristics.

Community: For the purpose of this study, the community is a group of people who share a common interest and support or oppose this interest.

Community-Development Model: A community organizational method which involves a wide spectrum of people at the local level who are involved in the identification of needs and problem solving. The impetus for this method of community change often results from group discussion and consensus. It is a self-help concept with reliance on community initiative (Ross 1970; Rothman 1974).

Community Organization: A process of both education and organization in which an individual or group will generate increased community awareness of a local problem and develop local organizational structure capable of planning and taking action to correct a perceived problem (Ross 1970).

Health Care Professional: For the purpose of this study, a health care professional is any individual who is licensed, degreed, or certified in any capacity as a health care worker.

Hospice: A program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency such as a visiting nurse association. . . . [A]n organized program of care for people going through life's last station. The whole family is considered the unit of care and care extends through the mourning process. Emphasis is placed on symptom control and preparation for support before and after death, full-scope health service being provided by an organized interdisciplinary team available on a twenty-four-hour-a-day, seven-days-a-week basis (U.S. Congress 1976:57689-90).

Also, the associated beliefs, values, and/or movement.

Social-Action Model: A community organizational method which involves agitation and organization as a prelude to negotiation. The social actionist attempts to coerce one's oppressor so redistribution of power, resources, and decision-making is done by the citizens of the community (Ross 1970; Rothman 1974).

Symptom Control: The regular use of medication without regard for the patient's psychological dependence. The aim is the management of physical distress without regard to the pain being a primary or secondary symptom (Cohen 1979; Lack and Buckingham 1979).

Summary

This study design is bibliographic with a purpose which is descriptive. It is based on accepted principles for a plan of action for the development of a health resource suggested by English (1979) and The Primary Care Development Project (1976). The ^{problem} ^{study} intention of this paper ^{was} is to give the health care professional an understanding of hospice and strategy of development. ^{Subject} Three areas that are approached to achieve this understanding, are as follows. First, information pertaining to hospice regarding history, types of hospice, operational needs, criteria for admission, symptom control, and understanding grief will give the health care professional the tools needed for a portion of this understanding. Second, community-development and social-action principles and strategies, organizational theory, history and background of community organization, and assessment factors are explained. Finally, a discussion that is an integration of hospice and community organization is delivered to complete this presentation.

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CHAPTER III

HOSPICE

Introduction

Advancements in health care have been numerous throughout the years (Yeager 1975). Caring for the dying as part of health care has only been recognized in recent years (Averill 1968; Bowlby 1961; Cohen 1979; Engle 1964; English 1979; Kubler-Ross 1969; Lack and Buckingham 1979; Parks 1967). During this same period of time institutionalized dying has received a good deal of criticism. Hospitals have been described as impersonal, cold, and laden with rules, schedules, and procedures. Hospital characteristics such as these are inappropriate and directly opposed to the needs of the terminally ill and his family. Moreover, the hospital staff has been charged with being insensitive to the needs of the patient and indifferent to the family's needs. An alternative is hospice care (Parks 1972).

The purpose of this chapter is to provide documentation so the health care professional will see that this alternative care for the dying is beneficial and necessary. The documentation will show the history of hospice, what types of hospice are available, who and what is needed

for operation of a hospice, which patients should be admitted to a hospice, and how to handle symptoms and provide understanding of grief.

History

The care for the dying has been unfamiliar to most Americans until recently. It is by no means a new concept. Hospice developed in Italy, England, France, and Germany during the Middle Ages. Hospices in and around European countries were places of rest for weary travelers. They were run by monastic orders which practiced medicine and cared for all who came. No one was turned away, especially the poor (Stoddard 1978).

During the crusades, the Knights of the Cross and the Knights of St. John established places of care for those who had become ill and could not complete their journey. Special attention, good food, and clean clothing were provided to weary travelers (Kron 1976).

There had been very little change in hospice care until the 19th century when the first modern hospice devoted to the care of the dying was established. This hospice was opened by the Irish Sisters of Charity as a skilled nursing facility for the dying in Dublin (Zora and Zora 1978). The Sisters offered a combination of skilled nursing, spiritual care, and emotional support.

This hospice of the Sisters', along with the English facilities developing at the same time, formed the foundation for the hospices of today (Cohen 1979).

During the 1960's, management of pain was pioneered and added to the components of care that the Sisters developed (Cohen 1979). Dr. Cecily Saunders is given primary credit for this management of painful symptoms for the terminal cancer patient. Her program at St. Christopher's supports quality of life while answering the patient's needs for support by incorporating pain management with multi-disciplinary team approach. This approach enabled the terminally ill patient to spend the last days of life responsive and pain free (Lack and Buckingham 1979).

The care for the terminally ill has become an issue for public discussion. Today care for the dying in hospice programs has begun to be thought of as a specialized medical classification. What makes hospice different from another approach to caring for the terminally ill is the nature of the services and the underlying philosophy. Standards today are set so that the philosophy of care in a hospice program is to improve the quality of life for patient and family. Those standards include alleviating pain, controlling symptoms, and recognizing the emotional, physical, social, and spiritual needs of the patient (Brooks 1980).

Types of Hospice

Where each hospice patient spends his last days is not important. Hospice is not a building. "A hospice is a program of care" (Cohen 1979:68). The United States and English hospice programs are based on the principles established at St. Christopher's. They incorporated the multidisciplinary team approach, management of pain, and regarded the patient and family together as a unit (Lack and Buckingham 1979). The major difference in the United States and the English approach to hospice care is the setting. The English primarily have free-standing hospices while the United States uses a variety of settings. These settings are as follows: free-standing, free-standing with a hospital affiliate, a special unit within a hospital, a hospice team within a hospital, and a home care team.

Hillhaven in Tucson and Hospice, Inc., in New Haven are examples of the free-standing hospices in this country. There has been concern expressed that free-standing hospices reduce emphasis on home care. This type of care can reduce family involvement. Both home care and family involvement are essentials in hospice treatment (Cohen 1979; English 1979; Plant 1977). Despite this concern of reduced family involvement, Hillhaven and Hospice, Inc. are the best known hospices in the country (Cohen 1979).

Riverside Hospice Program, a division of Riverside Hospital in Boonton, New Jersey, differs from Hillhaven and Hospice, Inc. because it is a free-standing hospice facility with a hospital affiliation. It was set up as a hospital affiliate to maximize tax and reimbursement advantages, but it is physically, managerially, and financially separated (Cohen 1979; English 1979; Plant 1977).

The prototype in this country for setting aside a special unit is Bellin Memorial Hospital in Green Bay, Wisconsin. Cohen (1979), English (1979), and Plant (1977) advise that this arrangement avoids reimbursement problems. The unit is treated as an additional service in the hospital by most third-party payers.

St. Luke's Hospital in New York has a hospice team operating within the hospital. The coordinator of these hospice services believes the presence of the hospice team has been good for patient care. The hospital administration feels that this method of hospice care does not jeopardize St. Luke's reimbursement status as an acute-care institution, but does provide the care needed for the dying (Cohen 1979; English 1979; Plant 1977).

Different from all other types of hospices is home care hospice. It is the most popular type in this country because of cost savings in operation. This "hospice

without walls" is typified by the organization of Marin in Kentfield, California. Its team of health professionals offers four types of services. These services are as follows: management of patient's pain and related symptoms, instruction of family members in care of the patient, consultation for emotional assistance to the family, and bereavement support for survivors. The patient or family is free to choose one or more of these services. Total hospice care would include all four services (Cohen 1979; English 1979; Plant 1977).

Operational Needs

Regardless of the setting, development of a multidisciplinary team to provide care for 24 hours a day, seven days a week must be considered before the opening of a hospice can materialize. Composition of the team may vary because of availability of personnel or the patient's needs. A nucleus for this team will be a physician, nurse, social worker, clergy, and volunteers. This team will provide the care for the dying patient and his family (Plant 1977).

Finding a qualified, compassionate, unselfish, and devoted person who is a physician, nurse, social worker, clergy, or volunteer will not be a simple task. English (1979) advises that the health professional who is interested in the dying and who is qualified is difficult to

find, but the number is growing. This special individual who is found usually needs to be trained. Past hospital practices of using all measures to maintain life should be forgotten. The health care professional's education will now be directed to the needs of the dying, understanding of the hospice philosophy, developing a coping mechanism in working with the terminally ill, and utilizing the multidisciplinary team approach to provide care (Plant 1977).

Once the team is developed, an issue that may be of more concern in the United States than who cares for the patient is who pays for the care? Only twenty Blue Cross-Blue Shield plans in the United States pay for part of hospice care (Houston Chronicle 1979). Cohen's (1979) survey of insurance companies in the United States indicated that 83 percent did not cover hospice care. Breindel and Boyle (1979) found United States third-party payers were not amenable to coverage for the terminally ill. An immediate concern to the operation, because of lack of coverage of hospice care, is a practical solution to reimbursement.

Other problems related to receiving reimbursement were reported by Brooks (1980). Laws and policies regulating reimbursement discriminate against the dying. Many of these laws and policies are written so that the

insurance company will pay for the cure but not for the care. Advocates of hospice want assurance that third-party payers will pay for the care under hospice programs. Insurance companies seek assurance that hospice programs will meet standards and are licensed. Most states' departments of public health will not license hospice programs without standards and a certificate-of-need. Without standards and a certificate-of-need, no payment will be made by third-party payers. Therefore, most hospices will not receive reimbursement.

Many law makers feel hospice program regulations are somewhere between hospital and nursing home. They also feel a hospice does not fit in either category when they are passing regulations. Even with this attitude, some hospice programs have taken advantage of specific licensors, such as those for skilled nursing facilities, home health agencies, and hospitals. These licenses permit reimbursement for some services if the service is performed in the proper setting, such as home care. In most cases, reimbursement for counseling the family, the patient, or for bereavement follow-up is not one of the services covered (Brooks 1980; Cohen 1979).

Cohen (1979) advised the health care professional must have a good understanding of what is covered service and who will pay for that service. Brooks (1980) reported

coverage of care depends on the state and the third-party payer who is covering the care, Medicare, Medicaid, or a commercial insurance. Some examples of the third-party payer's coverage or lack of coverage are as follows: The Social Security Act, Titles XVIII, XIX, XX, and the Older Americans Act programs do not reimburse for hospice services per se. Both Medicare and Medicaid cover in-patient skilled nursing facility services and hospital care. Both Medicare and Medicaid pay for doctors' services. Even though doctors' services are covered, there are restrictions on the number of physician visits allowed by many state programs. Medicaid, in addition, covers some intermediate care facility services. Those requirements that must be considered for eligibility for Medicaid are the patient's age, income level, and medical necessity. Home health services are provided by Medicare, Medicaid, and the Older Americans Act. To be covered under Medicare Part A for these home health services, the patient must have been hospitalized for three consecutive days. Medicare payments for home health services have other restrictions. Two of those restrictions are as follows: (1) patients must be home-bound and (2) the patient must not be able to leave the house except for brief periods to obtain services in another setting. The services received must be skilled nursing care.

Medicare also covers medical social services. These services must be provided by a qualified psychiatric or medical social worker, but providing family counseling and emotional support does not meet the Medicare requirements for payment. This is also true regarding meeting the requirements for payment under Medicaid, state social service programs and the Older Americans Act (Brooks 1980).

Medicare and Medicaid will pay for pain control treatments such as surgery and radiation treatments, but neither is used very often in hospice care. Medicare will pay for control of pain with drugs if they are provided to an inpatient or if the medication cannot be self-administered. Most hospice programs try to have medication self-administered. Almost all states will pay for physical and occupational therapy services when a doctor prescribes the services and they are restorative. Physical and occupational therapy is palliative for the terminally ill. Therefore, the therapy is not a covered service (Brooks 1980).

Medicare and Medicaid seldom cover death education and bereavement services. These services might be covered and reimbursable if they can be shown medically necessary, but in addition to the medically necessary, the family member receiving the service will have to be eligible

for Medicare or Medicaid. The major problem with being eligible for reimbursement under Medicare or Medicaid programs has been found to be that many of the patients are either too young for Medicare or have too much money to qualify for Medicaid payment (Brooks 1980).

The uncertainties of coverage and the need to find reimbursement for hospice services has prompted the United States Department of Health and Human Services to announce 26 demonstration grants through the Health Care Financing Administration. These grants will be conducted over a two-year period (Brooks 1980). Funds such as these from grants, pilot project money, and other community financial support may be short-term answers for hospice. Long-term operation of a hospice under today's reimbursement guidelines will be difficult, if not impossible, without being endowed (English 1979).

Voids in regulations present problems of what the future will bring in addition to the reimbursement problems. There has been little experience on what type of mechanism should be used to evaluate the quality of care being provided in hospice settings when regulations are written. Insight may be obtained from Affeldt (1980).

Affeldt (1980) expressed his feelings that the Joint Commission on Accreditation of Hospitals (JCAH) is the most logical choice to accredit hospice. His view is

because of the current and historical role of JCAH as a leader of the voluntary approach to quality assurance and their resources, and because some hospice programs are operating in facilities that are presently surveyed by JCAH. Affeldt (1980:12-13), president of JCAH, may be considered biased, however, he gave the following reasons as to what the JCAH role should be.

. . . the Joint Commission is currently exploring the feasibility of its involvement in a hospice accreditation program. JCAH staff are exploring various issues and funding possibilities for conducting such a study. The recommendations for the study will be submitted to JCAH's Board of Commissioners, who will determine the appropriate role, if any, JCAH should play in the field of hospice care.

Before JCAH can rationally determine its role in any health care program, it must fully understand the program's conceptual underpinnings, its current status, and its future directions. With this kind of information, a new accreditation program risks irrelevancy, dilutes its potential impact, and may obstruct rather than encourage appropriate innovation in the field. In attempting to explore and clearly define the hospice concept, JCAH will have to determine what it is about hospice care that takes it beyond other traditional concepts. Is it simply the attempt to organize care and purposely involve the family that makes this innovation provide the basis for the subsequent phases of the study.

With this background, it will then be possible to define the major characteristics of hospice programs. While they are staffed, the range and depth of their services, and the nature of their relationships with other organizations varies considerably. For example, today hospice programs

take the form of hospital-based units, free-standing facilities and expanded home care programs. Again, the organizational structure and staffing requirements of each setting may be different. These differences are of great importance to JCAH as it considers hospice program accreditation standards and survey procedures. For those hospice programs that are closely linked to a hospital, JCAH will need to explore the feasibility of incorporating hospice accreditation into its Hospital Accreditation program. Whether such integration is desirable or appropriate can only be decided in the context of detailed information about hospital-based hospice programs and the difference among other types of hospice programs.

The wide divergence found in the structure and operation of various hospice programs often tends to run at cross purposes to other pressures, which tend to force clear definition. These pressures include the need to precisely define hospice programs so that reimbursement by third-party payers could be arranged at a more rational and equitable basis, and to create standardization of staff and organization to enhance the quality of patient care and the efficiency of operation. The underlying theme of these pressures is the attempt to provide more options to the purchasers of health care services. Great care must be taken not to develop hospice care standards that would result in stifling innovation in the field.

A final ingredient in JCAH's determination about its role in the hospice field is an understanding of the future direction of this movement. While having an apparent solid base of principles and a consensus of concept, it is clear that there is less than full agreement that the current hospice care movement represents the best way in which to deal with the needs of the terminally ill and their families. The examination of this hypothesis will be subjected to careful and critical review by JCAH as an important component of its study.

Therefore, it is the Joint Commission's belief that it would be in the best interests of patients and health care field alike to propose a hospice accreditation program only after gaining a full understanding of the field's structure and direction.

This would be accomplished through a thorough examination of the patterns of providing care to the terminally ill as they relate to an accreditation effort. Important considerations include how such a program could enhance the quality of hospice care and whether it could be conducted at a reasonable cost.

The future of hospice care depends on public acceptance of its approach to serving the needs of the terminally ill and their families, successful demonstration of the consistent provision of high-quality care, and the predictable availability of third-party reimbursement. The Joint Commission will fully study and understand the forces at work that will influence these critical factors before any plans can be proposed. From this understanding, it is hoped that JCAH will gain better insight into the prospects for an appropriate role in a field that offers so much promise for providing the necessary support to a growing and neglected segment of our society.

Criteria for Admissions

English (1979) advises that criteria for admission for the terminally ill is next on the list of priorities that must be developed after operational needs. These criteria are essential to insure a good operation, integrity of the program, and protection of the funds available.

Certain basic considerations should be included in the admission standards (English 1979; Lack 1979). These considerations are as follows: First, the severely symptomatic patient who is not amenable to regular hospital care can be a good choice for admission to the hospice. Second, life expectancy of the patient should be less

than six months. Third, the requirement of residency, in a particular radius around the hospice, is specified in order to assure close family involvement. Fourth, the hospice program should require the patient's physician to continue to take some role in his care so continuity of care is not lost. Finally, a specific person must be available to serve as the primary contact and assume an on-going responsibility for the care. These requirements appear to be simple, but adherence is important if the needs of the patient and the hospice program are to be addressed.

Symptom Control

The care for the dying can start once admission requirements are met. The hospice patient should not want to die because of his pain. If the pain is properly controlled, as it is in the St. Christopher's Hospice, the patient can handle his death (Stoddard 1978). Lamerton (1976) advises that the patient is able to cope with any symptom for a short period of time; what he fears most is the pain that lasts for months. Palliative treatment should be started once specific therapy to produce a cure or remission has been abandoned.

Lamerton (1976) and Stoddard (1978) express similar opinions on symptom control. Each feel doses of analgesics, tranquilizers, and anti-depressants should be used regularly

for the control of pain before the pain pattern has been allowed to develop. Non-narcotic medication and other pain control measures, such as spinal blocks, should be used as long as they are sufficient. When pain is severe, narcotics should be given without concern about addiction when weighed against prevention of suffering. Narcotic dosage should be titrated carefully to suit the needs of the patient and lowered as pain diminishes.

Lack and Buckingham (1979:92) give additional advice relating to pain and symptom control as follows.

Every physician dealing with these patients should have a virtually inexhaustible store of remedies for all the common problems of terminal disease. A problem oriented approach is useful treating each symptom almost as a disease in itself to be diagnosed and treated. This enables the team to approach the patient with a positive, optimistic, realistic attitude. The benefits from such an approach for the patient and family are often dramatic.

A popular medication that many physicians use to control pain is "Brompton's Mixture." It is an oral preparation of morphine or diamorphine, cocaine, ethyl alcohol, a flavoring syrup, and chloroform water. The medications are given orally to many people. It is not given intravenous, so that mobility is at a maximum (Lamerton 1976; Saunders 1965).

Brompton's Mixture will not be the answer to all symptom control (Lack 1978). Attention must be focused on the whole person if affective control is to be achieved.

The aim of the treatment should be to identify the etiology. If it is a physical pain, the health care professional prevents the symptom with the measures that are needed. Lamerton (1976) advises symptoms may arise from almost any system or organ. The symptoms often change, and the care givers must be aware that terminal care differs from chronic care. Symptoms may vary from excruciating pain to undefinable weakness. Each requires an appropriate method of treatment. The correct approach is to define the cause of the symptoms and correct those disorders as quickly as possible. A great deal can be done with just good care. Three examples of this are as follows: (1) weakness can be managed with prevention of fatigue by the use of handrails, walkers, or other assistance devices; (2) anorexia may be treated by serving frequent, small, attractive, and nutritious meals; and (3) thirst can be alleviated by frequent sips of an acceptable liquid and good mouth care.

In addition to physical needs, it must be remembered that the patient has emotional needs. The dying patient feels isolated. A concerned ear and a sense of realistic optimism by the health care professional may do much to alleviate the patient's distress. It will only be after a review of all pain that a plan of

symptom control can be formulated for each patient (Lack and Buckingham 1979).

Understanding Grief

Even when the physical pain has been stopped, there must be more to offer the patient and the family. There must be an understanding of death. Death has not been a topic to be discussed freely with the terminal patient nor discussed at the time of an actual death with the family. Even though terminal patients and families have a need to communicate fears, anxieties, doubts, regrets, and fantasies to receptive listeners, they do not (Kubler-Ross 1969). The health care professional should have adequate training to help the patient and family understand their grief. Grief is not an illness. Experiencing grief will likely make one feel distraught, but the pain is not caused by the malfunction of an organ. Grief is a psychological condition. Relief lies only in the passing of time and in an emotional environment where one finds support (Dunlap 1978; Speck 1973).

This needed support can be given by the health care professional if he has an understanding of grief. Dunlap (1978) advised that three terms be recognized if this understanding of grief is to develop. These terms are often interchanged but are technically different in degrees. They are as follows: bereavement, grief, and mourning.

Not all researchers feel the same about grief.

Parks (1972) investigated post-bereavement grief. His belief is that grief is not a fixed state. It is a process and not a set of symptoms which start with bereavement and will then gradually fade away. Grief is a succession of clinical pictures that will blend one into another but may recur from time to time. There is a pattern, but the stages are not necessarily sequential and may not be clear-cut. The general rule is a person will usually cope with bereavement with the same psychological mechanism he previously used to contend with other stresses in his life. If he is silent during stress, he will remain silent during grief; if he cries during stress, he will cry; or if he has performed other acts during stress, those will be performed (Parks 1972).

Engle (1962), Kubler-Ross (1969), Linderman (1944), and Parks (1972) all agree the dying patient proceeds along a path characterized by various stages of grief until he is able to achieve the optimum. According to Kubler-Ross (1969), there are five stages of grief which are as follows: denial, anger, bargaining, depression, and acceptance.

Denial, the failure to acknowledge the facts, is the first stage. There is disbelief in the face of overwhelming medical evidence and a compulsion to be alone. The patient sometimes isolates himself and submerges

himself in the depths of depression and anxious thoughts (Kubler-Ross 1969).

Denial of death is a psychological defense. It is a process of refusing to acknowledge that death is a reality. In bereavement, denial is a buffer after the shock. It allows the patient time to collect himself (Kubler-Ross 1969). Natterson and Knudson (1960) advise that the problem with denial is that it cannot operate on an unconscious level to repress unwanted ideas or events. Denial activity has to be maintained at a conscious level. This makes denial a very tiring experience.

The denial defense will be strongest at the onset of a terminal illness rather than toward the end. The initial reaction is likely to result in momentary speechlessness, a blank look, dilated pupils, shallow and irregular breathing, fast but weak pulse, cool clammy skin with perspiration, and possible nausea. These are physiological signs of shock, but the symptoms are not likely to last any appreciable amount of time (Dunlap 1978).

Almost without exception, everyone will say "it is not time" or "the diagnosis is premature." The extent to which the person will continue to deny has to do with each person's individual makeup. This defense is usually temporary, although it may recur from time to time (Kubler-Ross 1969; Linderman 1944).

Kubler-Ross (1969) lists a denial that persists throughout the stages of dying. This denial is usually hope, hope of a new drug or hope of remission. Her feeling is that it is not human nature to accept death without leaving a door open for some hope.

The second of the five stages of grief is anger.

"Why me?"

The angry patient will raise his voice, he will make demands, he will complain and ask to be given attention, perhaps as the last loud cry of "I am alive, don't forget that. You can hear my voice, I am not dead yet!" The patient who is respected and understood, who is given attention and a little time, will soon lower his voice and reduce his angry demands (Kubler-Ross 1969:52).

Kubler-Ross (1969) and Mervyn (1971) advise that anger is the stage of grief that is the most difficult with which to cope for all concerned: family, health care professional, and patient. The patient may feel that the doctor does not know what to do and is no good. The health care professional may be seen more often than the doctor and receive anger for lack of care. The family does not understand. All these reasons have little to do with the people who are the targets of anger. Kubler-Ross (1969) advises if the health care professional or family reacts personally to this anger, their response will increase the anger on the part of the patient. This personal response will feed hostile behavior. Mervyn (1971) advises that an instinctive reaction is to soothe and pacify. This may

be instinctive but wrong. There should be help for the person to express his anger and to see that it is a normal response. Crying may be important. A distinction should be made between allowing someone to cry and saying they should cry. There may be guilt if he cannot cry. The most important thing to remember is to be available, not necessarily to talk, but willing to listen.

Bargaining is the third stage of grief. "If I do something heroic, there will be postponement of the inevitable death." It is typical for the patient to want more time, an extension of life. In return he will dedicate the remainder of his life to God, or leave his body to science, or stop some evil act he may be doing. This expression of bargaining may cause a guilt problem. The patient should be given the opportunity to work out his guilt if it does develop. It should be recognized that if strong guilt appears there may be need for a qualified professional to help resolve the problem (Kubler-Ross 1969).

The fourth stage of grief is depression. Kubler-Ross (1969) distinguished between two kinds of depression which the terminally ill will experience. The two types of depression are reactive depression and preparatory depression.

Reactive depression is described by Beck (1967). It is an acute, intensive, lonely, emotional response to a

particular distressing event. Problems of sleep and loss of appetite are reported with fatigue, low initiative, and activity. There is difficulty in concentration and various kinds of somatic distresses. When a reactive depression occurs in the dying patient, the usual technique for therapy is simple measures of reassurance and building self-esteem. In reactive depression the patient has a lot to share and may require a great deal of verbal interaction.

Preparatory depression is described in Kubler-Ross (1969) as beneficial. Patients who work through their anguish and anxieties are able to achieve acceptance. The emotional help suggested in reactive depression is not a good tactic for preparatory depression. The patient is in the process of losing everything and must be allowed to express sorrow if he chooses to do so. Preparatory depression does not require a great number of spoken words. It is usually silent. It is more a feeling, a touch of a hand, a stroking of the head, or just sitting quietly together.

The fifth and final stage, if it can be reached, is acceptance. The inevitable will come no matter what the patient does. During this time the patient seems to take comfort with a happy time. It is almost devoid of feeling. Events are now beyond control; the fight is over. During this phase, there may be a sense of detachment. It should

not be mistaken for rejection. There is no need for "toughness" at the end. If the terminal patient has reached peace of mind and has accepted it, others, too, should accept it (Kubler-Ross 1969).

Feifel (1967) felt we should accept the stages as a delineation and sequential steps in dying. He also felt they are a guide, and as a guide, it must be remembered that not all patients will pass through each stage and react in the same way. The patient may be in two or more stages at once, reverse stages, or even skip them.

Linderman (1944) discusses grief in the survivor who has had a loss. Striking effects are quite apparent when a family member dies. Grief becomes a syndrome with somatic and psychological symptoms. The most striking characteristics are weeping, feelings of exhaustion, and digestive disturbances. The bereaved may demonstrate a sense of unreality and detachment. He may be intensely preoccupied with the image of the dead. Guilt may plague him for acts done or not done. Accompanying this guilt is an extreme feeling of irritability. There may even be anger toward the dead.

Linderman (1944) and Kubler-Ross (1969) discuss some having grief before death. The family member may begin the grief the moment the prognosis is known. Then the process of mourning starts before the loss is

experienced. During the period of anticipated grief, the family member passes through the stages similar to the dying patient. He denies and disbelieves the medical evidence. He isolates himself because he fears sharing thoughts and doubts will aggravate his torment. He is angry at the patient because he has not taken care of himself and is going to leave the family member to face the world alone, perhaps to raise a family alone. Other anger may be at the doctor who is now incapable of doing enough or the nurse who is never around when he really needs her. He may even feel anger at God for lack of help when he really needs it.

Dunlap (1978) felt the family member who goes through this grief process is almost always a spouse or parent. Depression follows when reality of the present is thought of along with wondering about the future. During the illness, the family member has problems summoning up emotional strength to face the day. Finally, if it is reached, acceptance may be felt by the family member. This does not mean that the death is felt to be appropriate. It does mean that the death is accepted as happening and it is time to get on with other things.

Engle (1962:278) described the grieving person going through the process to acceptance with this new state of being as follows.

Many months are required for this process and if it is accomplished, the survivor's preoccupation with the dead person progressively lessens. Now, reminders of the dead person less often and more intensely evoke feelings of sadness and more ambivalent memories can be tolerated with less guilt. As the ties are progressively loosened, the earlier yearnings to be with the dead person, even in death, begin more and more to be replaced by a turning to life and wish to live. Now, the identification with the ideals, wishes and aspirations of the lost object provide an impetus to continue in life, often expressed as a wish "to be what he would have wanted to be" or "to carry on for him." When successful, this represents a developmental process, an actual growth experience, which may sometimes even contribute significantly to a characterological change in the mourner, as when a son settles down and assumes responsibilities which he had evaded prior to his father's death.

Bowlby (1961) and Parks (1972) agree with Engle (1962) about the grieving process. They all advise the loss should be mourned and the grieving person must come to terms with events in a reasonable amount of time. They also say that the person has to stop the grieving process and begin a rebuilding process. He must accept death as part of life.

Summary

This explanation of hospice was reported in terms of history, type of hospice, operational needs, criteria for admission, symptom control, and understanding grief. The literature has shown that both hospice and the patient will have needs. Answering those needs will be difficult. The primary problems center around two topics, reimbursement and understanding grief.

The first of these two problems is of immediate concern. The lack of financial coverage can shorten the life of any program. The solution must consider accepting patients on the basis of health care need, not ability to pay (Lack 1978). The next few years will be crucial to life of a hospice program until a solution for reimbursement is found (Cohen 1979).

The second problem, the understanding of grief, will always remain difficult because of the many factors involved (Dunlap 1978). Difficult does not mean the health care professional does nothing. He can explore all possibilities for relief to the patient with terminal illness and to his family. One such possibility is for the health care professional to develop and experience a working environment not usually found in health care agencies. In this environment there is education directed at understanding the needs of the dying patient (Lack 1978). If these problems are solved, the health care professional can be a part of hospice.

CHAPTER IV

COMMUNITY ORGANIZATION

Introduction

This chapter discusses techniques and approaches that people can use to help change their community as they deal with many complex and varied factors that influence their well-being. The community organizational process is the method used to make these changes to develop an organization in forming a hospice.

This hospice organization produced is a social system (Thompson 1967). A consideration for an understanding is found in organization theory (Hage 1965). This theory is not a prescription for the organizational process. It can give the health care professional an understanding of organizational behavior in terms of means and ends. This understanding will be relevant in the development of a hospice, which is of concern to the citizens of the community. To answer the concerns of these citizens, the information related to organizational means and ends will be presented broadly. This information will be addressed with sufficient scope to understand that there is a problem. Accordingly, the remainder of this chapter is divided into community development, social-action principles and strategies, and those factors that are an integral part of assessment.

Organizational Theory

Organizations can be seen as instruments for achievement of social purposes. Organizations, as agents, will be involved in efforts to achieve ends by the selection of appropriate means that should be measurable (Argyris and Schon 1978).

Hage (1965) listed four organizational means as complexity, centralization, formalization, and stratification. These concepts are defined as follows. (1) Complexity is a division of work. Hage reported that an organization divides its work into jobs which are used to achieve the ends of the organization. Complexity may be measured by the number of specialties and the length of training. Pugh, Hickson, Hinings, and Turner (1968) further defined this area as the number of specialists suited for that function. (2) Hage's (1965) concept, centralization, concerns the level at which the organization makes decisions. The concept is measured by the proportion of members who are in decision-making roles, such that the fewer who make decisions, the higher the centralization (Hage 1965). Pugh et al. (1968) agree that centralization is measured by the hierarchical locus at which decisions are made, the existing rules that limit authority of subordinates, and the frequency which a procedure is reviewed. (3) Hage's concept,

formalization, is measured by job definitions. Such definitions include the recording of role performance. Formalization refers to the extent of the written evaluation of the job function (Pugh et al. 1968). (4) Hage's (1965) measure of stratification is in terms of how the organization distributes its rewards. Stratification is measured by the differences in rewards between the top of the organization and the bottom.

With Hage's (1965) means, organizations will accomplish specific objectives. The objectives are the ends. Hage (1965) listed four organizational ends as adaptiveness, production, efficiency, and job satisfaction, which are defined as follows. (1) Adaptiveness is defined in terms of the flexibility of the organization. The number of new programs that are started in a given period of time is measured. Pugh et al. (1968) listed adaptiveness as traditionalism, but agreed with Hage's (1965) definition. (2) Production concerns the effectiveness of the organization. Production is measured by the increase in volume of a product or service in a given period of time. (3) Efficiency is the cost of the product or service. Efficiency is measured by how much more or less money is used in a given period of time. (4) Finally, Hage's (1965) job satisfaction is the morale in the organization. Job satisfaction

is measured by the number of new workers who have been hired in one position in a given period of time.

Hage (1965) felt that these organizational means and ends represent primarily what the organization does. These eight variables are formal characteristics of an organization. Hage felt that a major consideration in the choice of these variables was that they be general enough to be applied to any organization. Nadel (1957) noted that such formal characteristics are on a higher level of abstraction, and that they allow much greater generalities than content categories. Hage (1965) reported that there are three additional advantages of formal characteristics. These advantages are as follows.

(1) Formal characteristics can differentiate between different organizations with similar objectives as well as to indicate similarities between different organizations with different objectives. (2) Formal characteristics are not time specific or culturally bound. (3) Because formal characteristics are independent of time and culture, they are useful in the evaluation of organizations.

Hage (1965) developed with his means and ends a theory, an instrument of prediction. With the use of this theory, multivariate analysis may be performed to study systematically the relationship of each variable to one another in the development of an organization.

Hage (1965) reported that the theme central in his theory is the idea of functional strains. This dynamic, which is organizational behavior, functions such that an increase in one variable results in a decrease in another, or the maximization of one social means results in the minimization of another social means (Blau and Scott 1962; Parsons, Bales, and Shils 1955). This dependence of one variable on another is not new (Blau and Scott 1962). Hage (1965) specified which variables are in oppositions, as listed in the Appendix.

Hage (1965) bases much of his work on the writing of Weber (1947), Barnard (1964), and Thompson (1961). Hage (1965) formulated seven propositions from these three authors' works.

Weber (1947) centered his work on the structure in a bureaucratic framework. This framework is a system of rules and procedures which are controlled through official positions. These positions are the hierarchy arrangement. Weber (1947) reported the efficiency of bureaucracy was demonstrated by better discipline and control of role performance. Weber (1947) further discusses formalization of the job results in the development of an expert in a limited area. This results in greater efficiency in performance with fewer errors. This combination of centralization, how the organization makes decisions, and formalization,

well-defined jobs, are derived from Weber's (1947) variables. Hage (1965) combined two means, centralization and formalization, with two ends, production and efficiency, and then formulated his first three propositions as listed in the Appendix.

Barnard (1964) was interested in facts relating to status systems. His work concerned the reporting of an organization having different levels of leaders and followers. Motivation to work hard resulted in increased production because of more effort. This increase of production satisfied the man at the top but not the man at the bottom of the hierarchy. Barnard (1964) reported that lack of satisfaction from the man at the bottom built in failure because of the limited number of jobs at the top. This status system of the hierarchy reduces mobility and results in reduced job satisfaction. Barnard (1964) also noted that this stratification, reducing the rewards between the top and the bottom, reduced adaptiveness, the number of new programs started. Hage (1965) combined Barnard's (1964) work with his variables; one means, stratification, and three ends, job satisfaction, adaptiveness, and production, and then formulated his fourth, fifth, and sixth propositions as listed in the Appendix.

Thompson's (1961) work noted the proliferation of specialists in an organization was having an undermining

effect on the authority of the hierarchy. To make decisions, the hierarchy must consult the specialists. The specialists have the power to give or withhold information. This power increases the possibility of loss of control. The specialists have access to information and can cut across lines of authority. Thus, the increase in complexity results in decentralization. Hage (1965) combined these two means, complexity and centralization, and then formulated his seventh proposition as listed in the Appendix.

Hage (1965) assumed that his four means and the four ends could be used to derive additional hypotheses. He applied the rule of syllogism and formed twenty-one corollaries as listed in the Appendix.

Hage (1965) believed that there are limits to how much the organizational leader can emphasize organizational end over others. The limits of each of the means and ends is expressed in his eighth proposition as seen in the Appendix. The actual limits will require additional research. Understanding of organizational dynamics should be achieved if the relationship to organizational means and ends are known prior to development of an organization. This understanding will give the health care professional the needed tools with which to work within the community development process.

History and Background

The community organizational process is a means by which people recognize and protect their own lives collectively. They identify their needs and find resources to meet those needs (Ross 1970). The technique of community organization has been utilized in various programs around the world so indigenous people can influence their own community members to solve problems (Rothman 1974).

Community organizational process was originally perceived by society members as a form of charity. The process called for the involvement of the affluent to help the poor. Case workers gained involvement by assisting the affluent, then gained responsibility for direct service to the needy. At this point, the impoverished became increasingly less visible to the upper class. The original community organizational practitioner began working with the privileged members of the community to coordinate and plan various social services without respect to the total needs of the community. It has been only within the past few years that the community organizational worker has begun dealing with the entire spectrum of the community (Arstein 1970).

Help from the community organizational worker is not always welcomed. The practice of imposing projects, even in emergency situations, comes into a great deal of

criticism. People in the local community may not always recognize the project as an emergency. The indigenous citizen of the community has lived with the situation and has adjusted to his practices and ideas in relation to his perceived needs (Rothman 1974; Ross 1970).

There is an increased appreciation for the value of indigenous plans because of this adjustment. This recognition successfully works through problems that will increase the community's capacity to deal with other problems. This plan implies, and is true, that a community may develop a problem-solving technique in dealing with one problem that may be used for other problems (Rothman 1974; Ross 1970).

Ross (1970) advised that people who desire change and have problems will facilitate change. To seek change by imposing ideas on a community is poor technique. If there is no desire for change, the project that is facilitating change may not fail but will at best struggle. Support is the key ingredient to this change. Those people who make up the group, who share this common interest, and support or oppose these interests make up the community. This community may go through a process of identifying its needs and objectives, focus on these needs and objectives, and work through to a solution (Rothman 1974; Ross 1970). Rothman (1974) and Ross (1970) both agree that the

community-development model and the social-action model are basic approaches the community can use in the community organizational process to work through to a solution. These two approaches are not exhaustive of the potential possibilities but do describe the phenomenon of the process of community change.

Community Development: Principles
and Strategies

Ross (1970) felt the change should be a slow process with few conflicts between groups in the community-development approach. There should be an integration of needs of individuals in the community. Rothman (1974) reported approaches such as this would assess the needs as seen by the consumer. The community's indigenous leaders are used in this attempt to fit change into existing social structure by using basic principles. Power is gained from using the indigenous people, thus avoiding becoming a threat to the community. The existing power structure is integrated rather than confronted. The goals are to problem-solve and have people participate (Rothman 1974; Ross 1970). Selig (1975) agreed with this means. He discusses five basic principles, and explanations are as follows. (1) Understand the culture of the consumers. The health care professional needs to understand the attitudes, values, and orientations of the community before any planning or program development

can take place. Understanding gives insight into the community members' felt needs. What kinds of structures currently exist in the community, where the power is located, what kinds of communication patterns exist, and who the indigenous leaders are who will be involved in the program is of primary importance. (2) Meeting the felt needs of the community members is the second principle. The consumer needs to feel commitment and have desire for the program itself to see potential rewards. Without rewards, the likelihood of consumer participation and help will be minimal. (3) Using indigenous people is the third principle. People who are part of the community are more likely to understand culture and be accepted by other community leaders. This principle does not imply that everyone in a program necessarily needs to be indigenous. It does mean that a program which totally ignores the community members, especially its leaders, is likely to fail. (4) Fourth, communicating enthusiasm about the process, tasks, and objectives is essential. Projects without commitment are probably less likely to succeed than a second rate plan that is pursued with enthusiasm. (5) Fitting the program into existing structures is the fifth principle. It is much easier to use existing resources rather than to create a new set of resources. New programs and attempts at organizing are seen as being alien to

existing programs. These programs and attempts at organizing can be seen as a threat and are often sabotaged by the very people who could benefit from their implementation. The health care professional must keep in mind multiple goals in order to develop a program. This is done so that the needs of the consumer can be met. Utilizing existing resources also helps decrease duplication of services, which should be recognized as wasteful. In the case of hospice, utilizing existing health care facilities and home health agencies may be cost effective.

Dunham (1963) and Goodenough (1963) added assumptions and principles regarding community development to Selig's (1975) list. These assumptions and principles are as follows: (1) a program of community development should be dynamic and based on fact with objectives, sound organization, careful planning, and flexibility; (2) a self-help approach is basic to community development; all technical assistance should encourage self-help; (3) voluntary cooperation is the key to effective community development; (4) the development of attitudes of self-direction and cooperation are as important as specific accomplishments; (5) community development should be an educational process; (6) the community should have as much freedom and self-determination as the law allows; (7) participation of all groups is important; (8) the community development process will be

democratic; (9) the community-development model requires creative dynamic leadership participation; (10) the community-development model requires trained personnel; and (11) the health care professional must view the community as an equal and speak their language. The health care professional functions best when he is able to link into local customs, beliefs, and practices. He becomes intimately familiar with the emotional aspects of the culture because he may be changing health attitudes and etiquette. The health care professional also becomes aware of the economic and social organizations such as those of work, politics, leadership, and family patterns because they are emotional aspects of the culture (Ross 1970).

Insight into the culture can be obtained from Mead (1955). She studied various cultures. The purpose of her study was to form an understanding of these cultures so that change could be examined. One of her assumptions was that each culture is a systematic and integrated whole. A change in any one part of the culture will result in changes in other parts. Because of these possible changes, the health care professional should be cognizant of principles she recognized. Mead's (1955) principles are as follows: (1) the health care professional must recognize his own cultural bias; (2) he should remember that beliefs and

attitudes of the community have functions and purposes to serve; (3) he examines each change from the point of view of the community; (4) he avoids master plans because interdependencies of culture make prediction of response difficult; (5) he is cognizant that change produces stress, emotion, tension, and possible loss of identity; and (6) the health care professional recognizes that frustration usually follows incompatibility between some old methods and some new methods.

Dunham (1963) felt it was important to understand Mead's findings when working with the community development process. Reinforcement of Mead's beliefs was also documented by Paul (1955). Both researchers felt health must be viewed from the perspective of the client. The health care professional knows all the health practices of the community's culture. Warren (1965) felt the health care professional must be aware of attitudes and expectations of the community. Additionally, he felt that the strategies used to organize a community deals with certain community health practices and cultures while utilizing the principles that follow: (1) the health care professional comprehends the felt needs of the people of the community to fit programs into existing community structures when possible; (2) he needs to be committed to the process and objectives of the project; and (3) the health care

professional becomes acquainted with those who are leaders in the community. Once these respectable citizens are found, interested people in the community meet together to discuss their medical needs. The health care professional can help develop a cohesive problem-solving atmosphere for the group once the discussion starts. At this point, the process in developing a health resource becomes the effort of those people who are working together. The process is one that will develop communication, better listening, and sense of accomplishment when concrete gains have been made.

Power and competency over the ability to influence their community will be felt by those involved in the problem-solving process. The health care professional remembers his role and does not abandon being that of a catalyst. Success can be obtained if leadership, direction, and responsibility emerge from this process to the indigenous people of the community (Ross 1970).

Another proponent of community development was Piven (1966). He wrote of positive uses of citizen participation. Participation can be used to increase the effectiveness of policies, to increase the potential benefits of programs, or to promote health. Piven (1966) suggested a means that would foster participation. His basic idea behind citizen participation is that people should be involved in decisions,

policies, and programs that affect them. Citizen participation is the key to effective programs by using the community development model. Selig (1975) suggested that success of policies and programs are enhanced when the consumer is involved in the planning and implementation stage of a program like hospice. Piven (1966) felt the means that would foster this participation is a task-oriented self-help program. Self-help programs are associated with possession of scientific information (Paul 1955; Piven 1966; Spicer 1952). This type of program is more popular in the United States than other countries of the world (Spicer 1952). Paul (1955) supported self-help. He felt that people who did not participate were less likely to change. Spicer (1952) describes this group as several people who organize themselves around a particular issue without the aid of a professional. They are the advocates of the self-help approach. They are the people who have a common, shared problem, and hope that through their organization they will be able to help themselves and others. Common examples are Alcoholics Anonymous, Parents Without Partners, and La Leche League (Paul 1955; Piven 1966; Spicer 1952).

Caplan (1974) also emphasizes the importance of a self-help group. He described it as a "health-promoting force." This group represents a person-to-person social level which will assist people in mastering challenges and

strains of their lives. An example Caplan (1974) reported was a New England community that carried out a self-help project to meet a community health need. Systematic observation, recording, and interpretations were made showing how these people reacted to decisions, their plans, and how their action on programs was initiated and carried out. By keeping this information, he knew this method was effective for a small group of people to organize and act on their specific problem. Caplan (1974) felt this type of group usually develops a strong sense of solidarity and a strong sense of belonging. This sense of belonging is important in the community-development approach (Rothman 1974; Ross 1970).

Social Action: Principles and Strategies

Ross (1970) stated some feel that the social-action approach to community organization is at the opposite end of the spectrum from the community-development model. He did not feel this is so. He further stated the goals are similar to community-development model--both problem solve and have people participate. The approach by the social actionist to these goals is more revolutionary rather than evolutionary. This social-action model accentuates the building of a new organization. One group is organized to change another. It is through this organization and recognition of opposing views that a community becomes

cohesive. The social-action approach assumes change is not possible without a difference in power. The power comes from a group effort meeting the felt needs that are shared by the people in the community (Rothman 1974; Ross 1970).

One of the best known advocates of the social-action approach is Saul Alinsky (Sanders 1966). Alinsky believed that power is the key to change. Alinsky also believed power should be obtained through organization and obtaining a consensus on an issue. The lack of care for the dying is an issue about which something can be done and an issue in which a consensus can be obtained (English 1979). Moreover, Cohen (1979) felt that this lack of care is an issue that is controversial. Controversy makes it easier for the social-action approach. The organizer will have conflict and the rearrangement of power will be achieved when a consensus is obtained (Sanders 1966).

Ross (1970) advised that when conflict is present, the next step is to obtain leadership. Alinsky (1946) discussed the importance of leadership in connection with this social-action approach to community change. Alinsky's idea of indigenous leadership is very similar to the idea of citizen participation. The people themselves are the only ones who can build a "people's organization." Alinsky (1946) believed the only way people can express themselves is through their leader. He felt without the support of an

indigenous leader, an organizational venture will not work. Indigenous leaders are the only real representatives of the community. They must go through a process that allows the community to get together, talk, and reach a common agreement. Ross (1970) felt formal leaders often fail due to inability to gain support of indigenous leaders. A common problem that arises is that the health care professional judges leadership according to his own criteria and evaluates what is good for the community by his own standards (Ross 1970; Rothman 1974). Ross (1970) and Rothman (1974) both reported these standards are often based on criteria very different from what the community would choose.

This identification of these indigenous leaders may be difficult. The indigenous leader usually is not known by all involved. Locating the leader requires interviewing and observation in the local setting. Alinsky (1946) felt there is rarely a "complete leader." He felt that no one person has a large following in every sphere of activity. Rather, there are leaders in different areas of community life: intellectual leaders, religious leaders, athletic leaders, and political leaders. A leader who is a partial leader soon finds that his leadership will be tested in many areas to see if his abilities permit him to expand in the community. Sanders (1966) felt in developing a local community organization, the role of the local community

indigenous leader will be to represent the community and carry the organization onward.

The local indigenous leaders are made aware of the social-action approach. Levy (1968) felt this social-action approach can take place without a direct conflict but will not eliminate total conflict. The same basic principles are to be used in both conflict approaches but to a lesser degree in the latter. The target is still change. A consensus of what the problem is must be obtained. Participation is crucial and strategies that are appropriate are chosen carefully. Levy (1970) felt regardless of the strategies, direct conflict or not, the social-action approach is needed to keep the problem of health before the public continually as a means of assuring public support.

Libman (1969) described Mobilization for Youth, a project that was funded by the United States Office of Economic Opportunity, as an example of social action. In this project the work focused on help in a crisis situation. There was a lack of adequately trained personnel. Because of the nature of the issues there was a question as to whether the organization made a genuine contribution to the people's ability to handle a crisis. The workers of Mobilization for Youth decided that they needed to begin to produce institutional change. They became advocates

on behalf of their clients, leading confrontations with city governments and landholders. The workers became concerned with individuals and the community welfare. Voter registration places were organized. Mobilization for Youth attempted to change the community through and by people who came to them with problems. Libman (1969) felt this was a good example of an agency responding to the demands and needs of a community through a social-action model. Problems developed in trying to integrate all members' efforts with the needs of the community. The agency and people of the community used the social-action model to put pressure on landholders, city officials, and agencies to meet the community needs through power.

Ross (1970) stated conflict strategy of community organization puts emphasis on obtaining this power. Arstein (1970) promoted this concept that citizen participation is pointless without a redistribution of power. He felt there is a critical difference between going through the ritual of participation and having the real power needed to affect the outcome of the process. Citizen participation without redistribution of power is "tokenism." The health care professional attempts to raise the consciousness of the group he is going to organize. He raises their consciousness by pointing out conflicts between the consumers' goals and the whole community's goals. Increasing

health services where many feel the service is adequate in the case of hospice is an example. This is the methodology to hold together the organization and to organize change (Rothman 1974). It is the acquisition of power by the people that will become the basis for the change as well as a sense of competency and control over the community's future if this approach is used (Ross 1970).

Assessment

Gathering information is an integral part of effective planning (Bruhn 1973). Blum (1974) defines assessment as this information-gathering process. He further states assessment regarding community cultures, values, and standards are an essential part in determining strategies for the planning process. Bruhn (1973) felt an assessment was a continuous evolving process drawing on the past and present to predict the future. Blum (1974) noted that information obtained from assessment provides an early warning sign of impending problems. Assessment data should suggest intervention and provide a basis for discovering the problems of the community (Bruhn 1973). The health care professional should achieve knowledge and expertise in assessment if he is to participate actively in community planning (Reinhardt and Chatlin 1977).

Freeman (1970) understood the value of an assessment. She advised that the health care professional may

influence family, individuals, and community-level decisions toward more effective health care, using assessment. Blum (1974) agreed that knowledgeable participation in community planning and action for these health care needs will involve assessment. In developing a diagnosis of the community, the health care professional uses planning, evaluation, and problem analysis skills to complete a community assessment which is used to identify problems and solutions for input into planning (Freeman 1970). Effrat (1974) noted that a systematic assessment of interest groups will assist the health care professional's focus on the community's characteristics and needs. She also noted assessment may include aspects of the community which do not appear to be related to health. Knowledgeable participation would be impossible unless there is an understanding of the contributing agents that influence the community. This can be done only if the health care professional participates as he observes, assessing as he affects changes (Freeman 1970).

When making changes it must be understood that the health of the community is influenced by many factors (Blum 1974). Braden and Herban (1976) divided these factors into geographic, demographic, and socioeconomic characteristics. They further divided the socioeconomic characteristics into social class, education, occupation,

housing, physical and social environment, political structure, and resource availability.

The first of these assessment characteristics that will be reported is the geographical setting. The boundaries of a community, as well as the location, will have a bearing on the health of the citizens. The climate also affects the type of health problems prevalent in an area. Altitude, temperature, humidity, rivers, mountains, and highways all can play an important part in the health of a community (Braden and Herban 1976). The climate impact affects the types of diseases and infections found in a community, while boundaries such as mountains and highways affect accessibility of health services (Mausner and Bahn 1974). Kark (1974) noted that all physical aspects of the community are important in understanding where natural groupings of people occur. He advised some services may not be acceptable because of their being located in another section of the community that is unfamiliar, hard to reach, or undesirable. People in an area tend to move within a certain boundary and do not move or travel to facilities or services outside those boundaries.

The second characteristic reported is demography. Reinke (1972) reported demography as a study of size, territorial distribution, and composition of the population. Bogue (1969) stated the population is made up of components

of change. He listed the components as follows: fertility, mortality, migration, marriage, and social mobility. He felt these components determine the size, composition, distribution, and health of the community members.

Understanding the relationship of health and demography has special relevance to the health care professional (Effrat 1974). The health is affected by growth trends of the population, as well as change in age, sex, and racial makeup of the community (Braden and Herban 1976; Bogue 1969; Effrat 1974). Have there been any changes in the distribution of these groups within the community? It may be that a section of the community has become an age, sex, or racial ghetto. A concentration would affect the community's needs (Bogue 1969; Effrat 1974). Braden and Herban (1976) reported that the locations of these groups are an important demographic condition for the health care professional to note. There may be high-risk relating to health. The demographic data regarding a high-risk group may be of significant importance in evaluating the data of an assessment for hospice or other health services (Braden and Herban 1976; Effrat 1974; English 1979). The percentage of people in each age group may have a bearing on the health needs and priorities of the community. It should be determined what the age group is so that priorities in planning of services can be assessed. Mausner and

Bahn (1974) felt that age is the most important determinant among demographic variables. Mortality and morbidity rates of almost all conditions show a relationship to age. Chronic diseases increase as the age of the population increases.

Sex as a demographic variable has definite impact on health planning. Death rates are higher in males than females, but morbidity rates are higher in females (Mausner and Bahn 1974).

Bogue (1969) and Mausner and Bahn (1974) stated the ethnic makeup of a community is a variable that affects the health of a community. Disease incidence is shown to differ between racial groups. There is a question as to whether this is related to race or socioeconomic conditions (Mausner and Bahn 1974). Most diseases are reported in categories of white or non-white. Non-whites have higher death rates than whites in many classifications of age and sex. Examples of this are hypertension, heart disease, cerebrovascular accidents, and tuberculosis. All have higher death rates among non-whites. However, arteriosclerotic heart disease and cancer contribute to higher death rates in whites. Braden and Herban (1976) reported it has not been determined if the difference in health statistics of ethnic groups is related to sociocultural, genetic, or environmental factors. The interaction of these factors may be important to the causes of some disease states. Ethnic groups may be a

determinant of the response of an individual or group to an illness, pain, death, or disability (Kark 1974). These factors may be vital in determining the makeup of the population of the hospice (English 1979).

The third of the characteristics reported is socioeconomic. This third characteristic can be further divided into six components. These components as listed by Mausner and Bahn (1974) are as follows: social class, education, occupation, housing, political structure, and resource availability. Tinkham and Voorhies (1972) felt that this socioeconomic characteristic has a great influence on the health of the community. They reported that socioeconomic levels are differentiated by the degree of prestige, education, income, access to products, residence, and availability of services. Members of "class" associate with each other more than other members of a community outside their "class." This economic reference must not be overlooked in relation to health care (Mausner and Bahn 1974). Where people live, work, or who goes to school is important. These considerations make up part of the picture of the community (Kark 1974). This picture will include the first component social class.

Social class is a strong element linked to mortality rates, physical and mental morbidity growth and maturation, and intelligence. The difference in health

of various social classes has been linked to different behavior patterns, resources, and environment (Kark 1974). Education, occupation, and locality are just a few indicators of social class that have been used for measurement. Kark (1974) reported that education should be investigated as a separate component. He suggested, as an example, sometimes poor nutrition is due to lack of money to buy proper foods and not lack of education. Poor nutrition could be attributed to ignorance as to what is good nutrition, however, economic status and educational levels have independent effects on health. A member of the community may have little formal education and still have good nutrition. Kark (1974) advised these considerations make education a difficult component to weigh.

Mausner and Bahn (1974) reported that the third component, occupation, can exert a profound effect on the health of the individual, as well as that of the community. It can contribute to a large difference in mortality and morbidity rates. These effects may be due to exposure to extremes of stress, noise, chemicals, and biological causes. Working with extremes are not the only causes. Living near extremes will be just as hazardous. Examples of these extremes are as follows. Excessive stress may produce hypertension or a "stroke." Chemical plants may cause the community to have increased

lung cancer. Controlling of animals and insects may be beneficial or detrimental to one's health. All these aspects contribute to the condition of the community's health (Fox, Hall, and Elvebach 1970; Kark 1974; Mausner and Bahn 1974).

Effrat (1974) reported on the fourth component. There is an interdependence on the physical and social environment. The physical environment includes water, air quality, and transportation. The social environment includes recreational facilities, quality of social planning, and the stability of the population. Where a person is living will have a great deal to do with the quality of life and, consequently, with his health.

The fifth component is an individual's housing conditions. This includes location, the state of repair, insect or rodent infestation, overcrowding, and safety factors. All have been linked to health problems (Tinkham and Voorhies 1972). They reported certain diseases are known to be prevalent in areas where the community has problems in controlling their environment. This information may be helpful when trying to gain support for a health service. English (1979) advised communities with large numbers of cancer patients are easier to organize in favor of hospice, especially those whose homes are near chemical plants.

The sixth of the socioeconomic factors reported on is a highly developed political structure. Rothman (1974) and Ross (1970) felt this would be advantageous to the community-development model in a community organizational effort. They also stated that when agencies, facilities, and services are not available and political structure is resistant to change, then the social approach might be best. It is important to know who the leader is in the political structure and which facilities are available.

The final component is the type and location of resources. These are an integral part of a community health or a hospice assessment (Blum 1974; Effrat 1974; Kark 1974). Blum (1974) listed four categories of health resources as important to assessment. These categories are health manpower, other manpower, available tax dollars, and recognized organizations. Examples of each are as follows: (1) health manpower pertains to the number of physicians, dentists, nurses, and others who are felt needed; (2) other manpower describes untrained but available categories of workers that are needed for non-medical care; (3) available tax dollars pertains to the dollars needed for each skill, the money that is available, and the source of money; (4) recognized organizations pertains to organizations that can be utilized as a resource in the development of a hospice (Blum 1974; Effrat 1974; Kark 1974).

Kark (1974) advised once the data is collected it must be used appropriately. See if there is a need for health care as well as if the resources for development are available. Kark felt the completed assessment data points to clues and suggestions to existing problems and areas of need in the community. The descriptive information is of no value unless an analysis of the data is carried out to identify solutions to problems. Buck (1967) reported the health care professional should assist in the establishment of priorities. This is dependent on findings during identification and analysis. Once the identification and the analysis have been completed then it is time for the community leaders to develop the organization for the needed health care (Braden and Herban 1976).

Summary

This chapter discusses organizational theory, community organization history and background, the principles and strategies of two community organizational approaches, and those factors that are an integral part of assessment. Through understanding of Hage's (1965) organizational theory, the health care professional can see how means and ends of organizations interrelate. Additionally, the health care professional can identify the development of community organization and how

community-development and social-action approaches can be used to develop a health resource. Finally, assessment factors that are needed in the development of health resources are discussed. This information-gathering process is an integral part of effective planning (Bruhn 1973). Assessment is needed to determine if resources are available for hospice. The terms of assessment presented for the present purpose is as follows. First, there is geographical setting. This is the boundaries of a community as well as the location of the community. Altitude, temperature, humidity, rivers, mountains, and highways are all factors that are to be considered in the geographical setting (Braden and Herban 1976). Next, there is demography. This is the study of the community size, territorial distribution, and composition of the population. Fertility, mortality, migration, marriage, and social mobility are factors that make up demography (Bogue 1969). Finally, there are socioeconomic characteristics. This assessment factor is made up of social class, education, occupation, housing, political structure, and resource availability (Mausner and Bahn 1974).

CHAPTER V

DISCUSSION

Rothman (1974) felt that in the community organizational process, a combination of models is useful in the formation of a program of action to answer health needs. The health care professional becomes sensitive to the mixed uses of techniques within a single project optimizing their use as he develops objectives for them. To do this, the health care professional promotes community development when there appears to be consensus regarding problems. He promotes social action if services are not available and there is resistance to change. He uses blending, mixing, and a phasing in or out relationship when it appears neither of the models will be completely right. A given project may begin in one model and then at a later stage move into another to produce the best results for health planning (Ross 1970; Rothman 1974).

Planning for health at the community level can be one way to promote community participation. Since the early years of this century, many voluntary health interest agencies have worked at reducing the incidence of specific disease entities by developing treatment and prevention programs. Some of these agencies chose to become less

fragmented and combined efforts. These agencies moved away from the emphasis on reduction of disease incidence and moved toward planning for health care, giving consideration to manpower, facilities, economies, education, and promotion of health. This attempt to consolidate planning efforts under a central agency resulted in the development of the United Way in 1918 (Reinke 1972).

As can be seen, planning is not new, but citizen participation in the planning is new. The role of community organization in planning is to assure that persons affected by new programs are involved in determining what and how they are implemented (Alinsky 1946). With the enactment of the comprehensive Health Planning Act (PL 89-749), health planning was authorized at the community level (Miller, Schuh, and Moore 1978). It was acknowledged that problems real to the community are not understood as urgent by the outside planners, and that planning is appropriate if input is received from the community which the planning ultimately affects.

Even when the plan for a new health service has been implemented by the indigenous citizens, there still are problems. Individuals and groups concerned about a new health service assume their concern is widely shared throughout the community. This assumption is not valid in the case of hospice (English 1979). Local health

providers often do not recognize the existence or extent of the problem. Everyone in the community is not experiencing equal difficulty in obtaining care for the dying. In fact, some citizens do not know what a hospice is and do not care whether or not it is provided. Bonneau (1979) advised that these possible different viewpoints suggest that all members of the community are not experiencing the lack of adequate terminal care with the same sense of importance or urgency.

Recent experiences by some hospice groups in a number of areas indicate that a community lacking hospice care will face problems in resolving the situation (English 1979). Concerned citizens are surprised and discouraged to learn that many people just do not care. They are not informed enough to make a decision regarding care for the dying (Bonneau 1979). More importantly, the people who first become aware of the problem usually do not have technical knowledge or sufficient resources to devise and implement an appropriate solution to the care of the dying (English 1979).

Substantial work will be required to move from a small initial perception of hospice to a community-supported resolution of the problem. A first step is to use the community development model to gain support of various recognized community groups and individuals (Ross 1970).

Variation in the nature and extent of support can be anticipated. Some individuals and groups in the community will become eager and active participants; others will not. Some less concrete endorsements from individuals or groups will provide passive support in addition to the active support (Rothman 1974). Any kind of support is valuable in promoting hospice because efforts to develop a solution to provide care for the terminally ill will be difficult (English 1979).

An essential component in the community organizational process before activities get too disorganized is the establishment of a basic organizational structure. This is done so that subsequent activities can be carried out efficiently (The Primary Care Development Project 1976; Ross 1970). Do not underestimate the importance of the development of the basic organization. It allows the group to keep track of its progress and develop a task oriented and systematic approach to efforts. The establishment of a formal structure will ease the way for carrying out future activities. The following six-point work plan, suggested by English (1979) and in The Primary Care Development Project (1976), will allow that structure to be created: (1) select or designate members as officers with specific responsibilities; (2) establish a schedule for meetings with advance mailing notices; (3) prepare and follow an agenda

for each meeting to keep discussions focused; (4) assign responsibilities to members to promote continued interest and involvement; (5) record minutes to keep track of progress, decisions, and assigned responsibilities; and (6) communicate activities and progress to the community.

Certain basic skills are necessary for the organizers to build and maintain a successful organization in addition to the establishment of this basic structure. Leavitt (1970) suggests that these skills include the ability to motivate people, focus discussions, set priorities, assign tasks, delegate responsibilities, and follow through on decisions. Initial efforts may falter or fail without these skills.

When the basic organizational structure is established and meetings are functioning smoothly, it is essential to assess and document the existence of the need for hospice. An effective method of creating an awareness is to provide the data gathered in an assessment such as geographic, demographic, and socioeconomic characteristics of the community being organized (Blum 1974; Bruhn 1973; Reinhardt and Chatlin 1977). This information will call attention to what seems to be current care for the terminally ill patient. Specific data regarding case studies and what other communities are doing for terminal care will create questions regarding what the community is doing for the dying. Many

of the answers can be obtained along with assistance from the community health systems agency (The Primary Care Development Project 1976).

English (1979) advised that the documentation of the need for hospice is difficult to obtain even with health systems agency assistance. The original level of community awareness will determine the extent to which additional documentation is needed to convince others of the importance of hospice (Plant 1977). There is a difference between the perceived needs of the community members and the actual needs of the community (Ross 1970). Some citizens feel that the difficulty in securing care means it is not needed. Careful examination of the assessment data should give the health care professional the information so that he can facilitate the organization of members into an appropriate solution (Blum 1974).

The basic organization and those with whom the members have been in touch is to be objective. They seek a common understanding of what effect a hospice will have on the community. If evidence supports the need for hospice, the next step is to gain more community support (English 1979).

To gain additional community support, additional awareness is a necessary step. Some of the effort is made while gathering information. The next step is to enlist

as many people as possible who are involved in community affairs and who are also influential citizens. The people to identify and contact are those with recognized positions of influence. It is these indigenous leaders who may affect the health care system and who have access to established community groups. They are intellectual leaders, religious leaders, athletic leaders, or political leaders. Their involvement needs to be active. The first contact is made in an effort to keep them aware of hospice. Additional contacts are made to continuously make them aware of the activities and utilize their support. A list of these influential citizens are drawn up, and group members are assigned the responsibility of contacting each for their support (English 1979; Ross 1970; Rothman 1974; The Primary Care Development Project 1976).

Each person contacted is given the background of hospice, documentation of the need for hospice, and an invitation to support and participate in the group's effort to establish a needed health care service such as hospice. Ask for suggestions; are there others whom should be contacted? If certain names are mentioned over and over, there are others who need to be part of this group. A special effort is made to contact and gain their support (Bonneau 1979).

In addition to leaders of the community, consumers of the health service are part of this group. Those people

who are terminally ill, their families, and those who did not have hospice care, but could have used it, are made members of the group (English 1979).

Further community support can be obtained by reporting to all major organizations the progress by newsletter. Have group members serve as speakers to local civic clubs and organizations. Cite data such as case studies where there was need for hospice. Another effective technique is to relate the hospice problem to the goals of each organization or club. Ask each of these organizations to appoint a representative to the hospice group. Establish contact with the local radio, TV, and newspaper. Brief them on the group's concerns and activities. Let them know of the case studies. If the needed community support has been obtained, the group for hospice is able to hold a community-wide meeting open to the public and the press. The program is planned so that there is good attendance. Have encouraging individuals to explain in their own words how they have experienced the need for the hospice. Documentation about the problem is presented and discussed. This kind of meeting is an important opportunity to increase support for hospice. This meeting is not approached casually. It must be well-planned and handled correctly, an agenda must be followed, minutes recorded, and progress

communicated to the community (English 1979; The Primary Care Development Project 1976).

At this point, the interest and support are generated so that membership is representative of the entire community. This group will assume the responsibility for the development of an acceptable and functional solution to care for the dying (English 1979; The Primary Care Development Project 1976). Many of these steps that will be used to form this new group into a functioning unit were used in formulating the original group. These steps suggested by English (1979) and The Primary Care Development Project (1976) are as follows: (1) identify individuals among supporters who are willing to be working members; (2) keep influential members of other organizations informed and active, and appoint these people to serve on committees when possible; (3) seek individual members to represent portions of the community not yet represented; (4) formalize the organizational framework; (5) incorporate as a not-for-profit organization; and (6) appoint an executive committee if the organization becomes too unwieldy to handle business.

This group will consist of individuals who have not previously worked together. It will take time for them to develop a group identity. This identity is important as a cohesive factor (Ross 1970). Elements that may effect the length of time for a group to be cohesive and work as one

were reported on by The Primary Care Development Project (1976). These factors are as follows: (1) the size of the representative group; (2) the extent members have known each other previously; (3) the skill of the chairman focusing activities and discussions; and (4) the skill of the chairman to encourage participation. Once the group has developed an identity of its own, a goal is to get at least one recognized community organization to endorse hospice. This reinforces the legitimacy of the movement within the community. This encourages public support and acceptance of the recommendations that emerge from the group's effort. This relationship establishes a responsibility for solving the problem of caring for the dying (English 1979; The Primary Care Development Project 1976).

This group then needs to address its educational needs. All members of the group do not share the same amount of knowledge about the dying. Subjects that the expanded group find of value are financing care, statistics about who the patient is or where he comes from, and legislation that will affect the development of hospice (English 1979). All members are not expected to be experts. Lamer-ton (1976) advised to make members aware of new developments and to give each a basic course in the fundamentals of hospice care. This on-going education is necessary to enable the group to understand the problems faced convincing the

community of the validity of the project, and find an appropriate and viable solution to their problems (The Primary Care Development Project 1976). More educational needs can be obtained if a dialogue with the community is maintained. This flow of information will be used to (1) gain and maintain acceptance of hospice and establish an identity for the group within the community; (2) provide a channel for continuing community input into the planning efforts; (3) create awareness and be able to respond to potential obstacles to the implementation of hospice; (4) explore future resources; (5) lay groundwork for more active support; and (6) provide the objectives toward which the hospice group works. English (1979) suggested activities that make these objectives a reality. These are similar to what were developed in formulating the initial group. Those activities are as follows: (1) develop a mailing list of persons and organizations who will be regularly notified of the group activities; (2) publish regular press releases covering the activities, objectives, and progress; (3) hold open meetings to develop more community awareness; and (4) schedule members of the group to speak at various organizational meetings. English (1979) advised the scheduling of members to speak to organizations will be the most important project. He felt hospice will change attitudes in the community on how health care is to be delivered. English (1979) further

advised that all attitudes will not shift completely to pro-hospice. It will be because the hospice program will be in direct conflict with the interests of some individuals.

The individuals who are in direct conflict are not to be forgotten or ignored. A social-action approach to the problem will assist the organization at this point. Point out the conflict. Tell the community what the opposition's reason is for opposing health care for the dying. Use the conflict to the advantage of the pro-hospice group. With this planned effort, the organization will gain a significant following. The next step is evaluating and synthesizing assessment data so that a program geared to the community's needs will be developed (English 1979; Ross 1970; Rothman 1974; The Primary Care Development Project 1976).

The evaluated and synthesized data will indicate if funds will be limited. The representative group evaluates and modifies expectations as it moves toward achievement of program objectives according to resources available. The ideal program may not be practical considering what the community can afford. English (1979) advised to decide what the services are to be as soon as possible. Even though a program is agreed upon, it may be subject to change if resources are not available. The program plan is an organized set of specified components covering the following:

- (1) service to be provided;
- (2) who will provide the service;

(3) how it will be delivered; (4) how it will be financed; and (5) the role of ongoing community involvement (The Primary Care Development Project 1976). This program plan is not a simple step. This process will take many hours of discussion and revision of all plans. Expectations of all members of the group will not be obtainable. It is important to review expectations of hospice with the group so a list of services wanted can be weighed against available resources. There are necessary services and desirable services. This step will move from the ideal to the practical. All data is considered then reconsidered to determine what type of a hospice the community can provide. Will it be a free-standing, free-standing with a hospital affiliation, a special unit within a hospital, a hospice team within a hospital, or a home care team? The acceptance of the majority of people in the group is essential if the program plan is to have a chance to succeed. Obstacles will appear, but the program is responding to expressed needs of the majority of the community (English 1979; The Primary Care Development Project 1976).

Some of these obstacles include finding answers for funding, licensing, and accreditation (Affeldt 1980; Brooks 1980; Cohen 1979). In the community there are answers to these problems. The answer is intervention by a trained community organizer who can problem-solve and help identify

these answers as he assists in the development of hospice (Rothman 1974). If the problems are to be solved within the community, the citizens will be part of the solution (Phillips 1968). The process used by the community is community organization. It is the means by which the citizens of the community can recognize and protect their own values (Ross 1970). It is not a panacea, but it is a method that will work (Ross 1970; Rothman 1974).

Conclusions

The components needed in the construction of a guide for the health care professional that will give ^{them} ~~him~~ an understanding of hospice, community organization, and the organizational tasks needed in the development of this new community health resource are answered in ^{the} ~~at~~ three areas. Those components are as follows. First, the history of hospice, types of hospice, operational needs, criteria for admissions, symptom control, and understanding grief were provided. Second, the information related to community organization--community development, social-action principles and strategies, organizational theory, history and background of community organization, and the explanation of assessment factors--was discussed. Finally, the information that was provided in the discussion, that integrated hospice and community organizational information, completed the task needed for understanding the development of hospice.

The amount of material available is copious regarding hospice and community organization, but there has been very little written on the organizing of a hospice. Because of this, the literature review regarding organization was taken from areas of development other than hospice and then adapted.

The material available does not reflect that a hospice is only as good as the service it can provide (Cohen 1979; English 1979; Lack and Buckingham 1979). Cohen (1979) felt that a hospice should strive to meet the highest standards possible within its financial and legislative restraints.

The health care professional participating in a hospice program has the responsibility of providing physical, psychological, social, and spiritual support to the dying and to his family. This support can be supplied if special training to cope with death and dying is learned (Dunlap 1978; Lack and Buckingham 1979; Lamerton 1976; Plant 1977).

Analysis of the literature indicated ⁱⁿ addition to lack of material relating to the organization of hospice, at least five other areas needed supplemental investigation. Those areas are as follows: (1) what type and where is death education being taught; (2) what is the effect of working with the dying on the health care professional;

(3) how many hospice programs are needed for the total population; (4) is there one or more groups, such as age, sex, income level, or particular diagnosis, treated more effectively than others in a hospice; and (5) what is the attitude of our lawmakers toward death and hospice? If these areas are investigated, some of the answers to many questions may be uncovered.

APPENDIX A

THEORY OF ORGANIZATION

The eight variables

Variable	Indicators
<u>Organizational means</u>	
Complexity (specialization)	Number of occupational specialties. Level of training required.
Centralization (hierarchy of authority)	Proportion of jobs that participate in decision making. Number of areas in which decisions are made by decision makers.
Formalization (standardization)	Proportion of jobs that are codified. Range of variation allowed within jobs.
Stratification (status system)	Differences in income and prestige among jobs. Rate of mobility between low- and high-ranking jobs or status levels.
<u>Organizational ends</u>	
Adaptiveness (flexibility)	Number of new programs in a year. Number of new techniques in a year.
Production (effectiveness)	Number of units produced per year. Rate of increase in units produced per year.
Efficiency (cost)	Cost per unit of output per year. Amount of idle resources per year.
Job satisfaction (morale)	Satisfaction with working conditions. Rate of turnover in job occupants per year.

Major Propositions

- I. The higher the centralization, the higher the production.
- II. The higher the formalization, the higher the efficiency.
- III. The higher the centralization, the higher the formalization.
- IV. The higher the stratification, the lower the job satisfaction.
- V. The higher the stratification, the higher the production.
- VI. The higher the stratification, the lower the adaptiveness.
- VII. The higher the complexity, the lower the centralization.
- VIII. Production imposes limits on complexity, centralization, formalization, stratification, adaptiveness, efficiency, and job satisfaction.

Derived Corollaries

1. The higher the formalization, the higher the production.
2. The higher the centralization, the higher the efficiency.
3. The lower the job satisfaction, the higher the production.
4. The lower the job satisfaction, the lower the adaptiveness.
5. The higher the production, the lower the adaptiveness.
6. The higher the complexity, the lower the production.
7. The higher the complexity, the lower the formalization.
8. The higher the production, the higher the efficiency.
9. The higher the stratification, the higher the formalization.
10. The higher the efficiency, the lower the complexity.
11. The higher the centralization, the lower the job satisfaction.
12. The higher the centralization, the lower the adaptiveness.
13. The higher the stratification, the lower the complexity.
14. The higher the complexity, the higher the job satisfaction.
15. The lower the complexity, the lower the adaptiveness.
16. The higher the stratification, the higher the efficiency.
17. The higher the efficiency, the lower the job satisfaction.
18. The higher the efficiency, the lower the adaptiveness.
19. The higher the centralization, the higher the stratification.
20. The higher the formalization, the lower the job satisfaction.
21. The higher the formalization, the lower the adaptiveness.

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