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THE INTEGRATION OF HOSPICE PROGRAMS INTO THE TRADITIONAL HEALTH CARE SYSTEM:

A SOCIOLOGICAL STUDY

By

Lenora Toby Finn Paradis

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ABSTRACT

THE INTEGRATION OF HOSPICE PROGRAMS INTO THE TRADITIONAL HEALTH CARE SYSTEM: A SOCIOLOGICAL STUDY

By

Lenora Toby Finn Paradis

A collective interest in death and dying has progressively developed in American society since the 1960s. The development of hospice as an alternative form of care for the terminally ill is, to a large extent, a manifestation of the heightened awareness of death, coupled with growing disenchantment with the traditional medical model.

The recent upsurge in the number of hospice programs throughout the United States constitutes a social movement, and therefore presents an opportunity to examine sociological theories about the integration of a social movement organization into the larger society. In the case of hospices, it provides an opportunity to assess those factors which affect the integration of hospice programs into the traditional health care system.

Using Michigan as a case study, this research investigates the relationship among several independent variables--organizational size, structure, inter-organizational affiliations, program goals, board composition, professional leadership and environmental support--on the dependent variable "integration."

"Integration" refers to the participation of an organization in the larger society. In the case of hospice programs, integration refers to the participation of the program in the health care reimbursement system, the reliance on trained health care professionals such as physicians, nurses, and social workers, and the

political involvement of program leaders to gain status through licensure and the development of accreditation standards.

The intent of early hospice program organizers was to ensure that the hospice concept became an integrated part of the existing health care delivery system. Early hospice movement founders encouraged tactics which would establish important and relevant links to the existing health care system. The goals of subsequent organizers became much different. They viewed hospice as a distinct and separate provider classification, which is not to be confused with, or integrated into, the existing medical care system. Claiming the concept of "hospice" will be lost in the traditional system, opponents of integration contend providers in the traditional system are unable to fulfill the needs and guarantee the rights of the dying patient.

The development of hospice organizations as independent non-integrated health care providers caused conflict among hospice program organizers, as well as between local hospice programs and existing provider groups, specifically home health agencies. While many home health agencies supported the development of local hospice programs, they expressed concern that these new programs were merely duplicating their services under a new name.

Regardless of the desire of some hospice program organizers to remain distinct from the existing health care system, results indicate that hospice programs are, in fact, becoming an integrated part of that system. As hospice programs become increasingly integrated into the traditional health care system, support for the creation of independent community-sponsored programs is decreasing, while support for programs created by existing health care institutions (e.g. hospitals and home health agencies) is increasing. The reduction of support for independently created hospice programs is creating fragmentation and conflict within the hospice movement. In the case of hospice

programs, the decision to become integrated into the traditional health care system is one source of conflict. The data presented in this study provide support for the possible demise of non-integrated hospice programs and describe the changes that have occurred in the development of Michigan hospice programs during the past five years.

To my grandmother Sophie Rudner,
1889-1963, died stomach cancer

To my father William Finn,
1912-1969, died lung cancer

To my mother Eva Finn,
1912-present

To my husband Dennis Paradis
for his patience and support

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CHAPTER I

INTRODUCTION TO HOSPICE PROGRAMS AND PROBLEMS

The study of hospices as social movement organizations presents practical as well as theoretical problems. At the practical level, the recent upsurge in the number of hospice programs throughout the United States has forced health care policy makers to re-examine the existing health care system, especially in its provision of care for the dying patient. At the sociological level, research on hospices provides a basis for assessing theories of social movements, division of labor, organizational structures, professions of medicine and environmental dynamics.

The purpose of this research is twofold: 1) to collect descriptive data on the growth and development of hospice programs in Michigan as a data base for use by health care providers, decision makers and legislators and 2) to provide empirical data to assess sociological hypotheses regarding the development of hospice as a social movement organization.

The Concept of Hospice

Hospice is a "medically directed, nurse-coordinated program providing a continuum of home and inpatient care for the terminally ill patient and family. It employs an interdisciplinary team acting under the direction of an autonomous hospice administrator" (Flexner, 1978, p. 248).

The upsurge in hospice programs throughout the United States can be viewed as an organized reaction to a social problem: the depersonalization of care for the terminally ill. The hospice movement is considered by some to be a human rights movement which began in the early 1960s and focuses not only on the terminally-ill patient's rights but also the failure of the existing medical care system to care for the needs of the dying.

The chief objective of the hospice program is to provide supportive care for the dying person. The program focuses on keeping the patient at home. The principal products of the hospice program are nursing, palliative care, and counseling services to the dying; its central concern is the comfort of the dying patient.

The hospital, on the other hand, is most concerned with the treatment of illness within the limits of present-day technical-medical knowledge (Georgopoulos and Mann, 1962). The principal products of the hospital are medical, surgical, and nursing services to the patient and its central concern is the life of the patient.

In its pristine, ideal form, hospice care welcomes "guests" into a "high person, low technology" setting, unsegregated from sights, sounds, persons and activities of the world of wellness. Patients surrounded by staff, volunteers, family members, and friends receive "holistic" care from persons who spend non-medical as well as medical time with them. The major objective is to dispel psychic pain and suffering, anxiety and fear of death. The control of physical pain is another central concept and goal of hospice.

"Attending the emotional, social, spiritual and physical needs of the terminally ill and their families is considered essential to the hospice's commitment and to its capacity to transform the process of dying into a tolerable, meaning-filled experience for all those who participate in it" (Fox, 1980, p. 32).

Senator Jennings Randolph, in establishing National Hospice Week (S.J. Resolution 170, March 18, 1982) stated, "Hospice is a place, people, and a philosophy. It is a system of care that seeks to restore dignity and a sense of personal fulfillment to the dying. The focus is on the patient and the family, rather than on the disease--and the aim is not to extend life ends, but to improve the quality of the life that remains."

While Randolph's description is vague, Section 1811 of the Social Security Act (Appendix 1) is fairly specific in what constitutes hospice care. The act requires that the patient is terminally ill with six months to live as diagnosed by a physician licensed in the United States. Care for the patient must center on pain and symptom control provided by an interdisciplinary team of health care professionals including nurses, physicians, social workers, clergy and specially trained volunteers. The Act requires that a majority of a patient's care is rendered in the home, that care is available 24 hours a day and that the family participates in the care of the patient.

Although the appearance of hospice programs in the United States is recent, the concept has existed for centuries. Medical historian David Reisman (1935) noted that the concept of hospice antedates A.D. 475 and that there is proof of a hospice founded in the Port of Rome by Fabiola, a disciple of Saint Jerome, to care for pilgrims returning from Africa.[1]

According to the New World Dictionary the word "hospice" means a place of shelter for travelers. During the medieval period hospices were maintained by religious orders as resting places for individuals on pilgrimages to the Holy Land.

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[1] Dozens of articles and books have been written detailing the history of hospices dating from 475 A.D. (see: Riesman, 1935; Kubler-Ross, 1969, Kron, 1976; Stoddard, 1978; DuBois, 1980, Osterweis and Champagne, 1979; Wald, et al, 1980). See also Western Attitudes Toward Death: From the Middle Ages to the Present by Philippe Aries (1974).

Hospices were in operation throughout Europe in large densely populated areas as well as in more rural ones. Some estimates indicate there were as many as 750 in England, 40 in Paris and 30 in Florence as well as others in monastic hermitages in wilderness areas, at mountain passes and river crossings. Hospices could be found anywhere travelers to the Holy Land could experience the greatest hazards (Stoddard, 1978).

In the mid-1800s Sister Mary Aikenhead opened a home in Dublin for the dying, calling it "hospice" in consonance with her view of death as part of an eternal journey. The modern concept emerged in 1842, when Catholic widows established a hospice in Lyon, France, for poor women who had incurable cancer. Around the turn of the twentieth century, the Irish Sisters of Charity set up St. Joseph's Hospice in London. An Anglican order and a Methodist Church mission established two other English hospices.

It was to St. Christopher's Hospice, in a suburb of London, and its founder, Dr. Cicely Saunders, that the U.S. hospice movement has looked for direction (Porter, 1979, p. 60). The Hospice of Connecticut--America's first hospice program--is modeled after St. Christopher's.[1] Although Hospice of Connecticut opened its doors to patients in 1974, it actually began in 1963 following a speech given by Dr. Saunders at Yale University, paving the way for open discussion on the concept of death and dying.[2] Less than a decade later (Spring 1971) the Hospice of Connecticut became incorporated (Fulton and Owen, 1980).

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[1] There are currently 77 programs in the United Kingdom; 42 inpatient hospice programs; 12 hospital-based programs, 23 community based home care programs and 6 day care units. Fifty percent of the funding for hospice is received by the NHS and the remaining comes from private sources. Other countries with hospice programs include Taiwan, Japan, China, Johannesberg, South Africa, Canada, Holland, Israel, and Sweden (Olsen, Edwin J. p. 7).

[2] I'm told by some of the attendees that Elisabeth Kubler-Ross was present during that speech.

As the collective interest in death grew it took on a significant moral and value-laden quality; the inalienable right of everyone to die in a comfortable manner which afforded them the most dignity and which allowed them to be surrounded by their loved ones. The book, On Death and Dying by Elisabeth Kubler-Ross (1969), gained national attention. Early interest groups pressured legislators to introduce death-with-dignity legislation. In 1972, the Special Committee on Aging of the United States Senate held hearings on "Death with Dignity: An Inquiry Into Related Public Issues."

Within two years after the formation of Hospice of Connecticut (1974), the National Institutes of Health (NIH) held a symposium on management of pain and humanitarian care for the dying.

In May 1978, the National Hospice Organization was formed to act as a national clearinghouse, and several years later it became a powerful lobbying force which shepherded through an amendment to the Tax Equity and Fiscal Responsibility Act of 1982, which provided for hospice benefits to Medicare beneficiaries. Later that year, a Senate resolution was passed asking President Reagan to proclaim the week of November 7-14 as National Hospice week.

Although the number of patients enrolled in hospice programs is small, the hospice movement "has entered the American health care scene with an intensity of a religious revival and a growth rate characteristic of a boom town" (Carney, 1982, p. 1). The number of hospice programs across the United States has grown from a handful in 1978 to more than 1,000 in 1981, according to the Joint Commission on Hospital Accreditation. The hospice movement has planning groups in rural and urban areas throughout the country. The efforts of hospice programs to gain status as legitimate providers of health care for the terminally ill have been successful with the recent enactment of Medicare entitlements to provide reimbursement for hospice care and the negotiation of hospice benefits in third-party payment contracts. Further, 11 states have passed hospice licensing statutes and others are considering passage of regulatory measures (Blum and Robbins, 1982).[1]

Michigan has a large number of hospice programs, and according to the National Hospice Organization (NHO), is one of several states with a rapid growth in absolute number of hospice groups. The state is one of 11 states with hospice licensure. (The NHO estimates that 25 states will have licensing legislation by December 1983.) The state contains at least one example of the five variations of "model-type" hospice programs as defined by the United States Government Accounting Office (GAO).[2] Lastly, the state has formed a trade association (the Michigan Hospice Organization, MHO) which has been instrumental in helping other states initiate similar associations.

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[1] California, Connecticut, Delaware, Florida, Hawaii, Illinois, Maryland, Michigan, New York, Virginia and West Virginia had passed hospice licensing legislation. (See Appendix 2 for Michigan Law)

[2] Five predominant types or models have been identified by the GAO:

1) Free standing hospice
2) Hospital-affiliated, free standing hospice
3) Hospital-based hospice
    a) acute care hospital with centralized palliative care or hospice unit
    b) acute care hospital hospice team who visit patients
    c) units operated as part of an HMO
4) Hospice within an extended care facility or nursing home
5) Home Care program only
    a) hospital based
    b) nursing home based
    c) community based

Social Factors Influencing Hospice Development

Changing views of death and euthanasia, the women's movement, home birth movement, a burgeoning medical technology and issues of health cost containment all influenced the development of hospice as a social movement.

The recent U.S. concept of hospice care grew out of a burgeoning death awareness movement which, according to Huntington and Metcalf (1979), had its origins in the 1963 publication of Jessica A. Mitford's expose, The American Way of Death. The book attacked America's funeral industry, claiming it was excessively commercial and capitalized on death. Mitford attacked the funeral industry for profiteering through selling of unnecessarily expensive services and goods to a captive clientele under great temporary stress. Mitford's questioning of the appropriateness of the funeral ritual, especially the elaborate preparation of and display of the corpse, provided a basis for public reassessment of the death ritual. As Metcalf and Huntington (1979, p. 3) note, "There began a broader reconsideration of all aspects of the experience of dying and the significance of death in modern society."

The stage was set for death and dying to become what Blumer calls a "general social movement." The general social movement consists primarily of "groping and uncoordinated efforts" toward vague goals or objectives. It lacks organization, leadership and structure. It grows gradually out of what Blumer (1969) calls "cultural drifts," which are "gradual and pervasive changes in the values of people." As a general movement begins to form from a cultural drift, it gradually acquires spokespersons who are more like "voices in the wilderness" than real leaders.

In the United States, the leader, or more accurately promoter, of the death-with-dignity movement was Swiss-born physician Elisabeth Kubler-Ross. Her book On Death and Dying sold millions of copies shortly after publication (1969), and is credited with prompting widespread debate on the rights of the dying patient[1] and fostering the concept of "death with dignity."

The "classical death of Western nostalgia," presented by Kubler-Ross (1969, p. 5-6) provides a memorable example of the genre:

> I remember as a child (in Switzerland) the death of a farmer. He fell from a tree and was not expected to live. He asked simply to die at home, a wish that was granted without questioning. He called his daughters into the bedroom and spoke with each of them alone for a few minutes. He arranged his affairs quietly, though he was in great pain, and distributed his belongings and his land, none of which was to be split until his wife should follow him in death. He also asked each of his children to share in the work, duties and tasks that he had carried on until the time of the accident. He asked his friends to visit him once more, to bid good-bye to them. Although I was a small child at the time, he did not exclude me or my siblings. We were allowed to share in the preparations of the family just as we were permitted to grieve with them until he died. When he did die, he was left at home, in his own beloved home which he had built, and among his friends and neighbors who went to take a last look at him where he lay in the midst of flowers in the place he had lived in and loved so much.

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[1] Fox (1980, p. 50) writes that Kubler-Ross's book catapulted her to the top of a newly emerging specialty, thanatology (the study of death, and working with and caring for the dying): "It made her the 'Death-and-Dying Lady,' a national and international celebrity. It launched her on a perpetual round of house calls to dying patients and their families, in the United States and abroad, and a continuous cycle of public lectures and 'Life, Death, and Transition Workshops' attended by hundreds of persons."

Fox notes that Kubler-Ross's book contended that the contemplation of death and the acceptance of mortality are not morbid, but life-enhancing, "conducive to respect for life, personal growth, loving relationships, and a happier sense of meaning. She has also consistently affirmed that persons passing though the 'final stages of life' can be our teachers and that those who get close to the terminally ill 'will learn much about the functioning of the human mind, the unique human aspects of our existence and will emerge from the experience enriched. . . perhaps with fewer anxieties about their own finality'."

There is also a demographic source of the heightened awareness and pondering of death and dying (Parsons, 1963; Fox, 1981). Declining fertility rates and declining mortality rates have enhanced both the proportion and number of persons who are living longer. Whereas in 1900 approximately three million persons, or four percent of the American population, were 65 or older, today 25 million persons, or close to 12 percent of our population, belong to this age category.[1]

As sociologist Otto Pollak writes, this "increase in the numbers of persons who live out the full span" has helped to make "the anticipation of dying a national experience" and aging a process of "dying in installments."

Pollak (1980, pp 71-73) points out that social and cultural factors are as responsible for these associations between aging and dying as demographic and biological ones:

> Old people in the United States live in a society which puts a premium on being young. . . . Youth is hope and hope is life-sustaining. . . . Old people symbolize hopelessness, the renunciation of fantasies, the pain and despair of dying. . . .

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[1] Michigan Department of Public Health, Office of Vital Statistics and U.S Census Bureau 1980 Census.

A growth in our aging population has led to a shift in the cause of death. As Fox writes (1980, p. 42), certain chronic illnesses that have not yielded to the progress of medicine are now the primary causes of mortality, among them cancer, heart disease and stroke.[1] Thus, a considerable portion of the American preoccupation with death and dying is concerned, directly or indirectly, with chronic illness and the care of the chronically ill.[2] The disease most dreaded and feared in this connection is cancer. It has become the archetypical metaphor of "insidious, malevolent, uncontrollable, ugly, and pain-filled aspects of these chronic-illness-associated problems. . . " (Fox, 1980, p. 44).

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[1] "Diseases of the heart ranked fourth among the leading causes of death in this country during the 1900's; this category caused 137.4 deaths per 100,000 and accounted for 8.0 percent of all deaths. By 1966, however, it had risen so far in importance that it had become the leading cause of death, far outranking all others. Its mortality rate had risen to 375.1 deaths per 100,000 population, and it accounted for nearly 40 percent of all deaths in that year. . . . The pattern of increase for malignant neoplasms (cancer) as a cause of death was quite similar. This disease ranked eighth among the leading causes of death in 1900. It accounted for 64 deaths per 100,000 population and less than 4 percent of all deaths. By 1966, however, its rank among the leading causes had risen to second, its rate per 100,000 to 154.8, and its proportion of the total of all deaths exceeded 16 percent. . . ." (Lerner, 1980 p. 95).

[2] Aries (1974) divides changes occurring in the death of populations and attitudes toward death into four stages: "tamed death" (pre-Renaissance); diachrony (Renaissance to middle-ages); achronic (post middle ages); and comtemporary. In the pre-contemporary society death warnings occur through a "magical premonition, the dying is prepared for death through steps dictated in traditional ceremony (e.g. lying in bed, in a position, arms crossed over the body, etc.). At the end of the 18th century (contemporary period) doctors discovering the first principles of hygiene complained about overcrowding bedrooms of the dying. With the advent of poor farms and subsequently hospitals the isolation of the dying from the family is complete.

Death in the hospital is no longer the occasion of a ritual ceremony, over which the dying person presides amidst his assembled relatives and friends. Death is a technical phenomenon obtained by a cessation determined in a more or less avowed way by a decision of the doctor and the hospital team (p. 88).

The hospice philosophy includes a commitment to transform the process of dying into a tolerable, meaning-filled experience for all those who participate in it. Hospice provides a "waystation" for patients suffering from cancer. It is designed to both control pain and attend to the patient and family's anxieties and fears of death.

The development of hospice programs as social movement organizations (SMOs) is a manifestation of deep cultural changes occurring in our society and in its world view. The upsurge in hospice programs appears at a time when other health care and social reforms are also being proposed. For example, in 1968, the Journal of the American Medical Association (JAMA) ran dozens of articles regarding legal decisions physicians may face when using biomedical advances to prolong life. Concern surrounding this issue escalated, reaching a peak one decade later when two judicial cases made national headlines: the 1976 Quinlan decision of the New Jersey Supreme Court and the 1977 Saikewicz decision of the Massachusetts Supreme Court. Both of the courts questioned the patients' physical or legal incompetency to express their own views about continued survival and the morality of using of heroic biomedical techniques to prolong life.

The Quinlan case involved the question of whether to withdraw a comatose young woman believed to have suffered irreversible brain damage from a respirator, even though she did not meet the widely accepted Harvard criteria for brain death. The court said the decision properly belongs with the patient's parents and physicians, providing a hospital-appointed ethics committee concurred with their decision. The Quinlan decision was widely acclaimed by the medical profession because it supported long-standing medical tradition, the court's ruling did not appear to call for any major change in medical practice (Relman, 1978).

In the Saikewicz case, the court emphatically rejected the Quinlan solution, asserting instead that only the courts were qualified to decide life or death issues for incompetent patients. Saikewicz, a profoundly mentally retarded man of 67 who developed acute leukemia, was denied medical treatment at the request of his parents and physicians.

As interpreted by some lawyers, the Saikewicz decision established new laws mandating probate judicial hearings before any life or death decision could be made for incompetent patients, excepting only emergency cases (Relman, 1978).

The Quinlan and Saikewicz cases provided a public forum for the country to address the issue of euthanasia and the question of whether life-prolonging medical techniques should be applied to forestall the natural death of one who is in an irreversible unconscious state.[1]

While the medical profession and the courts were debating the utilization of appropriate medical technology and the role of the physician in the care of the terminal patient, other related issues were being publicly addressed. These included the cost of medical technology and of hospital care in general, as well as the consumer's right to choice in health care matters.

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[1] Arien Mack in Death in American Experience (1974) discusses the relation of the physician to the patient as treatment becomes increasingly technical. Using the Parsonian concept of "definition of the situation," Mack (p. 29) writes: "Orientation to the nearly absolute 'commandment' to combat the death of his patient provided a strong definition of the situation for the physician in several respects. It assured the physician that be could act in direct relation to a value of great importance without having to embroil himself in a broad range of difficult problems of meaning. It permitted, indeed required, he pursue the 'saving' of life at almost any cost, that is, by subordinating almost all other value considerations."

Medical costs have been escalating dramatically during the last two decades and have consumed a greater proportion of our country's Gross National Product (GNP). Figures from the Department of Commerce (1980) show that in 1960 health care expenditures were $26.9 billion or 5.3 percent of the country's gross national product. By 1980 that figure had increased ninefold to $249 billion or 9.5 percent of the GNP.

Beginning in the early 1970s the U.S. Congress developed a series of programs designed to contain health care costs,[1] the most recent of which was P.L. 93-641, the National Health Planning and Resources Development Act. Passed in 1975, this act created a series of state and national planning authorities responsible for reviewing the efficacy of capital expenditure requests by hospitals and nursing homes.[2]

The concern over inflation of medical care expenses intrudes into nearly every aspect of health care today. Cost containment is the dominant catchword. The reasons for this phenomenon are varied, but the largest culprit, according to Hunt, is the expansion of medical technology.

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[1] 1972: The Social Security Amendments of 1972 (PL 92-603) added two relevant sections to the Social Security Act. They were Section 234, which mandated planning by health care institutions as a condition of Medicare participation, and Section 1122, which specified that health facilities in participating states would receive reimbursement by Medicare, Medicaid, and Maternal and Child Health Programs for claims relating to capital expenditures only if the expenditures were deemed necessary by the state planning agencies.

1975: The National Health Planning and Resources Development Act of 1974 (PL 93-641), Titles XV and XVI of the Public Health Service Act, was enacted to create a mechanism for coordination of planning efforts. Title XV establishes a new programs for health planning and resources development. Title XVI revises existing programs for the construction and modernization of health care facilities (the former Hill-Burton Program).

[2] For additional information see Connor, 1977. Appendix 3 contains the original state certificate of need law (Part 221 of PA 368 of 1978). It has since been amended to include review of hospice programs.

> There seems to be general agreement that much of the excess inflation in medical care is related to expansion of use of technologically complex and costly methods of diagnosis and treatment. While such development is generally welcomed as evidence of scientific medical progress producing higher quality patient care with demonstrably improved results, "over utilization" is becoming the watchword in the struggle to limit costs. That too many patients are hospitalized, that too many hospitals have CAT scanners, that too many laboratory tests and x-rays are done on too many people, and that over use of drugs and expensive treatment methods are all too common statements being made with increasing frequency (1980, p. 2).

Care for terminally ill patients in hospital settings is extremely expensive. As one administrator of a large urban hospital noted, "People often spend more on medical care during their last two weeks of life then they spend at any other time." The costs for care of the terminally ill in conjunction with the preservation of life have lent support to the development of hospice as a alternative treatment of care.[1] Stressing the importance of inexpensive home based care, hospice programs offered an option to the highly technological and labor-intensive hospital environment.

The use of the home to care for patients was seen as a potential alternative to the hospital by another group: those demanding more control for mothers over the births of their children. Beginning in the early 1970s[2] a series of books were published asking why women did not have control over their own bodies. This question recurred during debates on abortion as well as home birth.

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[1] A November 1982, study by Blue Cross/Blue Shield noted that it costs an average of $15,836 (1980 dollars) for terminal patients during their last six months of life. The majority of expenses occur in the last month of life when inpatient hospitalization is highest.

[2] See Richard, Barbara. The Women's Movement, New York: Harper & Row, 1975; Suzanne Arms. Immaculate Deception, Boston, Mass: Houghton Mifflin, 1975. Sheila Kitzinger. The Experience of Childbirth, London: Victor Gollancy, 1972.

As Fox (1981, p. 55) points out, the death-and-dying movement "intersects with the broad affirmation of individual rights taking place in American society since the 1960s and with organized attempts to expand the scope of these rights." The articulation of the right to die closely parallels that of the right to choose a birthing place. In both instances, groups organized to oppose restrictions concerning "constitutionally" guaranteed rights to give birth and to die in the settings which one wishes without interference from others.

As women discussed the propriety and costs of their gynecological care prior to, during and after childbirth and their needs for more than site-specific care, the doors were opened for other types of debates, including the role of the physician in the care of the terminally ill. The same issues raised in discussion of birth became the focus of a larger societal phenomenon in which claims for the extension of individual rights, a "self-care movement," and a patient's rights for choosing the method of birth and death, figure prominently (Veatch and Tai, 1980).

As the "death-with-dignity" movement gained public support in the early 1970s a second countermovement was beginning to develop which was largely sponsored by "right-to-life" groups.[1] Originally founded in the late 1960s to defeat "pro-choice" (pro-abortion) efforts, the right-to-life movement became concerned with the issue of euthanasia raised by the death-with-dignity

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[1] Robert Veatch of the Hastings Center reported in 1977 that "forty pieces of legislation were introduced into state legislatures during this period in an attempt to legalize one or another aspect of euthanasia" (Fulton and Owen, 1980, p. 5). By 1982, 13 states and the District of Columbia had Right to Die bills and another 28 pieces of legislation were being introduced (Appendix 4).

movement.[1] As Michigan Representative Dave Hollister noted, "The meetings my committee held on death-with-dignity legislation were becoming increasingly dominated by members of the Catholic Church and right-to-lifers who worked hard for the defeat of the proposed legislation."[2]

Debate in the 1970s over right-to-death issues led to the development of several factions: those who were unalterably opposed to any legislation which did not support the continued use of life support mechanisms and heroic surgeries to sustain life; those who were adamantly opposed to continued life-support measures and medical techniques against the patient, his or her family or close companion's wishes; and those who were anxious to promote death with dignity but who focused on the humane aspects of the care for the dying while rejecting any talk of euthanasia. It was this third group which, in most states, became the foundation upon which the current hospice movement is based.

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[1] As one right-to-life organizer wrote in her letter to me, "Our concern over the abortion issue included the prediction that loss of respect for life at the beginning would lead to a similar loss of respect at the end of life. Our literature, presentations, etc. in the early days of our organizations predicted that this loss of respect would spread to those who were also helpless due to old age, retardation, handicap, etc. In those days, we were told that we were exaggerating, and that it would not happen. The growth of the so-called 'death with dignity' movement confirmed our early predictions.

Euthanasia became an issue with right to life as the various pieces of legislation's court cases began to unfold. It was not unexpected, and as a result, our focus broadened to include not only the unborn, but all human beings whose right to life appeared to be threatened. However, abortion remains the main focus and the reason for the existence of right-to-life organizations."

[2] In 1978 one state (Arkansas) had enacted right-to-die legislation (Rosen, 1982). By 1982 eleven states, including Michigan, had passed laws regulating hospice program growth and a dozen other states debated the passage of licensing statutes (Blum and Robbins, 1983).

An unofficial alliance between church officials, right-to-life and death-with-dignity supporters formed and focused on an organized approach to care for the terminally ill. They promoted the concept of hospice as a method of care for the dying that involves the traditional health care providers but also gave the patient and the family some choice in the continuation of medical interventions. The hospice movement did not address the issue of families of unconscious patients making any decisions for the patient and focused instead on care for the conscious and aware terminal patient. This was an important point since early death and dying legislation focused on treatment, or lack of it, for unconscious patients regardless of long-term prognosis.

The hospice concept provided earlier discussions of death and dying with what Blumer terms a "specific" focus. Organizers defined as its goal the development of hospice programs to care for the terminally ill and a revamping of the existing health care structure. As Lyn Lofland (1978, p. 37) points out, death and dying are not salient concepts for many individuals because so many people in our society die in segregated organizational settings. However, once these numbers of "individuals begin to reach a sufficient size, they become aware of themselves as a group and can begin publically articulating those concerns which its individual members had kept private. The hiatus on death and dying as public discourse ends. The emergence of death and dying as fad, fashion and social movement begins."

The hospice movement points to a failing of the traditional health care system to provide for the needs of the dying patient. It is a struggle against what Turner and Killian (1972, p. 259) have pointed out is some "wrong which ought to be replaced." That sense of something wrong is sustained by a sense of "righteous indignation. A sense of injustice that is vital enough to have consequences requires not only a situation that appears unfavorable by comparison with some reference group, but also an oppressor, so that the situation can be seen as a product of human will."

Some movements--for example, the nuclear power movement as noted by Useem and Zald (1982)--are "fortunate" in facing an opposition that is organized and articulated. The members of these organizations can be identified and personified: the oppressor is real.[1] However, not all movements have "enemies" which are clearly identifiable. The thing or idea which is found unconscionable is a consequence of the way things are done, the way they have evolved. The practice which is abhorred may be merely a de facto creation.

De facto enemies are not very useful in creating "righteous indignation." As Lofland (1978, p. 89) writes; "They do not articulate any opposition. They do not seem to be enemies at all. If they are to be useful to a movement, if they are to provide the emotional springboard for a sustained sense of injustice, they must be evoked by the movement itself. If they do not speak for themselves, they must be articulated by the movement."

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[1] Nathanson in his book, Aborting America (pp 51-52), describes how the pro-abortion movement focused on the hierarchy of the Catholic Church as an "oppressor of women's rights."

"Historically. . . every revolution has to have its villain. It doesn't really matter whether it's a king, a dictator, or a csar, but it has to be someone, a person, to rebel against. It's easier for the people we want to persuade to perceive it this way . . . now, in our case, it makes little sense to lead a campaign only against unjust laws, even though that's what we are really doing. We have to narrow the focus, identify those unjust laws with a person or a group of people. A single person isn't quite what we want, since that might excite sympathy for him. Rather, a small group of shadowy, powerful people . . .. It's got to be the Catholic hierarchy. That's a small enough group to come down on, and anonymous enough so that no names ever have to be mentioned, but everybody will have a fairly good idea whom we are talking about."

The hospice movement had no specific enemy (e.g. an individual). However, it was able to sustain an "emotional springboard" by which it set up an ideal and then pointed to the imperfect presumed real. William Goode describes the way in which critics of contemporary family arrangements evoke an ideal which he calls the "classical family of Western nostalgia," by painting a picture of the kinfolk and life on grandma's farm and the harmonious living arrangement (Lofland, 1978).

Philippe Aires provides an example of this view:

> For thousands of years man was lord and master of his death, and the circumstances surrounding it. Today this has ceased to be so. . . . Today nothing remains either of the sense that everyone has or should have of his impending death, or of the public solemnity surrounding the moment of death. What used to be appreciated is now hidden; what used to be solemn is now avoided. . . . We have seen how modern society deprives man of his death, and how it allows him this privilege only if he does not use it to upset the living. In a reciprocal way, society forbids the living to appear moved by the death of others; it does not allow them either to weep for the deceased or to seem to miss them. (Aires, 1974, 136, 138, 143).

By creating an image of the ideal or preferable state of affairs, the "ideological crafts-person" then describes the way in which the real world fails to measure up (Lofland, 1978). In doing so, the opposition is "articulated"; a social problem is "created" (Blumer, 1971).

Proponents of the hospice movement, in working toward an "ideal way of death," have asserted that the existing system has failed for a number of reasons, viewing secular discussion of death as taboo and preventing public discourse of the subject. The consequences of this denial lead to exorbitant funeral costs and barbaric funeral practices, inhumane handling of dying patients in hospitals, ostracism of the dying from the living, false communication with the terminally ill, rejection of the needs of the dying person's family, a mechanical, non-organic view of life, and so forth.

Because hospice is a relatively new movement, it has not been fully evaluated.[1] Much of the existing literature is characterized by an evangelical flavor extolling the virtues of hospices without objective analysis. Information is needed about their organization, their growth over time, their experiences in caring for the dying, and their cost. Although two major national studies are under way--a demonstration project on hospice costs financed through Health Care Financing Administration (HCFA) and a study of the quality of hospice care by the Joint Commission on Hospital Accreditation--data from these studies are not expected until 1984. For many legislators who feel pressure from local constituents to provide licensing laws and rules for hospices, one year is too long to wait.

This dissertation provides a description of the status of hospice programs in Michigan, their organizational approach to providing health care, and their history of change.

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[1] Most authoritative studies of social movements are conducted long after the movement is over and it is possible to assess more than its immediate social impact. However, this approach has the inevitable bias of stressing the end rather than the beginning of the movement. According to Freeman (1975, p. 8), there is "value in an early assessment . . . . Primarily among these include the opportunity to collect data on origins and early growth which would otherwise be lost with time and fading memories . . . . Further, the collection of such data allows us to place it in its contemporary environmental context uncontaminated by hindsight and to make some early assessments on its problems, impact, and potential, which when compared later with subsequent development, can provide some standard for judging those assessments."

ACTIVITIES IN THE UNITED STATES LEADING TO HOSPICE DEVELOPMENT AS A SOCIAL MOVEMENT ORGANIZATION

1963 - Cicely Saunders speaks at Yale University about hospice care in England, sparking development of first U.S. hospice.

- Jessica Mitford publishes critical expose on funeral industry.

1966 - National Organization of Women is formed.

1969 - Elisabeth Kubler-Ross publishes On Death and Dying.

1970 - Abortion law is passed in New York State; abortion is legalized.

1972 - Right to life movement gains strength in the U.S.

- Social Security amendments regarding health planning are passed.

- Senate holds hearings on death-with-dignity legislation.

1973 - Supreme court decision allowing abortion (Doe vs. Bolton & Roe vs. Wade).

1974 - Hospice of New Haven, Connecticut, opens doors to patients.

1975 - National Health Planning Resource Development Act passed.

1976 - Quinlin decision, New Jersey Supreme Court.

- Hospice of Merin, California, opens doors to patients.

1977 - Saikewicz decision, Massachusetts Supreme Court.

1978 - National Hospice Organization formed.

- Secretary of Health, Education and Welfare (HEW), Joseph Califano, announces that HEW is requesting proposals for experimental funding.

- Senators Abraham A. Ribicoff, Edward M. Kennedy, and Robert J. Dole, ask the Government Accounting Office to review the development of hospice across the United States.

- Connecticut becomes the first state to have regulations governing the licensing of hospices.

1980 - W. K. Kellogg Foundation funds a Joint Commission for Accreditation of Hospitals, releases a project to draft standards for hospice programs.

1982 - Tax equity's fiscal responsibility act includes a section for Medicare covering hospice care.

CHAPTER II

HOSPICE AS A SOCIAL MOVEMENT: HISTORY AND CONCEPTS

The events which lead to the development of hospice as a social movement and the hospice organization as a social movement organization provide insight into the evolutionary process of social movements and the development of organizational structures. In this instance we can see how environmental factors provided a basis for discussion of the hospice concept. The women's movement, home birth movement, issues in cost containment, negotiations between death-with-dignity and right-to-life advocates were all responsible for creating a climate for the development of hospice as a social movement.

For the purposes of this investigation, social movements are defined as consciously and purposively structured types of collective behavior which aim at effecting changes in society (McCarthy and Zald, 1973). Social movements contain organizations which consciously attempt to coordinate and mobilize supporters for the movement (Zald and Ash, 1966). The organizations directing the social movement--in this case the hospice programs--will be referred to as "social movement organizations."

Social movements range from those that are radical and all-embracing, aimed at totally changing the structure of a society, to specifically focused reform attempts. They encompass idea movements which are aimed at changing society by changing individual thought and movements tied to specific ideologies and tactics. At the level of the social movement organization (SMO) they include radical and clandestine terrorist groups, retreatist sects that re-evaluate the world, reform-oriented political action groups such as Common Cause and interest groups aimed at changing a law or policy to benefit their members (McCarthy and Zald, 1973).

The study of hospices as social movement organizations (SMO) provides an opportunity to assess select sociological propositions by Weber (1946), Michels (1949), Zald and Ash (1966), and Selznick (1953) that provide a theoretical framework to predict the development of a social movement organization (SMO). The propositions deal with integration of SMOs as measured by shifts in goals, leadership and external affiliations.

The proposed research represents a shift from traditional SMO research which has been largely descriptive and conceptually focused on factors such as ideological base and social/psychological characteristics of members in the general context of societal change (Gurr, 1970; Turner and Killian, 1972; and Smelser, 1963). This study, in contrast, will follow in the tradition of Gusfield (1957), Messinger (1955), Gordon and Babchuk (1959), Zald and Ash (1966), Curtis and Zurcher (1974) which focus on social movements as complex organizations.

Articles by Curtis and Zurcher (1974), Zald and Ash (1966), Bush (1978), McCarthy and Zald (1973) critique the theoretical constructions outlined by Weber and Michels which suggest that three types of changes in social movement organizations occur: 1) goal transformation, 2) shift to organizational maintenance and, 3) oligarchization. While the model proposed by Weber and Michels provides a broad framework from which to analyze growth, development and change in social movement organizations, Zald and Ash (1966) claim it is incomplete:

> There are a variety of other transformation processes that take place, including coalitions with other organizations, organizational disappearances, factional splits, increased rather than decreased radicalism, and the like. And in fact, the Weber-Michels model can be subsumed under a more general approach to movement organizations which specifies the conditions under which alternative transformation processes take place (p. 463).

McCarthy and Zald (1973) have also criticized this model, claiming that it makes certain assumptions about the psychological state of members in attempting to account for the motives of involvement. Tension, frustration and related deprivation are key terms in such an account. Even as the interdependence of the movement with environmental forces beyond its support base are analyzed, the psychological state of the support base remains crucial. Yet, in spite of these criticisms, the classical model provides us with a mechanism for understanding the evolution of a social movement. As we shall see, it also provides insights for assessing hospice program development.

Potential for Social Movement

Social strain creates a potential for social movements (Freeman, 1975). The strain is often perceived as a break with past methods or systems and is usually used as a benchmark to pinpoint a movement's origin. For example, the 1954 Supreme Court decision on school desegregation is usually marked as the beginning of the civil rights movement. In the case of the hospice movement, Elisabeth Kubler Ross's book On Death and Dying is credited with the beginning of the movement in America (Stoddard, 1978).

A variety of taxonomies exist which delineate the creation of social movements and their evolution over time. Freeman (1975, p. 46) considers the many theories confusing and, to a large extent useless. She notes that movements are rarely studied as distinct social phenomena but are usually subsumed under one of two theoretical traditions--that of collective behavior (Smelser, 1963; Olson, 1968; Blumer, 1939) or that of interest group and party formation (Turner, 1969; Lang and Lang, 1961; Heberle, 1968). The first of these traditions views social movements in the same genre as fads, riots, crowds and panics. From this perspective a social movement is a form of "elementary collective behavior on a large scale" (Smelser, 1963).[1] The other approach sees social movements as one way in which interest groups or political parties are formed. These theories are primarily concerned with the organized aspects of a movement, its public program and its institutional impact while neglecting the social changes the movement might make.

In understanding the development of hospice as a social movement it is important to understand that movements are neither fully collective behavior nor incipient interest groups. As Freeman (1975, p. 47) points out, they "contain elements of both. . . being purposive in direction, involving a critical amount of group consciousness, and resulting in both personal and institutional changes. It is the dual imperative of spontaneity and organization that sets social movements apart from collective behavior on the one hand and pressure groups on the other."

It is the social movement organization which Zald and Ash (1966) pointed to as central to understanding the structured aspects of a movement. The social movement organization not only determines much of the movement's conscious policy but also serves as a focus for the development of the movement's values and activities. Just as it has been argued that society as a whole has a cultural and structural "center" around which most members of society turn, so too a social movement can be conceived as having a center which directs its activities and a periphery (Shils, 1970).

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[1] Anthony Obershall, in his book Social Conflicts and Social Movements (1971, p. 22) critique's Smelser's theory of collective behavior as "emphasizing discontinuities and differences. While other sociologists are seeing rational components of collective behavior, Smelser's emphasis is in the non-rational components; when other sociologists emphasize the diversity of beliefs, motives and perception in collective behavior that lead to heterogeneity of crowd behavior and of differential participation in social movements, Smelser emphasizes the homogenizing effects of generalized beliefs."

An investigation into a social movement's origins must be concerned with microsociological and macrosociological preconditions for the emergence of the movement center. From where do people come who make up the initial, organizing cadre? How do they come together and how do they come to share a similar view of the world which compels them to take action? In what ways does the nature of the original center affect the future development of the movement? What environmental factors support the development of this movement? The next section examines the evolution of hospice as a social movement and the development of hospice programs as social movement organizations from which to direct the movement.

History of the Hospice Movement

Most movements have inconspicuous beginnings. The significant elements which sparked the movement are often forgotten over time and retroactive analyses are often incomplete. However, it is useful when trying to analyze the development of a movement to apply some theoretical framework regardless of how weak or loose that framework is. For a guide, we can turn to Armand Mauss.

Mauss (1971), describes five broad stages conceptualizing the natural history of a social movement: 1) incipiency (early unorganized activities), 2) coalescence (gradual formation of leadership), 3) institutionalization (passage of laws, formal organization), 4) fragmentation (early conflict) and 5) demise (co-optation or repression). The chief impetus projecting a movement through these stages is the interaction between the movement and the society, the movement's dependence upon the host society. A movement must try to maintain its identity, integrity and a continuing commitment to principles while simultaneously trying to broaden its membership and support base. The host society, on the other hand, may try to contain the movement. Mauss' conceptualization forms a basis for understanding formation of hospice.

The original hospice founders wanted to integrate the hospice philosophy into the traditional medical system. They sought to alter the way in which physicians, nurses and families dealt with death. They also wanted to change societal attitudes toward the dying and to provide them with a more dignified and humane life ending, free of mind-altering drugs and excessive interventions.

The early, uncoordinated efforts of the movement during what Mauss' terms its "incipiency" consisted of small living-room gatherings where people discussed their frustrations with the existing system of care for the dying. As one man said,

> When we first met we didn't have any overall idea. We just talked about our anger at the system, nobody in particular, just the way things were. We felt better being with others who experienced similar frustrations. All of a sudden someone came up with the idea of hospice and we were off. We began to discuss developing a program and making it work. We didn't want to belong to any other organization. We just wanted to work by ourselves.

Over time, the movement "coalesced" and several leaders formed. Most prominent among them were Elisabeth Kubler-Ross and Cicley Saunders, who prescribed hospice as method of care for the terminally ill. As Saunders (1969, p. 52) wrote, "There is a difference between prolonging living and what can really only be called prolonging dying."

As discussed earlier, movements have an "enemy." The targeted enemy during the movement's coalescence stage was the medical care system, an elusive enough symbol at which to throw barbs without ever targeting anyone in particular. Early organizers blamed "the system" for its failure to deal with the needs of the dying. To some, the system included physicians and nurses, to others it targeted hospital administrators. Society's inability to discuss death was also a target of early founders. They attacked the distancing of the family from the patient during the final days. As an early article about hospice noted:

> I realize that I have been shielded from the idea of dying. That I was the product of an enlightened society that banished the idea of death. . . and by banishing the idea, we have too often banished the dying to physical and emotional isolation, to denial of reality, to unnecessary pain, both psychic and physical. . . . Americans are uncomfortable with the idea of death. Their ability to comfort the dying and their families is thereby diminished. (Zorba, 1978).

As hospice concept moved through the second stage the enemy and the plan of attack became more specific. De-institutionalization of the dying was the battle plan, "death with dignity" the slogan. According to hospice directors interviewed, the home must be re-established as a place for death. The hospitals society created are not appropriate for the terminally ill. The structure of health care in hospitals is designed to deal with acute diseases. In order to serve the purpose for which it was created, the hospital must cure the pathologies of the ill. In order to survive as an organization, the hospital must make money. It does both these things--makes money and treats disease--through medical heroics. A hospital is not intended to deal with emotional issues surrounding not only the patient but also the family. It is not designed to provide a home-like atmosphere for patients and a "rest stop" during their final days. As one organizer wrote, "hospice is not a means to fill hospital beds. Rather, the goal of such a program is to help the patient live at home as long as possible."

By directing attacks at the hospital system, the hospice founders were able to do three things. First, they were able to provide a rationale for the existence of hospice programs outside the confines of the hospital. Second, they were able to recruit nurses and physicians to their cause since it was not these professionals that had caused the problem, but rather the system itself over which they had little or no control. Third, they were able to develop a specific ideology containing their particular brand of explanation for problems and solutions. As one early movement organizer said,

> We were all just mad. We sat in my living room. . . there must have been about 20 of us. . . and talked for what seemed like hours. We all had some horror story. We were angry at the doctor, the nurse, someone. After a while we realized that our loved one might have received better care if he was at home. It was the place of care that caused the problem. All of us had had a bad experience with hospital __________. Now we knew what we had to do. . .[1]

It was during this time of coalesence that advocates discussed the need to be isolated from the traditional system. After all, it was the existing system that caused the problems, that failed to provide appropriate care for the terminally ill. Therefore, it followed that change from the system meant a break with it and the formation of independent hospice organizations.

"We didn't want to be associated with the area hospital," said one board president. "We wanted our own ten-bed inpatient facility and our own staff. We had no intention of working cooperatively when we began. We just didn't think the home health agency or the hospital did a good job of caring for the dying."

The early hospice programs in this country were largely small volunteer organizations. They had little, if any, program of care for the dying. They sought to do "good things" and to provide the dying with an option from the existing system. Some organizers turned to England for guidance, others sought help from leaders such as Elisabeth Kubler-Ross. The majority of the early organizers, however, were non-medically trained individuals--clergy, consumers, funeral directors, etc. The dynamics of the period of coalesence were described by one woman:

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[1] This type of organizational mobilization is described in Obershall, *Social Conflicts and Social Movements*.

> Let's face it, we didn't know anything. It sounded like a good idea. . . . We thought we knew all the problems. . . we envisioned a cadre of volunteers. . . neighbors, who would help each other during the final stages. The articles we'd read were so appealing. The family, clustered around the dying patient's bed. A small child kneeling, a dog looking in. It was so ethereal. . . . The patient had a slight smile on his face, he looked so peaceful. The news articles were always the same. They had testimonials from people who described the beauty of death. There wasn't a lot of information back then. We all read Kubler-Ross' book and discussed it. . . . It's funny. Things changed. They became so different once we really got started. We had so many things to think about. We realized we needed to provide more than emotional and social support. We had to do actual physical patient care. This boggled our minds. We didn't know how or where to begin. . . . I remember, it was one year after we began meeting that we'd heard of this other program in Michigan. It was started by a doctor. We received some information. It looked terribly involved. We decided at that meeting that we had to expand our group. We had to have a physician who would work with us.

As the impetus for hospice grew across the country and in Michigan, concerted efforts were made by organizers to involve physicians and nurses into the planning and development of individual hospice programs. The National Hospice Organization hired a physician, Josephine Magno, as executive director. This provided a further push toward involvement of medical care personnel.

The media played an important role in promoting program development. Between 1974 and 1981 thousands of articles were printed which described the hospice philosophy of care and provided examples of hospice programs operating in England and in the United States. A 1978 article by June Bingham in the Detroit News noted, "Hospice is an idea whose time has come--for people whose time has come. . . . By the time I am dying," she continued, "I hope there will be enough good hospices in the U.S. for one to be near my home."

Another article, written two years later in The Michigan Catholic praised and underscored the fact that the hospice philosophy was consistent with the Vatican declaration on euthanasia, issued June 26, 1980. The author, Catherine

Vatican declaration on euthanasia, issued June 26, 1980. The author, Catherine Haven, quoted from the Vatican Declaration, "What a sick person needs, besides medical care, is love, the human and supernatural warmth with which the sick person can and ought to be surrounded by all those close to him or her, parents and children, doctors and nurses."

The press coverage on hospice followed the organizational development of the movement from an idea to an organized form of health care for the terminally ill. The primary thrust during this period (approximately 1973-77) was the emphasis of the dying at home and the development of programs of care to deal with the pain--both physical and mental--associated with terminal illness.

By the end of 1977 the movement entered a third stage, that Mauss refers to as "institutionalization." It was during this time that organizers stopped calling for a program of care that was separated from the existing health care delivery system and began to develop strategies for integration. Then Secretary of Health and Human Services, Joseph Califano, called on his staff to devise a number of steps to ease the progress of the hospice movement. The National Hospice Organization was incorporated in 1978 and one year later, the W.K. Kellogg Foundation provided funds for the Joint Commission on Hospital Accreditation to develop standards for hospice care.

The organizers were now discussing ways in which they could become integrated into the existing system. The change in attitude did not occur overnight. It was the result of five major factors.

First, hospice organizers realized that caring for the terminally ill had to include some level of nursing care. They realized their expertise in this area was limited and needed to ally themselves with individuals who had appropriate background. This meant including nurses and physicians in their organizational deliberations.

Second, programs based on strictly volunteer help were having a difficult time coordinating and providing care. While most volunteers were enthusiastic about working with patients, someone needed to coordinate the volunteers, organize records, and recruit members. Administrators suffer from burn-out after a while, this is especially problematic if they are unpaid. These volunteers who devoted hours of their time were tiring; some needed money for their personal support. Hospice programs began to seriously pursue ways of seeking funds from third party insurers and private foundations. In order to do this they needed legitimation. They needed to develop a program of care for the dying that was organized and could be sold. Operating without the support of the medical community, area hospitals and home health agencies was not going to help their drives for outside financing.

Third, as more medical personnel were invited to participate in the organization and development of hospice programs, they brought with them the values and standards of the system of which they were a part. They wanted the hospice programs to be "of high quality." This meant that they had to have standards of patient care.

As one medical director said, "We had to make sure that not every charletan would open a hospice program. We realized, after we got our feet wet, that we needed procedures, policies and standards. . . . After all, we are providing care for the dying. This is a very complex area. We have to make sure that quality of care is maintained." It was this elusive term "quality" to which many organizers referred when asked why they wanted standards developed and procedures followed.

Fourth, hospice programs developed technologies for pain and symptom control and palliative care. Only licensed medical and nursing personnel can administer these drugs. If hospice programs did not become institutionalized, they risked withdrawal of support from the professionals they needed to assist in administering their most important technology, pain control.

Fifth, the American population is socialized to accept Western medicine and to expect some uniformity. When someone describes a hospital, we have a mental image and expect certain standards of cleanliness, sterility, types of personnel, etc. Similarly, when someone describes a hospice program it is only natural to expect certain uniformities regardless of where in the United States you live. As one hospice administrator said,

> We've got to have standards for hospice care. It would be un-American if we didn't (laugh). Joking aside, people expect certain things. They expect that when they enter a hospice program they are going to receive a type of service. If I transfer one of my patients to Hospice X, I have a right to expect that he will receive a certain standard of care which continued the care he received here. . . . I really don't think it's asking too much to want hospice programs standardized. After all, we are a provider of health care services, aren't we?

Hospice programs are still in Mauss' third stage. Yet, as we shall see later, they are beginning to step into Mauss' fourth stage, fragmentation. The drive of the hospice program directors for institutionalization is also a call for integration. In order to achieve this end, hospice organizers sought passage of legislation to provide Medicare reimbursement for hospice patients, support from third-party insurers, and status as official providers of care for the terminally ill through state licensing statutes.

In general, efforts toward integration have been successful--so successful, in fact, that organizations once excluded as legitimate providers of hospice care are now becoming a major force in the development of new programs. According to NHO Executive Director Josephine Magno, 40% of the hospice programs developing are hospital based. Another 20% are home health agency affiliated. Increasingly, existing providers are entering into the hospice industry. Similarly, some hospice programs are seeking alternative status as home health agencies.

Hospice programs were recently granted "independent provider" status under the federal Medicare regulations. This allows the programs to receive federal reimbursement for patient care. The program is responsible for determining patient care plans, hiring appropriate personnel, etc. The hospice program, in short, has a provider classification and can be considered a part of the traditional health care system. It must conform to standards and protocols if it is to receive federal funds. Further, licensed personnel are responsible for patient care plans.

Mauss (1975, p. 60) notes it is rare for a movement to outlast its host society, unless, of course, the movement is a successful revolution. Brinton (1952) shows how a society can absorb revolutionary leaders as they turn to realities of governance in an established cultural setting. They can be co-opted or integrated into the host society.

The dynamics between the development of a social movement and its interaction with the host society provide an opportunity to study the degree to which a movement becomes integrated or co-opted by the larger social system. While the subject of this research is integration, it is often erroneously used as a synonym for co-optation and requires a discussion.

Co-optation refers to ameliorative gestures in the direction of meeting and neutralizing the movement's criticisms, combined with a propaganda effort emphasizing those interests and values which the society shares with the reform movement (Mauss, 1971). Integration, on the other hand, is the societal acceptance of a movement and a shift in laws, norms or rules to address the criticism levied at the society by the movement. Because these are both operating during the interaction of the movement with its host society, it is important to analyze them separately.

Co-optation and Integration

Selznick (1953) defined co-optation as "the process of absorbing new elements into the leadership of policy-determined structure of an organization as a means of averting threats to its stability of existence." Selznick describes how the reform program of the Tennessee Valley Authority (TVA) encountered strong opposition from powerful entrenched forces in the area and how the TVA's grass-roots policy enabled it to achieve success by co-opting some representatives of the opposition into its management. However, since these new elements influenced the policies of the organization so that they reflected their own interests, the earlier objectives of the TVA were modified and transformed.

Gamson (1968) noted that the process of co-optation may not be all bad. Although co-optation "removes some of the insulation between potential partisans and authorities, it makes the former subject to other control techniques which were not previously available" (Gamson, 1968, p. 135).

The trend toward conservatism brought on by pressures from the larger society has been identified in discussion of political movements as a trend toward bureaucratization or routinization. According to the theories of Weber (1947) and Michels (1949), as a social movement organization attains an economic and social base in a society, the original charismatic leadership is replaced, original goals are transformed to conform to external pressures and a bureaucratic structure emerges. By this Weber meant that an organization has an on-going base of financial support.

> . . . bureaucracy as a permanent structure is knit to the one presupposition of a constant for maintaining it. . . (Weber, 1946, p. 208)

In his discussion of social base, Michels noted that the organization must play to the interest of "possible adherents and sympathizers who can join or support the movement" (Michels, 1949, p. 334).

Implicit in this model is the notion that the chief goal of a social movement organization is organizational maintenance. According to Michels' (1949) "iron law of oligarchy," a successful social movement organization adjusts its goals to conform to those of the larger society.

Movements which conform to the norms of behavior in order to survive and participate in existing institutions often find themselves forsaking their original goals for social change. Long-range ideals become warped for the sake of short-range gains. However, movements that hold steadfast to original, often radical, goals and disdain affiliation with existing organizational structures find themselves isolated in "splendid ideological purity" which gains nothing for the movement or its participants. They become paralyzed by their own fear of co-optation; and "such paralysis is in turn the ultimate co-optation as inactive revolutionaries are a good deal more innocuous than active reformists" (Freeman, 1975 p. 6).

Integration refers to the participation of the SMO in the larger society or, as Wilson (1973) defines it, "behavior in harmony with the environment." Integration of a social movement organization is one form of organizational development which is achieved by expanding organizational domains in order to reduce or eliminate significant contingencies (Thompson, 1967), or by improving cohesiveness so that organizations which exhibit similar values and norms are more highly integrated than those which exhibit dissimilar values and norms (Blau and Scott, 1962).

In the case of social movement organizations, the movement is considered integrated if the larger system passes laws, establishes norms and so on which conform to the goals and objectives of the social movement organization. If, on the other hand, the social movement organization adopts the goals of the system it seeks to change while down playing or significantly changing its original goals so that they are no longer recognizable, it could be argued that the SMO has been co-opted.

In the case of hospice, the intent of most early organizers was to ensure that the hospice concept became an integral part of the existing health care system. Early hospice movement founders encouraged tactics and exchange relationships which would establish important and relevant links to the existing health care system. They sought to include hospice as a legitimate[1] form of health care and promoted the drafting of hospice standards, passage of hospice legislation, adoption of reimbursement for hospice patients, involvement of physicians and other members of traditional health care on hospice boards, as strategies to integrate hospice into the larger health care system. To use Mauss' term, the hospice movement sought "institutionalization" and integration.

To many hospice program founders, integration was the key to success. They felt that unless the traditional system accepted hospice as an alternative form of care for the dying, the programs would not survive. Because of their emphasis on palliative care for the dying patient, hospice programs are highly dependent on the physicians and home health agencies. The state and federal laws required that traditional providers become an integral part of hospice care. Reimbursement programs, such as the Medicare entitlement, mandated the involvement of a physician and the provision of home-based skilled and basic nursing care by licensed nurses.

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[1] Legitimacy is one of the criteria that Gamson (1975) used to measure success of social-reform groups. He defines legitimacy as whether a challenging group is accepted by antagonists as speaking for its constituency. By acceptance, Gamson means consultation, negotiation, formal recognition, or inclusion in the antagonists' organizational structure.

Yet, for some hospice program leaders, integration was a much dreaded outcome. These individuals view hospice as a distinct health care provider which should not be confused with or integrated into the existing medical care system. Claiming that the concept of hospice will be lost, opponents of integration contend providers in the traditional system are unable to fulfill the needs and guarantee the rights of the dying patient. These divergent viewpoints have caused conflicts among hospice program organizers and have led to a fragmentation within the hospice movement which is examined in detail in the results and discussion sections of this research.

The next section describes integration as a concept used in this research. It examines factors which influence a program's integration such as size, goals, external affiliations, development of environmental supports, board composition and organizational competition.

Integration as a Construct

The major concern of the research was the ability of hospice programs to become an integrated part of the existing health care system. Integration was seen as important to the long-term survival of hospice programs as they could not exist as separate isolated service providers. They needed an on-going source of funds and the acceptance by the medical community. Moreover, attempts to exclude the existing health care system would have meant certain doom.

As one founder noted,

> We started by trying to set up a hospice program within the local hospital. . . . Some people in our group did not want to be part of the hospital. They thought it would hurt us in the long run. The other areas' hospitals wouldn't refer patients to us and the home health agency nurses might not want to work with us. . . . We decided to establish an independent organization. . . . After a while our meetings turned to the discussion of how we could get the area hospitals to work with us. . . . We wanted and needed their support.

The concept of integration might best be explored by contrasting two hospice programs. The ideal integrated program would be one that attracts support from members of the medical and business community. It is bureaucratic in form having a paid staff, assignment of specific tasks (division of labor) and goals directed toward building a stable economic base.

In contrast, the ideal non-integrated program relies heavily on volunteers, especially use of volunteer staff, has limited support from the medical and business community, has low division of labor and is more concerned with promoting the hospice concept then with building a stable economic base.

Hospice **"Divine"** is the largest integrated hospice program in the state. It is located in a heavily industrialized area with a tri-county population of more than four million.

Divine is an "inpatient" hospice. This is particularly important since Divine is a fairly new program and is located in an area of the state with a large surplus of acute-care beds. The tri-county area in which Divine offers services has approximately 75 hospitals ranging in size from approximately 80 to more than 1,000 beds.

Divine was established by the Metropolitan Northwest Hospitals Corporation (popularly known as the Square Corporation), a non-profit hospital consortium. The history of Divine is recounted in one of its documents.

> . . . In 1976, the executive director of the Square Corporation, Mr. Ed, learned of the hospice concept from his wife, a registered nurse. He began to saturate himself with knowledge about hospice care and visited several hospices in the United States. He invited a local physician who was also studying the hospice concept to make a presentation on hospice care to the administrators of the Square Corporation hospitals, with the goal of convincing them of the need for a hospice within the service area of the four hospitals. His strategy was successful, and a physicians' task force was appointed from the medical staffs of the hospitals. After several months of review, the task force endorsed the concept, and Mr. Ed moved into the planning phase.

> Mr. Ed, a Fellow of the American College of Hospital Administrators, was astute enough to realize that he could lose the competitive advantage of submitting the first application for a hospice certificate-of-need in the state if hospital administrators other than those in the Square Corporation prematurely learned of his actions. He was acutely aware of the necessity for conducting his planning as quietly as possible. He reasoned that since 90 to 95 percent of hospice patients would have terminal cancer, cancer deaths in the tri-county area would approximate the number of potential hospice patients, and he sought statistics from the local cancer foundation and the Divine Chapter of the American Cancer Society. The data may have been somewhat inaccurate, but Mr. Ed believed the figures were suitable for planning purposes. He learned there were 10,888 cancer deaths in the tri-county area in 1975, 11 percent occurring in nursing homes, 8 percent in private homes and 81 percent in hospitals or in transit to hospitals. The place-of-death percentages strengthened his opinion that hospice planning was appropriate for acute care hospitals.[1]

The original planning body of Divine included of representatives from the hospitals that comprised the Square, including a director of planning and government relations for St. N Hospital, a chaplain from St. J Hospital, a member of the board of trustees from Mt. T Hospital and the chief executive officer from H Hospital.

In the process of planning for the certificate-of-need application for his hospice program, Mr. Ed worked with state public health officials as well as state and local planning groups to gain support for his hospice concept. Area health planners suggested that Mr. Ed broaden Divine's scope to include other hospitals. In exchange, the local health planning agency--responsible under an earlier discussed health planning statute for determining the need for new hospital based services--proposed they would provide Square with the certificate of need approval. If Square had the approval other area hospitals would not be able to start their own competing hospice.

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[1] Paper on the historic development of Hospice Divine. Confidential document presented to the researcher by Divine's executive director.

Mr. Ed sent letters to "selected hospital administrators" inviting them to participate in Hospice Divine. His letter, along with publicly and privately issued statements from the local health planning agency, "subtly implied to the more reluctant hospital Chief Executive Officers (CEO's) that the Square Corporation hospitals already possessed strength in numbers, and that the local health planning agency would be hesitant to endorse more than one hospice at present."[1]

The strategy worked and in October 1978, seven hospitals were involved in an effort to form Hospice Divine. Each hospital paid a "one-time-only" membership fee of five thousand dollars for development funds which included payment of legal fees, a financial feasibility study and the salary of a hospice director.

According to Hospice Divine records, within one and a half years, 13 hospital corporations representing 22 acute care hospitals in the tri-county area in which Divine was located, were members of Hospice Divine. The hospital members included three Catholic-sponsored and one Jewish-operated hospital. Three of the 13 corporate members were osteopathic hospital corporations, representing six of the 22 acute hospitals.

The hospitals involved with Hospice Divine have invested thousands of dollars in the program. Reasons for the investment are varied, as Divine administrator Ms. Mic points out,

> Hospice Divine was an experiment. Each hospital wanted its own program but didn't know if it was worth the investment. Because hospice was so new, no one knew what they were doing back then. It made good business sense to start the consortium and let one central place treat terminal patients, collect data, and work out the problems. . . . I wouldn't be surprised if many of the participating hospitals formed their own program eventually. We would still have a function and, as I see it, would have a major role in consulting with those hospitals on what we've learned.

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[1] Taken verbatim from confidential document.

In terms of the criteria for integration, Divine is formally affiliated and dependent upon area hospitals and reimbursers for economic support. While some of its two million dollar operating budget is from memorials and private donations, Divine depends on third-party reimbursement from Blue Cross/Blue Shield and other third-party payers for most of its operating funds. Divine's administrator actively seeks outside funding and was recently awarded a $250,000 grant from the State Department of Social Services to analyze the cost effectiveness of providing hospice care to terminal Medicaid patients.

Divine enjoys wide range support from members of the community. The 25-person board is composed of 14 representatives from the local hospital members in addition to 11 other non-medical professionals from the community. Divine has a high number of paid staff--the highest number of any hospice program in the state--and pays most staff full-time wages.

Individuals from the public are not invited to become members of Hospice Divine. Interested individuals can volunteer their time and services to work with the hospice, but most volunteers do not provide direct patient care.

As Ms. Mic noted, "We can't use them the way some other hospice programs do. We also have quite a few trained staff who care for most of the patient needs. Volunteers can help us in our business office, or they may spend time reading to patients, speaking for hospice, or helping the relatives of the patient."

The use of volunteers at Divine is similar to that of the hospital participants. Volunteers are used primarily to staff the reception area, deliver packages or food trays to the sick, and sometimes spend time with patients in their rooms.

The staff at Divine are a close-knit group, according to the administrator. They spend lots of time working in an intense environment. Team meetings are held Monday mornings from 8:00 to noon.

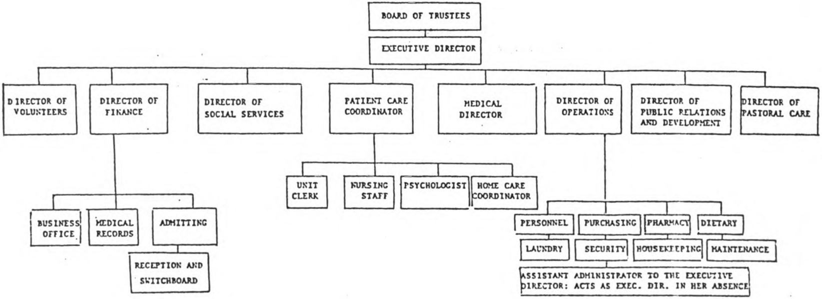
"They are an important way to begin the week and to get in touch with what needs to be done," said Ms. Mic. Volunteers do participate in the team meetings, which are held every Monday. The medical director, nursing, social work staff, chaplain, physical therapist, and occupational therapist are present at these meetings.

Hospice Divine meets most of the criteria for an integrated program and has high reliance on paid staff, high interest in seeking outside funds, is formally affiliated and dependent upon area hospitals and third-party reimbursers for survival, and is supported by the medical community. According to Ms. Mic, "The long range goal of the area hospitals which founded Divine was to make it a self-sufficient program."

Hospice Divine is a highly structured inpatient hospice care facility. Its organizational chart (attached) looks similar to those of the local hospital affiliates. Patient charges for Divine are $220.00 per day. The 38 inpatient beds are almost always filled. "We run a 90 percent occupancy," said Ms. Mic. "We could go higher but we observe a policy of keeping the bed of a dying patient vacant for 24 hours. We place a rose in the center of the bed as a memory of the patient. The staff person treating the patient needs time to work through his or her grief."

The discussion of Hospice Divine has focused primarily on its inpatient unit. However, Divine also has a home-based program. For patients with insurance which reimburses for home care, Divine uses area home health agencies to provide care to patients in their home.

HOSPICE DIVINE



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"We emphasize the home care program," said Ms. Mic. "But many of the patients who are referred to us have no home and no family or primary care provider to take care of them. We try to provide a home-like atmosphere in our facility. . . . It's the best we can do for now. . . . Also, I should mention that home care is difficult for some patients because their insurance will not pay for it."

Hospice **"Idlewood"** is much different from Hospice Divine. Located in a sparsely populated area of the state known for its wood harvest and iron ore shipping, Idlewood was incorporated in the summer of 1979, after months of planning, and accepted its first patient in fall 1979.

The hospice serves residents in several rural communities totaling between 35,000-40,000 people in a service area of about 1,300 square miles. A single Catholic 127-bed acute care hospital and four nursing facilities are available to community residents. The nearest tertiary care center, with full oncology and radiation therapy services, is about 70 miles north of the hospice. A family practice teaching module of a university medical school is located in the community and provides office space and telephone answering. In its plan for a hospice program, the founders of Idlewood described the residents of the service area and the death rates.

> . . . . The people are primarily of Northern European background and are employed in forestry, manufacturing, tourist and service industries. Sixty percent are Roman Catholic with a broad group of Protestant denominations also represented. Approximately 350-370 deaths are recorded in the county each year, with about 50-60 of the deaths from causes likely to have a terminal phase, such as cancer and advanced organ failures.[1]

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[1] ("Basic Introductory Information Package," For internal use only by Upper Hospice)

The small group of Idlewood founders consisted of a funeral director, physician, hospital nurse, minister, and a nursing home administrator. One of the early founders, the funeral director, proposed the hospice concept to the community, to "fill a void" in the traditional health care system.

> Families I served, following the death of the patient often described the final days and weeks of hospitalization as "good" but lacking something. The "something" I believed was the basic human needs of the terminally ill. I just knew in my blood that there had to be a better way. As my friend Dr. J. William Warden of the Harvard Medical School once described those needs:
>
>> They want to be free of pain, though not to the extent where medication will interfere with their awareness. They want continued companionship of family and friends and continued support, the familiar things they enjoyed while well: children, favorite foods, flowers, music and even their pets. Most of all, they want to be accepted as they are, to maintain their own individuality, and to be assured that when they die, they will not die alone, and that they will be cared for and be remembered with love and respect.
>
> I had been following the movement since 1975 and saving articles written on hospice. I visited the Bellin Memorial Hospice in Green Bay in 1978 and shared this information with a good friend, the director of the family practice teaching module and some of the local hospital staff. We all became very excited and immediately began to pursue the idea, forming an ad hoc committee to investigate the concept and complete a needs assessment. The assessment proved a positive and the hospice concept the facilitator.

A manual describing the services of Idlewood notes:

> . . . . Hospice Idlewood is a non-profit organization which charges nothing for its services and pays its volunteer staff only expenses. The Hospice has no inpatient facility; it assigns a single nurse to each family unit and attempts to coordinate care no matter what the setting. The nurse provides daily contact and services as the conduit for other services from volunteers, pastoral counselors, physicians, and social services. The family's own physician and pastoral care provider, as well as the patient's family are incorporated as part of the care team for each patient. Bereavement services continue for up to 23 months post-mortum. All services coordinated through the assigned nurse, are given in

> whichever location the patient is found--home, inpatient hospital or nursing home. . . . . Community support, both in terms of new referrals and financial aid, has been outstanding and feedback of those served extremely gratifying.

The hospice receives no third-party funds. It depends entirely on community donations, fund-raising events and small grants from local foundations and service organizations. The annual operating budget is less than $9,000 with a yearly patient load of approximately 30 persons. In 1982 Idlewood provided 1022 care days to 26 patients, five of whom were still living at the end of December. The average number of days per patient in the program were 40 with 12 deaths occuring in the hospital, 7 at home and 2 in a nursing home. The greatest cause of death was lung cancer and the average age was 64 years. Of the 26 patients, 15 were female.

Idlewood serves as a model non-integrated program. It is totally dependent on volunteers, has informal relationships with area health care providers but emphasizes its independence from them, emphasizes bereavement services, accepts only contributions and is not dependent on third-party reimbursement, encourages program membership and boasts a high degree of community support. A secretary is paid for 20 hours weekly. A board of directors administers the program.

Idlewood has no formal organizational chart, but does use a "hospice care process" diagram to explain organizational flow. The flow diagram shows the importance placed on team processes. The team includes the volunteer assigned to the patient, a nurse and a physician. Team meetings are held weekly.

Organizationally, Idlewood is much smaller than Divine and serves a much smaller population. It has not applied for a certificate of need from the state and strongly resists any affiliations with existing institutions. It can easily do so because there are few medical care organizations in the area and those existing

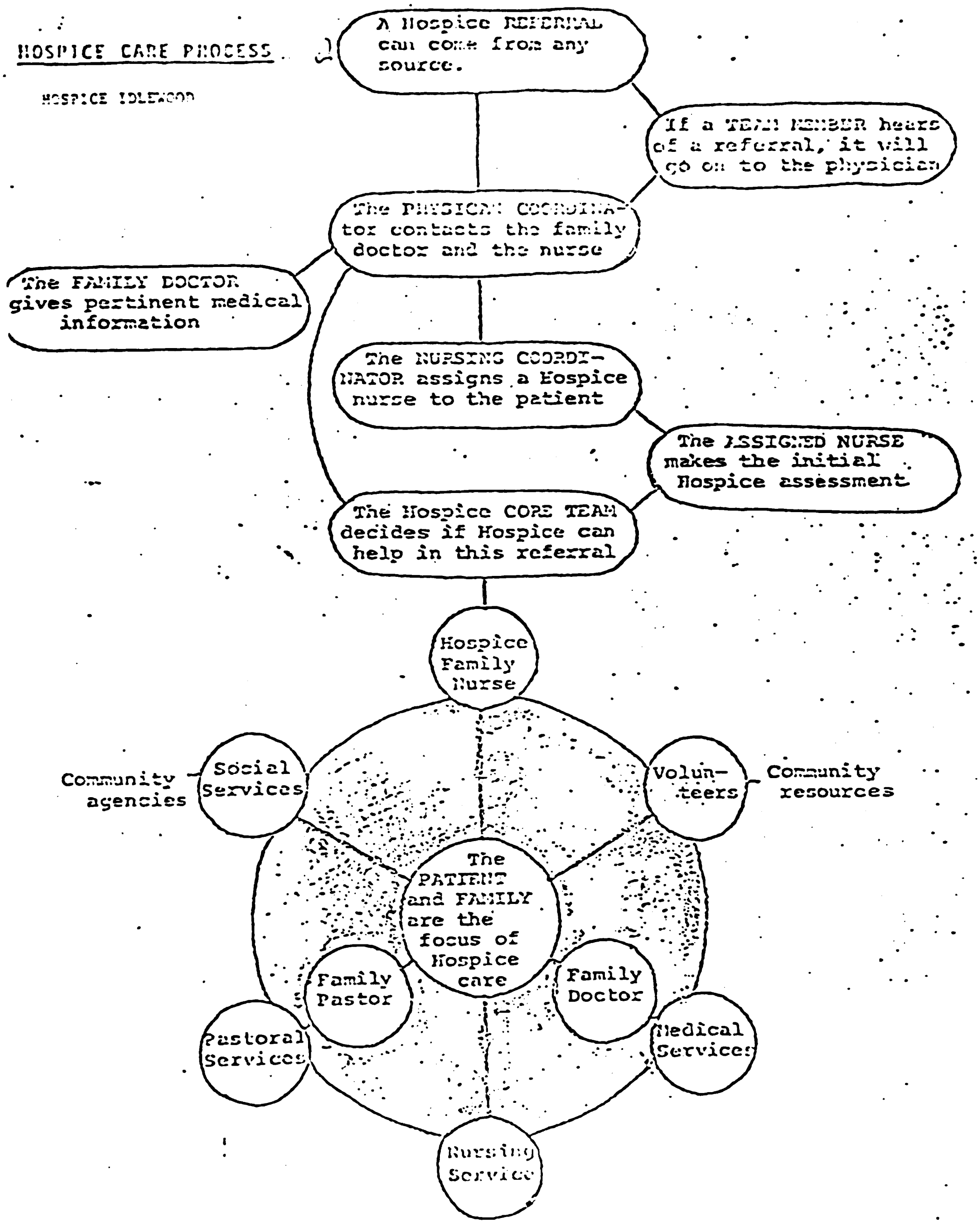


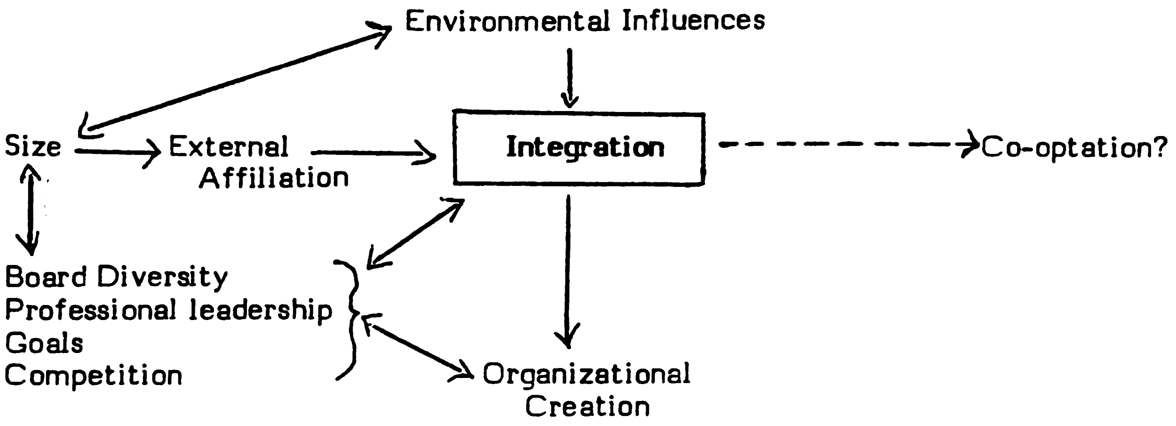
Figure 4. Example of a Hospice Care Process Flow Diagram

are filled to capacity. Because Hospice Idlewood provides these services for free, the local hospital and nursing homes view Idlewood as another support system to assist them in providing patient care.

Hospice Divine, on the other hand, is in a much different situation. Taking referrals from local hospitals, it can be viewed as a competitor. As one administrator noted, "We're going to begin our own hospice program. . . . not that we don't value the program of Divine, but now that we can get Medicare reimbursement and the third parties are coming along, there is really no need to refer patients out. . . . It was a good program for getting hospice started and accepted by the medical establishment. Now we see the need for it and can incorporate it in our own institution. . . ."

The histories of Hospices Divine and Idlewood provide concrete examples from which to understand the effects of integration on hospice program structure and development. As can be seen, integration is affected by a variety of organizational elements: size, goals, board composition, professional leadership and competition.

Because the social movement organization literature is vague with respect to specific propositions that could lead to hospice program integration, research on organizational growth and development was examined. Seven variables were selected as most likely to affect hospice program integration: organizational goals, size, environmental influences, leadership, external affiliations, organizational creation and competition. The diagram below provides an overview of how these goals impact integration.



At the center of the diagram is the dependent variable "integration." It is proposed that a hospice program's integration is affected by its size. Size, as we shall see later, is an important organizational variable which influences the degree of external affiliations an organization forms as well as the recruitment of professionals, diversity of a board of directors, the goals of the organization and the degree to which the organization competes with others in a given area. While this research does not examine the effects of size on board diversity, professional leadership, organizational goals and competition, it is important to note that size may be related to each of these variables. Size was not used as an intervening variable from which to analyze board diversity, professional leadership, goals and competition, because many of the hospice programs were small at the time of the survey and with little, if any variation in size. It was decided that an analysis of the effects of individual variables on integration would be more beneficial than a study of the interaction among the variables and organizational size.

External or environmental influences were seen as an important factor in effecting integration as is described in detail in the next section. Organizational creation, that is, the way in which a hospice program was created, is also viewed as impacting the degree to which a hospice program becomes integrated.

Co-optation was not an issue for this study. However, it lurks in the background and is an important concept in much of the social movement literature (Weber, 1947, and Michels, 1949). When integration stops and co-optation begins is an unanswered question. As we shall see later, there is some evidence to argue that the hospice program has changed patterns of care in the traditional system toward what hospice promoters consider "more humane methods of treatment for the dying" while at the same time the hospice program has also altered some of its original goals to reflect those of the existing system. One could argue there has been some co-optation on the part of both the hospice providers and the traditional providers.

The following section provides a brief overview of the variables involved in this research.

Organizational Goals

Goals or objectives are "universal characteristics of organizations," according to Parsons (1956). Yet, the concept of organizational goals is an elusive one. One source of difficulty in defining and employing the concept of goals is the many ways analysts and organizations have employed and defined goals. Thus, as Scott (1981) points out, rational systems analysts such as Simon emphasize that goals provide criteria to generate and to select among alternative courses of action. These analysts stress the cognitive function of goals in decision-making. Natural systems analysts such as Barnard (1938), Selznick (1949) and Clark and Nelson (1961) view goals as a source of motivation for participants, which can be employed as "ideological weapons" with which to garner environmental resources.

Regardless of one's analytic perspective, goal statements are a useful tool for evaluating social movements and SMO development. Goals may be transformed by a variety of factors and serve as a basis for leaders to evaluate the behavior of participants or of entire organizations (Scott, 1977). The social movement organization's goals provide a mechanism for evaluating growth, decay or change.

For example, an SMO's change in goal orientation is tied to the ebb and flow of sentiments within the social movement. According to Zald and Ash (1966), an organization shifts its tactics to respond to changing external and internal sentiments. Social movement organizations that compete among themselves and with rival groups such as home health agencies and hospitals to provide palliative care with limited resources will shift their goals and strategies to conform to those of that larger social system. In the process of accommodating to the society, the goals of the social movement organization may become watered down as the organization shifts to a more bureaucratized and conservative form. There is a greater probability that an SMO will become integrated if its goals reflect a shift toward accomodation to the larger social system.

Size

Size is another important variable and has been used by a variety of theoretists to show aspects of structure differentiation (Lipsky, 1968; Blair, 1970; Hall, Haas and Johnson, 1967; Meyer, 1972). For organizations, Blau (1970) noted that large size is associated with structural differentiation which, in turn, creates pressures to increase the size of the administrative component. Larger organizational size increases both the number of different types of organizational subunits, and the size of the administrative component which coordinates the work of these units, up to a point where it levels off.[1] A

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[1] It is understood that Blau did not intend to equate growth with size.

Weberian model of structure indicates that the larger the size of the organization the more formalized its structure. Blau and Schoenherr argue that size is the most important condition affecting the structure of organizations. (Scott, 1981).

According to Scott (1981) analysts vary in their treatment of the construct size:

> . . . Some analysts treat it (size) as a dimension of organizational structure like formulation or centralization--one of several properties of an organization that may be seen to co-vary (for example, Hall and Tittle, 1966). Others treat size more as a contextual variable, measuring the demand for an organization's services or products, which provides opportunities for and imposes constraints on the organization's structure (for example, Blau and Schoenherr, 1971; Pugh et al, 1969). Like technology, size appears to be a variable that is on the interface between the organization and its environment. Both variables are, on the one hand, internal features interacting with other structural properties and, on the other, features strongly shaped by external conditions, and, because it is externally driven like technology, size is more likely to be treated as an independent variable acting to shape and determine other structural variables (Scott, 1981 p. 235).

In addition to affecting organizational division of labor, administration, and structure, size can provide an organization with stability and enhance its chances for survival. As Starbuck has noted; "The importance of survival to an organization cannot be overstated," (1965, p. 463). Steindl (1945) found that small firms were more likely to disappear than large ones. Large firms, because of their size, have larger constituencies to look after them and have formed external links to segments of the community with which they deal.

As Pfeffer and Salancik note, size enhances the organization's survival level by

> . . . providing a cushion, or slack, against organizational failure. Large organizations develop larger sets of groups and organizations interested in their problems with willingness to assist in survival. For even interest groups making demands on larger organizations are better off

> with the survival of the organization than without it. This is illustrated nicely by the rush of labor unions to petition the government to save Lockheed. The unions' demands for wages have a better chance of being met by a surviving firm than by one that is bankrupt. (Pfeffer and Salancik, 1978, p. 139)

For the social movement organization, size plays a dominant factor in its future structure and its establishment of ties to the larger social system in which it exists. In the classical social movement model size impacts the amount of activity of a movement, the SMO and the extent to which it gains supporters from the larger society (Lipsky, 1968; McCarthy, 1973). As Zald and Ash (1966, p. 469) write, "The size of the organizational potential support base, ... directly affects the ability of the organization to survive and/or grow."

As the SMO grows and broadens its membership base, it also begins to conform to traditional values and norms of the host society. In the case of hospice programs, the growth in program size will lead to changes in its organizational structure which facilitate integration into the larger health care system. By virture of its size, the hospice program will need financial support and assistance from the traditional system if it is to sustain its operations. As the level of outside support increases to accomodate growing size, the hospice program will be pressured to make structural as well as ideological changes to conform or become integrated into the existing system.

Interorganizational Exchange

The study of interorganizational exchange relationships has received increasing attention from sociologists in recent years. There are studies which described the transactional interdependencies among organizations (Selznick, 1949; Levine and White, 1961; Thompson, 1962; and Elling and Halbsky, 1961). Others stress that the processes of both conflict and cooperation provide bases for understanding interorganizational exchange (Coser, 1946; Caplow, 1964; Litwak and Hylton, 1966).

Many studies of organizational interdependence "conceive of the organization as an entity that needs inputs and provides outputs, linking together a number of organizations via the mechanisms of exchanges and transactions" (Aiken and Hage, 1966, p. 586). Some types of organizational exchanges involve the sharing of clients, funds, and staff in order to perform activities for some common objective (Levine, et al., 1963).

The definition of organizational exchange used in this research is defined by Levine and White (1961, p. 549) and refers to "any voluntary activity between two organizations which has consequences, actual or anticipated for the realization of their respective goals or objectives."

According to Levine and White (1961, p. 549), elements exchanged by health organizations fall into three main categories: (1) referrals of cases, clients, or patients; (2) the giving or receiving of labor services, and (3) the sending or receiving of non-labor resources, e.g. funding. The interdependence of the parts of the exchange system is contingent upon three related factors: (1) accessibility of an organization to elements outside of the health system; (2) objectives of the organization; and (3) existence of domain consensus among other organizations.

The hospice program is a social movement organization which must operate in a larger social system, and like the National Association for the Advancement of Colored People, the National Organization of Women, and Common Cause must form alliances to supporters. It must develop external, mutually beneficial associations (Obershall, 1973). Thus, a hospice program must ally with a network of individuals and groups which will help it achieve its goals, and which, in turn, will receive some benefit--whether psychological, social, physical or economic.

Practically speaking, the program must have clients to serve, access to specialized equipment (e.g. a respirator), specialized knowledge, and personnel. To acquire these elements, a hospice program must have relationships with professionals and health care organizations.

Clients served by the hospice program, for example, are obtained through exchanges with other organizations, such as home health agencies, rather than through independent case-finding procedures.

The exchange relationships into which a hospice enters will exert an influence over the organizational structure of the program, its acceptance by local health care providers and also its future growth, development and integration. An organization which refuses to enter into any agreements will not be able to sustain itself within the traditional health care system. In order to survive, a hospice must establish a set of relationships, formal and informal, voluntary as well as mandatory, which provide it with the resources it needs to perform its goals. Without pharmaceuticals and providers to prescribe, dispense, and administer the medication, the most important goals of the hospice program--to maintain the patient as symptom-free as possible--would not be achieved.

Board Composition

Zald (1974) in his discussion of the power and functions of boards of directors, notes that individual board members and executives bring resources to the organization. These resources include "detachable resources, personal characteristics and strategic contingency situations." Board member experiences, linkages to other organizations and political liaisons are all examples of these resources.

The power of board members is closely related to their service on and control of key committees, the extent to which other board members and management are bound by their perspectives and ideas, and their linkages and positions in the external environment.

The linkage of board members to the external environment was found useful as a way of neutralizing hostile groups, as Selznick (1949) noted in his TVA study. On the other hand, boards can be used to co-opt an organization as Price (1963) and Zald (1967) have noted.

Pfeffer (1972) considered an organization's use of the board of directors as a vehicle for dealing with problems of external interdependence and uncertainty, resulting from "its exchange of resources with important external organizations." He described how boards have access to important external resources. In the case of hospice program boards, not only are external resources important but so is the ability of the board to provide the program with legitimation within the community. Boards of hospice programs control legitimation in that they represent diverse groups or interests which can be mobilized in support of the organization. According to Zald (1974, p. 176), "The more diverse and intense the interests (of board members) in a given organization, the more likely the organization is to be politicized and the more likely board members are to represent community segments."

For the social movement organization, board diversity can have both positive and negative effects. Positively, a diverse board can bring a variety of resources to the organization and may serve to facilitate the SMO's long-term goals and ensure survival. Negatively, a high degree of board diversity could lead to a significant shift in the SMO's goals so that it is no longer pursuing its original ideals. Large diversity may even lead to the co-optation of the organization and its eventual demise.

In the case of hospice programs, board diversity is seen as a mechanism for influencing integration. By ensuring various health and non-health professionals are represented on the board, the hospice program is more likely to develop strategies which lead to its integration than if the board were comprised of only one or two interest groups.

Professional Leadership

The social movement literature points to the importance of leadership in the development of a social movement (Weber, 1974; Michels, 1949; Olsen, 1965; Zald and Ash, 1966; Obershall, 1973; McCarthy and Zald, 1973; Zurcher, 1973; Jenkins, 1981). The leader personality, social class, gender, occupation and status are all considered important variables to social movement growth and change. Similarly, in the case of an organization the board leadership is influenced by these characteristics. As Holloway, Artis and Freeman, (1963, p. 88) point out:

> Sociologists have commonly assumed that important economic status occupants are also key people in the community influence and decision-making process--an assumption not without empirical support. If this assumption is correct, and if we can assume that a hospital board is an important decision-making structure in the community, then it follows that occupants of important economic statuses. . . will also attempt to influence or control the actions of a hospital board.

As a new social movement organization, the hospice program provides us with an opportunity to assess the effects of leadership on program integration. The hospice program relies heavily on professionals with high status, such as physicians, who are increasingly dominating patient care in hospice programs. As Freidson (1970) notes, the medical professional "has been granted autonomy" in his or her profession as well as a great deal of control over entry and exit of patients into the health care system. The physician determines who is sick and who is well; who is living and who is dying. The physician has been trained by and is a major actor part in the traditional health care system. He or she views health care in terms of the Western Medical Model (Stevens, 1971).

The existing medical model calls for the majority of health services to be rendered in a hospital under the direction of a physician with little influence from the family or the friends of a dying patient. Traditional care for the dying is institutionally based and not home based.[1] Given this set of relationships, it is proposed that the involvement of medical professionals, particularly hospital administrators and physicians, in the formulation of a hospice program will increase the probability of its integration into the larger health care system.

Community Support

There are many definitions of what is meant by the term "community" (Durkheim, 1947; Gusfield, 1975; Bernard, 1973; Nisbet, 1953; Goffman, 1961; and Minar and Greer, 1969). Regardless of the paradigm or definition used, three characteristics of community are usually agreed upon as a minimum: locale, common ties and social interaction (Bernard, 1973).

In the case of the hospice program, the community refers to the hospice service area (generally a county) and both the individuals and organizations located in the geographic area who could benefit from the hospice program's services.

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[1] The Michigan Department of Public Health, Office of Vital Statistics estimates that 62% of the deaths in Michigan in 1981 occurred in a hospital while 13% of all deaths occurred in the home (Appendix 5).

It was proposed that the involvement and support of area physicians and home health agencies is important to hospice program integration. The integration of hospice programs into the traditional health care system cannot occur if the system rejects the values and goals of the hospice movement. According to Zald and Ash (1966, p.46) the social movement organization begins to mobilize resources and potential supporters when it feels that there is an "ebb and flow" of public sentiment which is favorable toward the goals of the social movement and the legitimacy of the values of the social movement.

In the case of hospice, which is heavily dependent on the support and involvement of the medical and home health community, public sentiment or community support can be gauged by some measure of the support of area physicians and home health agencies for hospice programs. A hospice program cannot function for an extended period of time without support from area physicians. Lack of support from home health agencies will restrict a hospice program from offering the home-based care it heavily emphasizes, unless it hires its own staff (a luxury which most programs cannot afford).

Community support can be achieved through the donation of funds, resources and time from area residents and health care professionals. The more diverse the base of support the more likely the hospice program is to become integrated into the traditional health care system.

For the purposes of this paper, the concept of community support is concerned with the active participation of members of a given local hospice service area (generally a county), who volunteer their services, resources or expertise to the hospice program.

Competition

Competition among social movement organizations has not been described in the literature. There is material describing the interaction between movements and countermovements competing for existing resources in which to influence social change (Useem and Zald, 1982; McCarthy, 1973). However, there is a dearth of sociological literature which addresses the issue of competition.

Studies of organizations and environments, for example, describe competitive exclusion and the way in which two organizational forms can only coexist in equilibrium in the same environment if they depend on different resources or there are other constraints that limit competition between them.

Competition among SMOs does not necessarily involve direct interaction. As Simmel states, "Here the struggle consists only in the fact that each competitor by himself aims at the goal, without using his strength on the adversary" (1955, p. 58).

Blau (1962, p. 196) in his review of Thompson and McEwen's work on organizational goals, notes a distinction between competition and three types of cooperative relationships: "1) bargaining (in which agreements are negotiated between two or more organizations for the exchange of goods and services), 2) co-optation (in which new elements are absorbed into the leadership of an organization as a means of averting outside threats) and 3) coalition formation (in which organizations become formally committed to joint decisions)."

Blau contends that as an organization's goals are redefined in relations with other organizations, new strategies are developed with support from the other organizations but, in each case, support is paid for with surrendered sovereignty.

"Competition among organizations entails the least reduction in the autonomy of the organizations involved, bargaining permits organizations to maintain more independence than does co-optation" (Blau, 1962, p. 197).

For the hospice, competition occurs not only between hospice programs in geographic proximity, but also between hospice programs and other types of health care providers, specifically home health agencies and hospitals.

Hypotheses on Integration of Hospice Programs

Thus far, this chapter has examined the history of hospice within the framework of a social movement organization. It has also explored the histories of two hospice programs to illustrate the concept of integration. Finally, this exploration lead to the identity of certain factors influencing integration, such as size, external relationships, board composition and other structural organizational characteristics.

The task that remains is to link these organizational characteristics and social movement concepts to integration through a set of specific propositions and hypotheses.

Proposition 1: THE LARGER THE SIZE OF THE HOSPICE, THE MORE LIKELY IT WILL ESTABLISH EXTERNAL RELATIONSHIPS (FORMAL AND INFORMAL) AND THE GREATER THE PROBABILITY OF INTEGRATION.

The size of a hospice program is defined by its budget, number of staff (paid and volunteer), patient and family load. External relationships refer to interorganizational affiliations which may be formal or informal. To understand the differences between formal and informal relationships, Merton's discussion of formal and informal membership is helpful.

In his work on reference group theory, Merton (1957, p. 285-87) discusses not only the way in which interacting persons define themselves as members of a group, but also the degree to which others, outside the group, think of someone as a member of a group. The formal membership of a group can be described by an avowed public statement or actions which indicate that membership is implicit. The individual who has some marginal link or informal relationship to the group does not show the same level of commitment as one who has a formal relationship and may not be considered a member of the group by others.

In the case of hospice programs, a formal relationship may be publicly avowed and described in a written document or it may be implicit in the actions of the individuals involved. For example, a hospice program may officially sign a contract with a home health agency for skilled nursing or it may consistently use the services of a single agency over a long period of time so that both hospice staff and other area home health agencies perceive the relationship to be formal.

An informal relationship, on the other hand, does not require that organizational ties are established. In this case, the hospice program director may call on home health agency A to perform skilled nursing at one time and home health agency B to perform skilled nursing at another time. The hospice program director understands that she or he may call upon the services of either agency and, conversely, the agency program directors perceive a loosely defined service relationship between the hospice and their agencies.

As a hospice patient load increases or services are expanded, the hospice program begins to seek outside funds, hire additional staff (paid or volunteer), recruit additional volunteers and increase division of labor among workers. The ability to rely on community goodwill to meet expanding resource needs is usually limited. As the demands for hospice services increase, its will have to expand the number of external formal (contractually identified) and informal (not formally established) arrangements it has with other institutions. As the number of external relationships increases the probability of SMO integration also increases.

Proposition 1 deals with the effect of size on the establishment of external relationships and the subsequent probability of integration.

Hypothesis 1A: The larger the hospice program, the more likely it is to have a larger number of external relations.

Hypothesis 1B: The larger the number of external relationships (formal and informal) a hospice program has, the more likely it is to be integrated.

Proposition 2: HOSPICE PROGRAMS CREATED BY OTHER ORGANIZATIONS ARE MORE LIKELY TO BE INTEGRATED THAN THOSE WITH LINKAGES TO INDIVIDUAL SUPPORTERS.

Early hospice programs in the United States were initiated by community based groups with few linkages to existing organizational structures. The word "linkage" in this situation refers to a hospice program's base of support. Programs with strong support from the community, as exemplified by financial and other resource contributions, are considered to have individual linkages. Programs which are initiated and supported by existing health care providers such as hospitals, nursing homes, and home health agencies are considered to have linkages to other organizations. Gradually hospice program linkages have shifted from community-based to other organizations so that currently more than 50% of the hospice programs in the United States are sponsored by existing institutions (e.g., hospitals, home health agencies and nursing homes).[1] Programs initiated by these existing agencies tend to reflect the goals of the founding organization and are controlled by members of those organizations (often paid

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[1] National Hospice Organization interview with Josephine Magno, Executive Director.

staff); therefore, they are more likely to be integrated than those which are not institutionally based.

As the trend toward institutionally based hospice programs grows, there is a general shift in the goals of the organizations. The programs are gradually folded into the mainstream of the host institution's programs. They may be kept separate in name or symbol, but for all practical purposes, function as a part of the host institution.

Hypothesis 2A: Hospice programs created by hospitals, nursing homes, and home health agencies will more likely be integrated than those created by individuals.

Proposition 3: THE GREATER THE INTER-ORGANIZATIONAL COMPETITION FOR SUPPORT THE MORE LIKELY A HOSPICE PROGRAM IS TO TRANSFORM ITS GOALS AND TACTICS TO FACILITATE INTEGRATION INTO THE LARGER SOCIETY.

As Zald and Ash (1966) note, the greater the external competition the more likely the SMO is to change goals and strategies to conform to those of the larger social system. In reiterating Michels' position, they state, "The major thrust of the iron law of oligarchy deals with the internal bureaucratization as SMO's officials gain a vested interest in maintaining their position and in having a stable and nonconflictful relation to the society. In the process of accommodating the society, the goals of the SMO become watered down" (1966, p. 49).[1]

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[1] Zald and Ash qualify their statement by noting that an SMO may also shift to the extremes in its competition for resources. However, in the case of an organization which seeks to receive funds from the larger social system, it is assumed that goals will shift toward the center rather than toward one of the extremes.

In the case of hospice programs, competition can occur between hospice programs or between the hospice program and other agencies, such as an area home health agency, a hospital or a nursing home. Competition is considered most vigorous between two hospice programs trying to serve patients in the same service area.

Hypothesis 3: The greater the degree of competition between hospice programs the greater the probability a hospice program will change its goals to facilitate integration.

Proposition 4: THE INVOLVEMENT OF HEALTH CARE PROFESSIONALS IN THE FORMATION OF HOSPICE PROGRAMS WILL INCREASE THE DEGREE OF INTEGRATION.

The involvement of diverse occupational groups in the formation of a social movement organization will influence the direction of the movement and its long-term survival strategies. In the case of hospice as a health care movement, a hospice program developed or founded by a large number of health care professionals (for example, physicians and nurses) is more likely to reflect the values and norms held by the traditional health care system than a program developed by professionals in other areas, for example, in business.

Hypothesis 4: The greater the degree of health care professional leadership among hospice program founders, the greater the probability a hospice program will become integrated.

Proposition 5: THE GREATER THE DIVERSITY OF BOARD MEMBERSHIP, THE GREATER THE PRESSURE FOR THE HOSPICE PROGRAM TO CONFORM TO GOALS AND PRACTICES OF THE LARGER HEALTH CARE SYSTEM.

Like professionalization, board diversity also influences the development of the hospice, its long-term goals and survival strategies. As Zald (1974) noted, board membership influences community acceptance of an organization and the inflow of needed organizational resources such as funds for operation.

Diverse boards are seen as more likely to impact the integration of a program than are boards comprised of one or two interest groups. That is, a hospice program with broad-based board membership of individuals representing business, health, union, funeral, legal and other groups, is more likely to adopt goals that are in concert with those of the larger social system than are boards comprised of individuals representing one or two interest groups. Board diversity is seen as a mechanism for influencing hospice program integration.

Hypothesis 5: The greater the diversity of the membership of a hospice program board, the greater the probability that the program will become integrated.

CHAPTER III

DATA AND METHODS

In order to explore the research problem--the degree to which certain factors influence hospice program integration--this study uses a research design employing data from three sources: (1) self-administered survey questionnaires; (2) in-depth interviews using an unstructured format; and (3) historical review of hospice documents and regulatory information.

The data contained in this study were provided by hospice program directors, board members and staff, home health agency directors, hospital administrators, physicians, legislators, third party insurers, state bureaucrats and state and national hospice organizers.

This chapter presents a discussion of the research design and the assumptions that underlie it; the samples, the data (including survey techniques), the measurement of variables and an analysis plan.

Research Design

It is argued in this study that hospice programs are more likely to become integrated if they have certain characteristics (e.g. large size, affiliations with existing health care institutions, high board diversity). Furthermore, it is argued that the support of local physicians and home health agencies in the health care community is essential in order to ensure that a hospice program will survive over time. In order to test the validity of these premises, the following research plan was developed.

First, survey instruments were designed to obtain information which could be used to answer research hypotheses presented in Chapter II. Second, a list of all hospice programs in the state was obtained in order to select a sample of hospice programs. Third, two judges were selected to develop a measure of integration, the dependent variable in the study, and then to rate each of the hospice programs in the sample according to that measure. Fourth, a list of candidates for in-depth interviews was drawn up and a set of questions was developed. Fifth, interviews were conducted. Sixth, a sample of physicians and home health agencies was drawn. Seventh, survey questionnaires were administered to physicians and home health agency representatives. Finally, data were collected that provided historical background about the formation of hospice programs in Michigan and about the hospice movement nationally, the state and national regulations which had been created to govern hospice program development, and articles describing the problems of hospice programs during the past decade.

The Samples

The survey data for this study were provided by three categories of respondents: (1) hospice program directors employed by state hospice organizations, as of July 1982; (2) a random sample of physicians in the specialties of oncology, internal medicine or general practice who practiced their specialty in hospice program service areas; (3) a random sample of home health agency directors located in a hospice program service area.

The interview data for this study were provided by hospice program directors, staff and board members, legislators and bureaucrats involved in the development of hospice regulation, and home health agency directors.

The next section describes the way in which respondents were selected.

The survey samples.

Four samples were selected. The first "sample" consisted of 56 hospice programs comprising the entire list compiled by the

Michigan Hospice Organization (MHO), the state trade association. According to the MHO executive director, the list provided contained the names of "all known hospice programs in Michigan."[1] (Appendix 3)

The programs selected were located throughout the state in communities ranging in size from 1,000 to more than two million inhabitants. The surveys were sent to the executive director of each hospice program for completion.

A second, random sample of 258 physicians (199 allopathic and 59 osteopathic) was selected. The physicians were selected first according to whether a hospice program existed in their county of practice, and second if they were board-certified specialtists of family practice, internal medicine or oncology.

Physicians were chosen according to these two criteria because they were more likely to have some contact with a hospice program than physicians in counties without a hospice program. Further, in the case of the specialties selected, practitioners in oncology, internal medicine or family practice were more likely to treat terminal patients than physicians in other specialties. Therefore, these specialists would have the most interest in the development of hospice programs. It was assumed that if these specialists showed a lack of knowledge about hospice or a lack of support for area programs, that long-term changes of integration were slim.

Physicians were randomly selected from the three specialties so that the final sample reflected the distribution of specialists in the larger population. For example, the state medical society (MSMS) estimated that there are approximately 1.5 family practitioners in the state for each internist. Therefore, the final sample consisted of a ratio close to that for the state.

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[1] Since the time of administration of the survey, six new groups have identified themselves as hospices. The number of other hospice groups which may be forming is unknown.

The names of physicians were selected from Michigan State Medical Society (MSMS) and Michigan Association of Osteopathic Physicians and Surgeons (MAOPS) directories. Both directories included physician specialty. Only board-certified specialists were selected as part of the sample because certification offered a reliable indication of the specialty in which the physician was practicing. In the case of physicians who were certified in two specialties (e.g. internal medicine and oncology), the specialty most reflective of the type of practice was selected according to the physician's listing in the local yellow pages. For example, physicians certified in internal medicine but listed as oncologists were categorized in the oncology specialty designation. Because the field of oncology is small--the State Department of Licensing and Regulation estimates that less than one percent of all physicians in the state are actively practicing in the area of oncology--all physicians listing themselves as oncologists and located in hospice program service areas were selected for inclusion in the sample. This included 20 physicians who were not designated as certified in oncology in the MSMS and MAOPS directories, but who were listed in area phone directories as oncologists.

The size of the sample (N=258) was determined by resources available. The Michigan State Medical Society provided the researcher with $100 to cover costs of postage. The size of the mailing allowance determined the size of the sample.

The third sample consisted of 57 home health agencies. A parallel procedure was used to select this sample. Home health agencies were randomly selected among those located in hospice program service areas. Agency names were selected from the Home Health Assembly Directory which included the names of both Assembly members and non-members. The sample of 57 is slightly more than half the total number of home health agencies in the state (the total is 110).

As in the case of physicians, the size of the sample (N=57) was determined by resources available. The Michigan Home Health Assembly donated $25 plus stationery to cover the costs of mailing the survey. The size of the mailing allowance determined the size of the sample.

The fourth sample consisted of 35 hospice program directors, staff and board members; six home health agency directors, one state legislator, three state officials, the director of the Michigan Hospice Organization (MHO), three members of the MHO Board who were not hospice directors, the executive director of the National Hospice Organization, and two representatives of third-party insurers. Hospice program directors and staff were selected based on the type of program in which they were involved (highly integrated, moderately integrated or not integrated), their length of service with the program, and their willingness to participate in this study; board members were selected if they were with the program for six months or more. Of the hospice program directors and staff interviewed nine were from highly integrated programs, ten were from moderately integrated programs and seven were from programs which were not integrated. Executive directors were interviewed regardless of their length of service with the program. This was necessary due to the high turnover of executive directors.

The populations. Several populations were used for this study: Michigan hospice program staff and board members; all licensed, actively practicing osteopathic and allopathic physicians in the state specializing in oncology, family practice or internal medicine; and all home health agencies in the state.

The first population was defined by the Michigan Hospice Organization (MHO) that maintains a list of member hospice programs as well as are non-member hospice programs. Michigan Hospice Organization board members located throughout the state verified the list and made several corrections to the original list. Six other hospice programs have incorporated since the original population was defined, these programs were not included in the sample because they were not operational at the time of the survey (July 1982). These programs, however, are considered part of the state hospice population. From the population of hospice programs, board members and staff were selected for hour-long interviews. The population was selected from lists of hospice program board members and staff (paid and voluntary) provided by each hospice program director.

The second population, osteopathic and allopathic physicians, consists of all physicians licensed and in Michigan. The lists of physicians maintained by the respective medical and osteopathic associations are considered accurate and contain names of all licensed Michigan physicians (18,849 allopaths and 3,856 osteopaths).

The third population consists of all home health agencies operating in the State of Michigan. The Michigan Home Health Assembly Association directory included the names of all 110 agencies in the state. Table 1 summarizes the samples used.

TABLE 1

SUMMARY OF SURVEY SAMPLES

Sample	Number of Individuals*
Hospice organizations	56
Allopathic physicians	19
Osteopathic physicians	59
Internists	82
Family practitioners	130
Oncologists	28
Home health agencies	57
Interview participants	48
TOTAL	479

*Total population of programs as of June 1982

The data from this study were derived from three sources: (1) self-administered survey questionnaries; (2) in-depth interviews using an unstructured format; and (3) historical review of hospice documents and regulatory information. This section describes the data collection procedures, their advantages and limitations and variables employed.

Data Collection Procedures

Survey questionnaires. A 36-item survey instrument developed for this study (Appendix 7) consisted of 45 closed and eight open-ended items. The instrument was designed to collect data on hospice program development over time, and contains questions on board composition, organizational goals, membership, services offered, external relationships, size, and professionalization. Duplicate questions were inserted to test for reliability on some items. Several questions were inserted at the request of the Michigan Hospice Association in exchange for assistance with mailing costs. The survey was pre-tested twice prior to administration on five program directors who were included in the final sample.

Two short questionnaires were designed for the survey of physicians and home health agencies. The physician questionnaire consisted of seven closed-ended questions and one open-ended question. The home health agency survey consisted of 16 closed-ended and one open-ended question. Seven of the questions on the home health and physician survey were identical (Appendices 5 and 6).

Advantages and disadvantages of survey questionnaires. Survey questionnaires provide an opportunity to collect data that can assist in linking hospice program integration with external environmental factors as well as organizational development efforts. The structured nature of the instrument also provides an opportunity to collect comparable data from all respondents for use in quantitative analysis. It is efficient and less costly than in-depth interviews where much time is spent talking to informants.

Further, as Babbie (1973) notes, survey instruments are useful in secondary analyses by other researchers later on. The development of a survey instrument provides a mechanism for the re-examination of the original findings. In the case of this research, it provides an opportunity for noting change in hospice program development which may lead to new theories about the integration of hospice programs into the traditional health care system. While the survey method provides a tool for analyzing dimensions of the integration of Michigan's hospice programs into the larger state health care delivery system, it has some limitations. Responses may be too brief and lack sufficient details for drawing conclusions. Some questions may be misinterpreted or answered according to what a respondent would like to see and not what actually exists. This may be particularly true of the section which asks respondents to rate importance of several organizational goals. Respondents may have rated goals they thought were important even though their organization had not adopted them. The combination of the survey method with interviews is expected to relieve the majority of problems with survey data and improve both validity and reliability.

In-depth interview. A short, structured, informal interview format was developed for in-depth interviews which varied depending on whether the hospice board member, executive director or staff was being interviewed (Appendix 7).

While time and resources prohibited the researcher from visiting each program and spending time with all executive directors and staff, visits have been made to 12 programs, including two in the Upper Pennisula, two in northern

Michigan, three in the Detroit area and several in western and eastern corners of the state. Information obtained during visits and in interviews is integrated with survey results in the results section.

Of the six programs observed over time, two programs were considered to be highly integrated, two were considered to be moderately integrated and two were considered to be non-integrated with the traditional health care system. The judges' ratings of integration (discussed under the section entitled "Measurement of Variables") was used in the selection of hospice programs along with considerations of travel time and willingness on the part of the hospice program director to participate in the study.

The interview covered the following topics: the development of the hospice program; the reason for the informant's participation; the involvement of area hospitals, home health agencies, and physicians on the hospice board; the ability of the program to seek funds; the informant's view of third-party funding for hospice care; the future of the hospice program, including discussion of problems encountered, and the interaction of the program with existing area health care agencies.

Advantages and disadvantages of interviews. In-depth interviews provide an opportunity to collect data that can illuminate and add richness to quantitative data. In addition, face-to-face interviews provide an opportunity to collect data that can provide alternative analytic strategies. They enable the researcher to develop a rapport with informants and to have access to information which might not be reported on questionnaires. They allow the researcher to observe the informant's facial impressions and body language. Discomfort around certain issues by the informant can present opportunities for probing additional information.

While face-to-face in-depth interviews provide opportunities to enrich data, they are not without liabilities. The interview is subjective and its usefulness is based on the researcher's attitude toward the data. Its additive value is dependent on whether the interviewer perceives it as such. The interviewer may visualize or use certain expressions which alters the respondent's answer. Finally, the respondent may be less candid in a personal interview than he or she would be in private.

Historical Data Collection

Background on the rationale for developing hospice licensure regulations was reviewed and discussed with sponsoring legislators and state bureaucrats. Hospice trade organization materials at the state and national level, along with news clippings and hospice program board meeting notes were collected. Organizations representing the right-to-life and euthanasia societies were contacted for information regarding support for or against early death-with-dignity legislation. Files of legislator David Hollister, the sponsor of Michigan's death-with-dignity legislation, were reviewed. Early hospice program literature was also obtained from the files of the Michigan Hospice Organization.

Survey Technique

This section describes the techniques used in surveying hospice programs, physicians and home health agencies and in selecting individuals for interviews.

Hospice survey technique. On July 26, 1982, surveys were sent to 56 groups identified by the State Hospice Organization as hospice programs. Informants were asked to sign the questionnaire noting their position with the program and the length of time they had been in that position. Informants were promised that their surveys would be confidential and would be returned to them if so desired.

After seven weeks, 92% of the questionnaires had been returned, N = 52. Four informants failed to complete the questionnaire. Three of these indicated that their program "was not, and, did not intend to become a hospice program." The other respondent stated he/she was "uncomfortable answering any questions because the group had just formed and had made no decisions regarding any direction."

All questionnaires were keypunched without regard to completion date. Distinguishing among respondents according to completion date was unrealistic for two reasons: first, many individuals who responded after the cut-off date did not respond earlier because the questionnaire was received while they were on vacation; second, the small sample size would render differential analysis between early and late respondents useless.

In order to obtain the high response rate, the researcher used follow-up phone calls and letters. A call was placed four days after the mailing to see if all respondents had received their questionnaires; two respondents indicated had not received the questionnaire. Address checks noted that mailings were correct for one non-respondent and incorrect for the second. Duplicate surveys were sent to each person. All individuals contacted indicated their willingness to complete and return the questionnaire.

Each group indicating it was not a hospice program was verified by the director of MHO. Each non-respondent received several phone calls and letters (as needed) encouraging him/her to respond. Two weeks following the initial mailing, a second call (Appendix 8) was placed to all non-respondents, approximately two-thirds (38) of whom stated they were busy but would "try to respond to the questionnaire." Subsequent to the second phone call, four more questionnaires were received. Individuals who could not be reached at the time the second call were sent a letter (Appendix 9), asking them to please cooperate with the survey. A third call was made to remaining non-respondents on August 24, which stressed the importance of the research and asked informants to please fill out the survey and return it as soon as possible. Two hospice programs in the Upper Peninsula indicated they were "too busy" to bother with questionnaires. Because these programs were significantly different from other programs to warrant special consideration, the researcher traveled to the Upper Peninsula and met with the executive directors in order to complete the survey. These programs were all volunteer and hired no personnel. The president of the Michigan Hospice Organization contacted several programs who had not responded and requested their participation. These efforts resulted in the high response rate of 92 percent.

Physician survey technique. On November 8, 1982, surveys were sent to 258 licensed physicians, selected for the research sample. Informants were asked to return the questionnaire as soon as possible and were promised that their surveys would remain confidential.

A letter from a physician delegate to the Michigan State Medical Society accompanied the allopathic physician surveys. The letters asked physicians to please participate in the study because of its importance to the development of medical society programs surrounding issues in death and dying. A letter from the dean of the osteopathic medical school accompanied the osteopathic surveys. The letter also encouraged physicians participation (see Appendix 10).

Because of time and resource constraints no follow-up letters or phone calls were made to non-participants. There was no analysis of non-respondents which may pose subsequent problems in the analysis of results. This problem is described in detail in the section on conclusions.

All questionnaires were keypunched without regard to completion date. All responses were received within 18 days of the time in which they were sent and before the deadline noted by the researchers on the physicians survey instrument.

Home health agency survey technique. On November 10, 1982, surveys were sent to 57 home health agencies selected for the research sample. A letter from the president of the Michigan Home Health Assembly accompanied each survey. The letter asked the agency director to please cooperate with the research and described its importance to the assembly in future program development. Informants were advised that their responses would be kept confidential (Appendix 11).

Because of time and resource constraints no follow-up calls or letters were sent to non-respondents. There was no analysis of non-respondents which may pose problems in the analysis of this data. This issue is discussed in the section on conclusions.

All questionnaires were keypunched without regard to completion date. This was done because all responses were received by the deadline noted on the survey instrument.

Interview technique. Before selecting informants for interviews, the researcher attended meetings of the Michigan Hospice Organization for eight months, in addition to attending organizational meetings for a local hospice. MHO regional meetings and state meetings were also attended by the researcher.

Time was spent with Michigan Hospice Organization board members in restaurants and bars after meetings.

After several months, the researcher knew many of the program directors. The program directors were advised of the purpose of the research and were promised copies of aggregate information collected (Appendix 12).

Once the judges' ratings were applied to hospice programs, the researcher selected executive directors she knew and had worked with for participation in in-depth interviews. Among those selected for interviews, two were from programs rated by judges as highly integrated, two were moderately integrated programs, and two were non-integrated programs.

Executive directors were asked to provide a list of board members and staff who would be interested in participating in an interview. From a list of names, the researcher selected a group to be interviewed.

Executive directors were asked about their involvement with the hospice program prior to becoming the executive director, their educational backgrounds, perceptions of their program's directions and changes over time, future organizational goals, the admission procedure, the training of volunteers and their view of the status of hospice programs in general.

Hospice program staff were asked similar questions and also asked to describe the specific areas in which they worked (e.g. volunteer training, bereavement counseling, etc.) Board members were asked about their educational background, their reasons for participating in hospice, their perceptions of their program's future role in the community and future ability to survive, and problems they feel their executive director will have to overcome.

Prior to each interview, interviewees received a phone call from the researcher, an overview of the research project (Appendix 13), and a brief summary of the type of questions that would be asked.

Interviews were taped unless the respondent asked otherwise, which happened in two cases. Notes from tapes were transcribed. All respondents were guaranteed confidentiality. Six informants were interviewed twice. In two cases the second interview was initiated by the informant.

Measurement of Variables

This section describes the measurement of the dependent and independent variables used in this study. Integration, the dependent variable, is described first.

Measurement of dependent variables: Measure of integration. Integration, the major dependent variable in this research, is measured by two expert judges asked to identify characteristics of a program they perceived as highly integrated into the traditional health care system and those of a program they perceived was non-integrated into the traditional health care system. The judges were selected because they had a familiarity with 95% of the hospice programs in the state and because they were not actively involved in starting a hospice program.

The judges were interviewed separately by the researcher. Based on the criteria described by each judge in the interview, the researcher developed a profile of the "ideal type" integrated hospice program and the "ideal type" non-integrated hospice program. The profiles were sent to each judge in writing for approval. There was disagreement on one characteristic "team meetings" (item 11, below). One judge did not identify team meetings as an important factor in the initial interview and questioned its inclusion in the description. The retention of the "team concept" was decided by the researcher by flipping a coin.

After the characterizations were identified, each judge received a list of all 56 hospice programs and was asked to rate all programs as highly integrated, moderately integrated or not integrated according to the characterization they had defined earlier. Judges agreed on 52 of the 56 programs, (93% agreement). A coin flip determined in which category the other four programs were placed.

The elements identified by the judges as characteristic of an "integrated" and a "non-integrated" hospice program are listed below.

An ideal non-integrated program has:

1. High reliance on volunteers
2. High expression of caring hospice philosophy as part of the goal statement (goals 10A, a-f on the questionnaire)
3. Employment of an executive director as a volunteer or for a minimal salary (i.e. under $18,000)
4. High use of volunteer staff
5. Formal/informal relationship with non-profit visiting nurses agency's local community support groups
6. Heavy emphasis on bereavement services
7. Operation of hospice with monies from memorials, contributions or donations from service organizations or public foundations
8. Not licensed as a hospice, home health agency or other institution
9. High encouragement of membership from the general public
10. High degree of community support including high number of lay persons on the board and involved in the program
11. High emphasis on team meetings including volunteers, physicians and staff

An ideal integrated program has:

1. Low or no reliance on volunteers
2. High interest in seeking outside funds and for adding specific types of service into the overall hospice program in order to bring in outside funds
3. Employment of an executive director for a high salary (more than $20,000)
4. High use of paid staff, most of employees are hired rather than volunteer
5. High number of formal relationships with hospitals, for-profit and non-profit nursing service organizations, nursing home and other health care institutions
6. Low emphasis on bereavement services
7. High dependence on third-party reimbursement
8. Merger with hospital or other established health care provider or application for licensure as another type of agency, e.g. home health agency
9. Low encouragement of membership from general public and screening of members
10. High support from select community members with special emphasis on physicians, nurses, people in health care professions
11. Low emphasis on team meetings, exclusion of volunteers from meetings

Each program was given a rating of integration based on the judges' classification. All programs were classified as highly integrated, moderately integrated or not integrated.

Measurement of independent variable: Measurement of size. It was proposed that the larger the size of the hospice program, the more likely it would be to establish external relationships (both formal and informal) and the greater the probability it would become integrated into the larger health system.

To measure the size of hospice, nine variables were combined into an overall index of size. The variables were: number of hospice program staff, funds or budget, patient and family loads (see page 85). Table 2 illustrates the mean and standard deviations on these variables. The standard score coefficient alpha (an index of internal consistency based on a correlation matrix) measured $r = .95$. The highest item total correlation among variables was for the variables "Funds received in 1981" and "Funds received in 1982" which yielded an r of .98. The lowest item total correlations were for the variables "Families served in 1981" and "Families served in 1982" that yielded r's of .65 and .60 respectively.

As the measures of size are in different units--budget was measured in dollars and patient load was measured by number of patients--the measures were made comparable through the use of $\underline{z}$ transformations. This converted all items to a uniform metric which was both easy to work with and to understand. A z-score of one has the same meaning for budget as it does for patient load. The z-scores were summed to develop a measure of size.

The use of several items to derive size was necessary because of the small responses to any one variable (see "Valid Cases," Table 2). As the measures are so highly correlated, the size measure is computed as the average of those variables present, if at least two of the variables are present. The reason for this computational decision was due to the high number of missing values in the data collected.

TABLE 2

MEAN AND STANDARD DEVIATION OF VARIABLES USED TO CONSTRUCT MEASURE OF SIZE

Variable	Mean	Standard Deviation	Valid Cases
Number of staff 1981	12.3	27.4	12
Number of staff 1982	11.9	27.7	15
Funds received 1981	$87,033	$ 233,697	18
Funds received 1982	$67,114	$ 197,798	26
Total patients served	70.9	130.8	33
Patients served 1981	18.4	12.6	15
Patients served 1982	15.7	13.3	27
Families served 1981	19.3	15.4	13
Families served 1982	18.1	15.3	22

Total number of cases with two or more variables = 35

Measurement of external relationships. External formal and informal relationships were operationalized by counting the number of formal and informal relationships self-reported by hospice program directors. The relationships with the following types of organizations were reported: hospitals, home health agencies, nursing homes, health maintanence organizations, ambulance services, auxilliary services, social services, other hospices, local health departments, local mental health agencies, disease-related organizations and local churches.

Respondents were asked to indicate with which agencies they have a formal, informal or service agreement. Marginal totals of the number of formal and service available relationships noted by hospice programs are presented on the survey instrument (Appendix 14). Because respondents showed no difference between the types of formal and informal relationships maintained, formal and informal relationships were not distinguished for purposes of analysis.

Two Guttman scale analyses were performed on items in Question 25 which asked programs to list external formal, informal and service affiliations. In the first scale, all affiliations listed were combined. Results showed there was no hierarchical ordering among the affiliations; the coefficient of scalability was .2273. In the second scale, items relating to health functions were combined. These items included: reported hospice linkages to hospitals, home health agencies, nursing homes, local health departments and social service agencies. A coefficient of scalability of .4286 showed there was no hierarchical ordering among these variables.

A test of internal consistency, however, showed there was high internal consistency among items measuring the tendency to establish external relationships (coefficient alpha = .91). Therefore, a unidimensional scale was constructed by summing the scores received for each affiliation noted. Programs received a score of "1" for each relationship indicated (formal, informal or service) with hospitals, home health agencies, nursing homes, health maintenance organizations, ambulance services, auxilliary services, social services, other hospices, local health departments or mental health departments, disease related organizations or churches.[1]

Organizations received a "0" score when they did not indicate the existance of a relationship with any of the above listed service. The score possibilities ranged from 0 - 12. The mean was 8.02 and the standard deviation was 3.89.

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[1] The variable "cleaning and chore services" was eliminated because it was of no importance to the researcher.

Measurement of program "creation". It was proposed that hospice programs created by other organizations would be more likely to be integrated than those with linkages to individual supporters.

Hospice program creation was operationalized from responses to two survey questions. Question 1 asked respondents to indicate which statement best describes their primary focus of care. Respondents indicating their focus of care was hospital-based, home-based nursing care, and free-standing facility were considered to be created by another organization. Respondents indicating their focus of care was home-based nursing care were considered to be created by individual supporters.

Question 10C asked respondents whether their program was part of a hospital, nursing home, or home health agency and, if so, to answer a series of questions about that affiliation. Informants answering 10C were considered to have been members of hospice programs that were created by other organizations.

Questions 1 (regarding focus of care) and 10C (regarding affiliation with another institution) were cross-tabulated. Four programs were found to be inappropriately categorized when reviewed by the investigator. The judgment was based on the investigator's knowledge of the individual programs. For example, one hospice indicated it was created by individual supporters which contradicts the oral history taken by the investigator in a meeting with the program director and staff. The program director indicated that the hospital administrator from a local hospital initiated the hospice program with assistance from other hospital staff and community leaders. The program was originally housed in the hospital and later moved to an independent location. The hospital founders are still involved in the program but the hospital's role has changed significantly. This program's executive director reported it was initiated by individual supporters but because the researcher's interview data showed it was created by hospital administrators it was re-categorized as being founded by "another organization" by the researcher.

Three other program respondents indicated that the primary focus of care was hospital based but failed to complete question 10C. A call to the executive director indicated that the program was created by hospital personnel who involved the community in the development of the hospice once the hospital had decided to offer hospice services. These programs were reclassified by the researcher into the category, "created by another institution."

Data were coded correctly "created by other organizations" or "created by individual supporters." Since the data/variables were nominal and original in nature a chi square analysis was performed. This was performed in order to assess whether there were significant differences in level of integration among those created by individuals and those created by other organizations.

Measurement of competition. It is proposed that the greater the inter-organizational competition for support, the more likely a social movement organization will transform its goals and tactics to facilitate integration into the larger community.

Two methods were used to measure competition among hospices, based on the work of Hawley (1950). The first measure asked program directors if there are other hospice programs in their service area. The proximity of other hospices as noted by directors was considered a measure of potential competition. The second measure of competition was based on the creation of a variable called "hospice density" which includes an assessment of hospice to population by county.

To obtain the first measure, hospice program directors were asked whether or not there were other hospice programs in their county or city. This question measured respondents' knowledge of proximity of potential competitors and served as an basis for the researcher's calculations of the second measure, program density. That is, perceived density was compared to actual geographic density.

Hospice program density was calculated by dividing the number of hospices in a geographic area by the number of persons living in that area. The population of the counties served by the programs was obtained from 1980 census data. The hospice programs reported which counties they considered themselves to be serving. In the case where a hospice program served more than one county, the average population of all counties served was used. All programs were plotted on a map of Michigan and, using the scale noted in the map key, a radius of 25 miles was drawn around each program. Programs falling on or within the circle were considered in the hospice's area. Programs outside of the circle were considered to be outside of a hospices service area. Programs within the service area were counted and divided into the county populations. The result was the density measure for each hospice. For example, if a county population measured 100,000 and the number of programs falling within the 25-mile radius measured ten, then the hospice density for that program was 10,000. If there was only one program in an area of 100,000 people, then the density measure was 100,000. The range of programs within a 25-mile radius varied between one and ten with an average of three and standard deviation of three. Table 3 shows the density distribution.

TABLE 3

HOSPICE DENSITY BY AREA

Number of Hospices In An Area	Frequency*
1	7
2	7
3	3
4	6
5	3
6	2
7	1
8	3
9	0
10	1

* Some hospices are located in more than one 25-mile radius.

Measurement of professional leadership. It was proposed that hospice programs with high involvement of health care professionals, specifically nurses and physicians on boards, were more likely to be integrated than those programs which did not involve these individuals. Questions 8A and 9B of the survey asked programs to indicate the involvement of different types of professionals in the formulation of the hospice program (e.g. health care professionals, educators, lay consumers and clergy).

Two operations were performed to obtain an index of professional leadership. First nurses, physicians and hospital administrators were grouped together as a medical unit for purposes of constructing an index of professional leadership. If a respondent indicated that one of these professionals was involved in the formation of the program, it was predicted that the program would be more highly integrated than programs that did not have high involvement of these professionals. A preliminary analysis showed that all informants indicated that at least one or more of these types of professionals was involved in the formulation of the program.

The second analysis, a Guttman Scale Analysis of question 9B--which asked respondents to indicate the occupational categories of those individuals involved in starting the hospice--showed there was no hierarchical ordering among the individuals responsible for the hospice program's development; the coefficient of scalability was .4679. However, when the items were correlated with each other to develop a unidimensional scale to measure professional leadership, (the reliability coefficient alpha was α =.85.) The following items were combined into a seven range scale of professional leadership: physicians, nurses, social workers, professionals outside of medicine, health care administrators, homemakers, clergy. Table 4 below shows the number of programs indicating they had different types of professionals involved in starting the hospice board.

TABLE 4

CORE PROFESSIONALS INVOLVED IN STARTING AN AREA HOSPICE PROGRAM

Type of Professional	Number Reporting	% of Total N
Nurse	40	83.3
Clergy	37	77.1
Social Worker	34	70.8
Physician	31	64.6
Hospital Administrators	30	62.5
Professionals outside medicine (e.g. business, law)	30	62.5
Homemakers	25	52.1

The data indicate that nurses, clergy and social workers are more likely to be involved in starting a hospice than physicians or hospital administrators. These findings are consistent with interviews taken and are discussed in greater detail in the "Discussion" section.

Measurement of board diversity. The hospice program board composition was used as a measure of the degree of integration. It was proposed that the greater the number of different types of health care providers on a hospice board, the more likely the program is to be integrated. This is because boards with members who represent other organizations are more likely to involve the hospice program with other groups. For example, a hospice program with a hospital administrator might find that it is offered meeting space in the hospital along with the use of hospital equipment.

A Guttman scale analysis was conducted for question 19A, which asked informants to indicate which professions were represented on their program's board. A coefficient of scalability of .3464 showed that there was no hierarchical ordering of the types of individuals serving on a hospice board. However, there was a high degree of reliability (alpha = .76) among items which allowed the construction of a unidimensional variable board diversity. The scale ranged from 0 to 9, with 9 being the most diverse and included the following professions: physicians, home health nurses, hospital administrators, lay consumers, clergy, nursing home administrators, private foundations and third party insurance representatives and other hospice program employees.

Involvement index. An index of involvement was constructed using questions on the physician and home health agency surveys (see Appendices 15 and 16). In the surveys sent to physicians and home health agencies, several questions measured "support." These questions ask both physicians and home health agency directors if they are members of a hospice board or committee, or if they would serve on a hospice board or committee. The highest achievable score on the involvement scale was given to agencies (a score of 3) and physicians (a score of 2) who served on a hospice board and committee. The next highest score was given to home health agencies (a score of 2) and physicians (a score of 1) who indicated they had served on a board or a committee or would be "willing" to become involved. Individuals indicating they did not serve on a hospice board or committee and would not serve in the future were given a score of "0." The involvement scales are summarized in Tables 5 and 6.

TABLE 5

DEGREE OF INVOLVEMENT SCALE: PHYSICIANS

Question #	Answer	Score			
4	Physician member of board or committee	1	1	0	0
5	Physician willing to serve on hospice board or committee	1	0	1	0
	Total Score	2	1	1	0

0 = No
1 = Yes

TABLE 6

DEGREE OF INVOLVEMENT SCALE: HOME HEALTH AGENCIES

Question #	Answer	Score					
15e	Agency representative on hospice board	1	0	1	1	0	0
15g	Agency representative on hospice Committee	1	1	0	1	0	0
5	Willing to serve on hospice board or committee	1	1	1	0	1	0
	Total Score	3	2	2	2	1	0

0 = No
1 = Yes

The involvement of physicians and home health agencies in general was analyzed to make inferences about hospice program future integration.

It must be emphasized that the issue of community support was developed as an addition to the original research design and therefore was not analyzed with the other variables to predict integration. A discussion of the problems associated with this technique appears in the section on measurement problems.

Use of Regression Analysis

Multiple regression analyses were used to predict the determinants of integration. This multivariate technique enables a researcher to assess joint contributions of a set of variables in explaining another variable. Specifically, the independent contributions of the variables size, composition, professionalization, external relationships, organizational creation, and board diversity were used to predict the criterion variable, integration. In conducting the multiple regression analysis three questions were asked. First, the researcher asked how--in the absence of any other information--size, external relationships, professionalization, board diversity, organizational creation, and competition are related to the variable integration. The answer was constructed using Pearson (zero-order) correlations between integration and each of the aforementioned variables.

The second question asked by the researcher was, if you know five of the aforementioned variables, does knowing a sixth variable provide additional explanations of integration? In other words, if size, organizational creation, external relationships, professional leadership and board diversity are known, does competition provide additional information in predicting integration? The answer to this question was constructed using step-wise regression. Each variable (size, competition, created, professionalization, external relationships and board diversity) was entered on the "last step." If the "F to Enter" was significant, then the variable entered last does provide additional information that can be used in predicting integration. Every step of a multiple regression is based on the partial correlations remaining from the previous step. In the first step there are the Pearson zero-order correlations, the variable with the biggest correlation of the criterion is entered first and subsequently partialled out of the entire matrix which changes the remaining correlations with the criterion. The next biggest relationship among the partials with the criterion is entered and again partialled out of the matrix which changes the remaining correlations with the criterion, and so on.

The third question asked "What is the optimal order for entering the variables size, created, competition, external relationships, professionalizations and board diversity, to predict the dependent variable integration?" A step-wise regression was computed to answer this question. The regression identifies, in decreasing order of importance, the best predictors of y if x variables are known.

CHAPTER IV

RESULTS

This section presents research findings using methods presented earlier. The results may be generalizable to hospice programs nationally. The first part of the section describes the results of the hypotheses presented in Chapter II. The second section addresses methodological problems.

Results of Hypothesis Testing

The following sections present results of the hypotheses presented earlier. The hypotheses to be reviewed are presented at the onset of each discussion. The significance level is set at .10 ($p < .10$).

Hypothesis 1A: The larger the size of the hospice program, the greater the number of external relations.

Hypothesis 1B: The larger the number of external relationships (formal and informal) a hospice program has, the more likely it is to be integrated.

Pearson correlation coefficients were computed between the variables size, external relations and integration. The measure of integration was taken from the judges' ratings on all 48 hospice programs participating in the study. It has three points: highly integrated, moderately integrated and not integrated.

The size of a hospice program is significantly positively related to integration. The larger the size of a hospice program, the greater the likelihood of integration ($r = .37$, $p < .02$). There is, however, no relationship between the number of external relationships and size ($r = -.05$, $p < .362$).

Other analyses of size were computed. The researcher asked the following questions:

1) Is there a relationship between size and population? Are larger programs located in more heavily populated areas than smaller programs?

2) Is there a relationship between size and number of donors? Do larger programs have more donors than smaller programs?

3) Is there a relationship between size and types of services offered? Do larger programs offer more support services, care services and therapy services than smaller programs?

Table 7 shows there is a significant relation between size and population. Larger programs are located in more heavily populated areas. However, Table 7 shows no significant relationship exists between size and number of donors at the .10 level.

TABLE 7

COMPARISON OF SIZE TO POPULATION AND CONTRIBUTORS

	Donors	Population
Size	.1048 (35) p = .275	.4146 (34) p = .007

Table 8 shows there is a significant positive correlation between number of services offered and size at the .10 level.

TABLE 8

RELATIONSHIP BETWEEN SIZE AND TYPES OF SERVICES

	Support	Therapy	Care
Size	.1877 (33) p = .148	.3091 (28) p = .055	.0888 (31) p = .317
Support		.2958 (35) p = .042	.5127 (40) p = .001
Care		.4905 (36) p = .001	

There was no significant relationship between number of external relationships and integration.

Hypothesis 2A: Hospice programs created by hospitals, nursing homes, and home health agencies will more likely be integrated than those created by individuals.

After data were correctly placed in categories created by "other organizations" or by "individual supporters," a chi square test was performed. Table 9 shows the results of the chi square to be significant ($\underline{x}^2 = 13.25$; df = 2; $p < .002$). There is a greater probability that hospice programs created by other organizations will be integrated into the larger health system than those created by individual supporters.

TABLE 9

HOSPICE PROGRAM CREATION COMPARED TO
JUDGES' RATING OF INTEGRATION

Judges' Ratings	Other Organizations	Individual
High integration	12	3
Moderate integration	9	13
Low integration	1	10

$x^2 = 13.25$, df = 2, $p < .002$ Gamma .7897*

N = 48

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* Gamma is the probability of correctly guessing the order of a pair of cases on one variable once the ordering on the other variable is known. (Klecka, 1975)

Hypothesis 3A: The greater the degree of competition between hospice programs the greater the probability a hospice program will change its goals to facilitate integration.

Goals

Questions 10A and 11A asked hospice programs to describe original hospice goals and current goals. A Pearson correlation was conducted between the respondents' ratings on each of the initial and current goals. The goals were highly correlated across time except one: "To care for the patient at home as long as it is within the wishes and ability of the family and patient," ($r = .03$, $p > .10$). This goal shifted in importance over time. Table 10 below notes the correlations between initial and current goals.

TABLE 10

CORRELATIONS BETWEEN INITIAL AND CURRENT GOALS

Goals	Correlation
Improve patient comfort	.99 (44) p = *
Increase organization participation	.86 (45) p = .001
Self sufficient program	.80 (42) p = .001
Change community attitudes	.77 (44) p = .001
Recruit members	.75 (43) p = .001
Increase third-party funds	.71 (42) p = .001
Include family in care plan	.70 (44) p = .001
Establish linkages	.68 (43) p = .001
Obtain third-party funds	.67 (43) p = .001
Symptom control	.36 (44) p = .009
Promote hospice concept	.35 (43) p = .20
Care for patient at home	-.03 (44) p = .415

* = no variance
N in parentheses

Only two goals were not significantly correlated over time: (1) "To promote the hospice concept," and (2) "To care for the patient at home." Results showed that these goals changed over time while other goals remained the same.

It is difficult to determine the reason for these two shifts. It can be speculated that in the case of goal (1)--promotion of the hospice concept--the degree of importance in this goal was reduced as programs became more developed. As the hospice program gained acceptance in the community, established a stable funding base and patient load, program directors may feel that it is less important to promote the hospice concept and more important to address goals related to organizational structure. This shift is consistent with the social movement life-cycle predictions of Turner and Killian (1962), Reisman (1972) and Mauss (1971) described in an earlier section. These authors maintain that the goals of the social movement shift as the social movement redefines its needs. For hospice programs in later stages of development the needs shift from gaining community acceptance and support of the concept, to establishing and maintaining a program structure.

For goal (2) "caring for the patient at home," reasons for the shift are similar to those for goal (1). That is, as the program developed its emphasis shifted from one of promotion to one of patient care. Early founders echoed the hospice philosophy but, because they did not accept patients--recall it takes about two years for a program to reach a point of accepting patients--early organizers were not concerned about caring for the patient at home. Their energies were focused on the design and building of a hospice program and not daily activities of patient care. As their patient loads expanded their emphasis shifted to patient care. As one director noted in the open-ended comment section of the questionnaire. "Our goals shifted as we increased in size and became operational. When we first started we focused our attention to community education; now our energies are devoted to patient care."

The Spearman rank-order correlation between the mean response for initial goals and the mean responses for current goals was r = .97. Therefore, there was little change in the ordering of goals.

Difference scores were calculated by subtracting the score on current goals from initial goals. These difference scores were then correlated with the mean score for the independent variable, integration. One significant value was recorded: The difference between the initial and current goals, "To promote the hospice concept." Results are reported in Table 11.

TABLE 11

CORRELATION COEFFICIENT'S DIFFERENCE SCORES ON INITIAL AND CURRENT GOALS AND LEVEL OF INTEGRATION

Goals[1]	Promote hospice	Change attitudes	Self-sufficiency	Third-party funds
Integration	.2631 (43) p =.044	.0961 (44) p =.268	.0387 (42) p =.404	.0593 (43) p =.353

Goals	Increase funds	Establish linkages	Recruit members	Involve physicians
Integration	-.1311 (41) p =.203	.0460 (43) p = .385	-.1537 (43) p =.163	.0014 (45) p =.496

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[1] For purposes of analysis goals that did not have any variance were eliminated.

With the exception of "promoting the hospice concept," the measure of goals as an index of change showed no significant relationship between integration and the difference in initial and current goals over time. To reevaluate the existence of change, an attempt was made to construct a second "index of change," using different variables. Three survey questions asked respondents for information regarding organizational change. One question asked if membership policies had been altered, another asked if there had been more than one executive director of the hospice program, and a third asked if goals for the program had been altered. It was assumed that if these items were highly correlated, an index could be constructed and used to analyze integration. Table 12 shows there is no correlation among items. Therefore, given the present data, it was impossible to construct an index of change.

TABLE 12

HOSPICE PROGRAM CHANGE

	Number of hospice program directors	Altering goals	Altering structure
Membership change	-.1400 (30) p =.230	-.0231 (30) p =.452	-.2722 (30) p =.073
Number of hospice program directors		-.1351 (48) p =.122	.1715 (48) p =.180
Altering goals			.2023 (48) p =.084

Competition

Results show that the hospice program respondents stating they "did not have hospices nearby" had fewer hospice programs nearby, than those indicating "another hospice program existed" in their city or county. Table 13 below shows 17 respondents had almost five other hospice programs within a 25-mile radius.

Thirty-one of the respondents indicating there was "no program nearby" were within 25 miles of an average of two other hospice programs.

TABLE 13

PROXIMITY OF OTHER HOSPICE PROGRAMS

Hospice program director response	Average number of programs per 25-mile area	Number of responses
Yes, there is another program nearby	4.94	17
No, there is not another program nearby	1.94	31

N = 48

Pearson Correlation Coefficients were computed between the density measure and its components (county population and the number of hospices in an area) and integration. The results were significant ($r = .23$, $p < .06$). A summary of the results is reported in Table 14 below.

TABLE 14

CORRELATION BETWEEN DENSITY, COUNTY POPULATION AND NUMBER OF HOSPICES IN A 25-MILE RADIUS

	Integration	County population	Number of hospices
Integration			
County Population	.17		
Number of Hospices	.15	.70*	
Density	.23**	.94*	.51*

* p < .001
** p < .06

There is a significant positive relationship between the number of hospices in a county and the county population ($r = .70$, $p < .001$).

Based on the results of the correlation, it is concluded that the degree of density between programs was significantly related to hospice program integration.

Does density have a differential impact on the integration of hospice programs depending upon whether they are large or small, non-institutionally based or institutionally based (typically hospital based)? Are larger hospice programs located in denser population areas than smaller hospice programs? Are institutionally based programs located in higher density areas than non-institutionally based programs?

Hospice programs were divided into categories of large and small for purposes of analysis (median = -.355). The judges' ratings for integration were cross-tabulated with degree of density.

Table 15 shows that density is not related to the size of the program, that is there is no significant difference between the location of large and small programs.

TABLE 15

RELATIONSHIP OF SIZE OF HOSPICE PROGRAM TO HOSPICE DENSITY

	Degree of density	
Size of Hospice	Low	High
Small	10	7
Large	5	13
Total 15	20	

$N = 35$

$x^2 = 2.29$ df = 1

$p < .25$

Table 16 shows a significant relationship between degree of density and integration. The more hospice programs located in an area, the more likely that the programs are to be integrated.

TABLE 16

RELATIONSHIP BETWEEN HOSPICE PROGRAM DENSITY AND DEGREE OF INTEGRATION

	Degree of density	
Integration	Low	High
None	8	1
Moderate	5	10
High	4	7
TOTAL	19	18

N = 37
$x^2 = 7.91$ df = 2
$p < .02$

There is a relationship between density and integration but not between size and integration. Integrated programs tend to be located in higher density areas.

Professional Leadership

Hypothesis 4: The greater the degree of professional leadership among hospice program founders, the greater the probability a hospice program will become integrated.

Results show there is no significant relationship between professional leadership and integration ($r = -.07$; $p < .312$).

Board Diversity

Hypothesis 5: The greater the diversity of the membership of a hospice program board, the greater the probability that the program will become integrated.

Table 17 shows the correlation between size, integration and the components of the board diversity measure. Results show a significant negative correlation between board diversity and integration ($r = -.27$; $p < .01$), and no correlation between board diversity and size ($r = -.10$; $p < .29$).

TABLE 17

CORRELATION OF HOSPICE PROGRAM SIZE AND INTEGRATION WITH BOARD MEMBERSHIP TYPES

Membership types	Size	Integration
Other hospice employer	.08 (35) p = .29	-.07 (48) p = .33
Physicians	.043 (35) p = .40	-.26 (48) p = .03
Home health nurses	-.12 (35) p = .24	-.19 (48) p = .09
Hospital administrators	.15 (35) p = .20	-.09 (48) p = .28
Lay consumers	.003 (35) p = .50	-.37 (48) p = .01
Educators	-.26 (35) p = .07	-.25 (48) p = .04
Clergy	-.06 (35) p = .04	-.32 (48) p = .02
Insurers	-.15 (35) p = .20	-.13 (48) p = .19
HMO representatives	.48 (35) p = .002	.09 (48) p = .28
Nursing home representatives	-.09 (35) p = .30	-.198 (48) p = .09
Private foundation representatives	-.07 (35) p = .34	-.20 (48) p = .08
Board diversity (All professions)	-.099 (35) p = .29	-.37 (48) p = .01

Results show the more integrated a program, is the more likely the program is to have a diverse board.

Multiple Regression Results

The correlations between the measures of the variables size, external relations, organizational creation, density, professional leadership and board diversity are shown in Table 18.

TABLE 18

PEARSON CORRELATIONS BETWEEN DEPENDENT AND INDEPENDENT VARIABLES

Variables	Integration	Size	External relations	Manner of program creation	Density	Professional leadership
Size	.3656* (35) p =.02					
External relations	-.0524 (48) p =.36	-.1101 (35) p =.26				
Created	.5241* (48) p =.001	.2559 (35) p =.07*	-.0050 (48) p =.49			
Density	.2290* (48) p =.06	.0366 (35) p =.42	-.0657 (48) p =.33	.1856* (48) p =.10		
Professional leadership	-.0725 (48) p =.31	-.0849 (35) p =.31	.4470* (48) p =.001	-.0007 (48) p =.50	.0187 (48) p =.45	
Board diversity	-.3701* (48) p =.01	-.0999 (35) p =.28	.6214* (48) p =.001	-.3015* (48) p =.02	-.1915* (48) p =.10	.3898* (48) p =.003

* = significant at $p < .10$ or below

Table 18 shows density and mode of creation are positively related to integration whereas diversity of board is negatively related to integration. No relationship exists between professional leadership and external relationships and integration.

In terms of other variables, a positive relationship exists between density and size, professional leadership and external relationships; board diversity and external relationships; and board diversity and professional leadership.

This relationship shows that larger programs are located in area with other hospices nearby--generally larger urban areas. Further, diverse professional leadership is linked to greater board diversity and numerous external affiliations.

A strong negative relationship exists between board diversity and mode of creation, and between board diversity and density. In other words, those programs created by other organization are likely to have boards which are not comprised of diverse interest groups. Further, programs existing in areas with several other hospice programs are also likely to have boards which do not have many diverse interest groups.

A multiple regression analysis to predict integration used five variables: mode of creation, size, board, competition, and external relations. "Created by other organizations" was strongest in predicting integration. Further, the variables size and board composition were significant at the $p < .10$ level in predicting integration.

The multiple regression analysis was recomputed so that each of the variables (size, competition, external relationships, board density, and mode of creation) would be the last variable into an equation. In that way, the independent contribution of each variable, holding all other variables constant, could be assessed. The results presented in Table 19 show that at the $p < .10$ level, the variables board diversity, density and mode of creation have a relationship with integration that is independent of all the other variables.

TABLE 19

SUMMARY OF REGRESSIONS SHOWING CONTRIBUTION OF EACH VARIABLE WHILE HOLDING OTHERS CONSTANT

Variable entered last	F to enter	Significance	R^2 change
Board	3.09	.089	.06
Density	.50	.483	.01
Mode of creation	4.30	.047	.08
External relationships	1.15	.293	.02
Size	3.16	.086	.06

Multiple r = .64305* $p > .006$ R Squared = .41351

*Correlation between integration and a linear composite of the predictor board, competion, created, external relations and size.

When ordering the variables (size, mode of creation, density, external relationships and board diversity) into the regression equation, the variables entered statistically in the following order (Table 20):

TABLE 20

STEP-WISE REGRESSION OF VARIABLES PREDICTING INTEGRATION

Ordering of variables	B**	F to enter	Significance	Multiple R percent of variance shared	Simple R	Overall F	Overall significance
1 Created	.33	12.500	.001	.52414	.52414	12.500	.001
2 Size	.26	2.747	.107	.57625	.36561	7.954	.002
3 Board	-.35	2.342	.136	.61562	-.37014	6.306	.002
4 External relations	.20	1.222	.278	.63506	-.05236	5.069	.003
5 Density	.10	.505	.483	.64305	.22905	4.089	.006

*Variables contributing at least one percent to explained variance are reported
** B = Standardized regression coefficient or beta weight
R Squared = .41351

Other factors that might influence integration were examined. Does the multiplicity of donors (Question 29) influence integration? Are programs with many varied types of donors more likely to be integrated than those with only one or two types of donors or vice versa?

The variables in Question 29 were reviewed for reliability. A coefficient alpha of .77139 indicates high correlation among items. Therefore, items can be added and used as a scale of donors.

A correlation between multiplicity of donors and integration was not significant at the $p < .10$ level and therefore, not reported in this analysis.

Physician and Home Health Agency Response Rate

Earlier it was mentioned that physicians and home health agencies were surveyed in an attempt to understand their involvement with area hospice programs. Results from the physician and home health survey as they relate to hospice program involvement are noted below.

Physician Survey Response

One hundred and forty-three responses were received; 55% of the allopathic physicans responded and 58% of the osteopathic physicians responded. Of the 143 responses, seventy-six percent (109) were M.D.s and twenty-four percent (39) were D.O.s.

The majority of the respondents were in general practice (70 respondents), while approximately one-third were in internal medicine (35 respondents), and one-fourth (28 respondents) were in oncology. Table 21 below shows the respondents by specialty and practice type.

TABLE 21

PHYSICIANS PRACTICE TYPE AND SPECIALTY

	General practice	Internal medicine	Oncology
M.D.	50	35	24
D.O.	20	10	4
Totals	70	45	28

Home Health Survey Response

Forty-two of the 57 home health agency directors selected for this study responded to the research questionnaire (74% response). The majority of the programs (60%) were nonprofit home health agencies; twelve programs (29%) were health department affiliated programs, two programs (5%) were affiliated with a hospital, two programs (5%) were for profit (proprietary) agencies and one was a hospice program.

TABLE 22

RESPONDENT BY AGENCY TYPE

Type of organization	Frequency	Percent
Nonprofit non-affiliated	25	59.5
Nonprofit health department affiliated	12	28.6
Nonprofit hospital affiliated	2	4.8
Nonprofit hospice	1	2.4
Proprietary	2	4.8
Total	42	100.

Involvement

Physicians. In general, physicians with higher numbers of terminal patients are more likely to be on hospice program boards of directors or willing to serve on hospice program committees than those with fewer terminal patients. Tables 23 and 24 show that as the number of terminal patients seen by physicians increases, so does their willingness to serve on a hospice board or committee.

TABLE 23

PHYSICIAN MEMBERSHIP ON A HOSPICE BOARD BY NUMBER OF TERMINAL PATIENTS

	Membership on a hospice board	
Number of terminal patients	Member	Non-member
Low (less than 14)	2	37
High (greater than 15)	11	28

N = 78
Chi Square = 5.908
D.F. = 1
$p < .02$

TABLE 24

PHYSICIAN WILLINGNESS TO SERVE ON A HOSPICE BOARD OR COMMITTEE BY NUMBER OF TERMINAL PATIENTS

Number of terminal patients	Willing to serve	Not willing to serve
Low (less than 14)	18	18
High (greater than 15)	26	9

Chi Square = 3.47
D.F. = 1
$p < .06$

Tables 25 and 26 show physician service on a hospice board or committee and willingness to serve in relation to physician specialty. A greater percentage of oncologists are members of a hospice board. However, there is a strong change in terms of physician willingness to serve. A greater number of people indicate a willingness to serve than actually serve.

TABLE 25

PHYSICIAN HOSPICE BOARD MEMBERSHIP BY SPECIALTY

Specialty	Member	Non-member
General practice	4	62
Internal medicine	2	41
Oncology	13	14

Chi Square = 32.784
D.F. = 2
$P < .00001$
N = 136

TABLE 26

PHYSICIAN WILLINGNESS TO SERVE ON A HOSPICE BOARD BY SPECIALTY

Specialty	Member	Non-member
General practice	33	31
Internal medicine	16	19
Oncology	16	6

Chi Square = 4.219
D.F. = 2
$P < .12$
N = 121

An analysis, using the scale of involvement, shows that there is a significant positive relationship between physician involvement and referral of patient to a hospice program. Table 27 shows the relationship between program involvement and referral.

TABLE 27

PHYSICIAN INVOLVEMENT AND HOSPITAL REFERRAL

Degree of involvement	Referral	No referral
None (0)	23	42
Little (1)	25	27
High (2)	18	1

Chi Square = 20.7415
P < .0001
D.F. = 2
N = 136

Home health agencies. Results show that there is no significant difference between agencies with high and low terminal case loads and participation on a hospice board or committee (Tables 28 and 29).

TABLE 28

TERMINAL PATIENT LOAD AND HOSPICE BOARD REPRESENTATION

	Board representation	
Terminal Patients	Yes	No
1-12	6	6
13-39	4	6
40-69	5	3
70+	6	6

Chi Square = .900
D.F. = 3
P < .83
N = 42

TABLE 29

TERMINAL PATIENT LOAD AND HOSPICE COMMITTEE REPRESENTATION

	Committee Representation	
Terminal Patients	Yes	No
1-12	6	6
13-39	4	6
40-69	5	3
70+	6	6

Chi Square = .900
D.F. = 3
P < .83
N = 42

Using the involvement scale, results also showed no significant difference between the number of terminal patients an agency had and the degree of involvement in a hospice program (Table 30).

TABLE 30

TERMINAL PATIENT LOAD AND HOSPICE PROGRAM INVOLVEMENT

	Number of terminal patients			
Scores	12 or fewer	13-39	40-71	71+
Not involved (0)	0	0	1	1
Slightly involved (1)	5	4	3	5
Involved (2)	2	1	2	2
Highly involved (3)	5	5	2	4

Chi Square = 3.85
D.F. = 9
Sig. = .92
N = 42

Although the number of terminal patients a home health agency had did not affect involvement, other factors such as the number of competing home health agencies did. This relationship is described further in the discussion section.

Methodological Problems

Construct of size. This section describes the problems of variable measurement, instrument design and sample selection.

The size of the hospice program is used as an independent measure constructed with a variable using average hospice staff, budget and patient load for the years 1981-82.

The reliability of the size measure was computed using all nine variables. However, because of the large amount of missing data for the variables entering into the construct size, the size measure was computed if any program had two or more variables used to measure size. That is, if a program had a measure for items such as number of patients and staff 1981, it received a size measure.

Using any two of the indicators is not as reliable as using all nine. There may be a reliability problem.

Construct of goal change. The change of organizational goals was measured by two questions asking respondents to recall initial organizational goals and subsequently (one page later) to identify current goals. There was little, if any, variance between initial and current goals as reported by the respondents. Based on a review of the results it appears that respondents were unable to differentiate between goals over time because of the close proximity of the questions.

Further, the question on goals was too general to use in the constructing of a measure of organizational goal change. Other questions used to construct a measure of change yielded no results. Therefore, there was no measure of goal change which could be used to construct a variable of program goals.

Construct of density. It was assumed that the more programs per population in a geographic area the more likely the programs were to experience competition. The program density measures constructed to measure competition fail to consider need for the service (e.g. number of cancer deaths per county) or the specific proximity of one program to another. Programs were considered in a 25 mile radius but conceivably programs within 15 minutes are more competitive than programs located within a half hour's drive.

Construct of integration. Two judges were used to construct independent definitions for the construct integration. Their definition was then used to rate each of the 48 programs. While judges advised the researcher that they were "familiar" with each of the programs, the degree of familiarity varied greatly. After the analysis was completed, one judge stated that she was a bit unsure about some of the programs and was making an "educated guess."

Realizing the inadequacy of two judges, attempts were made to find a third individual. Ten individuals were contacted all of whom advised the researcher they did not have adequate knowledge of all 48 hospice programs to participate in the rating. The inability to obtain additional researchers is viewed as a handicap.

Professional leaders. The question involving the leaders or founders of the hospice organization asked program respondents to check from a list those types of professionals involved in the formation of the program. The question did not ask for the number of individuals in each category. This proved to be a mistake and could have dramatically changed the results. Finding out that a physician was involved is not as important as knowing whether there were one or four physicians involved. Results may have shown that a highly integrated program had more than one physician involved in the formation of the program where as a non-integrated program had only one. In the redrafting of the questionnaire, this question should be revised to ask respondents for the number of individuals in each category involved in the formation of the program.

Board diversity. Similar to the case of professional leaders, the question measuring board diversity did not ask for the number of individuals involved in various professions, but rather whether or not a profession was involved on the board. This is a poor measure. There was little variance among respondents. Differences may have resulted if the question asked for the number of each type of professional on the board. A board with seven physicians, three hospital administrators and three nurses, might impact hospice program development much differently than a board with one physician, one hospital administrator and one nurse.

A project is being designed to examine hospice board composition more fully. The project is described in detail in the section on additional research issues.

Sample selection physicians and home health agencies. Even after four revisions and several reviews there were problems with question wording on both questionnaires. In the physician survey, the questionnaire contained a typographical error which caused one question to be completely illegible. Although a letter explaining the error was sent to respondents, data were lost on 28 questionnaires.

Of even greater concern is the fact that these surveys were not designed as part of the major study. It was after research on the hospice programs was underway that the researcher sought answers to questions concerning community support. Because the instruments were not designed as part of the original research, statements regarding the relationship of integration to community involvement cannot be statistically supported.

Two additional problems were the instrument design and sample selected. The instrument for the physician study was purposefully designed to be very brief because the researcher had been told by other investigators and members of the medical profession that a physician would not answer any questionnaire longer than one page. Interested in a high response rate (the average physician response rate is 25%, the response rate for this study was 55%) the investigator excluded some questions which would have been valuable to the study. In hindsight, this trade-off should not have been made.

In the home health agency questionnaire, the researcher identified several poorly phrased questions. For example, question 4 and 5 asked the respondent whether they are a member of a hospice board or committee. The question should have asked whether anyone in the agency was a member of the board or committee. Fortunately, a second question, included for the purposes of reliability, did ask the respondent whether someone in the agency was a member of a hospice board or committee.

The sample sizes were too small. Had ample resources been available it would have been preferable to sample physicians in other specialties--in addition to internal medicine, oncology and family practice--to determine their understanding and familarity with the hospice concept of care. In this way the researcher would have had data on the extent to which physicians with low terminal patient loads are involved with area hospice programs.

For the home health industry, a few additional dollars would have allowed inclusion of all agencies in Michigan. This would have been a better and richer data base than a sample of half the programs. Because the sample size was small, some of the statistical procedures are questionable. For example, cell sizes in chi square analyses may be too small to provide any information regarding significance of the events under question.

CHAPTER V

DISCUSSION

Earlier it was shown that hospice program integration is most strongly influenced by how a program was created and secondly by its size. This section reviews the previous findings and provides an analysis of other factors which may influence the results. Interview data and additional survey material are presented to enhance the findings.

Size

The works of Blau (1970), Hall et al (1967), Blau and Schoenherr (1971), Zald and Ash (1966) and McCarthy (1973) were employed to describe the concept of size and its possible effects on a social movement organization. It was proposed that the larger the size of an organization, the more likely it is to become integrated. Results showed that size is significantly and positively related to integration.

Size has also been shown to affect other aspects of the hospice program. A review of the 48 programs surveyed shows that as a program increased in size (e.g. gained staff and budget) other changes occurred. The program became more formalized, division of labor among employees became more refined and tasks were specified. The informal network of relationships within the hospice programs changed as the size grew. As one director noted, "We used to all know everything about the patients we handled. Now we find we spend less and less time discussing cases in depth. There are just too many of us now . . . . Our relationships seem to have changed, we have more specific duties."

Hospice program membership was also impacted by size. Directors repeatedly commented on how the community had become more willing to support the program once they hired staff and had an operating budget. Analysis of social movements by Olson (1968), Clark and Wilson (1961), and McCarthy and Zald (1973) point to the importance of membership growth as an element in solidifying collective action. While a variety of factors influence group solidarity (such as shifting incentives, resources available and leadership), membership growth functions as an important determinant in the movement's long-term survival. As Judkins (1983) noted in his study of the brown lung movement, the organizers needed to recruit members and to develop a constitutency. Once the organization grew to a certain size it began to gain political clout and members' incentives changed from individual to solidaristic (for the group) to purposive (for the good of the cause). Olson proposes that the size of a group is dependent upon the benefits it is able to provide to its members. It appears, following Olson (1968, p. 50) that hospice programs are an "intermediate group in which the collective good cannot be obtained without group coordination or organization. Further no single member has sufficient incentive to provide the collective good alone."

Similarly, as the hospice movement grew in size it was able to affect legislative policies which would aid in the development of more hospice programs. Changes in federal and state reimbursement policies guaranteed new hospice programs an income as well as providing them with a legitimate standing in the traditional health care system. The guarantee of program funding also allowed programs to attain some degree of size by hiring staff and caring for patients. New volunteers were recruited into the program at the same time that fundraising campaigns were increasing. As one hospice employer said,

> I think we're going to stay the size we are for a while. . . . At first we were small and I noticed that some of the early members were getting burned out and spending less time with the program. . . . This national legislation was a shot in the arm. As more people learned about the federal program, our phones began ringing. We had a

> dozen new patients and at least 50 new volunteers within two months of the passage of the Medicare rules. . . . At first we enjoyed the attention and growth. After a while, we realized we'd better settle down and have put things on hold. It's odd though, the more people we get the more individuals are interested in volunteering their energies. . . . I guess we're going to have to be more careful in our volunteer screening.

While size impacted the organizational structure of a hospice program, it also had an effect upon the way in which the community (consumers as well as professionals) viewed the program.

"I noticed," said one nurse, "that as we added patients and received outside funds the doctors in the community took us more seriously. They were more willing to participate and listened to our concerns."

Size also impacted the number of external relationships the hospice program was able to acquire. Hypothesis 1-A proposed that the larger the size of the hospice the larger the number of external relationships. Results showed no relationship between the number of external relationships and size. Yet, interviews with hospice program directors indicate that the number of relationships did in fact increase. How can this discrepancy be explained? In the survey respondents were asked to check those agencies with which their hospice had an affiliation. However, the questions did not ask for the number of affiliations in each agency group. Larger programs could have had relationships with two or more home health agencies and the data would never have appeared in the survey responses.

It appears, from interviews, that as hospice programs increase in size, particularly in funding, they gain increased support and participation from the community. Thus, external relationships are expanded. As one volunteer coordinator noted, "A few agencies came to me and offered their members as volunteers. I was delighted and surprised. I just don't think this would have happened a few months ago." (The hospice program recently received a grant from an area foundation.)

Exchange relationships between area providers and the hospice also changed as a result of size increases. "The types of relationships we set up with area physicians and home health agencies changed as our program grew," noted one director. "As we began to hire our own staff, some of the relationships dampened." This issue is examined more fully in later pages.

Size not only provided a measure for assessing program integration, but also provided some insight into changing organizational structure and function. Larger organizations appear to develop new links to the community and found acceptance from previous skeptics. As the size increased, the internal structure of many programs also changed, division of labor was increased, formal communication mechanisms were established and the organizational structure became more tightly defined. The larger the hospice organization the more it began to take on the characteristics of the traditional system. Personnel schedules were organized, tasks were structured and responsibilities were assigned. The major goals of the organization shifted and were more concerned with obtaining funding, than, with educating physicians about hospice or promoting the hospice concept of care. As Weber and Michels pointed out the goals were oriented toward "organizational maintenance," thereby meeting the presupposition for bureaucracy.

Organizational Creation

It was proposed that programs created by other organizations would be more likely to be integrated than those created by independent supporters. Work by Zald and Ash (1966), McCarthy (1973) and Litwak and Hylton (1966) describe the importance of interorganizational relationships in the development of new

SMOs. While at first it appears tautological to suggest that a hospice program created by a hospital would be more likely to be integrated than one created by individual supporters, a review of histories of several highly integrated hospice programs shows this is not the case. Of the four program histories examined, three programs were created by efforts of hospital staff, two of which terminated formal relationships with the hospital in order to become "community oriented." The hospital administrators remained on the hospice board of directors, but the hospice left the confines of the hospital, operated in a separate building, and refused to continue to take money from the hospital.

As one board member stated, "We were beginning to feel that the hospital was taking us over. That's not what we wanted. I may work for the hospital, but I didn't want to start a program to benefit the hospital. I was interested in addressing a need of our community."

In one case, a hospice created by a hospital decided to establish its independence, refused all support from the hospital, established its own community-based program and eventually merged with a local home health agency. The home health agency was not involved in the very early organizational stages of the hospice program, but did eventually work with the program in its development. This same program at one time applied for certification as a home health agency and was planning to compete for the same patient load with the home health agency which it is now affiliated.

"There were some hard feelings," said the home health agency director. "We had worked closely with the local hospice and felt they double-crossed us. We were pleased to see that they were not going to be affiliated with the hospital and tried to work with them. When we saw them moving to compete with us, we withdrew from their board. It was open warfare. . . ."

The way in which an organization is created provides insights into future structures of the organization. Generally, an organization's goals are developed by initial creators. A hospital creating a hospice program is more likely to emphasize traditional medical care than an independent community-based program. However, this factor also varies depending on the geographic area, who in the hospital is involved, and the importance of the program to the overall goals of the hospital (Elling and Lee, 1972). While this research did not specifically focus on uniqueness of each program's creation, oral histories were taken from directors of six different programs in order to understand the impact organizational creation can have on integration.

The interviews appear consistent with the findings; that is, programs affiliated with an existing health care organization did, in fact, exhibit characteristics of the parent organization. For example, hospice programs created by a hospital generally had a physician involved in the early planning while those which did not have hospital affiliation relied on a nurse or social worker for early planning assistance. Hospice programs created by existing institutions began discussing issues of funding earlier than those created by individuals in the community. Finally, programs created by other organizations moved more quickly to organizational tasks, such as conducting a needs assessment, than those programs which were linked to individual supporters. In the case of the latter, participants spent more time discussing the problems of the existing system and examining the poor system of treating the dying in local hospitals.

In addition, the growth of hospices seems to reflect the first three stages of the Mauss typology of social movements:

> Phase one: incipiency. This phase consists of discussions initiated by a small group of individuals concerning their experiences dealing with a

death within the existing health care system. The participants begin by discussing the grief associated with the death of a loved one and end with an exchange of horror stories about family members who died in a cold, isolated room in a hospital or nursing home, in pain and without the benefit of the warmth of family.

Discussants include local clergy members, nurses, lay consumers, and a counselor. Phase One ends when the group has developed an organizational structure, formalized its goals and objectives, established regular meeting times and accepted donations from the community for out-of-pocket expenses.

Phase two: coalescence. During this phase the hospice programs organization is firmer. A volunteer medical director and executive director have been recruited, community education and information sessions are underway along with active solicitation of funds and volunteer energy. A program for training volunteers is established and an assessment is undertaken to determine the need for the hospice program. Community leaders are contacted regarding donation of resources and expertise. Sometimes they are asked to serve as members of the board. Organizations such as hospitals, home health agencies and nursing homes are asked to participate in the development of the program.

As one respondent noted, "In our area, we thought we were becoming one big family. The hospitals, nursing home and a home health agency were working cooperatively with our founders."

Phase three: legitimation. At the end of the second phase and the beginning of the third programs begin to employ some type of paid staff.

Generally an executive director and part-time secretary are hired. If additional funds are left over, the program begins its search for a volunteer and patient care coordinator. Plans are made to admit patients and a pilot project may be underway; the pilot project allows the program to take a few patients on a trial run before full-scale operations are underway. A second board of directors has been selected and original organizational goals are assessed.

By the end of this phase whether or not the program will become integrated and to what degree becomes clear. Mergers with existing agencies are discussed at board meetings. The role of the hospice program in relation to other health care providers is discussed, and the continued viability of the hospice program as an independent organization is evaluated. Board members ask, is there sufficient community support to sustain the organization? Can patients be serviced adequately? Is the program financially viable? Are there changes which need to be made in the organizational structure to facilitate development?

If one were to speculate on a fourth phase it might be called "conflict and change." Many of the programs, after some experience with patients, begin to reassess what it is they are doing and where they want to end up. As one informant noted,

> Something happened... we began to feel different. We weren't discussing the hospice concept of care at board meetings. Instead we were discussing the day-to-day administrative operations. This had to stop. ...It was almost as if everyone was feeling the same thing. We decided on a retreat and spent a good deal of time discussing our differences and future orientation.... A few people decided to resign after that but the majority of us are still struggling with new directions.

There is increasing evidence, as noted earlier, that programs are entering stage four, fragmentation. Conflicts are occurring among programs and between programs and external organizations.

Michigan Hospice Program's Profile

Based on October 1982 responses from 48 hospice programs a profile of the typical Michigan hospice program can be detailed. (See Appendix 7 for marginal totals.) A typical hospice program in Michigan is home-based in its orientation, has been incorporated since late 1981 and accepts an average of 37 patients and families per month. Patients admitted to the program have a terminal diagnosis of cancer with six months or less to live, have a primary care giver at home and have received the consent of the patient's physician.

The hospice program is located in a county of between 10,000 and 250,000 inhabitants. Its annual funds total $35,000 with an average staff of two paid individuals (an executive director and a patient care coordinator) and two volunteers (a secretary and a medical director).

The primary goals of the hospice program are to promote the hospice concept, improve the comfort of the dying patient and care for the patient at home. The hospice seeks community memberships, requiring members to pay a small fee. It has a board composed of one or two physicians, two hospital representatives, at least one home health agency representative, a funeral director, an area educator and lay consumers including some hospice volunteers.

The hospice has affiliations with area hospitals, nursing homes, home health agencies or local health departments, and local churches. It offers the following services: basic nursing, companionship, psychological counseling, personal care, symptom control, social work, skilled nursing, bereavement counseling, errand running, housekeeping, home meal preparation, transportation and education about hospice care.

It took two years from the time of the first organizational meeting for the hospice program to begin accepting patients.

Organizational Density

Density was considered to be a function of competition. Based on the work of Hawley (Scott, 1981), it was proposed that hospice programs in close proximity would compete for patients and both would have a strong emphasis on goals which related to program integration. At the .10 level, density was significantly positively related to hospice program integration.

The question regarding density asked respondents how many other hospice programs existed in the immediate area. The researcher plotted programs on a map. Two or more programs within a 25-mile radius were considered potential competitors.

One important variable was excluded from this analysis: the number of home health agencies in an area which potentially provided hospice care to patients. In the southeast corner of the state, for example, a number of hospital and home health agency-based hospice programs were excluded. The primary reason for exclusion was that these institutions had not formally announced that they provide hospice care. A discussion with local providers in a separate study described later shows that both home health agencies, hospitals and in some cases physicians, see themselves in competition with the local hospice program.

As one home health agency director noted, "We don't call ourselves a hospice because there isn't reimbursement. But we do provide hospice care to our patients and very much resent the start-up of this new group. We didn't mind helping the hospice when it was talking about voluntary free care, but now it wants a share of the pie. . . . It's a whole different ball game."

Density and competition are important variables which need further investigation with more refined measures. Hospice directors working in areas with other hospice programs describe strategies they are undertaking to ensure that they will have "their fair share for the third-party money."

As one director noted," We don't really see ourselves in competition with the home health agency. They care for those people who are getting well and we care for those who are dying." When the researcher pointed out that the local home health agency had a 30% terminal patient population, the hospice director responded, "I simply don't believe it's that high. If it is, then it's about time their patients had some options. We can offer the same type of basic nursing and more."

As the interview progressed, it became increasingly apparent that the differences between the local home health agency and the hospice program in terms of actual services offered was not great. The hospice planned to add new services such as financial counseling and physical therapy, but at the time the interview was conducted had not. The director of the program prided herself on how similar her staffing was to the home health agency's but also mentioned that there were "differences in the intensity of the care delivered and the type of nursing personnel employed."

Organizational Goals

Obershall (1973), McCarthy and Zald (1973), Tilly (1978) and others point to the importance of goals in directing and mobilizing collective action. In his account of the brown lung movement, Judkins (1983) describes the goals employed by the movement organizers to gain credibility and to provide participants with some feelings of accomplishment.

Similarly, organizational leaders provide employees with goals which not only state the organization's primary purpose but also provide some means by which employees can measure the organization's growth and development. For hospice programs, organizational goals reflect the philosophy of the larger social movement and also provide the hospice program with both long- and short-term objectives.

In this research it was proposed that the greater the inter-organizational competition, the more likely a hospice program would be to transform its goals and tactics to facilitate integration into the larger society. The survey asked respondents to rate a series of goals noting the changes over time. While the measure showed no significant results, interviews with board members and hospice program directors suggest that goals are indeed shifting.[1] As one hospice director stated:

> We were first concerned with building a reputation. Our goal was to educate the community about the hospice philosophy and about our program. After we got started things started changing. We downplayed the education aspect and began to set fundraising goals. Every month, it seemed like we set a higher goal for ourselves. The board also began to discuss the importance of lobbying for third-party reimbursement. They wanted me to spend more of my time pursuing this goal. Looking back, I never would have believed that the goals or the organization would change so much.

Directors interviewed indicated that the biggest changes in their program's goals were toward seeking outside funds and the development of reimbursement mechanisms. In the case of the latter, it can be argued that this is a strategy for integration. Four programs noted that hiring personnel was a priority goal after

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[1] Reasons for this result discrepancy are two-fold. First, the measure was inadequate (see Problems section). Second, interviewees felt more restrained in their written answers but provided additional and unsolicitated information in the interviews.

the first year of operation planning. Again, one can see that programs becoming increasingly interested in strategies which allow them to mimic parts of the existing system. It can be argued that a desire to participate in the existing reimbursement system, hire medical care personnel and to seriously consider licensure as a home health agency (as several program directors indicated became new goals) are all manifestations of strategies toward integration. It is unfortunate that the questionnaire did not provide a mechanism for collecting goal change. The problems with this measure are discussed in a section on "methodological problems."

Professional Leadership

Research by Zald and Ash (1966), Gusfield (1968), Tierney (1981), McCarthy and Zald (1973), and Judkins (1983) identify the influence leadership has on social movements and their organizations. They stressed the early involvement of "outside" leaders--those who are not involved in the problem but who are able to organize others. For example, the Brown Lung Association, described by Judkins, provides an illustration of the way in which outside organizers identified the problem for workers and began organizing those affected by the disease. While many social movement theorists point to the importance of "outside" leadership, there is a need to look at what motivates organizers to become involved in a cause which does not directly affect them.[1] While it is not the point of this research to understand the reasons leaders become involved in promoting the hospice concept and hospice programs, it is important to note that hospice leaders are affected by the problems raised within the movement.

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[1] For an interesting discussion of social movement psychology see Hadley Cantril, The Psychology of Social Movement, New York: John Wiley and Sons, 1941.

Cicely Saunders and Elisabeth Kubler Ross--prominent movement advocates--are both physicians who have expressed their frustration and outrage with patient care in the traditional system.

It is interesting to note that a number of the leaders in the hospice movement have been women. The president of the National Hospice Organization is a woman physician, Josephine Magno. Many state organization directors are women. In Michigan women direct more than 95% of all hospice programs; only two programs in the state were headed by men at the time of the survey. Further, nurses, social workers and clergy comprised the majority of the early hospice founders. It was not the patients or the families of patients per se that led the hospice movement. Although they became an important force, it was a cadre of female health care professionals who pointed to the stressful, dissatisfying system under which they had to care for patients that formed the basis of the first public outcry.[1] It was the physician and the hospital administrator who became the targeted enemy. As one organizer said,

> We all knew who was at fault. It wasn't the system in general terms, it was the physician and the hospital administration. They designed the system so that they could get the biggest profits. Damm the rest of us. If they make the most money by viewing us as a piece of meat to be carved at their will, then that's what we were going to be. . . . Now the nurses, they are more sympathetic. After all, they're also viewed as a piece of meat, a helper. It's no wonder they are dissatisfied and have decided to speak out on behalf of their patients. . . . They know more about the patient's problems than most doctors. The nurse briefs the doctor, assists with the treatment, and gets thrown a peanut for a reward while the physician makes thousands of dollars. It just isn't fair and it isn't humane.

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[1] Veblem (1931) in his theory of the leisure class argues that the role of upper and middle class women is to support social movement which improve the "welfare" of society. Usually these women serve as volunters, although in the past decade, their role has been altered by the feminist movement.

Leadership of the hospice program does make a difference. During observations this researcher noted differences between programs in the same area based on the leadership. Programs organized by health care professionals had a different orientation toward patient care than those organized by lay citizens. Health care professionals placed a higher emphasis on meeting standards of patient care than did lay organizers. Social class and sex of the organizers appeared to impact development but information gathered is only speculative and based on limited observations. Further study should focus on these issues. The section on "other research suggestions" identifies related topics of investigation.

Board Diversity

Zald (1974), Elling and Lee (1966), Riska (1976), Holloway, Artis and Freeman (1963) identify the importance of an organization's board in influencing program decisions, providing organizational linkages and obtaining community resources. Earlier it was mentioned that membership on a hospice board is not as high in terms of organizational status as is membership on a hospital board or home health agency board. It was also indicated that the board membership diversity will change over time as the board becomes more highly integrated. The greater the diversity, it was proposed, the greater the probability of integration.

Results show a significant negative relationship between integration and diversity. That is, the lower the diversity the greater the integration. At first glance this result is surprising. However, a review of ten lists of original and current board members shows that as the programs adopt strategies for integration, they begin to alter the composition of the board. While early members were primarily hospice program founders, once a program hired an executive director and began to review critically its board composition several changes were made. Program directors replaced the variety of lay representatives on the board of directors with a more narrow band of individuals representing the medical care and business community. The lay composition was reduced and aggressive attempts were made to recruit physician members. Members of voluntary foundations were also sought after as were other individuals of high status who could provide the program with greater prestige as well as economic resources. The board began to represent a few dominant types of memberships rather than many divergent ones. Those dominant members also appeared, in some way, to control resources important to program integration.

The Status of Integration of Hospice Programs

The drive for institutionalization in hospice programs is also a call for integration. In order to achieve this end, hospice organizers have taken a series of steps, including promotion of legislation to provide Medicare reimbursement for hospice patients, support from third-party insurers, and status as official providers of care for the terminally ill through licensing statutes.

In general, efforts toward integration have been successful--so successful, in fact, that organizations that once shunned the idea of hospice care as being too costly are now becoming a major force in the development of new programs. According to NHO Executive Director Josephine Magno, 40% of the hospice programs developing are hospital-based. Another 20% are home health agency affiliated. Increasingly, existing providers are entering into the hospice industry. Similarly, some hospice programs are seeking alternative status as home health agencies.

Hospice programs were recently granted "independent provider" status under the federal Medicare regulations. This allows the programs to receive reimbursement for patient care. The hospice program is responsible for determining patient care plans, hiring appropriate personnel, etc.--in short, has a provider classification and can be considered a part of the traditional health care system. It must conform to standards and protocols, including licensed personnel responsible for patient care, if it is to receive federal funds.

The success of the integration drive has been met with mixed feelings among the hospice program directors. For some, classification as a provider and entrance into the existing health care service delivery is the "source of salvation" as one director noted. Proponents, short of funds and worried about long-term program survival, view the receipt of third-party funds as beneficial. As one staff physician recounted,

> We thought we might go under. . . . This Medicare money will save us. We can now be a part of the larger system. We can charge appropriately and provide much needed services. I think we're on the long road to good fortune.

While some applauded the passage of the bill to fund hospice care, others were deeply upset by the future.

> We didn't want to become involved with all these rules and regulations. We're just a small volunteer program and we wanted to keep funding without government interference. . . . You know, people keep saying hospice is cost effective, it saves dollars. Well, this is true. But if we become part of the larger system, we're going to have to charge more just to comply with all the regulations. Soon we won't be able to use volunteers. . . we'll be too worried about malpractice. . . . Things are changing and I don't think it's for the better.

The conflict between hospice programs seeking integration and those which desire to remain outside of the traditional system continues. In Michigan a coalition of rural hospice programs has been formed and has lobbied successfully against passage of licensing rules to regulate hospice programs. Without the rules, according to one state public health official, it is "impossible to license hospice programs." An official of the coalition said its tactics were organized to ensure that proposed rules did not prevent the small hospice programs from continuing.

> We are upset with the Michigan Hospice Organization (MHO). We don't think the organization represents the interests of the small, all-volunteer programs. When we opposed the licensing law, the state organization (MHO) lobbied for it, now we are concerned that the rules written by the state may wilpe out small volunteer programs. . . . The MHO isn't listening to our concerns. It's made up of those larger hospice programs that want regulation. . . . That's what made us decide to start our own organization.[1]

Conflicts between programs represent one area which may affect the ability of hospice programs to become integrated. Another potential problem is the divergent acceptance of hospice programs among home health agencies, physicians and hospitals, attitudes which may be due to exchange relationships which develop among the hospice program, physician and home health agency.

The physician refers a patient to the hospice program and receives, in exchange for the referral, access to the hospice program patient care plan as well as to the volunteers and support staff the program can provide to his terminal patient. For some physicians, the hospice program provides a way of caring for a patient after the physician has diagnosed the case as terminal and beyond curative care.

Many physicians view death of a patient as a failure (Parson, 1957; Parsons, Fox and Lidz, 1973), and helplessness is a common feeling among physicians with terminal patients. The hospice program offers an option. The physicians's time with the patient is better spent if the physician can use hospice technologies to keep the patient comfortable and also to provide a source of support for the family.

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[1] At the time of this writing, meetings were being held between MHO representatives and the rural hospice association to try to work out a compromise regarding the rules. According to Carolyn Fitzpatrick, MHO representative, "I think we have something worked out. I feel confident the problems have been resolved."

The physician, in addition to gaining support services, also has an opportunity to be reimbursed fully for services rendered. Under new Medicare regulations, a physician can bill for 100% of the hospice visit, while costs for a home visit under the old system could not be recovered.

The hospice program acts as a source of support for the patient, family and physician. A physician retains control over his patient's care plan, assists in symptom control and will soon be paid well for his or her efforts. The patient's physician is an integral part of the hospice care program, in sharp contrast to that of the home health agency.

Home health agencies receive a different type of exchange from hospice programs than do physicians. For many home health agencies, the nursing services they provide form the core of a hospice program of care.[1] Many home health agencies are linked in an informal arrangement with an area hospice program. In fact, a majority of community-based hospice programs receive the largest share of the patient load from health agency referrals.

The advantages to home health agencies are three-fold. First, the agency receives monetary compensation for the care of the hospice patient. Second, the agency receives the benefit of volunteer support services and bereavement counseling for patients, which free nurses' time and allow them to devote more time to more profitable nursing services.[1] Third, the agency may gain patients through physician referrals to a hospice program. A physician may refer a patient to a local hospice program even though the patient has no designated home health provider.

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[1] This will change if current Medicare regulations are passed.

Although the home health agency and the hospice program has a mutually beneficial exchange relationship established, the relationship between the two organizations is changing and the advantages to the home health agency are diminishing. In a few months Medicare will pay for hospice care for patients. Under the proposed rules, the hospice program will be mandated to hire its own nursing staff to make home visits. It will not be allowed to subcontract with the area home health agency. According to one hospice program director who is lobbying for change at the national level,

> This is essential. We hospice programs are separate providers. What we do is unique and much different from what home health agencies do. Home health agencies are designed to care for those people who are going to get better. We care for people who are not. This is a much different type of care. . . . I think we need to hire our own nurses. I don't care what you say, you can't run a program and know what's going on if you contract with other agencies. Hospice Y and Hospice Z are examples of the problems faced. They contracted with Visiting Nurse Services and are no longer able to control care for their patients. It's just not working. . . . If you're going to be another provider in the health care system, you need to establish your own program of care. Hospice is a new health care provider. . . . It's as simple as that.

The recently proposed Medicare regulations will encourage home health agencies to develop hospice programs. The advantages are fourfold.

First, the home health agency is capable of providing the essential core of a hospice program, home based nursing. While the hospice program must either hire or contract for nurses, the home health agency is already established and functions to provide patient care.

Second, home health agency referrals from hospice programs are diminishing as hospices grow in size and begin hiring their own staff.

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[1] Counseling is a non-billable item.

Third, competition to provide hospice care is coming not only from community-based hospices, but also hospitals who are attempting to establish their own hospice programs.

Fourth, agencies stand a chance of losing a referral patient to a hospice program. This is especially problematic for agencies which are not sole affiliates to area hospice programs. In Community X, for example, the hospice program is serviced by three home health agencies, each of which is concerned about maintaining a relationship with the patient referred to the hospice.

Under the new regulations, hospitals will also be encouraged to develop hospice programs. The Medicare regulations require access to an inpatient facility and a home care program. Since hospitals are inpatient facilities, this first requirement is met, and an increasing number of hospitals are developing home care programs.

As one administrator noted, "We started our program so that we could offer the patient a complex of services. We didn't like the idea of shifting the patient's care plan. . . ." In other words, the hospital can regain control over the patient's care, which has two advantages for the hospital. It can diversify its cost centers and increase its revenue, and it gains community loyalty by caring greater health needs of the patients. One area hospital, upon offering a home care service, held an open house for the community and distributed brochures which identified the hospital as "your home away from home."

While the hospital retains control over the patient, it can also use the hospice as a way of maximizing efficient patient use of hospital facilities. Hospitals are paid if beds are filled. They are able to profit more from individuals with treatable disease than they are from terminally ill individuals who are on a maintenance regime. A hospital can use a hospice to rotate patients out of a bed which can be more profitably used by an acute patient.

The federal Medicare regulations provide the hospice program with some degree of autonomy. Reimbursement allows programs to establish their own cadre of hospice professionals able to treat patients in their homes. However, the proposed rules also reduce the probability of coalition building between hospices and home health agencies. This benefits those hospice programs, and home health agencies which want to be independent and permits hospitals a free entry into the field of hospice care. A system of cooperating, interdependent organizations is thus proscribed by the proposed rules.

A hospice program, according to several area hospital administrators, is not to date a "money maker"; however, it does offer the hospital good public relations. Hospice denotes a "caring, nurturing attitude," said one administrator.

> We really don't profit from the hospice, in fact, now we're losing money. We do, however, get a good image from the program. It's like our home birth program. The community loved it and patients asked physicians to refer them to our hospital. We had some referrals last year from physicians who were on staff at another hospital. Their patients demanded a service only we offered. . . .

While hospitals claim that they hospice program has not been a "moneymaker," once the federal requirements are passed, hospice will certainly pay for itself. Home-based care will be reimbursed as well as physician home visits. Hospitals will not be reimbursed for any aggressive care under the hospice program, e.g. surgery. However, if a dying patient needs some type of surgery to ease the pain, the patient maybe shifted off the hospice plan.

This is not to imply that the hospital can arbitrarily shift cost centers to get the most funds from the Medicare payment system. However, the rules do contain a provision allowing the patient to be taken off the hospice program if the disease can be cured because of some new treatment, or if a procedure is required to relieve the discomfort of the patient in the last stages.

In Michigan, there is no restriction on the development of hospices for at least the remainder of the year because licensing rules have not been passed and there is a moritorium on certificate-of-need requirements. The moritorium, according to one legislator, was passed to encourage the development of small community-based programs. Based on the data, the number of community-based programs is dwindling and the number of institutionally affiliated programs is growing. This suggests that hospitals are beginning to dominate the field of hospice development and that the larger hospice programs are becoming more bureaucratically oriented.

What will the future hold? Probably there will be a greater number of home health agency and hospital-based hospice programs with concomitant reductions in community-based hospice programs. Physician involvement in hospice will continue to grow now that hospice has gained a strong foothold in achieving legitimacy as a new form of health care for the terminally ill.

The recognition of hospice by third-party payers has increased the credibility of such programs among providers and will make them more attractive in the medical care marketplace.

As hospice programs become increasingly institutionally affiliated, their philosophy of care may remain the same, but program elements will undoubtedly change. Volunteers will play a lesser role in caring for the terminal patient. Counseling, spiritual services and bereavement care will be handled according to legislated standards of care. The proposed Medicare rules require hospice programs to provide bereavement services, but contain no provision for reimbursement of these services. Without funds, many hospice programs may provide only minimum bereavement and counseling services. In time, this unique form of hospice care may be eliminated completely.

The physician will play a dominant role in the care of the patient as the involvement of home health agencies is reduced. Increasingly, hospice programs will hire their own nursing personnel. Some hospice programs will become home health agencies to increase their financial base of support. Hospital-based programs generally do not contract with local home health agencies for care. As the number of hospital-based home health programs increases, hospitals will reduce the number of patients they refer to home health agencies.

As medical professionals point to the importance and need for a specialty in care for the terminally ill, they will also require places in which to practice. The care for the terminal patient will likely become a recognized specialty in both medicine and nursing which will affect hospice as a social movement. For physicians, it may well become a subspecialty of oncology or geriatrics.[1] The nursing profession is currently discussing the development of a specialty in care for the dying. Continuing nursing education classes in care for the terminally ill have been offered and some nursing programs now list specific coursework for caring for hospice patients. A 1980 Michigan Nurses Association position paper calls for the direction of hospice nursing care by a "registered professional nurse with experience and education in the care of the terminally ill" (p. 11).

As the supply of physicians grows thereby encouraging entry into specialties such as geriatrics,[1] and as reimbursement for hospice care increases thereby providing monetary incentives for hospice treatment,[2] the development of specialties in care for the terminally ill will become increasingly promoted. The development of hospice care as a specialty will undoubtedly not only provide legitimacy to the movement but also escalate program development. For

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[1] Geriatrics is not an American Medical Association recognized specialty. However, plans are underway to make it a specialty and some medical schools are offering special courses in geriatrics as part of training in family practice and internal medicine.

example, as more nurses graduate with training in care for the terminally ill, they will need places in which to practice their skills. In a sense, the development of this specialty will take on a character of its own. As Bucher and Strauss (1961, p. 326) pointed out in their discussion of specialization in the medical profession, as specialties begin to develop they

> look out for themselves and proclaim unique missions. They issue a statement of the contribution that the specialty, and it alone, can make in a total scheme of values and, frequently, with it an argument to show why it is peculiarly fitted for this task. The statement of mission tends to take a rhetorical form, probably because it arises in the context of a battle for recognition and institutional status . . . .

Research on hospice program development is only beginning. Because it is a relatively new social movement, more information needs to be collected. Time based data will show if the trends predicted above occur.

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[1] The 1980 nursing supply totals 1.3 million, up 340,000 from 1970. (Johnson, 1982). The 1980 physician supply totals 467,679, a 40 percent increase from 1970 (GMENAC, 1980).

[2] The Michigan Nurses Association 1980 position paper on hospice recommends, "nurses through the professional association should establish criteria and guidelines for reimbursement of nursing care in hospice programs as a model for third party payers" (p. 11).

CHAPTER VI

CONCLUSIONS

Chapter I described the concept of hospice and its divergence from the traditional health care system. Hospice programs are designed to treat emotional, spiritual and physical needs of dying patients, and focus on palliative and not curative care. Hospitals, and other traditional health care organizations, are structured to focus primarily or the patient's physical needs and are designed to help the patient "get better."

It was noted that although hospice programs are not new, their current form developed in the early 1970s as an outgrowth of the larger death and dignity movement. Chapters I and II examined the forces that led to the development of hospice programs, including the growing concern over consumer health rights, medical care costs, use of medical technology and fear of cancer.

Chapter II combined organizational and social movement literature to identify propositions which could be used to understand the concept of social movement organizations and their integration into the traditional health care system. Integration, the independent measure, was constructed by outside experts and was selected as the basis for this research because hospice programs--similar to other types of health care reform organizations such as home birth programs--were designed by the founders to work cooperatively with the existing system, to offer consumers choices for types of care and to eventually become an integral part of the existing system. Integration was a goal identified by at least a dozen hospice program directors interviewed. As one director noted "we wanted to be a part of the system. . . . This is the only way we could survive and offer dying patients a choice. Eventually we hoped the system would change and adopt our goals."

The data showed the way in which the hospice was created and the size of the program were the two most important factors influencing its integration. The dissertation examined other factors such as program density, professional leadership, board diversity and external affiliations. These factors proved to be of little value in predicting integration.

The hypotheses proposed in Chapter II are based primarily upon the work by Zald and Ash (1966) predicting the changes social movement organizations undergo in order to survive over time. The data in this dissertation were not longitudinal and hospice programs are so new that it was impossible to predict survival. However, integration is certainly one strategy used to achieve survival (Selznick, 1953). Therefore, an organization's ability to integrate is related directly to its potential for long-term survival.

Zald and Ash (1966) noted that size was an important aspect of organizational survival. While their concept of size related to organizational memberships, the concept of size was borrowed from organizational literature (Blau, 1962) and is related to items such as budget and staff. It was shown that a significant positive relationship existed between a hospice program's size and integration, that is, larger programs are more likely to adopt integration strategies than smaller programs. Thus, it can be argued that the larger organizations are also more likely to survive over time than are the smaller organizations.

Zald and Ash (1966) also noted that social movement organizations created by other organizations are more likely to "go out of existence following success" than social movement organizations with their own linkages to individual supporters. They noted that organizations created by existing organizations would be more likely to be "becalmed when the organizations goals are achieved and that this would lead to the demise of the organization." The social movement organizations described by Zald and Ash in 1966, however, are goal-specific (for example the NAACP in its push for school desegration). The hospice movement, on the other hand, is designed not just to change a part of the system, but to actually offer an on-going alternative. Therefore, their linkage with an already legitimated entity will enhance efforts toward success in offering that service or integration. It is here where the Zald-Ash hypotheses are modified. Individual links are seen as less integrationist and counterproductive for long-term survival. It was proposed (Chapter II) that those hospices created by other organizations, such as hospitals or home health organizations, would have a higher chance of integration than organizations created by individual supporters. The one problem in this analysis is the inability of the research to measure whether the original goals of the hospice program changed over time as a result of its close affiliation with providers in traditional health care system. This question needs to be addressed in further research,. Has the movement and the programs which represent the movement been "becalmed?" Is it undergoing demise as Zald and Ash would predict?

As one board member said, "We only take paying patients now. We used to take anyone, but you can't run a charity system. The hospitals learned that a long time ago. . . . Hospice programs were originally founded by a bunch of do-gooders. Well, they certainly didn't know much about running and maintaining a program did they?"

Zald and Ash (1966) noted that external affiliations were another important indicator of long term success. They noted linkages could lead to coalition building and mergers which might enhance organizational survival. In this dissertation, it was argued that external affiliations would indeed influence integration. Although the measures were poor, the material collected on home health agencies and physicians showed that a series of exchange relationships had been established that provided the hospice program with an entry and necessary purpose within the traditional system. These exchange relationships, however, created competitive problems among home health agencies, hospice programs and hospitals with respect to control and access to patients.

Increasingly, home health agencies are viewing hospice programs as competitors and are building up strategies to hinder future hospice expansion. As one home health agency director noted, "The state is such that we are going to apply for hospice status. We've been refering our patients to the local hospice program, but I'll be damned if I keep it up. . . . They want our expertise and our economic base. . . . They started out as a volunteer group. They wanted to work along side of us. Now they want third party reimbursement. . . . It seems as if they're changing their tune."

Zald and Ash (1966) discuss goal change and goal fragmentation within social movement organizations. The early history presented in Chapters I and II provides some background as to the intent of early and future founders. Early founders wanted the hospice movement to "wake up" existing providers, and as one founder noted, "get the doctors and nurses off their butts to provide the kind of care dying patients needed." As the movement progressed, attempts were made to keep hospice programs separated from the existing system, To give hospice programs "a separate provider status." The debate over developing a cooperative relationship with existing providers and becoming more competitive with existing providers caused fragmentation within the hospice movement and, as Zald and Ash predicted, led to a time of goal reassessment. In Michigan, hospice program directors debated over the development of state regulatory standards. Program directors desiring greater integration and a close liaison with existing providers referred to themselves as "volunteer" programs. They emphasized their supportive role for terminal patients. They were opposed to any state control. Program directors favoring separate provider status on the other hand, argued for the build-up of patient care staff and emphasized the importance of having a distinct role in the existing system.

Zald and Ash contend that leadership and board composition also affect the ability of social movement organization to change. A hypothesis stating the greater the board diversity, the more likely the program's goals would be to reflect integration was tested. Similarly, the greater the number of leaders from the traditional system (e.g. physicians and nurses), the more likely the program would become integrated. The data did not support this hypothesis.

Integration is a useful concept for understanding the relationship of a new social movement organization to the larger society but unfortunately it is also a vague concept which needs further modification. It is hard to determine just which interactions between the larger health care system and hospice programs may be co-opting and may be integrating. Perhaps we should follow the lead of H. Simon (1962) and K. Weick (1976) and view different parts of an organization and varied types of interactions.

Viewing organizations as "loosely coupled systems" Simon (1962) and Weick (1976) argue that most organizations do not function according to very rationalized plans, goals and organizational charts. Rather, they are run by people and have parts which prove "intractable to analysis through rational assumptions" (Weick, 1976, p. 2).

Weick uses the term "loosely coupled system" to convey "the image that coupled events are responsive, but that each event also preserves its own identity and some evidence of its physical or logical separateness." (1976, p. 3). The concept of separateness allows the researcher to examine how subunits of an organization may function according to prescribed goals while others may break down because of external pressures. In the case of hospice programs, we can see the relationship between consulting physicians, the hospice director, the patient care coordinator (generally a nurse) and the volunteer coordinator. Each of these individuals may be tied to one another by organizational policy but may in fact operate in a very independent and separate way. The clearest example of separateness can be seen in the interaction between a patient care coordinator and a physician. Both individuals are responsible for the physical comfort of a terminally ill patient, yet communication between the two may be limited and the responsibility for the patient may be divided so that very little interaction needs to occur.

In an analysis of loosely coupled systems, the researcher is responsible for identifying the elements, noting their attachments and the boundaries of the elements coupled. The advantages to studying hospice from this perspective are numerous. First, loose coupling allows some portions of an organization to persist. Second, these systems preserve independent sensing elements and therefore "understand their environment better than tightly coupled systems." Third, adaptation to the larger system is easier. Fourth, it allows for a greater number of mutations and permutations than the tighter system. Fifth, if there is a breakdown in one portion of the system, the breakdown is sealed off and does not affect other portions of the organization. Sixth, it provides greater room for self-determination. Seventh, it is less expensive to run than tightly coupled organizations since it takes less time and money to coordinate people.

An implied theme in Weick's analysis is that people tend to overrationalize their activities and attribute greater meaning and predictability to them. Hospice programs claim to have fairly concise organizational charts--that is, those organizations which are established and have accepted patients--however, observation of those claims reveals that the relationships are not always in concert with the organizational scheme. For example, I was advised that the nurses in Program X called the physician at least once a week to discuss the patient's change and medications necessary. However, nurses generally called the physician as needed. Sometimes this was several times a week or after 4 or more weeks. The scheduled "check-in" often did not occur.

Much of the work done by hospice programs is fairly diffuse and difficult to use in exacting a specific organizational structure. From the Simon and Weick model we can critically examine the subparts of a hospice program and try to understand their linkages. Instead of creating a measure of size for the entire program, for example, we can view the number of people (size of a group) working to perform specific tasks. Other types of analyses include examining linkages between hospice professionals and lay providers, among hospice professionals and between hospice program resources and those of other area agencies.

Viewing hospice programs as loosely coupled systems may prove more beneficial in further research than organizational analyses which try to fit the hospice program into a particular mode thereby ignoring many of the distinctive features.

CHAPTER VII

POLICY IMPLICATIONS AND SUGGESTIONS FOR FURTHER RESEARCH

Studies on hospice program development and change over time are just beginning. While this study analyzed factors affecting integration of hospice programs into the traditional health care system, there are other aspects of this movement which warrant investigation. This section discusses policy implications and options for further research including: board composition, quality of patient care, costs benefits, socio-economic factors, and death and the family.

Policy Implications

Hospice programs are a much needed addition to our existing medical care system. They address a broadly defined social need: the humane treatment of terminally ill patients. The development of these programs throughout the United States has raised the consciousness of health care providers, consumers and third-party reimbursers. It has provided a forum around which the public can rally to alter the current health care delivery system. It has been described by some as the single biggest cost savings approach to health care in the past decade.

The new Medicare regulations will have both positive and negative impacts on the future of hospice programs. Positively, it has provided small programs with some hope of surviving long after community funds dry up. It has also provided national and statewide legitimation for for the continued development of hospice programs and has encouraged the involvement of the medical community.

Negatively, the new regulations separate hospice care as a distinct form of patient care rather than encouraging integration. The regulations maintain the dominance of the existing system, which is something early advocates opposed. Physicians continue to serve as the "gatekeeper" to hospice care. Because of their lack of training in the care and treatment of the dying, the ignorance of physicians in this area may slow down or even stop gains made by hospice advocates in their effort to care for the dying. Several nurses interviewed complained that physicians are still too cautious in prescribing pain medications and have "a long way to go" in understanding the hospice philosophy.

As one nurse said, "They still don't know what's going on. They are too locked into their old ways and are doubtful of any new concepts. It's the nurse that plays the biggest role in the care of the dying. She should have at least the same authority as she does in the current home health system."

The nurse continued to explain that under home health regulations, the physician supervises the home health agency but it is the nurse who really assists and cares for the patient. She expressed her displeasure at the fact that physicians are encouraged to make home visits under the hospice regulations because they receive 100% reimbursement.

"It will be just like the hospital is now," she said. "The physician will stop in for a few minutes, bill $40 or $50 and leave orders for the nurse. I think this is a rip-off in the rules."

The proposed regulations encourage hospice program independence and discourage program interdependencies. Programs are required to have their own nursing services rather than contracting with existing home health agencies. Access to an inpatient unit is also required and some hospice programs are considering building their own instead of contracting with a local hospital, reasoning that hospital space isn't properly organized to meet the needs of the hospice.

Further, she noted, "having our own inpatient unit will allow us to control patient inpatient days more carefully."

If the big push behind hospice is cost containment, then it seems most logical to have the programs intimately linked to existing health care organizations to prevent duplication of services. In the long run, the projected cost savings may be lowered.

The proposed regulations also provide physicians with 100% reimbursement for home visits to hospice patients. Depending on the final wording, this provision could open a Pandora's box and escalate the cost of hospice care. Recall, the early founders envisioned a rather small, community-based service with minimal medical intervention. The current programs are becoming increasingly dominated by the medical profession and are expanding rapidly in size and in type of services offered, including legal counseling, funeral service assistance, dietary counseling, vocational therapy, physical therapy, and a host of other services which duplicate those of existing agencies.

Another important policy concern is the use and development of bereavement technologies. At the heart of the hospice concept is the use of bereavement counseling as a form of mental illness prevention. Because bereavement service for terminal patients and their families is a fairly new field, there are few data which evaluate or describe the most effective types of bereavement care. For some hospice programs, bereavement consists of phone calls and mailed cards to the family shortly after the death, and at six- and twelve-month intervals, requesting the family to call the hospice if they have problems. Other programs send social workers or volunteer staff to the home and work closely with the family for the year following the patient's death.

As programs become more integrated there appears to be greater concentration on aids to controlling pain in the patient and less on other types of services such as bereavement. As one hospital administrator developing a hospice program noted, "We have to make this program solvent. In order to do so we are concentrating our efforts on the services that the third party will reimburse. Now we do provide bereavement therapy, but it's pretty limited. I doubt whether we'll expand that service in the next few months but we're trying to improve it."

Hospice programs are becoming increasingly structured and less flexible. The Joint Commission on Hospital Accreditation has been developing standards for hospice care. The Michigan Department of Public Health has written rules on hospice program development. These and other attempts are designed to standardize hospice care by providing mandates for staffing levels, staffing division of labor, requirements of boards of directors (governing bodies), types of services which must be offered and so on. While these standards are designed to protect patients and ensure that dying patients have good quality care, they also require the development of certain types of services and staff which cannot be met by small, all-volunteer community-based programs.

In an earlier chapter, the conflicts between small, all-volunteer programs and larger programs with paid staff were discussed. While the conflicts in Michigan seem to be addressed, new programs developing will be discouraged by the plethora of rules and regulations which they will have to address. Prior to the passage of the Medicare regulations, most of the hospice programs developing were small, community based organizations. In the past 18 months, the new programs have been institutionally linked. This trend has been happening across the country (Magno, 1982).

The federal regulations combined with state regulations are encouraging the development of more sophisticated types of hospice programs which are similar, in many ways, to programs existing in the traditional system. As one rural hospice administrator noted, "The regulations are taking away the flexibility of the smaller programs. They are trying to convert us and make sure we all look alike. Well, we're not going to buy into it. If we have to we'll change our name and stop calling our program a hospice but we're not going to buy into the system they want us to."

In sum, hospice has provided an impetus for alterations in the traditional medical system. Hospitals are more conscious of caring for the dying. Physicians are more willing to try varied approaches to pain control and are able to call for assistance from the community in caring for the terminally ill. The hospice movement has had a positive effect in raising societal consciousness and bringing about change. As Mauss (1971) noted, there is a reciprocal interaction between a movement and its host society. The movement changes some aspect of the tradiational institution and the society in the process of adopting some aspects of a movement "tames" the movement's goals.

> . . . reformist movements tend to be tamed or absorbed through accomodation in which both sides make compromises and come to terms with the other's position. . . . (Mauss, 1971, p. 60)

In the process of becoming integrated into the traditional system hospice proponents have altered their organizational structure to reflect those of the existing system, have given up some of the earlier flexibility they sought and have altered their long-range goals. Patients are taken, in a majority of programs, only if they have the means to pay. Volunteers who are not trained in nursing or related health areas generally do not participate in caring for the patient. Functions which could be performed by volunteers are done by professionals if there is some reimbursement for those procedures. This is, program directors admit, good business sense. However, it has also shifted the orientation of the original hospice idealists.

Programs, in their requirement that patients entering are able to pay for service, have limited their market to generally white, middle- and upper-class patients who can afford their services. While this issue is discussed in the following section, it warrants mention as a matter of concern for policymakers. The hospice movement in the process of shifting its goals has reached out to a particular segment of our society. Lacking the abiliuty to pay for services, economically disadvantaged individuals--generally minorities--will be unable to enter the hospice system. Although there is a push at the national level to lobby for Medicaid reimbursement for hospice care for this population, there is no current system in place to treat these patients.

Further Research

Board composition.

Legally, boards of directors are created in order to ensure continuity in management of organizations and to fix a locus of responsiblity for the control of independent organizations. In addition to these two functions, boards play another important role. They aid in the accomplishment of "desirable ends beyond the capabilities of individuals" by bringing important resources to the organization (Zald, 1969, p. 173).

By studying board composition of hospice programs, it is possible to understand the types of resources brought to aid the organization in its growth and change over time. For example, a program may ask a lawyer to serve in order to assist in drafting bylaws and incorporating the program.

In addition to resources, board members are an important source of power to the organization. Zald (1969) identifies two sources of board power: internal and external. Internal power refers to the board's ability to control the on-going operations of the organization. Organizations which have boards that perform a managerial function operate much differently than those with boards which are strictly advisory. External power refers to the resources the board members can bring to the organization to benefit its future growth. For example, a bank president may arrange a long-term loan for a developing hospice so that it can hire staff and begin its operations.

Riska (1975) noted that a study of boards of directors of hospitals is an indirect method of studying the community power structure. While hospice board membership may not represent community power, changes in the organization as it become integrated into the health care delivery system may be highly correlated with increased status of board members. For example, a hospice program in its early stages may have a board comprised of persons whose chief credential is interest in the hospice concept. As the program develops, board members change so that founders are replaced with members who have important resources, e.g. a hospital social worker is replaced by the hospital administrator.

Finally, studies of demographic characteristics of hospice board members will enhance sociological knowledge about the interface between organizational development and board composition. Will hospice board members be drawn from members of higher socioeconomic reaches as the programs become increasingly integrated? Do societal role definitions associated with sex still influence board member participation as Babchuk, Marsey and Gordon (1960) noted? Are women more likely to be on boards of smaller and low-prestige organizations than on the boards of larger voluntary agencies such as hospitals and universities? It there a relationship between individual socioeconomic status and board membership?

These are just some of the research suggestions for this area. An in-depth study of board membership among a sample of hospice board members may add important insights to sociological literature on organizational board of directors.

Socio-economic factors in health care. Hollingshead and Redlich in Social Class and Mental Illness (1958) described the relationship between social status and treatment for mental illness. The facilities, services rendered, and type of medical care were all influenced by the socio-status of a patient in the community. Antonovsky (1967), Goldscheider (1971) and Mechanic (1978) described socio-demographic effects on mortality and morbidity, noting that non-whites of lower classes die at a younger age and of different diseases than their white counterparts. Sudnow (1967) in his description of death and the social worth of corpses noted the "strong relationship between the age, social backgrounds, and perceived moral character of the patients and the amount of effort which is made to attempt revival when 'clinical death signs' are detected."

The findings of these and other researchers regarding relationship between the socio-economic status of a patient and their care appear to hold true in the area of hospice care. By and large, dying patients in hospice programs are white, middle class and have some college education. Studies by Vincent Mor, Sylvia Sherwood, Howard Birnbaum, et al (1982) indicate that nationally hospice patients are more than 65 years of age, white (89%), Protestant (41.1%), married (57.4%), have a median income of $10,000 yearly, have at least a high school diploma, and are dying of cancer. There is no sex difference among hospice patients.

The findings of the national studies raise questions regarding the development of hospice as a program of dying for a certain class of the population. Questions for future research include: (1) Have other health care programs, such as home birth, been class-related? (2) Are there racial differences in care for the dying that render hospice programs unnecessary for non-white populations? (3) What factors motivate the use or non-use of hospice and other forms of health care by socio-economic groups? Do these differences exist in other countries (such as England, Sweden, France) with nationalized health services?

These suggestions for research may illuminate the specific problem of the social inequality which seems to be present in the treatment of the dying and may suggest alternative solutions for diminishing such inequalities.

Quality of Patient Care

"Quality of care" is an elusive term. Many writers have tried to define it without success (Donabedian, 1966). Hospice program directors and advocates boast of the "quality of life for the dying" as part of the hospice program's goals. According to these individuals, quality of care for the terminally ill consists of several factors, including freedom from pain, ability to live at home with support of family and friends, assistance in dealing with death and the fear of death. These goals have been identified because of the belief among hospice advocates that the care of the dying in acute care hospitals is inappropriate and that hospital services should be limited to patients being actively treated for a curable illness.

A review of the literature on hospice program development shows no assessment of the quality of care received by patients in a hospice program. There is a wide range of material which describes the services a patient should receive but none which specifies whether or not these services are necessary in order to reach the goals of the program. Further, there has been no in-depth assessment of a hospice program to determine patient outcomes. This is especially difficult since the outcome is death and it is very hard to ask a person--unless you can some how communicate with his or her spirit--how he or she felt about the care given. Some research is currently being conducted on surviving family members which may shed some light on the subject.

It is suggested that a participant-observer investigation be considered. An investigator could participate in the hospice patient care by serving as a volunteer. He or she would have first-hand insights about the care given to the patient, may be able to draw inferences about the patient's satisfaction with the services, and ultimately make a concrete assessment of the concept "quality of care." An investigator may be able to observe first hand, for example if a patient is comfortable dying at home or would prefer to stay in an inpatient facility but is not comfortable asking for a dispensation from the hospice program. The researcher would also be in a position to record the intensive nature of the hospice program and address questions policymakers are asking regarding the benefits of hospice care over traditional health care.

Cost-Benefit Analysis

Hospice promoters claim that costs for caring for terminal patients in hospice programs are far lower than costs of caring for that same patient in the traditional health care system. Studies by Carney (1981), Berger-Friedman (1982), Kassakian et al (1979), Widmer et al (1978), and Creek (1982) suggest that hospice care is indeed cheaper than traditional hospital care. Some of these studies, however, also show that hospice care is more expensive than home health care and, in some cases, skilled nursing home care.

Hospice advocates contend that there is an overall cost savings of the hospice program since most terminal patients spend their last few weeks in a hospital because the family is unable to care for them at home.[1] With the support of hospice personnel, a patient is able to remain in his or her home until death and the family receives the support it needs to assist the patient.

Since data on hospice costs have been collected during the past two years--Health Care Financing Administration (HCFA) demonstration projects and work by individual researchers are the primary data sources--it is important to conduct other assessments after Medicare regulations are in effect and additional third-party payers offer hospice as a covered benefit. Will costs remain the same? What will be the new exchange relationships established between hospice programs and other health care providers? Will these new relationships affect the costs for care? Will the degree of integration (high, moderate, or none) influence costs of care? Will services change as Medicare and other third party insurers pay for hospice care? How does this interface with the questions of quality of care? These are just some of the questions which should be considered in future research endeavors.

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[1] A recent study by Blue Cross/Blue Shield, funded by the Department of Health and Human Services shows that the average cost for health care for a terminally ill cancer patient during his or her last six months of life is almost $16,000. Of the $16,000, 78 percent is for hospital expenditures, 16 percent is for physician's costs and less than one percent is for home care or skilled nursing facilities.

Death and the family. The focus of modern medical care has been the patient and the institution with a goal of curing the patient (Lerner, 1970). The vast majority of health care resources are allocated along these dimensions. In 1981, for example, hospital care costs totalled $118 billion or 46.3 percent of all health care expenditures (American Medical Association, 1982).

The pivotal role of home health care for dying patients is an important aspect of the hospice program. A complex of social, familial and residential changes in the past several decades have militated against dying at home. The change of locus of physician care from home to hospital, with the resultant decrease of availability of home medical care, has created a tendency to move seriously ill and dying patients into hospital or nursing home settings. In addition, home care requires the willingness and ability of a family member or members to become primary care-giver(s), with the physician, visiting nurse and other personnel as back-up support. The absence of a consistent and competent family agent makes home care virtually impossible (Krank, 1978).

The movement back to the home as a place for birth and death may alter family structure. Support systems, previously determined through institutional relationships, will be developed through extended family ties. There may be a reassessment of the family structure as members negotiate who will be the primary care-giver(s). The development of the hospice concept may provide an impetus for a reassessment of our family system. If people are successful and fulfilled in the process of caring for their loved ones at home, they may also begin to reassess other systems (such as education) which place the major responsibility for the development of a child outside the home.

The hospice movement provides opportunities for further research in this area. It allows us to examine among other issues the changing family role in the Parsonian sick role analysis, the ability of the family to participate in hospice care requirements, the long-term changes in family life styles and relationships as a result of caring for dying family members, the interactions among patients, families and health care providers, and the changes in attitudes and beliefs about death.

Because the hospice movement is so new, it provides researchers with a wealth of issues to investigate. The five areas described above are a few examples of the type of research in which sociologists can engage. Further work in the area of social movement organization growth, decay and change; integration and co-optation of social movements; division of labor in the treatment of the dying; professionalization of health care providers; and the re-involvement of the church in the provision of health care[1] are other examples of ideas for future research.

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[1] Church involvement in the care for the dying is specifically sanctioned in the proposed Medicare regulations which includes "spiritual services" as a form of counseling (Section 418.88). Counseling services are mandated under the proposed regulations. Perlstadt, in a conversation with the researcher, suggested that hospice may, in fact, be an expression of a "return to religion." He noted, "We've had different stages of social expression in our society. In the 1930s people 'dropped out' of society and became boxcar bums, in the 1940s people 'dropped out' because of World War II, in the 1950s you had the bohemians, in the 1960s you had political 'dropouts,' in the 1970s there was communal sexual orientation, in the 1980s there are the religious dropouts (e.g. Moonies). This is an example of the return to religion, return to the spiritual. You can see this spiritual movement in the development of hospice programs. Just look at the influence of the clergy in hospice development. It's a way the clergy are gaining control over people's lives. . . in a sense taking it away from the medical establishment."

Glossary

Bereavement care: The period of time during which a person or group of people experiences, responds emotionally to, and adjusts to the loss of another person through death.

Home health agency: An agency which coordinates nursing and related health care services to patients in their homes.

Hospice: A centrally administered program of palliative and supportive services which provides physical, psychological, social and spiritual care for dying persons and their families. Services are provided by a medically supervised interdisciplinary team of professionals and volunteers. Hospice services are available in both the home and an in-patient setting. Home care is provided on a part-time, intermittent, regularly scheduled, and round-the-clock basis. Bereavement services are available to the family. Admission to a hospice program of care is on the basis of patient and family need (National Hospice Organization, Hospice Standards Draft #6)

Types of hospice programs (National Hospice Organization, Final Report, September 1979)

1. Hospital Based
    a. Acute care hospital with centralized palliative care or hospice unit: Separate unit within a general hospital with the staff and beds designated for the provision of care for the dying.

b. Acute care hospital with consultant program: Specially designated interdisciplinary hospice team or existing staff of social workers, psychologists, and others provide services to hospice patients dispersed throughout the general hospital.

c. Hospital-based home care program: The hospice team may be separate from the home care staff or may be members of the home care staff with special training in hospice care techniques.

2. Hospital-affiliated free-standing

A separate facility with all beds and staff assigned to providing care to the dying patient. The facility is located adjacent to the hospital or in the community but is owned by the hospital.

3. (Independent) free-standing

A separate facility with all beds and staff assigned to providing care to the dying patient. It is an independent economic entity governed by its own administrative staff and board.

4. Home care (hospice without walls)

A program which provides and coordinates hospice services in the home, but does not own or operate an in-patient facility. The program is administratively and economically autonomous. Hospice team members are available for services in the home 24 hours a day.

5. Extended care facility or nursing home

A nursing home or extended care facility program which has converted beds or established a separate unit for the provision of hospice care. Staff is trained in the provision of hospice care. The facility is governed by its own board and administrative staff.

Interdisciplinary health care team: A group consisting of a physician, nurse, social worker, clergy, volunteer and members of related disciplines who interrelate in an effective working relationship enabling the provision of hospice services to patients and families.

Terminal care: The management of symptoms, provision of comfort measures and support of persons in whom death is certainly not too far off.

Terminal patient: A dying person for whom active therapy is determined to be ineffective for cure or control of disease or is deemed undesirable by patient and/or family. The life expectancy is in terms of weeks or months.

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APPENDICES

Text of the Tax Equity and Fiscal Responsibility Act of 1982

PART II—CHANGES IN BENEFITS, PREMIUMS, AND ENROLLMENT

MEDICARE COVERAGE OF FEDERAL EMPLOYEES

SEC. 121. For provisions providing certain employees of the United States and instrumentalities thereof with entitlement to hospital insurance benefits under part A of title XVIII of the Social Security Act, see section 278 of this Act.

Ernst & Whinney Comments

Summary: *This provision extends Medicare coverage to federal employees and makes them subject to Social Security hospital insurance taxes.*

Effective Date: *January 1, 1983.*

Implications: *This provision seeks to provide a more equitable situation for individuals in the private sector who pay FICA taxes. Prior to this new law, federal employees could secure jobs in the private sector for a short period of time after retirement and thus be eligible for Medicare coverage.*

To the extent that this is true, hospitals may not experience significantly increased numbers of Medicare patients; however, the increased revenues from these new taxes should help the financial condition of the Hospital Insurance Trust Fund.

HOSPICE CARE

SEC. 122. (a)(1) Section 1811 of the Social Security Act is amended by striking out "and home health services" and inserting in lieu thereof "home health services, and hospice care".

(2) Section 7(d)(1) of the Railroad Retirement Act of 1974 is amended by inserting "hospice care," after "home health services,".

(b)(1) Section 1812(a) of the Social Security Act is amended by striking out "and" at the end of paragraph (2), by striking out the period at the end of paragraph (3) and inserting in lieu thereof "; and", and by adding after paragraph (3) the following new paragraph:

> *"(4) in lieu of certain other benefits, hospice care with respect to the individual during up to two periods of 90 days each and one subsequent period of 30 days with respect to which the individual makes an election under subsection (d)(1).".*

(2) Section 1812 of such Act is further amended by inserting after subsection (c) the following new subsection:

"(d)(1) Payment under this part may be made for hospice care provided with respect to an individual only during two periods of 90 days each and one subsequent period of 30 days during the individual's lifetime and only, with respect to each such period, if the individual makes an election under this paragraph to receive hospice care under this part provided by, or under arrangements made by, a particular hospice program instead of certain other benefits under this title.

"(2)(A) Except as provided in subparagraphs (B) and (C) and except in such exceptional and unusual circumstances as the Secretary may provide, if an individual makes such an election for a period with respect to a particular hospice program, the individual shall be deemed to have waived all rights to have payment made under this title with respect to—

> *"(i) hospice care provided by another hospice program (other than under arrangements made by the particular hospice program) during the period, and*

Summary: *Beneficiaries of the Medicare Part A program may opt to receive hospice care instead of certain other benefits associated with treatment of terminal cancer. The benefit period consists of two periods of 90 days and one period of 30 days during the individual's lifetime.*

When an individual elects a particular hospice program, he waives his right to care under other hospice programs and to other services normally provided under the Medicare program. His physician's services will still be covered, however. An individual is entitled to one change in hospice program election in each period without forfeiting benefits.

If, during a 90-day period, an individual elects hospice care and then changes his mind, no payment will be made for the balance of the period.

To be eligible for hospice care, the individual's physician and the medical director of the hospice program must certify that the individual is terminally ill (i.e., has a life expectancy of six months or less) and must prepare a written plan for that individual's care. Reimbursement will be made to a hospice program based on reasonable cost. Bereavement counseling will not be an allowable cost item.

"(ii) services furnished during the period that are determined (in accordance with guidelines of the Secretary) to be—

"(I) related to the treatment of the individual's condition with respect to which a diagnosis of terminal illness has been made or

"(II) equivalent to (or duplicative of) hospice care;

except that clause (ii) shall not apply to physicians' services furnished by the individual's attending physician (if not an employee of the hospice program) or to other than services provided by (or under arrangements made by) the hospice program.

"(B) After an individual makes such an election with respect to a 90- or 30-day period, the individual may revoke the election during the period, in which case—

"(i) the revocation shall act as a waiver of the right to have payment made under this part for any hospice care benefits for the remaining time in such period and (for purposes of subsection (a)(4) and subparagraph (A)) the individual shall be deemed to have been provided such benefits during such entire period, and

"(ii) the individual may at any time after the revocation execute a new election for a subsequent period, if the individual otherwise is entitled to hospice care benefits with respect to such a period.

"(C) An individual may, once in each such period, change the hospice program with respect to which the election is made and such change shall not be considered a revocation of an election under subparagraph (B).

"(D) For purposes of this title, an individual's election with respect to a hospice program shall no longer be considered to be in effect with respect to that hospice program after the date the individual's revocation or change of election with respect to that election takes effect.".

(c)(1) Section 1814(a) of the Social Security Act is amended by striking out "and" at the end of paragraph (6), by striking out the period at the end of paragraph (7) and inserting in lieu thereof "; and", and by inserting after paragraph (7) the following new paragraph:

"(8) in the case of hospice care provided an individual—

"(A)(i) in the first 90-day period—

"(I) the individual's attending physician (as defined in section 1861(dd)(3)(B)), and

"(II) the medical director (or physician member of the interdisciplinary group described in section 1861(dd)(2)(B)) of the hospice program providing (or arranging for) the care,

each certify, not later than two days after hospice care is initiated, that the individual is terminally ill (as defined in section 1861(dd)(3)(A)), and

"(ii) in a subsequent 90- or 30-day period, the medical director or physician described in clause (i)(II) recertifies at the beginning of the period that the individual is terminally ill;

"(B) a written plan for providing hospice care with respect to such individual has been established (before such care is provided by, or under arrangements made by, that hospice program) and is periodically reviewed by the individual's attending physician and by the medical director (and the interdisciplinary group described in section 1861(dd)(2)(B)) of the hospice program; and

"(C) such care is being or was provided pursuant to such plan of care.".

(2)(A) Section 1814(b) of such Act is amended by inserting "(other than a hospice program providing hospice care)" after "The amount paid to any provider of services".

The amount of payment made to a hospice program for each patient will be "capped" according to the region in which it is located. The "cap amount" will be determined based on a national average of Medicare per capita expenditure amounts, which is then adjusted for regional differences in the cost of care. For each region, the "cap amount" is equal to 40% of the regional average, adjusted by the medical care expenditure component of the CPI.

Hospice services include the following:

a. nursing care,

b. physical and occupational therapy, speech-language pathology,

c. medical social services,

d. home health aide services,

e. medical supplies (including drugs and biologicals),

f. physicians' services,

g. short-term inpatient care, not to exceed five consecutive days, and

h. counseling for the terminally ill individual.

A hospice program is a public or private organization which:

a. Makes these services available on a 24-hour basis:

1. Provides the services identified above in the patient's home, and on an inpatient and outpatient basis;

2. Provides nursing, medical social services, physician services and counseling directly;

3. Assures the Secretary that the total number of inpatient days of care provided Medicare hospice beneficiaries in any 12-month period does not exceed 20% of the total days of hospice care during that 12-month period;

4. Provides bereavement counseling for family members.

b. Has an interdisciplinary group of personnel.

c. Maintains central clinical records on all patients.

(B) Section 1814 of such Act is further amended by adding at the end the following new subsection:

"Payment for Hospice Care

"(i)(1) Subject to the limitation under paragraph (2) and the provisions of section 1813(a)(4), the amount paid to a hospice program with respect to hospice care for which payment may be made under this part shall be an amount equal to the costs which are reasonable and related to the cost of providing hospice care or which are based on such other tests of reasonableness as the Secretary may prescribe in regulations (including those authorized under section 1861(v)(1)(A)), except that no payment may be for bereavement counseling and no reimbursement may be made for other counseling services (including nutritional and dietary counseling) as separate services.

"(2)(A) The amount of payment made under this part for hospice care provided by (or under arrangements made by) a hospice program located in a region (as defined by the Secretary) for an accounting year may not exceed the 'cap amount' for the region for the year (computed under subparagraph (B)) multiplied by the number of medicare beneficiaries in the hospice program in that year (determined under subparagraph (C)).

"(B) For purposes of subparagraph (A), the 'cap amount' for a region for a year is computed as follows:

"(i) The Secretary, using records of the program under this title, shall identify individuals (or a representative sample of such individuals)—

"(I) who died during the base period (as defined in clause (v)),

"(II) with respect to whom the primary cause of death was cancer, and

"(III) who, during the six-month period preceding death, were provided benefits under this title.

"(ii) The Secretary shall determine a national average medicare per capita expenditure amount by (I) determining (or estimating) the amount of payments made under this title with respect to services provided to individuals identified in clause (i) during the six months before death, and (II) dividing such amount of payments by the number of such individuals.

"(iii) The Secretary, using the best available data, shall then compute a regional average medicare per capita expenditure amount for each region, by adjusting the national average medicare per capita expenditure amount (computed under clause (ii)) to reflect the relative difference between that region's average cost of delivering health care and the national average cost of delivering health care.

"(iv) The 'cap amount' for a region for an accounting year is 40 percent of the regional average determined under clause (iii) for that region, increased or decreased by the same percentage as the percentage increase or decrease, respectively, in the medical care expenditure category of the consumer price index for all urban consumers (U.S. city average), published by the Bureau of Labor Statistics, from the fourth month of the base period to the fifth month of the accounting year.

"(v) For purposes of this subparagraph, the term 'base period' means the most recent period of 12 months (ending before the date proposed regulations are first issued to carry out this paragraph) for which the Secretary determines he has sufficient data to make the determinations required under clauses (i) through (iii).

d. Does not discontinue needed care based on inability to pay.

e. Uses volunteers.

f. Is licensed under applicable state law.

Beneficiaries receiving hospice care will be required to pay coinsurance in the amount of:

1. The lesser of $5 or 5% of the charge per prescription.

2. The home health copayment amount, beginning with the 20th visit for home health aide services.

3. Five percent of the reasonable cost of respite care, not to exceed the cost of the inpatient hospital deductible.

Current demonstration programs relating to hospice care will be continued until December 31, 1983. Prior to January 1, 1986 the Secretary will submit a report to Congress on the experience of hospice care reimbursement of the past two years.

Hospices in operation prior to January 1, 1975 may be granted exceptions to certain limitations if the Secretary deems it necessary.

Regulations regarding hospice care, standards of qualification and payment will be developed by September 1, 1983.

Effective Date: *Applies to hospice care provided on or after January 1, 1984 and prior to September 30, 1986.*

Estimated Savings Impact
on the Federal Budget:

Fiscal Years		
1983	*1984*	*1985*
$ (1m)	*$ (1m)*	*$ 16m*

Since this provision does not become effective until January 1, 1984, the estimated increased outlays in fiscal years 1983 and 1984 represent the costs associated with developing the methodology and start-up. The estimated savings in fiscal year 1985 will result as beneficiaries opt for hospice care in lieu of costlier inpatient services.

Text of the Tax Equity and Fiscal Responsibility Act of 1982

"(C) For purposes of subparagraph (A), the 'number of medicare beneficiaries' in a hospice program in an accounting year is equal to the number of individuals who have made an election under subsection (d) with respect to the hospice program and have been provided hospice care by (or under arrangements made by) the hospice program under this part in the accounting year, such number reduced to reflect the proportion of hospice care that each such individual was provided in a previous or subsequent accounting year or under a plan of care established by another hospice program.".

(2) Section 1816(e) of such Act is amended by adding at the end thereof the following new paragraph:

"(5) Notwithstanding any other provision of this title, the Secretary shall designate the agency or organization which has entered into an agreement under this section to perform functions under such an agreement with respect to each hospice program, except that with respect to a hospice program which is a subdivision of a provider of services (and such hospice program and provider of services are under common control) due regard shall be given to the agency or organization which performs the functions under this section for the provider of services.".

(c)(1) Section 1861(u) of the Social Security Act is amended by inserting "hospice program," after "home health agency,".

(2) Section 1861(w)(1) of such Act is amended by striking out "or home health agency" and by inserting in lieu thereof "home health agency, or hospice program".

(3) Section 1861 of such Act is further amended by adding at the end the following new subsection:

"Hospice Care; Hospice Program

"(dd)(1) The term 'hospice care' means the following items and services provided to a terminally ill individual by, or by others under arrangements made by, a hospice program under a written plan (for providing such care to such individual) established and periodically reviewed by the individual's attending physician and by the medical director (and by the interdisciplinary group described in paragraph (2)(B)) of the program—

"(A) nursing care provided by or under the supervision of a registered professional nurse,

"(B) physical or occupational therapy or speech-language pathology,

"(C) medical social services under the direction of a physician,

"(D)(i) services of a home health aide who has successfully completed a training program approved by the Secretary and (ii) homemaker services,

"(E) medical supplies (including drugs and biologicals) and the use of medical appliances, while under such a plan,

"(F) physicians' services,

"(G) short-term inpatient care (including both respite care and procedures necessary for pain control and acute and chronic symptom management) in an inpatient facility meeting such conditions as the Secretary determines to be appropriate to provide such care, but such respite care may be provided only on an intermittent, nonroutine, and occasional basis and may not be provided consecutively over longer than five days, and

"(H) counseling (including dietary counseling) with respect to care of the terminally ill individual and adjustment to his death.

The care and services described in subparagraphs (A) and (D) may be provided on a 24-hour, continuous basis only during periods of crisis (meeting criteria established by the Secretary) and only as necessary to maintain the terminally ill individual at home.

Ernst & Whinney Comments

Implications: *Currently, certain hospitals, nursing homes and home health agencies are reimbursed when they provide hospice-type services. Providers such as these may want to consider establishing qualified hospice programs if there is a need for hospice services in their area. To be reimbursed, providers must file a separate cost report.*

Recognition of the benefits of hospice care to many terminally ill patients has prompted this section of the law. Nevertheless, organizations providing this type of care must consider several limitations. Among the more important—inpatient care for Medicare hospice beneficiaries cannot exceed 20% of total hospice days; reimbursement is at only 40% of the regional average cost of care (adjusted by the CPI); and the benefit is limited to a total of 210 days.

Hospices will have to carefully monitor costs to avoid exceeding the caps. Hospitals may experience some decline in utilization if man Medicare beneficiaries opt for hospice care.

ATTACHMENT 2

Act No. 293
Public Acts of 1980
Approved by Governor
October 17, 1980

STATE OF MICHIGAN
80TH LEGISLATURE
REGULAR SESSION OF 1980

Introduced by Reps. Hollister, Forbes, Bryant, Spaniola, McNeely, Burkhalter, Conroy, Barcia, Bullard, Mary C. Brown, Stabenow, Morris Hood, Jr., Thomas H. Brown, Ryan, Harrison, Joe Young, Jr., Henry, Trim, Padden, Evans, Scott, Tomboulian, Jondahl, Gingrass, Hertel, Dongvillo, Gilmer, Campbell, Nick Smith, McNamee, Hadden, O'Neill, Welborn, Hillegonds, Brotherton, Ballantine, Cramton and Nash

ENROLLED HOUSE BILL No. 4909

AN ACT to amend section 20106 of Act No. 368 of the Public Acts of 1978, entitled "An act to protect and promote the public health; to codify, revise, consolidate, classify, and add to the laws relating to public health; to provide for the prevention and control of diseases and disabilities; to provide for the classification, administration, regulation, financing, and maintenance of personal, environmental, and other health services and activities; to create or continue, and prescribe the powers and duties of, departments, boards, commissions, councils, committees, task forces, and other agencies; to prescribe the powers and duties of governmental entities and officials; to regulate occupations, facilities, and agencies affecting the public health; to promote the efficient and economical delivery of health care services, to provide for the appropriate utilization of health care facilities and services, and to provide for the closure of hospitals or consolidation of hospitals or services; to provide for the collection and use of data and information; to provide for the transfer of property; to provide certain immunity from liability; to provide for penalties and remedies; and to repeal certain acts and parts of acts," being section 333.20106 of the Compiled Laws of 1970; and to add part 214.

The People of the State of Michigan enact:

Section 1. Section 20106 of Act No. 368 of the Public Acts of 1978, being section 333.20106 of the Compiled Laws of 1970, is amended and part 214 is added to read as follows:

Sec. 20106. (1) "Health facility or agency", except as provided in section 20115, means:

(a) Ambulance operation or advanced mobile emergency care service.

(b) Clinical laboratory.

(c) County medical care facility.

(d) Freestanding surgical outpatient facility.

(e) Health maintenance organization.

(f) Home for the aged.

(g) Hospital.

(h) Nursing home.

(i) Hospice.

(j) A facility or agency listed in subdivisions (a) to (h) located in a correctional institution or a university, college, or other educational institution.

(2) "Health maintenance organization" means a health facility or agency that:

(a) Delivers health maintenance services to enrollees under the terms of its health maintenance contract, directly or through arrangements with affiliated providers.

(b) Is responsible for the availability, accessibility, and quality of the health maintenance services provided.

(3) "Home for the aged" means a supervised personal care facility, other than a hotel, adult foster care facility, hospital, nursing home, or county medical care facility, that provides room, board, and supervised personal care to 7 or more unrelated, nontransient, individuals 55 years of age or older.

(4) "Hospice" means a health care program which provides a coordinated set of services rendered at home or in outpatient or institutional settings for individuals suffering from a disease or condition with a terminal prognosis.

(5) "Hospital" means a facility offering inpatient, overnight care, and services for observation, diagnosis, and active treatment of an individual with a medical, surgical, obstetric, chronic, or rehabilitative condition requiring the daily direction or supervision of a physician. The term does not include a hospital licensed or operated by the department of mental health.

(6) "Hospital long-term care unit" means a nursing care facility, owned and operated by and as part of a hospital, providing organized nursing care and medical treatment to 7 or more unrelated individuals suffering or recovering from illness, injury, or infirmity.

PART 214. HOSPICES

Sec. 21401. Article 1 contains general definitions and principles of construction applicable to all articles in this code and part 201 contains definitions applicable to this part.

Sec. 21411. (1) A hospice shall be licensed under this article.

(2) "Hospice" shall not be used to describe or refer to a health program, facility, or agency unless that program, facility, or agency is licensed as a hospice by the department under this article.

(3) A hospital, nursing home, home for the aged, county medical care facility, or any other health facility or agency which operates a hospice shall be licensed as a hospice under this article.

(4) If a hospice provides inpatient services which meet the definition of a hospital, nursing home for the aged, county medical care facility, or any other health facility or agency the hospice shall obtain a separate license as required under this article for that hospital, nursing home, home for the aged, county medical care facility, or other health facility or agency.

(5) This part shall not restrict any activity of a health facility or agency if the activity is permitted under the license held by that health facility or agency.

(6) If separate licensure is required under this section, the department shall conduct inspections and issue the required licenses concurrently.

Sec. 21413. The owner, operator, and governing body of a hospice licensed under this article:

(a) Are responsible for all phases of the operation of a hospice and for the quality of care and services rendered by the hospice.

(b) Shall cooperate with the department in the enforcement of this part, and require that the physicians and other personnel working in the hospice and for whom a license or registration is required be currently licensed or registered.

Sec. 21415. (1) A hospice shall provide a program of planned and continuous hospice care, the medical components of which shall be under the direction of a physician.

(2) Hospice care shall consist of a coordinated set of services rendered at home or in outpatient or institutional settings for individuals suffering from a disease or condition with a terminal prognosis. The coordination of services shall assure that the transfer of a patient from 1 setting to another will be accomplished with a minimum disruption and discontinuity of care. Hospice services shall address the physical, psychological, social, and spiritual needs of the individual and shall be designed to meet the related needs of the individual's family through the periods of illness and bereavement. These hospice services shall be provided through a coordinated interdisciplinary team which may also include services provided by trained volunteers.

Sec. 21417. An individual shall not be admitted to or retained for care by a hospice unless the individual is suffering from a disease or condition with a terminal prognosis. An individual shall be considered to have a disease or condition with a terminal prognosis if, in the opinion of a physician, the individual's death is anticipated within 6 months after the date of admission to the hospice. The fact that a person lives beyond a 6-month or less prognosis shall not disqualify the person from continued hospice care.

Sec. 21419. (1) Not later than 1 year after the effective date of this part, the department shall submit for a public hearing proposed rules necessary to implement and administer this part.

(2) The rules promulgated pursuant to subsection (1) shall not establish standards related to the credentials of an individual providing care in a hospice program, whether as an employee of a program or volunteer in a program, unless, with respect to the type of care the individual would provide in the hospice program, a license or other credential is required by law for an individual providing that care.

Sec. 21420. Notwithstanding any other provision of this act, all hospices shall be exempt from license fees for 3 years after the first hospice is licensed under this article.

Sec. 21421. This part shall expire 7 years after its effective date.

T. Thos. Thatcher

Clerk of the House of Representatives.

Secretary of the Senate.

Approved ______________________

____
Governor.

Sec. 21721. (1) Before issuance of a nursing home license under this article, the owner, operator, or governing body of the nursing home shall give a bond with a surety approved by the department if the nursing home elects to set up patient trust funds. The bond shall insure the department for the benefit of the patients. The bond shall be conditioned that the applicant shall do all of the following:

(a) Hold separately and in trust all patient funds deposited with the applicant.

(b) Administer the funds on behalf of the patient in the manner directed by the depositor.

(c) Render a true and complete account to the patient, the depositor, and the department when requested.

(d) Account for the funds received, expended, and held on hand on termination of the deposit.

(2) The bond shall be in an amount equal to not less than 1-1/4 times the average balance of patient funds held during the previous year. The department may require an additional bond, or permit the filing of a bond in a lower amount, if the department determines a change in the average balance has occurred or may occur. An applicant for a new license shall file a bond in an amount which the department estimates as 1-1/4 times the average amount of patient funds which the applicant, upon the issuance of the license, is likely to hold during the first year of operation.

Sec. 21731. A licensee of a nursing home operated for profit is considered to be the consumer, and not the retailer, of the tangible personal property purchased and used or consumed in the operation of the home.

Sec. 21733. (1) A nursing home licensed under this article shall adopt a policy regulating the smoking of tobacco on the nursing home premises.

(2) A nursing home policy governing smoking shall at a minimum provide that:

(a) Upon admission each patient or person responsible for the patient's admission shall be asked if there is a preference for placement with smokers or nonsmokers.

(b) Smoking by patients shall be restricted to private rooms, rooms shared with other smokers only, or other designated smoking areas.

(c) Visitors shall not be permitted to smoke in rooms or wards occupied by patients who do not smoke.

(d) Visitors shall be permitted to smoke only in designated areas.

(e) Staff shall be permitted to smoke in designated areas only.

(f) Staff shall not be permitted to smoke in patients' rooms or while performing their duties in the presence of patients.

(g) Eating areas shall have sections for smokers and nonsmokers.

(h) Cigarettes, cigars, and pipe tobacco shall not be sold or dispensed within the licensed facility except as provided for by the owner or governing board.

(i) A sign indicating that smoking is prohibited in the facility except in designated areas shall be posted at each entrance to the facility. Each designated smoking area shall be posted as such by sign.

(3) A nursing home licensed under this article shall retain a copy of the smoking policy which will be available to the public upon request.

APPENDIX 3

PART 221. CERTIFICATES OF NEED

Sec. 22101. (1) For purposes of this part, the words and phrases defined in sections 22102 to 22108 have the meanings ascribed to them in those sections.

(2) In addition, article 1 contains general definitions and principles of construction applicable to all articles in this code.

(3) The definitions in part 201 do not apply to this part.

Sec. 22102. (1) "Addition" means adding patient rooms or beds, ancillary service areas, or other accommodations to a health facility.

(2) "Capital expenditure" means an expenditure for a single project which exceeds $150,000.00 including cost of construction, engineering, and fixed equipment which under generally accepted accounting principles is not properly chargeable as an expense of operation. It includes a lease or comparable arrangement by or on behalf of a facility by which a person obtains a health facility or licensed part thereof or equipment for a facility, the expenditure for which would have been considered a capital expenditure under this part if the person had acquired it by purchase. It includes cost of studies, surveys, designs, plans,

replacement, and renovation of an existing building and initial equipment and the replacement of obsolete equipment in an existing building. It does not include normal maintenance and operational expenses.

(2) "New construction" means construction of a health facility where a health facility does not exist or construction replacing an existing health facility.

(3) "Organized ambulatory health care facility" means a facility other than a physician's private office that provides medical care on an organized basis to patients not requiring hospitalization and that is not part of a hospital but is organized and operated to provide medical care to outpatients. The department may promulgate rules to differentiate an organized ambulatory health care facility from a private office of a practicing physician, dentist, podiatrist, or other private practice office.

(4) "Person" means a person as defined in section 2106 or a governmental entity.

Sec. 22105. (1) "Secretary" means the United States secretary of health, education, and welfare.

(2) "State agency" means the state health planning and development agency designated pursuant to section 1521 of title 15 of the public health services act, 42 U.S.C. 300m.

(3) "Subarea" means the health facility service area defined by the department.

(4) "Tertiary health care service facility" means a facility that provides services for patients referred by a physician for diagnostic tests and that reports findings to the referring physician. It does not include a facility operated by an individual or individuals licensed to practice medicine, osteopathic medicine and surgery, dentistry, or podiatry who perform tests or procedures personally or through their employees solely as an adjunct to treatment of the licensee's patients.

Sec. 22111. A certificate of need program shall be established and shall:

(a) Provide for review and determination of need before new institutional health services, facilities, and organizations are offered or developed or substantial expenditures are undertaken in preparation for the offering or development.

(b) Provide that only needed services, facilities, and organizations shall be offered or developed in this state.

(c) Meet the policies and procedures governing the issuance of certificates of need required for projects under federal grant-in-aid programs and federal loan guarantee programs. Puff

Sec. 22113. (1) Except as provided by this part and rules promulgated under this part, a person shall not begin operation of a new health facility, make a change in bed capacity, make a change in service, or undertake a capital expenditure for the construction, conversion, addition to, or modernization in excess of $150,000.00 of a health facility or make a commitment for financing the offering or development of a new institutional health service without first obtaining a certificate of need which documents a demonstrated need and grants permission for the proposed project.

(2) Except as provided in section 22102(4)(b), a certificate of need is not required for a health facility to reduce its scope of services or bed capacity.

(3) Recommendations made by the health systems agency and decisions made by the department under the certificate of need program shall specify approval of the application, disapproval of the application, or approval of the application with conditions, if the conditions are explicit and the conditions specify a time, not to exceed 1 years, by which the conditions shall be met. Before issuing a certificate of need with conditions, the department shall provide the appropriate health systems agency with a list of the proposed conditions for review.

clarify

(4) A certificate of need shall not be required for a change in service in a facility defined in section 22105(3).

Sec. 22121. (1) The council and the state agency shall:

(a) Approve proposed rules for the administration of the certificate of need program established under this part.

(b) Advise on administration of the certificate of need program, the administration of Act No. 299 of the Public Acts of 1947, as amended, being sections 331.501 to 331.516 of the Michigan Compiled Laws, and the requirements of the hospital and medical facilities amendments of 1954, 42 U.S.C. 291 to 291o.

(c) Biennially conduct a review and prepare a written evaluation of the certificate of need program including recommendations considered appropriate by the council.

(d) Assist the department in other related matters as it reasonably requests.

(2) The certificate of need board is created in the department. The certificate of need board shall

working drawings, specifications, and other activities essential to the acquisition, improvement, expansion, addition, conversion, modernization, new construction, or replacement of physical plant and equipment.

(3) "Certificate of need" means a certificate attesting to need of a new health facility, change in bed capacity, change in service, or capital expenditure by or for a health facility issued in accordance with this part.

(4) "Change in bed capacity" means either of the following:

(a) An increase of licensed bed capacity of a health facility.

(b) A redistribution of beds which does not result in a reduction in licensed bed capacity, but which, with respect to hospitals, does result in an increase or decrease in beds in an obstetrical department, long term care unit, or psychiatric unit.

(5) "Change in service" means health services which are offered in or through a health facility and which were not offered on a regular basis in or through that health facility within the 12-month period before the time the services would be offered.

(6) "Consumer", except as provided in section 22131, means a person who is not a provider of health care as defined in section 1531(3) of title 15 of the public health services act, 42 U.S.C. 300n.

(7) "Conversion" means converting an existing building not previously licensed as a health facility to such use or converting of an area of any other institution to health facility use or converting the facility from one licensed use to another licensed use.

(8) "Council" means the state health coordinating council designated pursuant to section 1524 of title 15 of the public health services act, 42 U.S.C. 300m-3.

Sec. 22104. (1) "Health facility" means:

(a) A facility or agency licensed or authorized under parts 201 to 217, or a licensed part thereof, except a facility or agency licensed under part 203.

(b) A mental hospital, psychiatric hospital, psychiatric unit, or mental retardation facility operated by the department of mental health or certified or licensed under Act No. 258 of the Public Acts of 1974, as amended, being sections 330.1001 to 330.2106 of the Michigan Compiled Laws.

(c) A facility providing outpatient physical therapy services, including speech pathology services.

(d) A kidney disease treatment center, including a freestanding hemodialysis unit.

(e) An organized ambulatory health care facility.

(f) A tertiary health care service facility. Sec 22101

(g) A substance abuse treatment program offering inpatient treatment, to be included for certificate of need 2 years after the effective date of this code.

(h) An outpatient psychiatric clinic.

(i) A home health agency. This subparagraph shall not be effective until home health agencies are licensed in this state.

(2) For the purposes of this part, "health facility" does not mean any of the following:

(a) An institution conducted by and for the adherents of a church or religious denomination for the purpose of providing facilities for the care and treatment of the sick who depend solely upon spiritual means through prayer for healing.

(b) A health facility or agency located in a correctional institution.

(c) A veterans facility operated by the state or federal government.

(3) "Health systems agency" means a health system agency designated pursuant to section 1512 of title 15 of the public health services act, 42 U.S.C. 300-1.

(4) "Home health agency" means an agency that provides to individuals, in their places of residence other than in a hospital, nursing home, or county medical care facility, registered nurse services and 1 or more of the following services: nursing services by individuals other than registered nurses, therapeutic services, social work services, homemaker services, home health aide services, or other related services.

(5) "Hospital", for purposes of sections 22136 to 22155 only, means a hospital as regulated under part 215, but shall not include a veterans facility operated by the state or federal government.

(6) "Institutional health services" means health services provided in or through health facilities and includes the entities in or through which the services are provided.

Sec. 22106. (1) "Modernization of the physical plant" means a major upgrading, alteration, or change in function of a part or area of a health facility. It includes the alteration, expansion, major repair, remodeling, consist of 5 members appointed by the governor with the advice and consent of the senate. The members shall serve for a term of 4 years, except that of the members first appointed, 2 shall serve for a term of 4 years, 1 for 3 years, 1 for 2 years, and 1 for 1 year. One of the members shall be a physician licensed under part 170, 1 shall be a physician licensed under part 175, and 3 shall be consumer representatives of the general public. The members shall be paid compensation and reimbursed for expenses as determined annually by the legislature.

(3) A health facility which is not granted a certificate of need upon application may appeal to the certificate of need board. The certificate of need board shall hold a hearing on the appeal within 30 days after the appeal is filed. The hearing shall be conducted pursuant to the administrative procedures act of 1969. If the certificate of need board finds any of the following, it may grant the certificate of need or modify the bed reduction order for that health facility:

(a) The bed reduction plan or the limitation on the number of beds for the health facility is arbitrary and capricious.

(b) The denial of the certificate of need application was arbitrary or not in accordance with law or the appropriate bed reduction plan.

(c) The denial will cause a significant reduction in services by physicians of a particular school of medicine.

Sec. 22123. (1) The state agency and the department shall enter into an agreement under which the department, with the supervision of the state agency, shall develop and administer the state medical facilities plan and administer the state certificate of need program in a manner consistent with the requirements of Public Law 93-641, 42 U.S.C. 217a nt, 229 nt, 291b nt, 300e-4, and 300k to 300t, and this part. The governor shall request that the secretary approve the agreement pursuant to section 1523(b)(1) of title 15 of the public health services act, 42 U.S.C. 300m-2.

(2) The department shall promulgate rules necessary to implement this part. The rules may include:

(a) Requirements for letters of intent to inform appropriate agencies of the nature and scope of proposed construction projects at the earliest possible opportunity in the course of planning the projects.

(b) The form and content of applications for regular, emergency, and nonsubstantive certificates.

(c) Procedures for state and local review of applications for issuance of a certificate of need and modification including time limitations, hearings, periodic reports by applicants, and other requirements necessary under federal law. The administrative demands concerning facility utility services shall not exceed requirements established by federal law.

(d) The duration, modification, and extension of certificates issued under this part.

(3) The department shall promulgate rules to differentiate an outpatient psychiatric clinic from a private office of a practicing physician.

Sec. 22124. Where a health systems agency is not formed or is found incapable of assuming responsibilities for review of certificates of need, the department, with approval by the state agency, may enter into agreements with other appropriate public or private local agencies to review certificate of need applications. The agencies shall have the duties and responsibilities for review of applications described in this part for a health systems agency.

Sec. 22131. (1) In making determinations and conducting reviews for certificates of need, the department and a health systems agency shall apply at least the following criteria:

(a) The relationship of the health care facilities or services being reviewed to the health systems plan and annual implementation plan, if any, for all health services areas to be served.

(b) The relationship of the health care facilities or services being reviewed to the long-range development plan, if any, of the person providing or proposing the facility or service.

(c) The need of the population served or to be served for the health care facilities or services being reviewed.

(d) The feasibility and availability of less costly alternatives or more effective methods of providing the health care facilities or services being reviewed.

(e) The relationship of the health care facilities or services being reviewed to the existing health care system of the health services areas in which the facilities or services are provided or proposed, including the probable impact on the costs of providing health services in the areas served.

(f) In the case of health care facilities or services proposed under a certificate of need or other application, the availability or the potential availability of resources, including health personnel, management personnel, and funds for capital and operating needs for the provision of the facilities or services, and the potential for alternative uses of those resources for the provision of other health care services.

(g) The special needs and circumstances of institutional health care facilities and other entities which provide a substantial part of their services or resources to individuals not residing in the health service areas in which the facilities or other entities are located or in adjacent areas. The entities may include medical and other health professional schools, multidisciplinary clinics, and specialty centers.

(h) The special needs and circumstances of health maintenance organizations and other comprehensive health care programs. The needs and circumstances include the needs of, and costs to, members and projected members of the health maintenance organization in obtaining health services and the potential for a reduction in the use of inpatient care in a community through an extension of preventive health services and the provision of more systematic and comprehensive health services.

(i) In the case of a construction project proposal, the costs and methods of financing the proposed project; the probable impact of the project reviewed on the costs of providing health services by the applicant; and the specific requirements of law for building, zoning, fire, and safety standards and other permits and inspections applicable to the project.

(j) The degree to which the residents and physicians of the immediate community and region affected are provided access to the services and programs of the health facility applying for the certificate of need.

(k) The special needs and circumstances of biomedical and behavioral research projects which are designed to meet a state need and for which local conditions offer special advantages.

(l) That the health facility does not discriminate because of race, religion, color, national origin, age, or sex in its operations including employment, patient admission and care, room assignment, and professional or nonprofessional selection and training programs, and that the health facility governing body does not discriminate in its selection and appointment of individuals to the physician staff of the health facility or its training programs on the basis of licensure or registration or professional education as doctors of medicine, osteopathic medicine and surgery, or podiatry.

(m) That in the case of a nonprofit health facility, the facility is in fact governed by a body composed of a majority consumer membership broadly representative of the population served.

(n) When an application is made for a certificate of need to construct or expand an osteopathic or allopathic facility, the need for that facility on the basis of the need and availability in the community for services and facilities for osteopathic and allopathic physicians, other licensed health care professionals, and their patients and the impact of the application for a certificate of need on existing and proposed institutional training programs for doctors of medicine and osteopathy and other licensed health care professionals at the student, internship, and residency training level. This subdivision shall not be construed to dictate a departure from good health planning principles or to mandate unnecessary duplication of services or facilities.

(2) In order for a certificate of need to be granted to a health facility the following findings shall be made in writing by the department and the health systems agency:

(a) As to the efficiency and appropriateness of the use of existing inpatient facilities providing inpatient services similar to those proposed.

(b) As to the capital and operating costs, and their potential impact on patient charges, efficiency, and appropriateness of the proposed new institutional health service.

(c) That superior alternatives to inpatient services in terms of cost, efficiency, and appropriateness do not exist and that the development of those alternatives is not practical.

(d) That in the case of new construction, such as modernization or sharing arrangements, alternatives to new construction have been considered and have been implemented to the maximum extent practicable.

(e) That patients will experience serious problems in terms of cost, availability, or accessibility, or other problems identified by the reviewing agency in obtaining inpatient care of the type proposed in the absence of the proposed new service.

(f) That in the case of a proposal for the addition of beds for the provision of skilled nursing or intermediate care, the relationship of the addition to the plan of other agencies of the state responsible for providing and financing long-term care has been considered.

(3) In case of a church-sponsored health facility or if the nature of the nonprofit health facility is such that the legal rights of its owners or sponsors might be impaired by a requirement as to the composition of its governing body, an advisory board with majority consumer membership broadly representative of the population served may be construed to be equivalent to the governing board described in subsection (1)(m) if the role assigned to the advisory board is meaningful, its functions are clearly prescribed, and it is given an opportunity to influence policy formulation by the legally recognized governing body.

(4) As used in this section, "consumer" means a person who is not a direct provider as defined in section 1531(3)(A) of title 15 of the public health services act, 42 U.S.C. 300n.

Sec. 22132. In reviewing a request for a certificate for construction of, conversion of, addition to, or modernization of a health facility, including a project to correct a licensing deficiency, approval shall be based on, but not limited to, a demonstrated current and future need for the facility or a part of the facility. The determination of need shall be consistent with the criteria and guidelines published for this purpose in the state medical facilities plan.

Sec. 22135. (1) The department may promulgate rules to govern the application of special needs and circumstances under section 22131(1)(g) and (h). The rules applicable to mental health services shall be submitted to the department of mental health for review and recommendation before promulgation.

(2) The appropriate health systems agency may adopt and shall publish before their application additional criteria to carry out responsibilities under section 22131. Criteria applicable to mental health services shall be submitted to the department of mental health for review and recommendation before adoption. The criteria shall not be inconsistent with this part.

Sec. 22136. In applying for a certificate of need, an applicant shall include a statement addressing each of the criteria established by section 22131.

Sec. 22137. Before issuing a certificate of need, the department shall obtain the following:

(a) From the person applying for the certificate, evidence of the applicant's ability to finance the construction, conversion, addition, or modernization project for which the certificate is requested and ability to finance the operation of the new, converted, added to, or modernized facilities after completion of the construction, conversion, addition, or modernization.

(b) The recommendations submitted by the appropriate health systems agency as to the new institutional health services proposed to be offered within this state. If the department makes a decision inconsistent with the recommendations of the health systems agency, it shall submit to the appropriate health systems agency a detailed statement of the reasons for the inconsistency. The applicant and health systems agency may appeal a departmental decision pursuant to section 22165.

(c) Recommendations submitted by the department of mental health as to new institutional mental health services proposed to be offered within this state.

Sec. 22139. The department shall promulgate rules establishing a formula for certification fees. The rules shall provide that at least 1/2 the cost of implementing this part shall be provided by certificate of need fees.

Sec. 22151. The department, after consultation with the appropriate health systems agency, and as appropriate with the department of mental health, may waive certain otherwise applicable procedural requirements and criteria for review of projects considered nonsubstantive in nature and not warranting full review. The projects may include those meeting an already demonstrated need acceptable to the appropriate health systems agency and the department, if the projects are designed to meet state and local regulations or a full review of the projects could increase the cost by unnecessary delay or require inefficient use of staff review time.

Emergency C/N

Sec. 22152. (1) The department, after consultation with the appropriate health systems agency, and, as appropriate, the department of mental health, may waive otherwise applicable provisions of this part and procedural requirements and criteria for review upon a showing by the applicant, by affidavit or at a public, informal hearing, of all of the following:

(a) The necessity for immediate or temporary relief due to natural disaster, fire, unforeseen safety consideration, or other circumstances.

(b) The serious adverse effect of delay on the applicant and the community that would be occasioned by compliance with the regular requirements of this part and rules promulgated under this part.

(c) The lack of substantial change in facilities or services which existed before the emergency situation.

(d) The temporary nature of the construction or services which will not preclude different disposition of longer term determinations in a subsequent regular application for a certificate of need.

(2) The department may issue an emergency certificate of need after necessary and appropriate review. A record of the review shall be made including copies of affidavits and other documentation. Findings and conclusions shall be made as to the applications whether the certificate is issued or denied.

(3) An emergency certificate of need issued under this section is subject to special limitations and restrictions in regard to duration and right of extension or renewal or other factors imposed by the department.

Sec. 22154. (1) Within 45 days after the effective date of this section, the department, after consultation with the health systems agencies and with the approval of the state agency, shall prepare and submit to the council:

(a) Guidelines for identifying the appropriate hospital capacity and excess hospital beds in each subarea.

(b) Criteria to be used to review and approve the plan developed by a health systems agency pursuant to subsection (7). One of the criteria shall be the potential of the plan for assuring appropriate access to and quality of medical care services for residents of the area served and for achieving economic savings consistent with this objective.

(2) The guidelines and criteria submitted by the department and approved pursuant to subsection (5) and the plans developed pursuant to subsection (7) shall consider the factors and criteria in section 22131 and the following, where appropriate:

(a) Special circumstances of hospitals which are more than 25 miles or 30 minutes from the nearest hospital.

(b) The immediate and long-term impact of the actions proposed on the costs and charges for providing health services in the area.

(c) The relationship of the services proposed to be discontinued to the health care system of the area, including the impact on health manpower.

(d) The relationship, including the organizational relationship, of the health services proposed to be discontinued to ancillary or support services.

(e) The degree to which physicians and surgeons who are affected by the closure or consolidation of hospitals or professional services have access to the physician staffs of other hospitals in the area affected.

(3) Subsection (2) shall not be construed to dictate a departure from good health planning principles or to mandate unnecessary duplication of services or facilities.

(4) The council may approve the guidelines and criteria within 90 days after it receives the guidelines and criteria pursuant to subsection (1). The council may modify the guidelines and criteria before it approves them. If the council does not approve the guidelines and criteria within 90 days after the council receives them, the guidelines and criteria shall be considered approved as submitted by the department. The guidelines and criteria shall be included in the state health plan developed pursuant to section 1524 of title 15 of the public health services act, 42 U.S.C. 300m-3.

(5) Within 30 days after the guidelines and criteria are approved pursuant to subsection (4) and annually thereafter, said guidelines and criteria shall be submitted for approval to the joint committee on administrative rules. If the committee on administrative rules takes no action on said guidelines and criteria within 30 days the guidelines and criteria approved pursuant to subsection (4) shall be the approved guidelines and criteria.

(6) Within 30 days after the first guidelines and criteria are approved pursuant to subsection (5) and annually thereafter, the department shall prepare, in accordance with those guidelines and criteria, and publish a list which identifies each subarea having excess hospital beds. A subarea that has less than 25 excess beds shall not be included in the list. The list shall specify the appropriate hospital capacity and the number of excess hospital beds in each subarea.

(7) Within 210 days after the first list developed pursuant to subsection (6) is published, and annually thereafter, a health systems agency that serves a subarea which is on the list may prepare a plan for the reduction of excess hospital capacity in accordance with this subsection, subsection (6) and the guidelines and criteria approved pursuant to subsection (5). The plan shall specify how each hospital in the subarea is affected and shall prescribe an annual schedule for implementation, and shall take into consideration the ability of the hospitals affected by the plan to meet their financial obligations. The plan shall be submitted to the council. The health systems agency may develop and apply different criteria and guidelines to a subarea if the health systems agency believes that the subarea has unusual circumstances which cannot be readily resolved in accordance with the approved guidelines and criteria. The process under which the plan is developed by the health systems agency shall be consistent with the preparation and establishment procedures required by federal regulation for the development of health systems plans under Public Law 93-641, 42 U.S.C. 217a nt, 229 nt, 291b nt, 300e-4, and 300k to 300t. The plan shall provide for the adjustment of the hospital capacity to the appropriate level within 5 years after the plan is approved by the council or developed by the department.

(8) In developing a plan to reduce excess hospital beds, the health systems agency or the council shall first consider the possibility of consolidation of 2 or more hospitals in the subarea. If consolidation is inappropriate or insufficient for the plan, the closure of hospitals shall next be considered. The closure of hospitals shall only be considered after all reasonable efforts have been made to encourage and, if necessary, assist in the consolidation of 2 or more hospitals. A statement indicating what actions were taken to encourage or assist consolidation and the reasons why this priority was not selected shall be included in the plan. If closure of a hospital is inappropriate or insufficient for the plan, the consolidation of major clinical services among 2 or more hospitals shall next be considered. If the consolidation of major clinical services is inappropriate or insufficient, the closure of nursing units within a hospital shall next be considered. The council shall not approve a plan which does not address the priorities described in this subsection.

(9) If a health systems agency does not submit a plan within 210 days after the list is published pursuant to subsection (6), the council may develop a plan for that subarea. If the plan prepared by the health systems agency is not consistent with the guidelines and criteria approved pursuant to subsection (5) or the list published pursuant to subsection (6), the health systems agency shall provide satisfactory documentation to justify the differences. Within 120 days after the plan is submitted to the council, the council may do any of the following:

(a) Approve the plan as submitted.

(b) Amend the plan to conform with the criteria and guidelines approved pursuant to subsection (5) and the list published pursuant to subsection (6) and approve the plan as amended.

(c) Disapprove the plan and develop a substitute plan which conforms with the criteria and guidelines approved pursuant to subsection (5) and the list published pursuant to subsection (6).

(d) Permit a health systems agency to revise its plan and approve the plan as revised.

(10) If a plan is not approved by the council within 120 days after the plan is submitted to the council or 330 days after the list is published pursuant to subsection (6), the department shall develop a plan within 90 days.

Sec. 22156. (1) After the department publishes a list pursuant to section 22154(6), the department shall not issue a certificate of need to a hospital located in a subarea identified as having excess hospital beds until a plan for the elimination of those beds is approved by the council or the department or until 14 months after the date of publication of the first list pursuant to section 22154(6), whichever is sooner. This subsection shall not apply to a project exempt under subsections (2) and (3) or subsection (4) or (5).

(2) A project described in the certificate of need application shall be exempt from subsection (1) if, in addition to the conditions prescribed by subsection (3), the department, in consultation with the appropriate health systems agency, determines the project is one for which both of the following apply:

(a) The project does not include an addition to the bed supply.

(b) The project would not result in a significant increase in the hospital's service program, a major new service, or new technology.

(3) A project described in the certificate of need application shall be exempt from subsection (1) if, in addition to the requirements prescribed by subsection (2), the project meets 1 of the following conditions:

(a) The project is required to correct an emergency situation which if not corrected immediately would threaten the safety and welfare of the patients and staff; or is required by federal law as a condition of participation in title 18 of the social security act, 42 U.S.C. 1395 to 1395qq, or title 19 of the social security act, 42 U.S.C. 1396 to 1396j.

(b) The project constitutes a nonsubstantive project meeting an already demonstrated community need acceptable to the department and appropriate health systems agency.

(c) The project constitutes a change in ownership not resulting in a capital expenditure which is the result of a merger, corporate consolidation, or clinical service consolidation among 2 or more hospitals.

(4) A project described in the certificate of need application shall be exempt from subsection (1) if the department, in consultation with the appropriate health systems agency, determines the project is a substantive project intended to implement the results of a merger, corporate consolidation, or clinical service consolidation among 2 or more hospitals and will result in a significant reduction in bed or service capacity.

(5) A project described in the certificate of need application shall be exempt from subsection (1) if the application has been accepted by the department for filing as of the effective date of this section.

(6) Hospital beds and services for which a certificate of need is granted after the effective date of this section, but before the approval of a bed reduction plan developed pursuant to section 22154, shall not be exempt from subsequent identification for elimination in a plan for the reduction of hospital beds as provided for in section 22154.

APPENDIX 4

NEWS FROM
SOCIETY FOR THE RIGHT TO DIE
250 West 57th Street/New York, NY 10019/(212) 246-6973

9/16/82

1982 Right to Die Bills

	Bill #	Sponsor	Committee/Status
ALASKA	H.B. 855	Don Clockson/Brian Rogers	Session adjourned
CONNECTICUT	S.B. 62	Judiciary Committee	PASSED SENATE 28-7 Lost in House 67-78(4/27/
FLORIDA	S.B. 72	Paul B. Steinberg	Session adjourned
	H.B 841	Virginia Rosen	" "
GEORGIA	S.B. 638	Richard L. Greene	Session adjourned
	H.B. 180	Dr. J. Roy Rowland, <u>et al</u>	" "
HAWAII	S.B. 43	Clifford T. Uwaine	Session adjourned
	S.B. 108	Richard Henderson, <u>et al</u>	" "
	S.B. 985	Dante K. Carpenter, <u>et al</u>	" "
	S.B. 2924	Benjamin Cayetano/J. Kuroda	" "
	H.B. 82	Dennis R. Yamada, <u>et al</u>	" "
	H.B. 2063	Mazie Hirono	" "
	H.B. 2067	Connie Chun	" "
ILLINOIS	H.B. 1	Harold A. Katz	Study Committee
	H.B. 170	Bernard E. Epton	
INDIANA	S.B. 257	James Abraham	Session adjourned
	H.B. 1271	Loren E. Winger	Session adjourned
IOWA	S.B. 168	Julia Gentleman	Session adjourned
	H.B. 91	Betty Jean Clark	Session adjourned
MARYLAND	H.B. 301	Sheila Hixson	Session adjourned
MASSACHUSETTS	H.B. 4356	Richard A. Voke	Judiciary
	H.B. 4482	Salvatore Dimasi	Judiciary
	H.B. 5050	Royal L. Bolling, Jr.	Judiciary
MICHIGAN	H.B. 4492	David Hollister	Public Health
MISSISSIPPI	S.B. 2367	Bob Usey	Session adjourned
	H.B. 378	Hainen Miller	Session adjourned
MISSOURI	S.B. 486	Hardin Cox	Session adjourned
	H.B. 1381	Larry E. Mead	Session adjourned

<u>LAWS ENACTED</u>: ALABAMA, ARKANSAS, CALIFORNIA, DELAWARE, IDAHO, KANSAS, NEVADA, NEW MEXICO, NORTH CAROLINA, OREGON, TEXAS, WASHINGTON, and the DISTRICT OF COLUMBIA.
& VERMONT (4/[illegible]/82)

9/16/82

1982 Right to Die Bills

	Bill #	Sponsor	Committee/Status
ALASKA	H.B. 655	Don Clockson/Brian Rogers	Session adjourned
CONNECTICUT	S.B. 62	Judiciary Committee	PASSED SENATE 28-7 Lost in House 67-78(4/27/8
FLORIDA	S.B. 72	Paul B. Steinberg	Session adjourned
	H.B 841	Virginia Rosen	" "
GEORGIA	S.B. 638	Richard L. Greene	Session adjourned
	H.B. 180	Dr. J. Roy Rowland, et al	" "
HAWAII	S.B. 43	Clifford T. Uwaine	Session adjourned
	S.B. 108	Richard Henderson, et al	" "
	S.B. 985	Dante K. Carpenter, et al	" "
	S.B. 2924	Benjamin Cayetano/J. Kuroda	" "
	H.B. 82	Dennis R. Yamada, et al	" "
	H.B. 2063	Mazie Hirono	" "
	H.B. 2067	Connie Chun	" "
ILLINOIS	H.B. 1	Harold A. Katz	Study Committee
	H.B. 170	Bernard E. Epton	
INDIANA	S.B. 257	James Abraham	Session adjourned
	H.B. 1271	Loren E. Winger	Session adjourned
IOWA	S.B. 168	Julia Gentleman	Session adjourned
	H.B. 91	Betty Jean Clark	Session adjourned
MARYLAND	H.B. 301	Sheila Hixson	Session adjourned
MASSACHUSETTS	H.B. 4356	Richard A. Voke	Judiciary
	H.B. 4462	Salvatore Dimasi	Judiciary
	H.B. 5050	Royal L. Bolling, Jr.	Judiciary
MICHIGAN	H.B. 4492	David Hollister	Public Health
MISSISSIPPI	S.B. 2367	Bob Usey	Session adjourned
	H.B. 378	Hainon Miller	Session adjourned
MISSOURI	S.B. 486	Hardin Cox	Session adjourned
	H.B. 1381	Larry E. Mead	Session adjourned

1982 RIGHT TO DIE BILLS ARE CONTINUED ON THE REVERSE SIDE. . . . .(OVER)

LAWS ENACTED: ALABAMA, ARKANSAS, CALIFORNIA, DELAWARE, IDAHO, KANSAS, NEVADA, NEW MEXICO,
NORTH CAROLINA, OREGON, TEXAS, WASHINGTON, and the DISTRICT OF COLUMBIA.
& VERMONT (4/6 /82)

APPENDIX 5

Hospital and Home Deaths
Michigan Occurrences, 1971, 1975, 1981

Year	Total Deaths	Home Deaths	Hospital Deaths	Other and Unknown[1]
1971	76,499	10,026	49,880	16,593
1975	73,779	9,445	48,209	16,125
1981	74,685	9,634	46,654	18,397

[1] Includes enroute to hospital, convalescent and nursing homes, other hospitals, institutions, jails, State hospitals, all other and unknown.

Source: Table 43DP, Deaths- County and Hospital of Occurrence by Month of Death, Michigan Occurrences, 1971, 1975, 1981.

Prepared by: Information Request Unit
Office of Vital and Health Statistics
Michigan Department of Public Health
3500 N. Logan Street
Lansing, MI 48909

APPENDIX 6

UPDATED LIST OF HOSPICE PROGRAMS AS OF APRIL, 1983

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Lenawee, Inc., Hospice of 139½ N. Main Street Adrian, MI 49221 (517) 263-2323	Jan Gurdjian, Administrator H (517) 263-4727	Lenawee County
Wings of Hope Hospice, Inc. 555 Linn St. Allegan, MI 49010 (616) 673-8424	Ann Murphy	Allegan City Area (may expand in future)
Gratiot Community Hospital Home Care 300 Warwick Dr. Alma, MI 48801 (517) 463-1101	Margaret Boyd	Gratiot County, Montcalm County & hospital service area
Alpena, Hospice of 155 Gilcrest Alpena, MI 49707 (517) 354-5258	Chris Woleban	Alpena Couty
Washtenaw, Inc., Hospice of 2530 S. Main Ann Arbor, MI 48103 (313) 995-1995	Ann Ballew	Washtenaw County
Bay County Inc., Hospice of P.O. Box 253 Auburn, MI 48611 (517) 892-2507	June Michalski H (517) 662-6042	Bay County
Good Samaritan Hospice Care 450 N. Avenue Battle Creek, MI 49016 (616) 965-1391	Carolyn Fitzpatrick	Calhoun County
Mecosta Comm. Council on Aging 400 Elm., Room 209 Big Rapids, MI 49307	B. Schroyer	
Cranbrook Hospice Program 1669 W. Maple Rd. Birmingham, MI 48009 (313) 644-6116	Priscilla Sommers	Birmingham

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Charlevoix County Hospice P.O. Box 233 Boyne City, MI 49712 (616) 582-2576	Rev. Kathleen Smith	Charlevoix County
Cheboygan, Hospice of Community Memorial Hospital 748 S. Main Cheboygan, MI 49721 (616) 627-5601	Kim Sangster or Carol Hicks	Cheboygan County + outlaying areas
Branch County Citizens for Hospice 27 E. Chicago St. Coldwater, MI 49036 (517) 278-4655	Barbara Colvin	Branch County
* Bay De Noc Hospice, Inc. Suite 120, Doctors Park Escanaba, MI 49829 (906) 786-3915	Rick Chickering H (906) 786-7431	Escanaba Area
Fenton Area, Hospice of 111 Trealout Dr. Fenton, MI 48430 (313) 629-9818	Carol Sinclair (313) 750-0280.	Fenton + 10 Mile radius of
Bay Valley Home Health Service 1014 Gilbert Street Flint, MI 48504 (313) 733-3050	LaVerne McCombs	Genesee County +
Hurley Medical Center Hospice Program One Hurley Plaza Flint, MI 48502 (313) 766-0654	Jackie Koss	Flint +
Hospice Support Services P.O. Box 383 Garden City, MI 48135 (313) 522-4244	Therese Price	Westland, Livonia, Garden City, Dearborn Heights, Redford +

* NEW

Clinton Memorial Hospital/Home Health Services 13105 Shavey Road, Suite 4 Dewitt, MI 48820 (517) 669-8302 or 224-6981	Janet Graulich, R.N.	Clinton County

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Hospice of the North, Inc. P.O. Box 846 Gaylord, MI 49735 (517) 732-2602	Mary Niedzwiecki	Otsego County & fringe area
North Ottawa Community, Hospice of 1309 Sheldon Rd. Grand Haven, MI 49417 (616) 842-3600	Grace Stanton	Grand Haven area inland to 194 HWY
Grand Rapids, Inc., Hospice of Greater Emeritus Center Acquinas College Grand Rapids, MI 49506 (616) 454-1426	Marsha Zandbergen O (616) 454-1426	30 mile radius of Grand Rapids (redefining borders)
Grant Hospital (In conjunction with Newaygo County & St. Barthlemew's) 41 N. Lake Grant, MI 49327 (616) 834-5694	Bea Dozer	Northern Kent County Newaygo County
Bon Secours Hospice 468 Cadieux Grosse Pointe, MI 48230 (313) 343-1000	Sr. Rosaria or Joanne Doublsky	Reasonable distance of Bon Secours Hospital
Cottage Hospice Cottage Hospital of Grosse Pointe 159 Kercheval Ave. Grosse Pte. Farms, MI 48236 (313) 884-8600	Sondra Seely H (313) 247-0551	Open
Holland, Inc., Hospice of 21 West 16th Holland, MI 49423 (616) 396-2972	Sibilla Boerigter	Holland-Zeeland & Douglas Hospital area

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Livingston Care Center Hospice 1333 W. Grand River Ave. Howell, MI 48843 (517) 548-1900	Marlene Smith	Livingston County
Memorial Hospice, Inc., The Box 344 Iron Mountain, MI 49801 (906) 779-1830	Kristi Cellelo	Iron Mountain Area
Iron County Hospice Petrucelli & Petrucelli 131 Genesee Street, Box AA Iron River, MI 49935 (906) 265-5123	Nora Angeli Petrucelli	Iron County
Jackson, Hospice of 309 S. Jackson St. Jackson, MI 49201 (517) 783-2648	Jan Hendricks Executive Director	Jackson County
Kalamazoo, Inc., Hospice of 247 W. Lovell St. Kalamazoo, MI 49007 (616) 345-0273	Margaret Madden	Kalamazoo County
FISH Hospice for Voluntary Support 2220 W. Clarkston Lake Orion, MI 48035 (313) 693-8170	Karen Kacperski	Oxford/Orion Pontiac/Waterford Drayton Plains/ Union Lake/Troy/ Clarkston/Utica/ Rochester/Romeo/ Mt. Clemens
Lansing, Inc., Hospice of 631 S. Waverly Rd. Lansing, MI 48917 (517) 321-5936	Margaret McNiven	Lansing & Greater Metropolitan Tri County Area
Lansing General Hospital Hospice Care Concept in Bereavement & Grief 2800 Devonshire Lansing, MI 48909	Marylee Stapleton (517) 372-8220	Lansing General Hospital Patient only

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Lapeer Area Hospice 1375 N. Main St. Lapeer, MI 48446 (313) 664-8511 X 150	Donna O'Toole	Lapeer County
Northern Lights Hospice 205 Osceola Laurium, MI 49913 (906) 337-3100	Cheryl Karvonen	Northern Houghton County and Kewanee County
Manistee Area Hospice, Inc. 5700 Coates Highway Manistee, MI 49660	Julie Foltz * Secretary	
Lake Superior Hospice P.O. Box 819 Marquette, MI 49855 (906) 226-2646	Cynthia Nyquist or Josie Patrick	
St. Josephs Hospital 215 N. Avenue Mt. Clemens, MI 48043N. of 17-Mile Rd.) (313) 286-7700	Patricia Allen	Hospital Service Area (McComb County
Hospice of Central Michigan 400 S. Main Mt. Pleasant, MI 48858	Betty Harris *	
Muskegon County, Hospice of 313 W. Webster Muskegon, MI 49440 (616) 728-3442	Karen Nelson	Muskegon County
R.P. Hicks Memorial Hospice 502 W. Harrie St. New Berry, MI 49868 (906) 293-5181	Theresa Shifflet	New berry area + 30 mile radius
Shiawassee, Inc., Hospice of 826 W. King, Rm. 241 Owosso, MI 48867 (517) 723-5211 X 1565	Rick Meredith	Shiawassee County

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Petoskey, Hospice of P.O. Box 2091 Petoskey, MI 49770 (616) 348-4253	Dale LaBrie H (616) 526-2274	Emmet County
Michigan, Hospices of 73 Oakland Blvd. Pleasant Ridge, MI 48069 (313) 577-1822	Bill Simpson	
St. Joseph's Mercy Hospital 900 Woodward Ave. Pontiac, MI 48053 (313) 858-3000 X 4250	Ronnie Martin	Hospital Service Area N. Oakland City
Blue Water Hospice, Inc. Marian Manor 305 Bard St., P.O. Box 501 Port Huron, MI 48060-0501 (313) 982-1990	Ann Arcieri	St. Clair County Part of Sanilac County Part of Lapeer County N.W. Part of Tuscola County
St. Mary's Hospice Care Program 830 S. Jefferson Ave. Saginaw, MI 48601 (517) 776-8000	Audrey Machul	Saginaw & Surrounding counties as identified by patient need
Saginaw, Hospice of Division of Visiting Nurse Assoc. 3037 Davenport Saginaw, MI 48602 (517) 799-6020	Keith Markstrom	Saginaw County
St. Johns, Hospice of Clinton Memorial Hospital 805 S. Oakland St. Johns, MI 48879 (517) 669-8302	Michelle Weisman	
Hospice at Home, Inc. 913 Lane Drive St. Joseph, MI 49085 (616) 983-0402	Jane Gast H (616) 983-3396	Berrien County

ORGANIZATION	DIRECTOR/CONTACT PERSON	SERVICE AREA
Sault Area Community Hospice P.O. Box 936 Sault St. Marie, MI 49783 (906) 635-1508	Ned Bromley or Tina Hall	Sault Ste. Marie Area (not yet defined
Hospice of Southeastern Michigan 22401 Foster Winter Dr. Southfield, MI 48075 (313) 559-9209	Peg McCuistion	Southeastern MI
Tri-County Home Health Care 23155 Northwester Hwy. Southfield, MI 48075	Karen Hoffner, Administrator ≠ Director of Nurses	
Tawas-St. Joseph's Mercy Hospital Hospice Program 200 Hemlock St. Tawas, MI 48763 (517) 362-3411	Rose Blackmore or Michael Jones	30-35 mile radius of the hospital
Grand Traverse Area Hospice Sixth & Madison Streets Traverse City, MI 49684	Margaret McChrystal	Grand Traverse County, Leelenau County & Benzie County
Michigan Home Health Care (includes Hospice Program) 955 E. Commerce Drive Traverse City, MI 49684 (616) 943-8540	Dr. Lilo Hoelzel-Seipo	Grand Traverse County, Leelanau County, Benzie County, Antrim County & Kalkaska County +
Hospice of Helping Hands, Inc. P.O. Box 276 West Branch, MI 48661 (517) 345-7460	Gail Issette Iosco County	Roscommons County Ogemaw County

≠ New hospice programs not included in study

APPENDIX 7

Dear Hospice Program Leader:

Efforts are underway to compile data on characteristics related to the growth and development of hospices in Michigan. You are asked to participate in the study by completing the attached survey. Although the questionnaire may appear long, it has been designed so that you can complete it in approximately 20 minutes. It would be helpful if the individual completing it for your organization is knowledgeable about the development of your program and has access to data about funding, patient load, staffing, etc.

Information received will be compiled in a report and presented to all participating hospice programs. If you do not want to have information about your hospice included in the report, please check the appropriate box below and return this letter with your completed survey. Please complete the survey and return it in the addressed, stamped envelope, no later than July 10, 1982. If you have any questions, please call me at (517) 353-0676.

Information obtained will be used as part of my dissertation on the change in hospice organizations over time and will also be available for use by all participants as they debate state and federal government initiatives concerning hospice licensure, regulation, reimbursement and continuation.

I greatly appreciate your cooperation. Thank you.

Sincerely,

Lenora Finn Paradis

X, Yes, I want information about my program compiled in statewide report.

___, No, I do not want information about my program compiled in a statewide report.

MICHIGAN HOSPICE SURVEY INSTRUCTION

The following questionnaire is designed to collect information about Michigan's hospice programs. Questions asked deal with the size, location, type of patient population, funding sources, etc. of your hospice program. While the questionnaire seems a bit long, it is designed to take about 20 minutes of your time. Please answer as completely as possible.

Along the left hand margin you will see a space with a number below it (e.g. $\underset{1}{\underline{\quad}}\ \underset{6}{\underline{\quad}}$) . The number is for computer coding purposes. You are asked to insert the correct data in the blanks above.

For example, if you are asked to "please indicate the ownership type of your hospice program and are given several choices, please insert the number corresponding to the correct choice.

For example: 1. nonprofit 2. profit 3. Other

$\underset{7}{\underline{2}}$ The "2" tells the computer that your hospice program is classified as for profit.

In some cases you will see a question divided by the word "Card" followed by a number, for example, "Card 2". Please continue to answer the question. The "Card 2" is an instruction to the keypunch operator and is not an instruction to you.

If you have any questions about filling out this survey, please call Lenora Finn Paradis (517) 353-0676. Please return the questionnaire in the enclosed, stamped enveloped by July ___

Thank you in advance for your cooperation.

MARGINALS

HOSPICE QUESTIONNAIRE

INSTRUCTIONS:

Please complete the questionnaire as fully as possible. For each question check or circle the appropriate answer.

Please RETURN this questionnaire by AUGUST 5 in the enclosed, addressed and stamped envelop. If you feel a question can best be answered by attaching meeting minutes and other written materials please do so. If you have any questions please call Lenore Finn Paradis (517-353-0676) If you would like the questionnaire returned after it is computer scored for your files please check the box below. Thank you for your assistance.

☐ I would like the questionnaire returned for my files.

1. Which statement best reflects your primary focus of care? (circle one)

$\bar{X}$ = 5.87
Median = 6.84

5 a. hospital based hospice program–scattered or floating beds
2 b. hospital based hospice program–separate unit
3 c. hospital based oncology unit
0 d. hospital based palliative care unit
1 e. free-standing facility
1 f. free-standing hospice facility
35 g. home based hospice program
1 h. home based nursing care
i. other (please specify) ____________________

2. Which statement best describes your hospice program at present? (circle one)

$\bar{X}$ = 2.45
Median = 2.74

10 a. it is in the planning stage and has not officially identified itself as a hospice program
6 b. it is a corporated hospice program but has not yet accepted patients
31 c. it is an incorporated hospice program and has accepted patients
0 d. it is NOT considering becoming a hospice program but will provide hospice care
0 e. it is NOT considering becoming a hospice program and will not provide hospice care

IF YOU CIRCLED "e" PLEASE SKIP to question 36.

3. What is the approximate population of your service area.
Circle the letter that corresponds below:

$\bar{X}$ = 5.82
Median = 5.83

1 a. Less than 1,000 9 d. 10,000-24,999 9 g. 100,000-249,000
0 b. 1,000-4,999 8 e. 25,000-49,999 7 h. 250,000-499,999
3 c. 5,000-9,999 6 f. 50,000-99,999 3 i. 500,000 or more

4. What counties and cities does your organization serve.
Please list in the space below:

cities

counties ______________________________

5. Are there other hospice programs in your county or city? (circle one)

17 a. yes 31 b. no

6. Which category best describes your organization? (circle one)

0 a. for profit 45 b. nonprofit 0 c. does not apply

7. Below is a time line. Please place an "X" on the month and year which mos accurately describes when you program began; that is, when was it firs identified as a hospice program.

X̄ = 5/29/80
edian = 5/19/79

Earlier then / J F M A M J J A S O N D / J F M A M J J A S O N D /
Jan. 1976 1976 1979

J F M A M J J A S O N D / J F M A M J J A S O N D / J F M A M J J
1980 1981 1982 ⟶

8A. Thinking back to when your organization began, please use the scale below t rate the extent to which individual members of each profession were involve in your organization. Circle the number which best describes the involvemen categories of individuals listed below:

KEY: / 1 / 2 / 3 / 4 /

1	2	3	4
not involved	only occasionally involved	regularly involved	frequently involved

		1	2	3	4
a.	nurses	0	0	11	35
b.	physicians	5	6	16	17
c.	lay community members	2	10	[illegible]	[illegible]
d.	hospital administrators	14	12	7	13
e.	disease related organization representatives (ie., Michigan Cancer Society, Michigan Heart Association, etc.)	14	18	6	5
f.	medical society representatives	26	12	3	5
g.	clergy (includes rabbis, priests, etc.)	0	7	[illegible]	[illegible]
h.	survivors of dying patients	[illegible]	[illegible]	[illegible]	[illegible]
i.	insurance company representatives	35	6	[illegible]	[illegible]
j.	educators	[illegible]	16	[illegible]	[illegible]

8A. Continued

KEY:	1	2	3	4
	not involved	only occasionally involved	regularly involved	frequently involved

2 6 11 25

k. social workers / 1 / 2 / 3 / 4 /

l. other (please specify) / 1 / 2 / 3 / 4 /

8B. Are the individuals who assisted your program in its early foundation still associated with your program? (circle one)

X̄ = 1.9
Median = 1.9
Blank = 4

13 a. yes, all of them are still involved

22 b. yes, most of them are still involved

9 c. yes, some of them are still involved

d. none of them are still involved

IF YOU ANSWERED "b" or "c" in the space below please describe why thes individuals are no longer involved with your organization. (Attach separat sheets of description if necessary.)

9A. Is there a CORE group of individuals in your community responsible for your program's development? (circle one)

41 a. yes (skip to 9B) 4 b. no (skip to 10A) c. don't know (skip to 10A)

9B. IF YES from the list below, please check the occupational categories of COR individuals. (check all that apply)

31 ___ a. physicians

40 ___ b. nurses

34 ___ c. social workers

30 ___ d. professionals outside of medicine

25 ___ e. homemakers

37 ___ f. clergy

30 ___ g. hospital/nursing home or home health administrators

13 ___ h. other (please specify)

10A. Remembering back, what were the ORIGINAL goals of your organization. From the list below, circle the number on the scale which best describes the importance of each goal which was selected by your program. (Please attach any relevant information i.e. minutes, brochures, etc. which list original goals.)

KEY:		1 not selected as a goal	2 somewhat important	3 important	4 highly important
a.	To promote the hospice concept in the community	3	3	15	24
b.	To improve the comfort of the dying patient	0	0	0	47
c.	To change community attitudes toward the dying	3	10	20	13
d.	To help the dying patient be as alert and symptom free as possible	0	1	4	42
e.	To include the family in the care of the patient	0	0	4	43
f.	To care for the patient at home as long as it is within the wishes and ability of the patient and family	0	0	3	44
g.	To increase physician participation in emotional support in the care for the dying	4	8	17	18
h.	To become a self-sufficient hospice program	12	8	11	16
i.	To obtain funds from third party insurers, private donations, etc.	12	7	14	14
j.	To increase funds from third party insurers, private donations, etc.	17	9	7	11
k.	To establish linkages with other health care providers (i.e. nursing homes, hospitals, etc.)	6	7	20	13
l.	To recruit members	8	5	16	16
m.	Other (please list in the space below)	0	0	0	0

10B. In the space below, please describe how your program's INITIAL goals were developed (i.e. who drafted them, how were they approved etc.) (Please attach any relevant information)

ANSWER "10C" ONLY IF YOUR PROGRAM is part of hospital, nursing home, or home health agency. If you are an independen community based hospice, please skip to question 11A.

10C. What role did you hospital, nursing home, or home health agency administrator, board, or staff have in the development of your hospice program's goals. (circle one)

1 a. The board determined hospice program goals

3 b. The board in conjunction with administration determined hospic program goals

12 c. Staff involved with the hospice program determined goals which wer reviewed by the board and administration.

2 d. Staff involved with the hospice program determined goals which wer NOT reviewed by either the board or administration.

1 e. The administration determined the hospice program goals

f. Other (please specify) ____________________

____

____

11A. CURRENTLY what are the goals of your program. Use the same format previously described for the rating in question 10A circling the number whic best describes the importance of each goal. Please place an "X" alongsi those goals which your program has largely accomplished.

KEY: / 1 / 2 / 3 / 4 /

1	2	3	4
not selected as a goal	somewhat important	important	highly important

Place "X" here ↓

____	a.	To promote the hospice concept in the community	1 0 14 30 / 1 / 2 / 3 / 4 /
____	b.	To improve the comfort of the dying patient	0 0 0 44 / 1 / 2 / 3 / 4 /
____	c.	To change community attitudes toward the dying	2 6 15 22 / 1 / 2 / 3 / 4 /
____	d.	To help the dying patient be as alert and symptom free as possible	0 0 3 41 / 1 / 2 / 3 / 4 /
____	e.	To include the family in the care of the patient	0 0 1 43 / 1 / 2 / 3 / 4 /
____	f.	To care for the patient at home as long as it is within the wishes and ability of the family and patient	0 0 1 43 / 1 / 2 / 3 / 4 /
____	g.	To increase physician participation in emotional support in the care for the dying	4 2 16 23 / 1 / 2 / 3 / 4 /

11A. Continued

KEY: / 1 / 2 / 3 / 4 /

	1	2	3	4
KEY:	not selected as a goal	somewhat important	important	highly important

Place "X" here ↓			1	2	3	4
____	h.	To become a self-sufficient hospice program	9	3	15	15
____	i.	To obtain funds from third party insurers, private donations, etc.	10	3	16	14
____	j.	To increase funds from third party insurers, private donations, etc.	13	3	12	14
____	k.	To establish linkages with other health care providers (i.e. nursing homes, hospitals, etc.)	5	2	14	23
____	l.	To recruit members	3	1	10	16
____	m.	Other (please list in the space below)	0	0	0	0

11B. IF YOUR GOALS HAVE CHANGED OVER TIME PLEASE DESCRIBE THE REASON FOR THE CHANGES in the space below (For example, goals have changed as a result of changing leadership or earlier goals have been accomplished or current goals are more specific etc.)

12A. Some hospice program invite the general public to joing as members. For a small fee those individuals receive a newsletter and other information. Does your program have members?

24 a. Yes (skip to 12B) 12 b. No (skip to 12F) 8 c. Not yet, but planning to (skip to 13)

12B. IF YES, in the space below please indicate the methods used for recruiting members (circle all that apply)

15 a. by advertising 5 d. through affiliations with religious organizations

20 b. by word of mouth 5 e. through affiliations with area hospitals, nursing homes, etc.

20 c. other (please specify) ______________________________

____

12C. Are there requirement for membership (i.e. payment of a fee, participation as a volunteer, etc)? (circle one)

18 a. yes 6 b. no 4 c. not yet, but being planned

IF YES, in the space below please describe the membership requirements and attach any membership policy.

12D. In the space below indicate how heavily you rely on members for assistance in your program (i.e. to work as volunteers) (circle one)

	1	1	7	19
KEY:	1	2	3	4
	do not rely on members at all	rely on members occasionally	rely on members regularly	rely on members heavily

12E. Has your membership increased, decreased, or remained the same since your program began? (circle one)

27 a. increased 0 b. decreased 3 c. remained the same

13. Please indicate those actions you have taken by putting the month and year i which the activity BEGAN or WILL BEGIN in the space provided in the lef hand margin. If any activity does not apply, put an "X" in the space provided.

For example: June 1981 organized community members

Num. Mean Blank-Date		
9-5/78	____________	organized community members
10-6/79	____________	conducted an assessment to determine what your comm needed
12-5/81	____________	selected a board of directors
15-5/82	____________	employed an executive director or hospice program coordinator (employment refers to paid, voluntary, full or part-time)
5-5/82	____________	drafted organizational goals and objectives

13. Continued

Sum. Mean Rank-Date	
29-5/82	altered organizational goals and objectives (if more than once, most recent date)
12-5/82	developed an organizational structure
31-3/81	altered the organizational structure (if more than once, most recent date)
36-3/81	applied for a certificate of need
41-4/82	applied for a license as a hospice
43-3/80	applied for a license as a home health agency
13-4/82	accepted one or more patients
35-9/81	completed a pilot program
22-6/81	prepared a plan for developing the hospice service with time frames
25-6/81.8	employed a medical director
22-4/81	employed a patient care coordinator
26-4/79	employed a volunteer coordinator
16-6/79	developed staff training
11-6/82	developed volunteer training
21-6/80	developed a newsletter
15-6/81	developed community education programs
11-6/78	began to accept donations/contributions
19-6/78.7	began to solicit funds
23-4/80.7	employed nursing services
16-6/82	began bereavement counseling
42-5/81	considered merging with other hospice programs
42-6/82	considered merging with a hospital
42-6/82	considered merging with a home health agency
45-8/80	considered merging with a nursing home

14. Describe briefly the circumstances surrounding your program's beginning. (For example "because a community resident needed special care, or because Elizabeth Kubler-Ross came to speak", etc.) If you have any written history, please enclose.

15A. Does your hospice have an admission policy identifying who may adm patients?

31 a. yes (skip to 15B) 11 b. no (skip to 16)

15B. IF YES, please describe the policy in the space below or attach the policy to this document.

If your program HAS NOT EMPLOYED ANY INDIVIDUALS (on a volunta basis or for pay), please skip to question 18.

16. Below is a list of individuals who typically are employed (for pay or on voluntary basis) by hospice programs. In the space provided on the left ha margin indicate "1" if you employ the individual for pay, "2" if employed f pay on a part-time basis, etc.

Please Note:

1 = employed for pay full-time
2 = employed for pay part-time
3 = employed as a volunteer
4 = intend to employ for full-time
5 = intend to employ for part-time
6 = intend to employ on a voluntary basis
7 = employed as a volunteer but will be paid when funding is available
8 = no plans for this position

# Blank	$\bar{X}$	Median		
15	3.5	3.0	____	Medical Director, M.D./D.O.
17	3.0	1.4	____	Executive Director
21	5.3	7.3	____	Administrative Program Coordinator
18	3.1	1.4	____	Patient Care Coordinator

16. Continued

____ Volunteer Director

____ Education Director

____ Research/Evaluation Director

____ Chaplain

____ Other (please specify) ____________________

17. In the space below please indicate the average number of paid staff in your program from 1979-1982. Put an "X" by those years in which you did not have paid staff.

$\bar{X}$ = 4.6 # Blank $\bar{X}$ = 12.3 # Blank
Median = 4.0 # paid staff 1979 43 Median=4.2 # paid staff 1981 36
$\bar{X}$ = 5.6 # Blank $\bar{X}$ = 11.9 #Bl
Median = 2.5 # paid staff 1980 40 Median=4.6 # paid staff 1982 (Jan-July 1)

18A. Has your hospice program had more than one executive director since inception. (circle one)

37 a. yes (skip to 18B) 6 b. no (skip to 19A) 0 c. does not apply

$\bar{X}$ = 2.3 18B. IF YES, How many? ____________________

18C. Was your current executive director recruited from your geographic area?

24 a. yes 0 b. no

18D. Was your current executive director recruited from your hospice board?

23 a. yes 0 b. no

19A. What types of individuals comprise your program's board? (circle all apply)

12 a. other hospice program employees

36 b. physicians

9 c. home health nurses (in for profit industry)

29 d. home health nurses (in non-profit industry)

19A. Continued

30 e. hospital administrators or representatives

34 f. lay consumers

28 g. educators

35 h. clergy

5 i. insurers

3 j. HMO representatives

11 k. nursing home administrators/staff

17 l. private foundation or service organization employees

0 m. other ______________________________

19B. How is your board selected? (circle one)

32 a. by a vote of members 1 c. selected by the executive director

3 b. self-selected 0 d. other (please specify)

____

20. Does your program provide bereavement services or is it planning to provide these services?

43 a. We currently provide bereavement services

b. We plan to provide bereavement services

c. We are not planning to provide bereavement services. (IF YOUR ANSWER IS "c", please skip to question 25.)

21. On a monthly basis what is the average number of individuals for which you provide bereavement services? Use an estimate based on last year's (1981) average.

$\bar{X}$ = 12.5
med.-7.5______ # per month

22. What is the average length of time, in months, for which bereavement services are provided. (circle the appropriate time period)

2 a. Under 2 months 4 d. 6-8 months 0 f. 10-15 months

0 b. 2-4 months 0 e. 8-10 months 24 g. Over 15 months

2 c. 4-6 months

23. Do you provide bereavement services to individuals regardless of whether a family member was in your hospice program?

26 a. yes 0 b. no 7 c. undecided

24. In the space below please briefly describe your bereavement program. Attach separate sheets if necessary.

25. Please indicate which agencies your hospice has a relationship with by placin a "1" in the space in the left hand margin if the relationship is formal (contract has been written describing the relationship), "2" if informal (n contract describing the relationship exists), "3" if service is available but yo have no formal or informal agreement.

1 = formal   2 = informal   3 = service available

1	3		
29	11	_____	hospital(s)
25	12	_____	home health agency(s)
12	18	_____	nursing home(s)
4	13	_____	health maintenance organization
10	16	_____	cleaning/chore services
9	18	_____	ambulance services
12	16	_____	auxiliary services (i.e., P.T., R.T.)
26	11	_____	social services
17	14	_____	other hospice(s)
21	12	_____	local health department
15	15	_____	local mental health department
22	16	_____	disease related organization (i.e., Michigan Cancer Society)
22	15	_____	church
		_____	other

NOTE: NO ONE CHECKED 2 (informal agency)

26. Using the scale below circle the number of the category provided which describes the degree to which your program provides or plans to provide the following services:

1	2	3	4
not presently provided NOT PLANNED	provided but WILL NOT be continued	not presently provided BUT PLANNED	provided and WILL be continued

		1	2	3	4
a.	companionship	3	0	12	29
b.	financial counseling	9	0	13	19
c.	legal counseling	15	0	12	13
d.	psychological counseling	4	0	14	25
e.	personal care	1	13	0	29
f.	recreational therapy	23	0	17	9
g.	social work	2	0	13	29
h.	child care	9	0	15	19
i.	housekeeping	5	0	12	25
j.	errand running	4	0	14	27
k.	home meal preparation	6	0	11	25
l.	transportation	7	0	11	24
m.	basic nursing	1	0	11	31
n.	client education about hospice	0	0	12	32
o.	emergency answering service	5	0	13	26
p.	hospice doctor for patient consultation	4	0	14	23
q.	hospice doctor for patient management	12	0	12	17
r.	occupational therapy	15	0	16	10
s.	symptom control	1	0	[illegible]	[illegible]
t.	physical therapy	[illegible]	0	[illegible]	[illegible]
u.	respiratory	6	0	[illegible]	[illegible]
v.	skilled nursing	3	0	[illegible]	[illegible]
w.	speech control	16	0	[illegible]	[illegible]
x.	art/music therapy	16	0	[illegible]	6

27A. Do you charge, or INTEND to charge, patients fees. (circle one)

22 a. no, fees are not or will not be assessed (skip to question 28)

11 b. fees are not or will not be assessed to patients, but to third party payors (skip to 27B)

7 c. fees are and will continue to be assessed both to patients and also to third party payors (skip to 27B)

2 d. yes, fees are or will be assessed to patients (skip to 27B)

27B. IF YES: How are fees assessed? (circle one)

1 a. per hour

1 b. per service

7 c. per visit

6 d. other (please specify) ____________________

THE FOLLOWING INFORMATION IS ABOUT YOUR PROGRAM'S BUDGET
ALL RESPONSES WILL REMAIN CONFIDENTIAL.

28. In the space below indicate the total amount of funds your program he received beginning in the year 1979. If you have received no funds put a "0" in the appropriate space.

$\bar{X}$ = 27,300 Blank 42
Median = 450 amount 1979

$\bar{X}$ = 87,033 Blank 30
Median = 1,769 amount 1981

$\bar{X}$ = 33,100 Blank 39
Median = 25,000 amount 1980

$\bar{X}$ = 67,114 Blank = 22
Median = 6,084 amount 1982 (Jan-July

29. Which of the following contribute to your overall budget. (circle all that apply) 2 - what % do they contribute?

7 a. United Way

35 b. private individual donations

35 c. memorials

14 d. memberships

14 e. public foundations

15 f. third party insurers

24 g. service organizations ____________________

h. other (please specify) ____________________

30. Do you have or are you planning to seek funds from third party insurers? (circle one)

16 a. yes 11 b. no 16 c. don't know

31. Do you have or are you planning to seek funds from private individuals or foundations? (circle one)

33 a. yes 6 b. no 5 c. don't know

THE FOLLOWING QUESTIONS REFER TO PATIENTS OR FAMILIES IN YOUR PROGRAM. IF YOUR PROGRAM DOES NOT ACCEPT PATIENTS OR FAMILIES SKIP TO QUESTION 33.

32A. In the space below, please indicate the number of patients/families you hav accepted in your program since it began.

Blank	$\bar{X}$	Median
15	71	40

__________ since inception

32B. In the space below, please indicate the average number of PATIENTS pe month in your program from 1979-1982. Put an "X" in the space fo those years your program did not see patients.

__________ # patients 1979 __________ # patients 1980

__________ # patients 1981 __________ # patients 1982 (Jan-July 1)

32C. In the space below, please indicate the monthly average number o FAMILIES seen in your program from 1979-1982. Put an "X" in the spac for any years which your program did not see families.

__________ # families 1979 __________ # families 1980

__________ # families 1981 __________ # families 1982 (Jan-July 1)

32D. In the space below, write in the average number of days patients remain i your program.

__________ average length of stay per patient (in days)

33. In the space below, please list any problems your program has faced since i inception. (For example, problems attracting qualified personnel, or obtaini funds) Attach a separate page if necessary.

34. Federal legislation (H.R. 5180 and SB 1958) is being debated. The purpose the legislation is to provide Medicaid/Medicare reimbursement for hospi services. Using the scale below, please indicate whether your program (circ one):

35	0	5	4	0	0
1	2	3	4	5	6
Strongly supports the legislation	Supports the legislation	Neither supports nor opposes	Opposes the legislation	Strongly opposes the legislation	Unawa of the legislati

35. Rules for implementing the states licensing law are in the process being completed. Using the scale below, please indicate whether y program (circle one):

24	0	5	11	0	0
1	2	3	4	5	6
Strongly supports the rules	Supports the rules	Neither supports nor opposes the rules	Opposes the rules	Strongly opposes the rules	Unawa of the rules

TO BE FILLED OUT BY THE INDIVIDUAL COMPLETING T QUESTIONNAIRE

36. Please put your name and position with the hospice in the space below

Name ____________________

Position ____________________

How long have you been in this position? ____________

How long have you been involved with the hospice program? ________

Do Not Write
In This Space
For Computer
Use Only

HOME HEALTH AGENCIES SURVEY

APPENDIX 8

INSTRUCTIONS:

1 2 3 4 PLEASE TAKE A MINUTE TO COMPLETE THE SURVEY BELOW AND RETURN IT AS SOON AS POSSIBLE (BY NOVEMBER 29TH). INSERT THE COMPLETED QUESTIONNAIRE IN THE SELF-ADDRESSED, STAMPED ENVELOPE ENCLOSED.

5 6 7 8 THANK YOU FOR YOUR ASSISTANCE... IF YOU HAVE ANY QUESTIONS PLEASE CALL LENORA FINN-PARADIS AT (517) 353-0676.

9 1. Have you ever heard of the word hospice? (CHECK ONE)

40 yes (IF YES, GO TO QUESTION 2) 2 no (IF NO, GO TO QUESTION 18, PAGE 3

10 2. IF YES, please check the ONE statement which you think best describes hospice. (CHECK ONLY ONE)

___ It is a place where dying patients are sent for specialized care.

34 It is a program of care for the dying which involves the patient, family, and physician.

___ It is a unit of a hospital oncology ward which treats cancer patients.

8 It is a home-based service which offers care to the dying.

11 3. Have you ever referred a patient to a hospice program? (CHECK ONE)

34 yes 8 no

12 4. Are you a member of a hospice board or committee? (CHECK ONE)

21 yes 21 no

13 5. Would you serve as a member of a hospice board or committee? (CHECK ONE)

37 yes 3 no

14 6. Have you ever referred a patient or his/her family to grief or bereavement counseling? (CHECK ONE)

31 yes 11 no

15 16 17 7. In the space below, please estimate the number of terminal patients you saw last year. (WRITE IN NUMBER)

median = 39.5 terminal patients

18 8. Has your organization considered forming a hospice program? (CHECK ONE) (PLEASE GO TO QUESTION 9)

[illegible] yes 15 no

19 20 21 9. In the space below, please note the percentage of your patients who are covered both by medicare and have a terminal illness.

23 % (WRITE IN % WHO FIT BOTH CATEGORIES)

22 23 24 10. In the space below, please note the percentage of your patients who are covered both by medicaid and have a terminal illness.

4.5 %(WRITE IN % WHO FIT BOTH CATEGORIES)

25 11. Does your home health agency program provide bereavement services for terminal patients? (CHECK ONE)

16 yes (IF YES, GO TO QUESTION 12) 24 no (IF NO, GO TO QUESTION 13

12. If you have a bereavement program please check all of the following statements that apply to your bereavement program. (CHECK ALL THAT APP

26 27 10 a. It is provided for families of all patients who have suffered a death regardless of their ability to pay.

28 29 5 b. It is provided for 6 months to 1 year after the death of the patient serviced.

30 15 c. It includes visits and phone calls to the patients family.

5 d. It is provided by staff trained in bereavement counseling.

4 e. It is provided by volunteers.

31 32 13. In the space below, please note the number of home health agencies that service your county excluding your own. (WRITE IN NUMBER)

8 # of home health agencies

33 14. Has your agency considered merging with an area hospice? (CHECK ONE)

14 yes 24 no

15. If you have a relationship with an area hospice, please check any of the following categories which describe the relationship. (CHECK ALL T APPLY)

34 35 12 a. Formal contact for skilled nursing

36 37 8 b. Formal contract for basic nursing

38 39 9 c. Informal relationship (no contract exists) to provide basic nu

40 18 d. Informal relationship (no contract exists) to provide skilled

18 e. Agency representative serves as a member of hospice board

17 f. Advise hospice on patient care matters

21 g. Agency representative serves as a member of hospice committee

41 42 43

16. In the space below, please note the number of patients you serve on the average per month. (WRITE IN NUMBER)

$\bar{X}$=75 # of patients per month

17. In the space below please make any comments you'd like regarding your relationship with area hospice programs:

____

____

____

____

____

____

____

____

____

18. Please note your position with the home health agency and length of service in the space below:

______________________________ Position

____________________ length of service

THANK YOU. PLEASE USE THE ENCLOSED ENVELOPE AND RETURN THE QUESTIONNAIRE

Lenora Finn Paradis
Michigan State University
C201 E. Fee Hall
East Lansing, MI 48824

Not Write
This Space
Computer
Only

2 3 4

6 7 8

INSTRUCTIONS:

APPENDIX 9

PHYSICIAN SURVEY

PLEASE TAKE A MINUTE TO COMPLETE THE SURVEY BELOW AND RETURN IT AS SOON AS POSSIBLE (BY NOVEMBER 26TH). THIS IS A SELF-ADDRESSED, STAMPED FORM. PLEASE REFOLD THE SURVEY SO THAT THE CORRECT ADDRESS IS SHOWING AND STAPLE CLOSED.

THANK YOU FOR YOUR ASSISTANCE. IF YOU HAVE ANY QUESTIONS PLEASE CALL LENORA FINN-PARADIS AT (517) 353-0676.

1. Have you ever heard of the word hospice? (CHECK ONE)
123 yes(IF YES, GO TO QUESTION 2) 6 no(IF NO, GO TO QUES

2. IF YES, please check the ONE statement which you think best describes hospice. (CHECK ONLY ONE)

6 It is a place where dying patients are sent for specialized care.

121 It is a program of care for the dying which involves the patient, family, and physician.

___ It is a unit of a hospital oncology ward which treats cancer patients.

10 It is a home-based service which offers care to the dying.

11 3. Have you ever referred a patient to a hospice program? (CHECK ONE)
66 yes 70 no

12 4. Are you a member of a hospice board or committee? (CHECK ONE)
19 yes 117 no

13 5. Would you serve as a member of a hospice board or committee? (CHECK ONE) (GO TO QUESTION 6)
65 yes 56 no

14 6. Have you ever referred a patient or his/her family to or bereavement counseling? (CHECK ONE)
70 yes 48 no

15 16 17 7. In the space below, please estimate the number of ter patients you saw last year (1981-1982). (WRITE IN NUMBER
[illegible] terminal patients

8. In the space provided on the reverse side of this survey, pleas any remarks you would like concerning hospice. Thank you.

PLEASE RETURN SURVEY TO ADDRESS NOTED ON REVERSE SIDE OF THIS SURV

APPENDIX 10

OPEN-ENDED QUESTIONS FOR HOSPICE PROGRAM DIRECTORS

1. How long have you been involved with this program?
2. Please tell me a bit about your background.
3. How did you come to be director?
4. What is the role of your board of director and how is your board selected?
5. What changes have you seen in the board structure, the organizational goals and the services provided since you have been director?
6. What changes would you want to make to the hospice program?
7. What changes have you noticed in the hospice movement in general?
8. What is your relationship with the area hospitals?
9. What is your relationship with the area home health agency?
10. How much benefit does your volunteer program provide to patients (e.g. how many hours of service are provided by volunteers)?
11. Please describe your bereavement program.
12. What problems have you encountered since you have been director?

OPEN-ENDED QUESTIONS FOR HOSPICE BOARD MEMBERS

1. How long have you been involved with this program?
2. What factors encouraged you to participate in the hospice program?
3. What is your role on the board?
4. On what hospice committees do you serve?

APPENDIX (cont'd)

5. What do you see as the board's primary function?

6. What changes would you want to see in board composition or interaction with the hospice program?

7. What problems do you perceive the hospice program as having?

8. What do you see happening to the hospice movement in general?

9. How does your board relate to local hospital and home health agency boards?

10. What do you think the role of the hospice program director should be?

APPENDIX 11

Hello, my name is ______________. Michigan State University recently sent you a hospice questionnaire and we were wondering if you had received it?

A. You have? Good. Do you think you'll be able to fill it out and send it back as soon as possible? Oh good! Thanks so much for your time, we really appreciate it. Goodbye.

B. You didn't? Could I read you the address I have down for your hospice to see if it is correct? Could we send you another questionnaire? Thank you. We really appreciate it. Good bye.

APPENDIX 12

Hello, my name is ______________ and I'm calling about the hospice questionnaire you received from Michigan State University. We haven't received your's yet and we were wondering if you had returned it? Do you plan on filling it out? Good. Do you have any idea when you'll be able to get to it? In order for our study to be accurate we really need the information from your hospice and would really appreciate it if you could take the time to fill it out. Thanks.

APPENDIX 13

MICHIGAN STATE MEDICAL SOCIETY

120 WEST SAGINAW STREET EAST LANSING MICHIGAN 48823, PHONE AREA CODE 517 337-1351

November 5, 1982

Dear Doctor:

Enclosed you will find a self-addressed, stamped survey. The survey contains questions about your awareness and involvement in the field of "hospice care". The questionnaire was designed by Ms. Lenora Finn Paradis as part of her doctoral dissertation research at Michigan State University. The topic of her dissertation is, "The Integration of Hospice Care into the Existing Health Care Delivery System."

As the Michigan State Medical Society representative to the Michigan Hospice Organization, I am interested in learning about the extent to which physicians' know about and participate in hospice programs. Therefore, I encourage you to take a minute or two to complete the enclosed questionnaire. The results of the survey will be reported in an upcoming issue of Michigan Medicine. If you have any questions or would like more information about hospice programs in Michigan, please contact Mr. Kevin Kelly at MSMS headquarters (517-337-1351).

Thank you for your participation.

Sincerely,

E. Joseph Alberding, MD

P.S. Please try to return the enclosed survey form prior to November 26. I thank you in advance for your response to this survey.

APPENDIX 14

November 9, 1982

Enclosed you will find a self-addressed, stamped survey. The survey contains questions about your awareness and involvement in the field of "hospice care". The questionnaire was designed by Ms. Lenora Finn Paradis as part of her doctoral dissertation research at Michigan State University. The topic of her dissertation is, "The Integration of Hospice Care into the Existing Health Care Delivery System".

As the Dean of the the College of Osteopathic Medicine at Michigan State University, I am interested in learning about the extent to which physicians know about and participate in hospice programs. Therefore, I encourage you to take a minute or two to complete the enclosed questionnaire. Results from the survey will be presented in the College of Osteopathic Medicine <u>Communique</u>. If you have any questions or would like more information about hospice programs in Michigan, please contact Ms. Lenora Finn Paradis at (517) 353-0676.

Thank you for your participation.

Sincerely,

Myron S. Magen, D.O.
Dean

MSM:LFP:mpv

P.S. Please try to return the enclosed survey form prior to November 26th.

APPENDIX 15

November 5, 1982

Dear

Enclosed you will find a self-addressed, stamped survey. The survey contains questions about your awareness and involvement in the field of "hospice care." The questionnaire was designed by Ms. Lenora Finn Paradis as part of her doctoral dissertation research at Michigan State University. The topic of her dissertation is, "The Integration of Hospice Care in to the Existing Health Care Delivery System."

As the President of the Michigan Home Health Assembly, I am interested in learning about the extent to which Home Health Agencies participate in hospice programs. Please take a few minutes to complete the enclosed questionnaire. The results of the survey will be reported to you shortly after the data has been received. Please complete the survey by November 26. If you have any questions or would like more information about hospice programs in Michigan please feel free to contact Ms. Lenora Finn Paradis at (517) 353-0676.

Thank you for your assistance. I'm sure the information will be useful for all of us.

Sincerely,

Kay Hollers
Director

KH/crd

Enclosure

APPENDIX 16

Statement on the Purpose of Hospice Dissertation Research

Lenora Finn Paradis

Many people have asked me to detail, in writing, the purpose of my research on the growth and development of hospice programs in Michigan. This statement was developed as a broad overview of the purpose of the research, its design and ultimate use.

Purpose

The research on Michigan hospice programs has been designed to serve two purposes. First, to collect descriptive data on the growth and development of hospice programs in Michigan for use by health care providers(which includes hospice providers), health care decision makers and legislators. Second, to provide empirical data to assess sociological hypothesis regarding the integration of social movement organizations into the larger social system.

At the practical level, the recent upsurge in the number of hospice programs throughout Michigan has forced health care policymakers to re-examine the existing health care system, especially in relation to its provision of care for the dying patient. Yet, the rapid growth in hospice programs throughout the state(from a handful in 1978 to 53 in 1982) has hampered the development of an adequate information base regarding hospice program structure, policies, goals, patient load, focus of care, bereavement programming, and so on. Because of the lack of a coordinated data base, hospice programs in Michigan have had difficulty sharing program information and in providing important information to state health care policymakers.

At the theoretical level, the study of hospice as a social movement organization provides insight for testing sociological theories about the integration of a social movement organization into the larger society.

For the purposes of this research, a social movement is defined as consciously and purposively structured types of collective behavior which aim at changing individuals or societal institutions and structures. An integral part of any social movement is the organization which coordinates and directs actions toward the members' goals. The process of a social movement organization's integration into the larger society may be formal(through avowed public agreements) or informal(a response of individuals within a community). The process by which hospice is integrated into the existing health care system is the focus of the research.

Survey Techniques

The researcher is using survey techniques in combination with focussed interviews to obtain a broad base of data about the development of hospice programs in Michigan, their growth over time, their linkages and affiliations with other health care organizations, such as home health agencies and hospitals, and the direction of their leadership.

A closed ended survey has been sent to all hospice programs listed in the Michigan Hospice Organization Directory. A total of 56 programs were surveyed, 4 of which indicated they were not a hospice program. Response rate from the questionnaires was 92%. Ten programs indicated they were hospital-based, two indicated they were freestanding, and thirty-six indicated they were home-based hospice programs. Ten of the programs are in the planning stage and have not officially identified themselves as hospice programs. Six of the programs indicated they were an incorporated hospice program which has not yet accepted patients and thirty-one programs(65%) indicated they were an incorporated hospice program and had accepted patients.

Information from the survey is being summarized in a report which will be presented at the Michigan Hospice Organization annual board meeting scheduled for November, 1982.

In addition to the closed-ended survey, interviews are planned with hospice staff, volunteers, board members and executive directors, as well as with home health agencies, hospital administrators, local public health departments and physicians. The findings of the interviews will be incorporated into the research.

Research results will be available to hospice program directors, state legislators and policymakers, and other researchers. No individual or program will be identified in the research and all field notes will be destroyed once the dissertation is completed and approved by the University.