

Alternative to Co-opted:
An Examination of the Trajectory of the Hospice Movement

by

Chelsea Platt, BA

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Approved

Dr. Charlotte Dunham
Chair of Committee

Dr. Jason Adam Wasserman

Peggy Gordon Miller
Dean of the Graduate School

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ABSTRACT

Hospice began as a movement that was critical of the treatment of terminal patients within traditional medicine and its cure-oriented logic arguing that traditional medical practices and policies can be dehumanizing for the terminally ill (Dubois 1980; Munley 1983; Stoddard 1991; Levy 1994). The progressive and alternative ideals of the early hospice movement were loaded with political issues and challenged an assumed logic within traditional medicine. The movement then shifted the majority of its energies towards the growth and organization of hospice facilities. The transition from medical movement to a medical organization or service does not seem inevitable or natural given its critical origins. Historical accounts of the movement's development have highlighted the perceived need for an alternative way of dying and more recent studies document the current practices of hospice, but a complete narrative from movement to organization seems to be lacking. The purpose of this paper is to examine the transition of hospice from an alternative to accepted ideology and the movement's relationship with traditional medicine. Through a systematic analysis of *The Hospice Journal*, the official National Hospice Organization's publication from 1985-2001, a theoretical understanding of this movement's unique trajectory is be developed.

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CHAPTER I

INTRODUCTION

There are few truly universal human experiences. The most obvious exception is that each individual will experience death either through the loss of family and friends, or their own death. Although death and dying is universal, traditions and beliefs of different cultures vary. As society changes social expectations in death change as well.

One of the most significant writings about death in Western culture is Elisabeth Kubler-Ross' famous book *On Death and Dying*. This 1969 piece reflects on American society's approach to death, grief, and the end of life generally. Her book highlighted the problems with treating death as taboo and opened up communication about experiences of death. Pioneers of hospice philosophy commonly refer to the importance of this book in initiating cultural and social changes about the dying process. Foreshadowing these changes, Kubler-Ross wrote:

We would think that our great emancipation, our knowledge of science and of man, has given us better ways and means to prepare ourselves and our families for this inevitable happening. Instead the days are gone when a man is allowed to die in peace and dignity in his own home.

The more we are making advancements in science, the more we seem to fear and deny the reality of death. How is this possible? (Kubler-Ross 1969: 7).

Scientific progress cannot eliminate death. Kubler-Ross and those in the early hospice movement observed the negative effects of relying on scientific rationality when caring for dying patients, the dehumanizing nature of technological death:

One of the most important facts is that dying nowadays is more gruesome in many ways, namely more lonely, mechanical, and dehumanized; at times it is even difficult to determine technically when the time of death has occurred.

Dying becomes lonely and impersonal because the patient is often taken out of his familiar environment and rushed to the emergency room....When a patient is severely ill, he is often treated like a person with no right to an opinion. It is often someone else who makes the decision if and when and where a patient should be hospitalized. It would take so little to remember that the sick person has feelings, has wishes and opinions and has-most important of all- the right to be heard (Kubler-Ross 1969: 8).

These sorts of images and emotions represent the observed problems in the dying process that led to the development of the hospice movement.

Hospice began as a movement that was critical of the treatment of terminal patients within traditional medicine and its cure-oriented logic, arguing that traditional medical practices and policies can be dehumanizing for the terminally ill (Dubois 1980; Munley 1983; Stoddard 1991; Levy 1994). Early hospice leaders observed the need to treat terminal patients holistically and design individual treatment plans that maintain dignity through the dying process. Historical accounts of the movement's development have highlighted the need for an alternative way of dying and more recent studies document the current practices of hospice, but a complete narrative that traces the development of hospice from a movement to an organization is lacking.

Today participation in a hospice program is viewed as a natural final step in the dying process. The number of hospice facilities quickly grew and the movement obtained financial support through Medicare within its first ten years of existence (Mor 1988). Because of its rapid growth and cultural acceptance, the hospice movement presents an

interesting case in the study of social movements. The progressive and alternative ideals of the early hospice movement were loaded with political issues and challenged an assumed logic within traditional medicine. The movement then shifted the majority of its energies towards the growth and organization of hospice facilities. However, the transition from medical movement to a medical organization is not inevitable given its critical origins. The purpose of this study is to examine the transition of hospice from an alternative to the accepted ideologies within traditional medicine and toward the development of a formal organization.

To assess the developmental trajectory of hospice, a two-phase content analysis of *The Hospice Journal* was conducted. *The Hospice Journal* was published from 1985 until 2001. During this time period, it was the official journal of the National Hospice Organization publishing articles related to all aspects of hospice services and care. Examining the articles over this fifteen-year time frame creates a picture of the progression and development of hospice.

The analysis was completed in two phases. The first phase included a random sample of thirty articles. In this sample, each article was examined by summarizing the article's argument and extracting possible themes and patterns related to the discourse of the hospice movement. Changes in topics, terms, and issues over the fifteen years of publication highlight the potential changes within the hospice movement. After the completion of the first phase, a coding scheme was developed based on the findings from the first sample. A second random sample of 113 articles was then analyzed using this emergent coding scheme. The first phase utilizes a grounded episteme to allow the text to

speak for itself, while the second phase encompasses a larger sample size including at least one article from each published issue, which allows for a more reliable analysis about the existence of particular trends and significant differences across time.

Through this two-phase analysis the relationship of hospice to traditional medicine was examined through the themes and changes over time. This content analysis provides insight into the development of the hospice movement without imposing a predetermined coding scheme. After completion of the second phase, trends and patterns were analyzed to provide understanding of the unique development of the hospice movement. A three-stage model of development was constructed based on both statistical and qualitative analysis of the data.

CHAPTER II

LITERATURE REVIEW

Through the examination of the existing literature a historical and theoretical understanding of the emergence of hospice can be developed. Positioning the creation of hospice in the context of allopathic medicine highlights the need for an alternative in end of life care. Social movement theory also provides depth in analyzing the trajectory of the hospice movement. The purpose of this chapter is to provide both background information needed to study the hospice movement and situate the movement within existing social movement literature.

Hospice Philosophy and the Development of its Practices

Hospice is a philosophy of care for terminal patients that has had significant influence on current practices in end of life care. This philosophy developed out of observed shortcomings within the traditional healthcare system and attempts to restore dignity to the dying process. Hospice care is typically associated with a shift from curative treatments to pain management and symptom control (Osterweis & Champagne 1979). Hospice care providers take a holistic, multi-disciplinary approach to end of life care and acknowledge the importance of the entire family as the unit of care. Bereavement and grief are also addressed in hospice care.

In the United States three main methods of hospice care delivery developed early and have remained the most common ways in which hospice care is organized (Osterweis & Champagne 1979; Mor 1988). Originally, hospice care in the US was delivered in the

patient's own homes. This allows terminal patients to spend their final days surrounded by family and in a familiar setting. Home-based hospice continues to be a common method particularly as general home health care has grown generally within traditional medicine. The next development in hospice care was the development of freestanding hospice units. In the UK this was the first system developed and as US hospice grew, more freestanding hospice facilities were established modeling the UK system. A freestanding hospice unit is an in-patient hospice unit equipped with proper medical and support staff. All patients there are considered terminal and not given any curative treatments. The final development of hospice occurred within traditional hospitals or long term care facilities. Today, many hospitals have a hospice wing or have teams that offer hospice services to terminal patients.

The range of services that fall under the hospice care umbrella vary from pain management to spiritual counseling to daily nursing care. Each patient and their family direct what qualifies and is necessary within their hospice treatment plan. The main qualities of hospice care are that the treatments are not directed towards a cure and that they improve quality of life and maintain the dignity of the patient. Typically included in hospice care plan is the administration of morphine or other pain medication, assistance with daily health and hygiene, and counseling for the patients and family (Mor 1988). This individual approach allows for the unique needs of each patient to be met and expands the possible services that can be considered hospice care.

Hospice as a Social Movement

Although early hospice was commonly referred to as “the hospice movement”, early activity fits formal theoretical models of social movements. An early and basic definition of social movements by McCarthy and Zald (1977) is: “a social movement is a set of opinions and beliefs in a population representing preferences for changing some elements of the social structure or reward distribution, or both, of a society” (1217-18). Based on this definition of social movements, hospice represents a social movement by virtue of its clearly defined set of beliefs that attempt to change the structure of the dying process. Early hospice was more than just a service. It was an ideology critical of traditional medicine’s treatment of terminal patients that proposes a new approach to end of life care.

Because it lacked any famous, raucous protests in the streets characteristic of other social movements, hospice may not fit the typical image of a social movement. The focus of much of the social movement research has addressed more traditional conflict movements such as feminism, civil rights, or labor (McCarthy & Wolfson, 1992). In contrast to these movements led by minority groups, consensus movements are “organized movements for change that find widespread support for their goals and little or no organized opposition from the population” (McCarthy & Wolfson, 1992: 273-4). The hospice movement exemplifies this category of social movement. This is not to say that hospice was universally accepted from the beginning, but it certainly did not face the organized ideological opposition experienced by other movements. There is a defined goal for social change, but the goal received much support and little opposition.

Restoring dignity in the treatment of terminal patients is a goal that easily gained support by the larger society and also faced comparatively little institutional resistance.

Cooptation and the transition to a formal organization is common in consensus movements because this change does not alter the original goals of the movement and increased structural support can further the movement (McCarthy & Wolfson 1992). The hospice movement developed into a network of formal organizations with the implementation of structural support in the Medicare Hospice Benefit. Although this change within hospice seems to be a step away from the social movement origins, this theory of consensus movement ultimately predicts this type of organizational change.

The following sections describe the history of the hospice movement. The need for the emergence of hospice is rooted in the development of the cure-orientation within traditional medicine. After the need for an alternative approach to end of life care is established, the development of hospice will be discussed with an emphasis on the US hospice movement. This chapter concludes with a discussion of frame analysis within social movement theory and its relevance to studying hospice.

Development of Allopathic Medicine

Traditional healthcare has an evolving relationship to the death and dying process (Munley 1983; Stoddard 1991). Early medical theories including folk remedies and Galen's humors could do little to systematically treat illness and disease (Duffy 1993). Medical care offered few concrete answers and the success of procedures was based more on chance than on scientific evidence. Life expectancies were short due to acute diseases

and a multitude of social risks such as war and harsh labor conditions. Because doctors could offer few solutions to cure fatal ailments, the dying process was essentially viewed as outside of the medical realm. For centuries, both medical care and the dying process took place in the home in the presence of family and was relatively brief (Munley 1983; Stoddard 1991).

As medical knowledge expanded and gained understanding of the effects of bacteria on the body, medical treatments made quick strides towards success. Medical researchers used knowledge gained from the “bacteriological revolution” to make progress in the treatment and eventually the prevention of the major contagious diseases (Duffy 1993). The discovery of penicillin allowed for effective treatment of many bacterial infections, and the invention of vaccines essentially eliminated previously fatal diseases. These advances in medical knowledge changed the underlying mindset of doctors and the medical field as a whole. The ability to prevent and easily treat illnesses that had once been fatal dramatically increased the success rates of medicine. This new found success and control over diseases legitimated allopathic medicine and gave doctors increasing confidence. Success in treating acute illness created confidence in the medical field and bolstered the curative agenda of medicine. In relation to death and dying, the evolution of germ theory and the development of vaccines and penicillin did not immediately change the care given to the dying. However, it did begin to change the causes of death as life expectancies dramatically increased (Levy 1994). Most bacterial infections were no longer fatal after penicillin became widely available in the 1940s.

The success of medical treatment affected the ways in which health care was delivered. Doctors assumed an elite position within society and heavily relied on their abilities to cure as seen in Parson's concept of the sick role (Bird, Conrad, Fremont 2000). In the sick role, doctors are viewed as holding the answers to cure whatever ailment the patient presented. The success of medicine affected the actual delivery process as well. As lay people become more confident in medical treatments, more individuals abandoned home remedies and sought professional medical care. Hospitals and private practices received more patients who expected cures for their illnesses. The understanding and successful treatment of bacterial infections and other acute diseases created a new market for medical care. Vaccines and penicillin injections became a demanded commodity to promote the health of individuals. As the demand for these medical commodities increased the medical industry continued to be successful and in high demand.

As life expectancies continued to increase with the effective treatment of acute illnesses, new health issues arose. Health issues such as cancer, heart disease, Alzheimer's, and strokes became more prevalent with longer life spans. Penicillin and vaccines were no longer cure-alls, because these diseases could not be effectively treated or prevented with a shot. These illnesses represent a change in the types of diseases people began to experience. This transition from acute illness to chronic diseases is known as the epidemiological transition (Omran 1971).

Chronic illnesses have never been as effectively treated as acute illnesses. The successful elimination and treatment of many acute illnesses created a medical model that

gave physicians and patients inflated confidence in medical care. The repeated success in acute treatments gave doctors the sense that curing is possible and should be the goal. This medical model was transplanted onto the treatment of chronic illnesses as well. As medical knowledge and technologies have continued to develop new procedures and medications have been invented to at best alleviate pain and at least help prolong lives permeated by chronic illness. At the same time, the attitudes and beliefs towards finding a cure within the medical model lead to the development of intense treatments and increasingly invasive procedures for chronic illnesses. Life expectancies have been extended through these technologies, but actual cures for many of these diseases do not seem to be in our near future.

Formal Rationality and the Medical Model

In his writings about types of social actions, Max Weber examined motivations for action and developed the distinction between formal and substantive rationalities. Formal or instrumental rationality utilizes means/ends thinking. Actions that are formally rational are calculated to achieve the desired result in the most efficient and productive manner. Formal rationality is focused on the quantifiable results of any given action. “Action is instrumentally rational when the end, the means, and the secondary results are all rationally taken into account and weighed” (Weber 1914:227). Substantive rationality is the way of thinking based on values, emotions, and traditions. Substantively rational actions are based on the individual and group’s ideologies, affect, and habits. These actions do not have to be the most productive or efficient, but have to match group

norms. A substantive rational “orientation would be the actions of persons who, regardless of possible costs to themselves, act to put into practice their convictions” (Weber 1914: 227).

The development of the modern medical model reflects the implementation of formal rationality within the health care system. The success in treating acute illnesses created a logic that was based on physician’s ability to cure a patient. As this mindset was replicated through more medical successes, the medical model became more and more driven by formal rationality. Patients present with a disease (problem). The doctor then has the knowledge and technology to diagnosis and treat the disease (means). The treatment, if successful, then attains the goal of curing (ends). This became the model for medical treatment and created expectations of doctor and patient roles. Through formal rationality, the medical model treats the body as a factory seeking to remedy malfunctioning “parts” to produce cured bodies.

Weber’s conceptualization of formal rationality can be seen in the development of the cure-orientation within the medical model. Weber also argues that logics multiply in the culture through the continual replication of formally rational mindsets. As the cure-orientation in treating patients became more successful, and therefore was repeated within each medical case, a culture of means/ends thinking was established within medicine. It is the repetition of this logic that creates the biomedical model. The ability to cure acute diseases gave doctors confidence in their cure-oriented rationality. This assurance in the model gave way to the spread of this logic to other areas of the medical

system. The bureaucratization of hospitals and other healthcare delivery institutions reflect a focus on productivity and efficiency when treating patients.

As previously discussed, the advances in medical care and prevention have increased life expectancy and changed the ways in which people die. Because of the focus of the cure-orientation in the medical model, terminal patients often remain hospitalized and aggressively treated until their disease actually proves fatal. The formal rationality within the biomedical model creates a medical system with a secondary goal of avoiding death. This pattern was observed by early hospice supporters:

According to this model, disease is defined in terms of physical and biomedical deviations from the norm; physicians are to be problem solvers skilled in ferreting out the causes and remedies of disease; patients are to be compliant raw materials for the enterprise of curing; and hospitals are to be places designed and organized for the specific purpose of controlling death (Munley 1983:13).

The view that medicine has control of the death process has affected the ways in which dying patients are treated. However, when unchecked by considerations outside of formal rationality, the cure-oriented logic within the biomedical model can dehumanizes terminal patients. If the goal of a cure is not within reach, the goal often shifts to the prolonging of life through technology and not on the quality of life for the patient. Formal rationality maintains the focus of measurable (length of life) outcomes over subjective outcomes (quality of life). The inability to actual control death changes the formal logic that underpins the traditional biomedical model.

The bureaucracy within medicine has also affected the dying process. Weber explains that the characteristics of bureaucracies develop to maintain efficiency and productivity within an organization (Weber 1922). In the traditional biomedical model

death is viewed as deviant from those goals. A 1967 study conducted by sociologist David Sudnow, examined how bureaucratic hospitals were handling death issues (Munley 1983). He discovered that some hospitals allowed practices that would expedite post-death procedures. Some examples include:

Forcing a dying person's eyelids to close before death because it is more difficult to do so after death; inserting dentures in a dying person's mouth for the same reason; prewrapping portions of the body before death, 'leaving only a few moments of final touch-up work with the dead body'; and arranging for an autopsy or disposing of personal effects while the person is still living (Munley 1983: 18).

These cases demonstrate the dehumanizing consequences of the implementation of bureaucracy through formal rationality on the treatment of dying patients.

It took the success of allopathic medicine in treating of acute illness to highlight these problems within the biomedical model. If individuals were not living longer, the cure-orientation would not have been challenged through the dying process. As medical professionals and lay people began to observe these shortcomings in the biomedical model, space was created for a new ideology to emerge. The hospice movement offered an alternative to both formal rationality and the dehumanization of dying due to bureaucracy.

Emergence of the Hospice Movement

The hospice movement sought to move away from a cure-orientation and develop practices that respected individual circumstances and worked to provide comfort (Mor 1988). "Each patient would be appreciated instead as a total person who had vital connections to other people and who should not be expected to surrender values and

preferences developed over a lifetime in order to die in a manner convenient to the system” (Mor 1988: 9). The cure-orientation within the medical model created a pattern of intense medical treatment until the very end of life. As it became more common that patients died connected to machines in an isolated hospital room, a movement emerged presenting an alternative way of dying. Led by both medical professionals and lay people, the hospice movement was created to offer a different approach for the dying process.

Hospice maintains two goals for end of life care: “the terminally ill person’s own preferences and life-style must be taken into account in all decision-making and family members and other caregivers also have legitimate needs and interests that must be taken into consideration” (Mor 1988: 9). The hospice movement challenged the cure orientation of the biomedical model. Hospice allowed for different goals and treatment plans based on each individual’s preferences allowing patients to opt out of intensive end-of-life care that tended to produce small gains in the number of days lived, but at the expense of quality of life.

The movement began in England by medical doctor Cicely Saunders. She founded St. Christopher’s, the first hospice, in 1967. As a medical professional she was exposed to the shortcomings within traditional medicine. Her work with terminal patients and her professional experience led to critical evaluation. Saunders (1958:46) highlights the growing problems of end-of-life care:

It appears to me that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient’s own struggle within his compass and to bring hope and consolation to the end.

The goals of hospice diverged from traditional medicine since its beginnings. Saunders believed that terminal care should be holistic, attentive to pain management, and directed by the individual narratives of the patients (Clark & Seymour 1999).

Saunders was also crucial in the start of the hospice movement in the United States. In 1963, she was invited to present a lecture at Yale's nursing school discussing her philosophy about death and dying (Paradis 1986). Florence Wald, a nursing faculty member, and Edward Dobinal, a local minister, were in attendance. Together these two would eventually found the first US hospice. Inspired by Saunders lecture, Wald was later invited to learn and observe at St. Christopher's hospice and used this experience to model the early hospice work in the US. Cicely Saunders continued to lecture in the US through the sixties and early seventies. Her leadership and narratives of her work quickly made her a charismatic leader (Clark & Seymour 1999). At this same time Elisabeth Kubler-Ross was beginning to bring awareness about the dying process. Like Saunders, Kubler-Ross was a physician who made some critical observations about the typical experiences of terminal patients. Through interviews with dying patients, Kubler-Ross discovered in the US there was a lack of knowledge about death (Paradis 1986). Her famous book, *On Death and Dying*, brought a humanitarian view to death and opened communication about a private issue. Kubler-Ross also frequently gave lectures and is viewed as another important leader in the hospice movement.

By 1974 the first US hospice was started in New Haven, Connecticut by Florence Wald and Edward Dobinal (Mor 1988; Paradis 1986). Like the British system, US healthcare had not adapted to the changes in the dying process and was increasingly

criticized. The US hospice movement was driven by these problems in healthcare with the goal of drastically altering end of life experiences. A focus on the need for holistic care was crucial to early hospice:

The void exists partly because acute care hospitals are ill-suited to meet the physical and emotional needs of the dying, who must watch their own deterioration and the slow approach of death over a period of weeks or months. Such institutions are geared instead to cure patients and send them home as quickly as possible and to give efficient rather than individually optimized care (Kohn 1976:26)

The US hospice movement also saw the structure of the biomedical model as the cause of dehumanizing treatments for terminal patients. Restoring dignity was a goal of hospice care from its inception:

Whatever its efficacy in terms of cure, the bureaucratic, biomedical model has a vast potential for dehumanization. When a dying person is treated as a thing, a machine, a guinea pig, a problem, an inferior, or an isolate without options in impersonal, sterile environments, one is robbed of human dignity, of the freedom to die in one's own way and in communion with one's fellows (Munley 1983:13)

The hospice movement presented a critical alternative to traditional medicine's treatment of dying patients by proposing holistic care plans that preserve the dignity of every patient.

Early US hospices developed in three main models discussed previously (see also, Mor 1988). Saunders and the team at St. Christopher's encouraged visits to England for training and discussions (Paradis 1986). Using the British model, hospice in the US was able to grow quickly as a grassroots movement. Early organizers included physicians, nurses, and lay people concerned about maintaining human dignity throughout the dying process. In her lectures, Saunders stressed the importance of each hospice reflecting the needs of the individual communities (Osterweis & Champagne 1979; Paradis 1986). This

individual assessment of need is one of the reasons early hospices took different approaches to care delivery.

The first US hospice in New Haven, Connecticut utilized two methods of care delivery. The organization began by providing home care to terminal patients. Through federal grants, foundations, and individual donations, a forty-four bed freestanding facility was eventually built and staffed with a full-time multi-disciplinary team (Osterweis & Champagne 1979). The New Haven Hospice hosted the first hospice conference in 1975 which allowed for community organizers to gather from around the country (Paradis 1986).

Hospice grew quickly, with more than two hundred and nine hospice organizations existed in the US by 1979. The steady growth and increased national attention of hospice during its early years engendered structural support not always given to other social movements. Alongside the spread of hospice philosophy, policies began to reflect hospice ideals. The “Death with Dignity” movement was a political movement aimed to provide families and patient’s the right to discontinue life support (Munley 1983), a right guaranteed by the 1976 passage of the Natural Death Act. The emergence of the hospice movement paralleled the general increase in awareness of the need for dignity through all stages of life.

In 1982, legislation was passed allowing Medicare coverage for hospice services (Mor 1988). Hospice advocates and lobbyist were able to push this bill through Congress with relatively low resistance. The values of hospice and the focus of preserving dignity throughout the life course were accepted, not just as the interests of a small group, but as

a concern of all people (Mor 1988). This national recognition and financial support served to validate the goals of hospice, but at the same time, constraints were placed on its procedures and practices. Medicare is a bureaucratic system and requires specific documentation to receive benefits. Including hospice under Medicare coverage placed new guidelines on who could be admitted to a hospice program and how each hospice organization must operate. Physician referral was required and the documentation for each patient was formalized and standardized for each hospice organization. These changes led to an increase in uniformity for local hospice organizations and in the professionalization of the movement (Paradis 1986). Volunteers and laypeople are still crucial to hospice, but the increase in documentation due to Medicare requirements created a need for professionalization within the movement.

The three forms of hospice remain the same and the Medicare requirements have continued to standardize the functions and practices of each hospice organization. The late 1980s also saw an increase in the formalization of the movement. Professional organizations quickly formed to support education in hospice ideology and practice. The American Academy of Hospice and Palliative Care was founded in 1988 to promote hospice ideology through continuing education for physicians (www.aahpm.org). This organization started with 250 members and has grown to over 4000 members currently. The organization meets annually and offers hospice training for doctors. The Hospice College of America also serves a similar purpose in offering continuing education courses on hospice practices for medical professionals. The Hospice Foundation began in 1990 to provide information about hospice and end of life issues to patients and

doctors (www.hospicecollege.org). Currently this organization offers support and education to individuals and physicians through online resources, newsletters, and continuing education.

The National Hospice Organization was founded in 1978 and provided structure and support for the development of the movement (www.nhpco.org). The NHO offered assistance and guidance in starting a local hospice organization and also was involved in lobbying for Medicare benefits. The organization has remained central to the hospice movement and continues to offer support for local hospice organizations. The NHO also has worked to maintain professionalism and uniformity across different hospice organizations. In 2000, the NHO released standards of practice and a philosophy statement for hospice in general. The NHO now serves as a central organization point for the hospice movement providing resources for hospice organizations and politically advocating for the goals of hospice.

Creation of Palliative Care

Like the hospice movement, palliative care as a subspecialty in medicine also originated in England. Palliative care developed alongside hospice and has similar values and ideas about the dying process. The first palliative care teams were established in hospitals in England in 1976 (Clark & Seymour 1999). These early palliative care teams were from a variety of medical specializations and focused on providing emotional support for terminal patients as well as pain management. By 1987, palliative care was recognized as an official specialization within Britain's health care system. At this same

time, there was a shift in the language used to discuss end of life care. In the UK there was a clear transition away from the terms “hospice” and “terminal” and an increase in the use of “palliative care” (Clark & Seymour 1999). However, the concept of “palliative care” does not significantly appear in the United States until the mid 1990s with the opening of palliative care centers in hospitals that mainly focus on pain management (Byrock 1998).

Palliative care is a difficult concept to define and there are a variety of interpretations of what qualifies as palliative care. Quill (2001) defines palliative care as “focuses on relieving pain and other physical symptoms, enhancing psychosocial supports, and allowing patients and families to achieve meaningful resolution to their lives together” (2001:100). This definition offers a broad understanding of palliative care as a holistic approach to patient care. The World Health Organization sees palliative care as an alternative to curative treatments in this definition below:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. (WHO 1990).

Other interpretations of palliative care allow for implementation of palliative care throughout the life course not just in cases where a patient is out of curative options (Clark & Seymour 1999). This more current view allows palliative and curative treatments to be integrated into one treatment plan.

The increase in palliative care within hospitals in the United States can be seen as the result of two trends within contemporary health care. First, the ongoing debate on

physician-assisted suicide had sparked interest in end-of-life care (Byock 1998). Developing a strong palliative care programs offer an alternative to PAS that maintains dignity and quality of life. The second trend is the rapid growth and expansion of hospice programs through Medicare reimbursement. The acceptance of hospice philosophy towards death and dying prompted traditional medicine to become more self-critical and integrate the ideas of holistic care into traditional practices (Connelly 1998). Palliative care has become such a predominant approach to end-of-life care, hospice is now seen as one model of palliative care delivery (Byock 1998).

Frame Analysis and Social Movements

One approach to understanding the evolution of a group or organization is to examine the discourse within and related to the group. The history of discourse analysis within the discipline of sociology originates with Erving Goffman's important book *Frame Analysis*. Goffman defines a frame as a "schemata of interpretation" (1974:21). These frames guide how experiences are conceptualized and defined. The purpose of frame analysis is "to try to isolate some of the basic frameworks of understanding in our society for making sense out of events and to analyze the special vulnerabilities to which these frames of reference are subject" (1974:10). The book continues by elaborating the concept of frame and its function within interaction including the development of frames, the problem of breaking frames, and the frame analysis of talk.

The ideas within *Frame Analysis* have been used across a variety of disciplines. In sociology, social movement researchers have adapted Goffman's ideas into the study of

collective action frames. This theory developed in the 1980s and emphasizes the importance of meaning construction through interaction in social movements (Benford & Snow 2000).

From this perspective, social movements are not viewed merely as carriers of extant ideas and meanings that grow automatically out of structural arrangements, unanticipated events, or existing ideologies. Rather, movement actors are viewed as signifying agents actively engaged in the production and maintenance of meaning constituents, antagonists, and bystanders or observers (2000:613).

The creation of action frames is a dynamic process and gives meaning and structure to the organization of a social movement. This type of analysis examines the language used to position the movement and has been utilized to study a variety of movements (Benford 1993; Cress & Snow 2000; Donovan 1995; Haines 1996; Heitlinger 1996; Johnson 1997; Nepstad 1997 Weed 1997; Zuo & Benford 1995).

Action frames are seen as having three main tasks. Diagnostic frames serve to identify problems within society (Snow & Bedford 1992). This type of framing task highlights the issues within social structure and the causes of those problems. The next framing task moves beyond simply stating the problem. Prognostic frames also offer some direction towards a solution (Snow & Benford 1992). A direct plan of action is included in this framing task. The final framing task is to provide motivation for individuals to act (Benford & Snow 2000). The language used to establish these three tasks must resonant with potential members in order for the movement to fully organize and attempt to encourage social change (Snow & Benford 1992).

The history of the hospice movement illustrates clear changes over time in organization and function. Based on a contextualized frame analysis, an analysis of

language and issues over time will reflect these changes. The topics presented as significant for the movement at a given time reflect how the movement was framing its purpose. Discovering key changes over time in the discourse and language of hospice will provide understanding in the evolution of the movement.

CHAPTER III

METHODS

The importance of frame and language within social movements, led to a desire to study changes in the discourse of the hospice movement. An analysis of the changes in language and issues within the hospice movement over time would provide insight into the development of the movement. Content analysis was selected as the most suitable method to collect this type data.

Content Analysis

Content analysis developed as a research technique in the late 1800s starting with the analysis of the information published in popular newspapers (Krippendorff 1980). The method continued to develop and is commonly used as a technique in the social sciences especially in communication studies. A simple definition of content analysis is “a research technique for the objective, systematic, and quantitative description of the manifest content of communication” (Berelson 1952:18). The premise of this technique is that the researcher has the ability to make inferences from the data to determine the meaning of the content. Content analysis allows for a systematic method to empirically observe content within text (Sepstrup 1981). There are multiple designs within content analysis resulting in both quantitative and qualitative data. In quantitative content analyses, characteristics are recorded through quantifiable measures such as absence or presence of a particular word or concept. A qualitative content analysis treats narrative data in its natural form, looking for themes with a focus on meaning and rich description.

One strength of content analysis is this method allows the researcher to gain empirical information about events that are not directly observed and which often cover comparatively long periods of time. Analyzing historical documents through a systematic content analysis allows a researcher to collect data about a time period or event that has already occurred. Content analysis can also provide access to groups without physical observation of their interactions. The major critique of this technique is the difficulty to maintain objectivity (Carney 1972). Content analysis is based on the interpretations of the researcher and one criticism is that content analysis can become an “impressionistic reading” (1972:11). The manner in which a content analysis is designed can help combat this criticism. While complete objectivity is not possible, there are research designs that help maintain objectivity.

In an attempt to maintain objectivity, a two-phase content analysis was selected as the method to address the development of the hospice movement. By not using a predetermined coding scheme, a two-phase content analysis reduces the researcher bias. The themes and codes can emerge from the data objectively without the preconceived opinions of the researcher reducing bias in the examination. Establishing inter-coder reliability will also reduce the interpretive bias of this method. A two-phase method was developed to first let the data arise from the text and then to quantify these observations. The first phase analyzed the articles for patterns in language and topics to create an emergent coding scheme. The second phase was conducted as a traditional content analysis finding absence or presence of the codes. The following sections offer a detailed description of the sample, development of codes, and the analysis used in this study.

Description of Sample

For this analysis, *The Hospice Journal* was selected as the data source using articles published between 1985 and 2001. This journal was the official publication of the National Hospice Organization (NHO) and reflects how the movement framed itself and the issues of interest within the movement. This journal offers access to ideas and language of the past. This journal is currently being published as *The Journal of Pain and Symptom Management*. The name was changed in 2001 and because of this change in focus, the sample ends in the same year, even though the National Hospice Organization sponsored the journal under each of the names. Through this peer reviewed journal, NHO advances knowledge and understanding of hospice and palliative care from scholars in a variety of fields including medical, psychology, social work, sociology, and religion. Using the journal sponsored by NHO offers an insider's perspective into hospice as a movement during this fifteen year time period. The endorsement by NHO demonstrates the salience of the topics represented in the journal's content. Another reason this journal was selected over other hospice publications is its multidisciplinary approach. There are other reputable journals within the different hospice specializations, but *The Hospice Journal* includes articles from a variety of different subfields. This diversity in the content publish provides a more complete understanding of the overall discourse.

Two random samples were selected from the first fifteen volumes of the journal spanning the years 1985-2001. In this time period three hundred and forty-two articles

were published excluding book reviews and clinical notes. Issues were published quarterly and the number of articles in each issue ranged from three to nineteen.

The first sample selected was a small sample of articles. The purpose of this phase was to develop a coding scheme based on an emergent understanding of the language and main concepts related to the development of hospice. The third article was selected as a random starting point. Every fifth article was selected from that point totaling sixty articles. After analyzing the first fifteen articles, it was determined that the sense of the field was already clearly established as emergent themes were repeating. The sampling frame was therefore shifted to include every third article of the first sample. These articles were analyzed to reach saturation and the final sample of the first phase totaled thirty articles.

The second sample was much larger because of the nature of this stage of the analysis was partly quantitative. To gain a full understanding of the development of hospice in this time period at least one article from each issue was included in the sample. Since the shortest issue contained three articles, every third was selected starting randomly at the fifth article. If an article was selected that was previously included in the first sample, the preceding or following articles were selected alternating with each article selected for a second time. The count of every third article remained consistent with the original article selected regardless if it had been previously selected. The final total used for the second phase of the analysis was one-hundred and thirteen articles.

Development of Coding Scheme

To develop a coding scheme that reflected the data without imposing preconceived categories, the first sample was analyzed through line by line analysis. Each article was read closely and detailed notes on the language, topic, method, and field were recorded. This technique provided understanding of the overall discussion about hospice and allowed the codes to emerge from the data source. This analytical technique resulted in the observation of overarching trends, which were then broken down into more general themes. The abstract themes were then formalized culminating in the creation of forty-six discrete codes.

The themes and codes will be described more fully in the following chapter. The discrete codes represent the language and key issues found within this period of the hospice movement. In addition to the codes related to the discourse within hospice, each article was also coded for the field, year, method, data source, technique, and qualifications of the author. These descriptive codes provided further understanding of the journal's focus in topic and method.

Data Collection

After developing this emergent coding scheme, the second sample of one hundred and thirteen articles was analyzed. Each discrete code was marked as absent (0) or present (1) in every article. This technique resulted in the creation of binary variables for each of the codes. Along with these quantified observations, notes were recorded for each article about any patterns or interesting changes in the topics and language used. This qualitative element provided a richer understanding of the dynamics within the hospice

movement and ensures any changes neglected by the coding scheme will still be accounted for. Once the content analysis was completed the raw data was transferred to SPSS for statistical analysis.

The previous section describes the development of the coding scheme as a move from abstract observations to more general themes to discrete codes. The process produced forty-six discrete codes that represented specific language and topics within the hospice movement (see appendix). The presence of such a large number of discrete codes can present a challenge in obtaining statistical significance due to lower frequencies within the variables. To avoid this potential problem, the discrete codes were combined to reflect the more general themes observed in both the first and second phases of the content analysis. The combined variables represent a set of related conceptual categories related to the hospice discourse. The first phase provided a strong base in the understanding of the development of hospice and the notes on the second phase further fleshed out these concepts. Although the final themes are quite similar to the themes discussed in the development of the coding scheme, the qualitative analysis in the second phase provided a more detailed understanding.

A three stage model of the trajectory of the hospice movement was developed that will be explained more completely in the next chapter. For methodology purposes, only the combination of the variables that represent these stages will be discussed here. Six variables were created to reflect each stage. The first variable is more general and the second more specifically reflects the discourse for the stage.

To represent the first stage two variables were created for the analysis. Combining the discrete variables “alienation,” “alternative,” “non-traditional,” hospital as negative, bureaucracy as negative, isolation from family, and inability to cure created the variable “oppositional”. This variable represents the oppositional attitudes and language of early hospice. Also related to this stage the variable “movement language” was also created by combining the discrete variables political campaign, “Die with Dignity,” and “Movement”. This variable is more specific in representing the social movement elements of the oppositional stage.

Again, two variables were created to reflect the discourse of the second stage. The variable “institutional” is comprised of the discrete variables “program,” “organization,” scope of services, assessment, access to care, and definition of roles. This combined variable represents both the presence of a formal hospice organization and an internal awareness of this change to a formal hospice organization. One important factor in the formal organization of hospice was the introduction of the Medicare Hospice Benefit. Combining the discrete variables cost of dying and power of physician to reflect this facet of the institutional stage created the variable “medicare”.

For the final stage the general variable “incorporated” was created with the combination of the discrete variables hospital based hospice, patient as consumer, high technology, and discussion of integration. To more specifically address the language in this stage, the variable “incorporated language” was created using the discrete variables “palliative medicine,” “hospice physician,” and “hospice patient”.

The final combined variable, “ideology,” does not necessary fit within the three-stage model of hospice development. This variable will be used to assist in the explanation of the co-option of hospice philosophy in traditional medicine. This relationship will be explained more fully in the following chapter. Each of the seven combined variables was recoded back into a binary variable. This technique allows the presence of these variables to be observed instead of creating a scale and observing the intensity of the variables.

Inter-Coder Reliability

Because one individual coded the sample, reliability in the coding process needed to be established. A subset of the sample was selected to include every third article. The subset began at the sixth article as a random start totaling in thirty-six articles. These articles were distributed to a group of coders along with the description of the codes found in the appendix. After the articles were recoded, the data was entered into SPSS to test for reliability.

The Kappa reliability statistic ranges from -1 to +1 (Cohen 1960; Fleiss 1973). A score of -1 represents total disagreement, 0 represents total chance agreement, and +1 represents total agreement (Cohen 1960). The results of the reliability statistics demonstrate weak agreement ranging from -.065 to .357 and the results for each combined variable can be found in the appendix.

Although the kappa scores indicate low reliability, the coding scheme maintains reliability through its emergent design and the qualitative aspect of the analysis. The

problems with establishing inter-coder reliability are attributed to the difficulty in recruiting enough experienced coders. There were a few coders whose results differed from the original codes and when those are removed there is reliability.

Analysis

The purpose of this study is to gain understanding of the changes within hospice over time. ANOVA was used to test for significant change over the time span of the sample. The seven combined variables were used as the dependent variables and the independent was the variable “year”. This analysis examines the variance between the fifteen years individually. In this first analysis “year” is treated as a continuous variable. This resulted in a small case number for the combined variables in each individual year and there were no significant difference over time, likely because of low counts of presence on each variable when divided into fifteen years.

In order to address the small number of counts, a new variable to represent time was created. This variable is a modification of the variable “year” and divides the time period into three periods based on theoretical considerations. The years were divided into groups to reflect three distinct time periods within the sample. Years 1985-1990 were coded as time one. By 1990 the majority of the changes in hospice Medicare policy were enacted. The benefit was made permanent, reimbursement for services had been increased, and accreditation procedures were formalized (Mor 1988). Years 1991-1996 were coded as time two and years 1997 to 2001 were coded as time three. In 1997, changes in hospice’s relation to traditional medicine began to surface. The National

Hospice Organization notes this year as significant in the integration of hospice philosophy into palliative and end-of-life care (www.nhpco.org). The second division was used to test for differences before and after integration. A second ANOVA was then completed using this new “time” variable as the factor for the seven combined variables.

In conjunction with the statistical analysis, a qualitative analysis of the themes was also conducted. After data collection was complete, the notes on the articles were reviewed for further understanding of the language and development of the hospice movement. The themes developed in the first phase were reexamined with the data from the larger sample. Articles were divided into categories that reflected each theme. Then relevant sections and quotes from the articles were abstracted to be used in the analysis.

CHAPTER IV

FINDINGS

The purpose of this study is to examine the development of the hospice movement in relation to traditional medicine. Through a review of the literature, it was evident that hospice began as a consensus movement aiming to reform the dying process and now currently functions as a formal element within the health care system. The systematic analysis of articles from *The Hospice Journal* provided insight into the discourse of the hospice movement allowing for the conceptualization of a three-stage trajectory model for hospice (see appendix C for Three Stage Model).

Phase One

In the first phase of the study, articles were analyzed to determine key topics and language within the hospice discourse. The content analysis led to the observation of two interdependent transitions within the hospice movement. During the span of the sample, hospice can be seen as developing from a social movement to a formal organization and as transitioning from alternative to incorporated within traditional medicine. For each of these general patterns, themes were conceptualized and discrete codes were further developed.

In the transition from the hospice movement to hospice organization, three themes were observed (see Table 1). The first was discussion of hospice as a social movement and the strategies needed to develop the movement. Many of these topics are typical issues within any social movement such as obtaining members and spreading awareness

(see also, McAdam & Paulsen 1993). Under this category, there were nine discrete codes that represent the language and issues related to the movement strategies theme including volunteer recruitment, political campaign, “die with dignity”, community education, definition of movement, ideology/philosophy, program maintenance, rapid growth, and “movement”. A full description of all the discrete codes used in this analysis can be found in the appendix. The second theme in the progression away from hospice operating as a social movement is the presence of organizational awareness. Hospice framing itself as a formal organization instead of a social movement is one indication of the change within the discourse. Concepts of professionalization, critique of programs and practices, and the presence of national organizations all reflect the development of organizational awareness. Under organizational awareness there were nine discrete codes: scope of services, definition of roles, professionalization, program assessment, access to care, costs of dying, National Hospice Organization, “organization”, and “program”. The final theme related to the transition of the hospice movement into an organization is an assumed presence of hospice. This theme represents a point in the development of hospice in which the need for and definition of hospice are accepted and no longer need to be clearly defined. Three discrete codes were developed under this theme: no definition of hospice, role assumed, and no discussion of hospice. Table one describes the three themes related to the transition of hospice from a movement to organization.

Table 1. From Movement to Organization

Themes	Description	# of Discrete Codes
Movement Strategies	Grassroots organization, methods, and language used to promote hospice ideals	9
Organizational Awareness	Operations begin to formalize and hospice can be seen as a profession	9
Assumed Presence of Hospice	Role in death and dying process is assumed	3

Hospice programs and ideology also can be understood as beginning as alternative and over time becoming incorporated into traditional medicine. Four themes were observed that explain this trajectory (see Table 2). The first theme speaks to the oppositional attitudes present when hospice was viewed as alternative to traditional medicine. This theme has six discrete codes (“dehumanize,” role stress, hospital as negative, bureaucracy as negative, “alienation,” and isolation from family) and reflects the negative sentiments of the early hospice movement toward traditional medicine.

The next theme highlights the shortcomings within the medical model from the hospice and traditional perspective. There are four discrete codes that represent issues within the cure orientation of the biomedical model: inability to cure, high costs of dying, power of physician, and fear of no treatment.

The third theme is the need for hospice to be defined as fundamentally different from the practices within traditional medicine. By defining hospice care as unique and different than traditional care, a clear need for the presence of hospice can be established. There are four discrete codes related to this theme: family as unit of care, holistic care, “alternative,” and “non-traditional”.

The final theme in the transition from alternative to incorporated is evidence of co-option. Within this theme the language and organization of hospice programs reflect a change in the relationship between hospice and traditional medicine. Attitudes of opposition are no longer present and language of traditional medicine is incorporated into the hospice vocabulary. Eleven discrete codes were developed to reflect the dynamics of this theme: “palliative medicine,” general dying issue, hospital based hospice, “hospice physician,” multi-disciplinary team, pain management, patient as consumer, high technology, discussion of integration, cultural acceptance, and “hospice patient”. Table two summarizes the four themes within the alternative to incorporated transition.

Table 2. Alternative to Co-opted within Traditional Medicine

Themes	Description	# of Discrete Codes
Oppositional Attitudes	Negative sentiments and language used in relation to traditional medicine	6
Shortcomings of Medical Model	Topics related to the drawbacks of the cure orientation within biomedical model	4
Defined as Different	Establishing hospice as a fundamentally different approach to death and dying	4
Evidence of Co-option	Hospice becomes integral aspects of end-of life care	11

Phase Two

The first phase of the analysis produced this coding scheme that moves from general observations to discrete codes. The final coding scheme of forty-six discrete codes was applied to the second sample of articles. After the second phase of data collection was complete a model to understand the changes within the hospice movement

was created. The analysis produced an understanding of three distinct stages of hospice. An early grassroots movement started among a small group of volunteers and medical professionals organized around their passion to reform the dying process. Throughout the 1980s, this social movement grew quickly and began to formally organize and develop professional standards of practice. Finally, hospice currently operates as an integral aspect of end-of-life care working in conjunction with traditional medicine. Reflecting these observations, hospice can be seen as moving from an oppositional social movement to an institutional organization to an incorporated element of traditional medicine. Through the analysis of articles from *The Hospice Journal* an expected three-stage trajectory was developed and the sections below further explain these findings.

The Three-Stage Trajectory of Hospice

The first period finds hospice oppositional to traditional medicine. The discourse reflected this opposition and hospitalization was viewed negatively because of extreme, dehumanizing treatments and the alienation of the patient from their families. H1: Journal articles from this stage should contain significantly higher numbers of codes related to hospice as oppositional and the use of movement language.

The second stage of the hospice movement is institutional. This stage reflects the changes from a social movement to formal organization. The passage of the Medicare Hospice Benefit in 1982 created a new motivation to formally organize. Hospice practices and services become standardized through the accreditation process. Hospice became a profession at this time with the development of professional organizations and

education specializations. H2: Journal articles from this stage should contain significantly higher numbers of codes related to hospice as institutional and related to Medicare.

The final stage of the hospice movement is incorporated into traditional medicine. The stage is marked by the reduction of oppositional attitudes and language and willingness for hospice to operate within the medical system. Hospice is integrated into hospitals and home health care and uses language and techniques from traditional medicine. Hospice care and philosophies are no longer viewed as antithetical to allopathic medicine. H3: Journal articles from this period contain significantly higher number of codes relating to hospice as incorporated and the use of incorporated language.

Analysis of Variance between the Three Stages of Hospice

The transition from alternative, oppositional movement to incorporated, formal organization clearly happened gradually over time. It was hypothesized that variables reflecting the different stages of the development would change significantly in relation to time as stated in the previous section. Generally, two variables for each stage were tested for significant difference over time with an ANOVA. One variable broadly represented the sentiments and themes within the stage of development. The second variable reflected specific language or events associated with the developmental stage.

The results of this test were significant and are presented in table three. As the table illustrates, there is significant change over time when the years were divided into three time periods. While only one of the general stage variable was found to be

significant, all three of the specific variables experienced statistically significant variation.

Table 3. Effect of Time on the Three Stages of Hospice

		Mean	Standard Deviation	F	Significance
Oppositional		0.2301	0.42276	.355	0.702
	Time 1	0.2439	0.43477		
	Time 2	0.1842	0.39286		
	Time 3	0.2647	0.42276		
Movement Language		0.2743	0.44817	6.560	0.002*
	Time 1	0.2683	0.44857		
	Time 2	0.1053	0.31101		
	Time 3	0.4706	0.50664		
Institutional		0.708	0.45672	.121	0.616
	Time 1	0.6829	0.47112		
	Time 2	0.7105	0.45961		
	Time 3	0.7353	0.44781		
Medicare		0.2566	0.43872	3.622	0.030*
	Time 1	0.1463	0.35784		
	Time 2	0.2368	0.43085		
	Time 3	0.4118	0.49955		
Incorporated		0.2655	0.44356	4.237	0.017*
	Time 1	0.2195	0.41906		
	Time 2	0.1579	0.36954		
	Time 3	0.4412	0.50399		
Incorporated Language		0.3009	0.46069	3.459	0.015*
	Time 1	0.2195	0.41906		
	Time 2	0.2368	0.43085		
	Time 3	0.4706	0.50664		

*p<.05

Interpretation of the Results

The statistical findings provide space for in depth discussion of the data. The patterns of variance between the time periods provide interesting information about the trajectory of hospice. In addition to a report of the statistical findings, a qualitative approach to the data will offer further insight into the development of hospice. Each developmental stage will be discussed from a statistical perspective then expounded upon with qualitative observations.

Opposition and Movement Language

The “oppositional” variable combined codes that reflected the negative views of traditional medicine and the alternative language used in the early hospice movement. This variable did not change significantly in the three time periods. Sample size is one possible explanation for the lack of significance. While the total sample size was large enough to produce significant results, the coding scheme drastically reduced the number of cases. The variable “oppositional” was only present in twenty-six of the articles and the low frequency could contribute to a lack of significance. Another possible explanation for the lack of significance is the nature of the journal. As a peer-reviewed academic journal, strong oppositional sentiments could have been perceived as biased. The academic focus of the journal could have reduced the expression of oppositional attitudes.

“Movement language” reflects the terminology used during the oppositional time period. This variable was found to be significant ($F=6.560$, $p<.05$) with the significant difference occurring between the second and third time periods as revealed by the post

hoc analysis Tamhane. The third time period (1997-2001) contained the greatest use of “movement language” with a mean of .4706, which is almost twice the total mean. The second time period (1991-1996) has the lowest mean of .1053. These findings are peculiar when framed in the three-stage model. Movement language should have been most prevalent in the first time period and slowly diminished over time, but the data produces a different trend. Time one’s mean mirrors the total mean. Time two is lower and time three is higher than the total mean. One explanation for this pattern could be the presence of reflective articles in the later years. Discussing the past might have increased the use of terminology of the oppositional time period. In 1997 there was an entire issue dedicated to the history of hospice. This reflection on the past could have contributed to the increase of movement language in the third time period.

Another potential explanation both for the lack of significance of “opposition” and the unpredicted pattern in “movement language” is the time period of the sample. The journal began in 1985. At this point the Medicare bill had been approved and hospices had been operating in the United States for over a decade. Although the sample spans a fifteen year time period, these findings indicate that the sample fails to capture the earliest stages of the movement. Within the articles analyzed, hospice is only referred to as a “movement” in twenty-seven cases with thirteen occurring in the third time period. Alternative language such as “alienation” and “non-traditional” was only used in twelve cases. Discussing traditional medicine as negative only appeared in thirteen cases. These low frequencies in three areas that reflect the grass roots beginnings of the

movement indicate that this stage may not be represented within this sample. It can be argued that the sample begins in the midst of the institutional development.

A qualitative analysis of the articles further supports the notion of this sample failing to capture the oppositional phase. The dynamics of this stage were learned through articles that discuss the history of hospice and through the literature review. As a social movement, this stage of hospice was marked with goals, language, and ideals attempting to provoke changes in the way death and dying was viewed within the traditional medical system. One article describes the environment of the early hospice movement as impassioned and energetic:

The mood of hospice leaders in the 1970s was what you would expect from crusaders: the energy and enthusiasm for improving care of the dying was seemingly boundless. We were crusaders, visionaries-people committed to changing the way people lived and died. The inadequacies of the health care system in caring for terminally ill patients were the springboard for our action (Article 107, Tehan 1999:219).

This passion and clear opposition towards medicine was not fully captured within the time period of this study. An example of the strongest oppositional language within this sample comes from an article in the first volume of *The Hospice Journal*: “Lengthy terminal illness in hospital is often accompanied by loneliness, anxiety about death and a sense of alienation in the patient and his/her family”(article 5, Downe-Wamboldt and Ellerton 1986:17). This quote presents traditional terminal care in a negative light, but the impassioned sentiments of the early hospice movement are lacking. One of the more direct critiques of the medical model only addresses the logics embedded in traditional medicines leaving dehumanizing practices out of the assessment: “within medical ideology, death is the final enemy, and dying serves as a visible sign of staff failure”

(article 18, Levy and Gordon 1987:32-33). The low frequencies of variables representing this stage of the hospice movement suggest that the stage is completed before this sample begins. It was expected that the use of alternative language and negative presentations of traditional medicine would be reduced throughout the sampling period. Instead, this piece of the discourse is essentially absent from the sample.

I argue that this sample begins at a point of institutionalization. The publication of this journal begins three years into the Medicare Hospice Benefit. Managed care operates as a formal organization and requires policies and practices that promote efficiency and productivity. For hospice to maintain a Medicare benefit, the day-to-day operations must match those goals.

Institutionalization and Medicare

The “institutional” variable combined codes that represent the transition from movement to formal organization including professionalization, organizational awareness, and referring to hospice as an organization or program. Although this variable did not undergo significant change during the three time periods it was well represented at each stage. Low frequency of presence does not appear to be a factor with this variable. “Institutional” occurred in eighty-five articles. The high frequency and consistent presence of this concept supports the idea that this sample begins at the institutional stage. Hospice can be seen as operating as a formal organization throughout the sample.

A qualitative look at the data also reflects the evolution of hospice into a formal organization. Through the necessary accreditation process associated with Medicare, hospice organizations become standardized in their practices and hospice emerged as a

professional specialization (article 28 Dush 1988, article 36 Olson 1990, article 37 Kriebel 1990, article 58 O’Rawe Amenta 1993). “Hospice nurse”, “Hospice physician”, “Hospice social worker” emerged as job titles at this time. This sample presents the use of this terminology as relatively constant over time. Even from the beginning of the sample, professionalization had already begun to take place. One article offers a clear summary of the events that took place at this stage of development. The authors are assessing an existing hospice, but this pattern can be applied to the movement in general. “Standards and written policies were established, a formal accounting system was instituted, and more formal less personal communication networks emerged”(article 51 Hecht and Moser 1992:65). This single statement exemplifies formal organizations. In the literature review, the organization of traditional medicine was analyzed using Weber’s theory of bureaucracy and formal rational organization. This same rationalization occurs in the hospice movement at this stage of institutionalization. As hospice begins to operate as a formal organization, it is compared to other health care services and is even referred to as the “hospice industry” (article 107 Tehan 1999). One article written in the late 1990s argues that it is hospice’s ability to adapt that allows for its survival. “Tools and knowledge gained from business and industry, such as systems thinking and continual improvement, offer a means of understanding and planning for hospice’s position in the turbulent period in health care” (article 86 Goodlin 1997:72).

The existence of *The Hospice Journal* also speaks to this stage of institutionalization. The National Hospice Organization utilized this journal as a way to provide academic research that relates to hospice, but also as a way to communicate with

hospice organizations. The editors used the journal to publish official documents of NHO and allowed for special response articles to be published by leaders within NHO (article 12 1986, article 77 1996). The publication of this journal signifies some level of formal organization. Not only is NHO established, but also is formally producing information and knowledge on topics related to hospice care through the publication of the journal.

The enactment of the Medicare Hospice Benefit can be seen as one potential factor in moving hospice into the institutional stage of development. The “medicare” variable represents the implementation of the Medicare benefit by combining the discussion of Medicare and the need for a physician referral. “Medicare” was significant ($F=3.622$, $p<.05$) and post-hoc analysis Tamhane reveals that the significant change occurred between the first and third time periods a difference significant at a .035 level. The discussion of “medicare” increased steadily over time and was highest in the third time period (1997-2001) with a mean of .4118. The Medicare benefit shaped how hospices functioned in day-to-day practices, but also created a niche for hospice within the medical system. With reimbursement, hospice can provide inexpensive end-of-life care. Over time Medicare became essential to the application of hospice philosophy and care for terminal patients. The increasing discussion of “medicare” reflects this relationship.

The statistics indicate the importance of Medicare for the organization of hospice, but a qualitative analysis provides deeper meaning to this relationship. In an article about the history of hospice, a former president of NHO explains the relationship between hospice organization and Medicare:

It also became clear to me that we would not survive unless we were tied in to the health care reimbursement system- and the reimbursement system would not make big changes just for those nice hospice people in New Haven. One idea follows another. Hospice was going to need a national thrust. So in true American tradition, we created an organization (article 102 Beresford and Connor 1999:18).

This quote clearly establishes the connection between the Medicare benefit and creating a formal hospice organization. Hospice leaders were aware of the threats to the survival of hospice and saw the reimbursement system as a way to continue to grow. The organizational changes required were seen as necessary in the development of hospice. This same article later eloquently explains the effects of the Medicare benefit on the organization and structure of hospice.

This surprising legislative victory helped to secure the survival and growth of the hospice movement as a professional health care provider industry, but at the same time it solidified a certain philosophy of hospice care, as well as a structure and configuration of services (article 102 Beresford and Connor 1999:20).

The organizational changes spurred by the Medicare benefit shaped the operation and structure of hospice and allowed for the continued growth of hospice programs.

Incorporation and Incorporated Language

The final stage of development for hospice is the incorporated stage. At this stage hospice and traditional medicine are no longer seen as at odds with one another and there is cooperation and collaboration in providing end of life care. The variable “incorporated” combines discussion of integration and codes related to hospice’s incorporation into the medical model. In the ANOVA, “incorporated” was found to be significant ($F=4.237$, $p<.05$). The significant change occurs between the second and third time periods at a level of .027 shown through post hoc analysis Tukey. Discussion of

incorporation is greatest in the third period (1997-2001) with a mean of .4412. Finding significant change over time in the variable “incorporated” supports the evolutionary nature of the three-stage model. The incorporated stage as the final stage of development should be represented more in the latter part of the sample.

Many of the articles in the third time period assume hospice’s presence within the health care system. One article describes hospice as “now firmly set in the mainstream of American medicine” (Article 88 Jones, Nackerud, & Boyle 1997:44). Problems within hospice care begin to be compared with issues within other health care settings (Article 75 Gordon 1996). Hospice is no longer presented as a philosophy of care that is outside the traditional medical realm.

The specific variable under this stage examines the changes in the use of incorporated language over time. This variable represents the use of traditional medical language in relation to hospice. The variable “incorporated language” was significant ($F=3.459$, $p<.05$). Like the more general variable “incorporated”, “incorporated language” was more prevalent in the third time period with a mean of .4706 through the post hoc analysis Tamhane. The use of incorporated language is low and consistent in the first two time periods. The significant difference occurs between the first and third time periods. As discussed with the variable “incorporated”, these findings match the expectation of the three-stage model confirming H3. The use of medical language in relation to hospice should be higher in the final time period.

The three-stage trajectory for the hospice movement reflects the previous theory of a consensus movement. Consensus movement can more easily become formalized

through structural support in society (McCarthy & Wolfson, 1992). This is observed in the hospice movement. In the oppositional stage, hospice operated as a traditional social movement and attempted to use their humanistic philosophy towards death to change the delivery of end of life care. The transition to institutional and eventually to incorporated result in the structural support hospice received through the Medicare Hospice Benefit. The advent of reimbursable hospice care allowed for the movement to grow, but altered the organization of the movement. McCarthy and Wolfson (1992) predict this to be a more likely outcome with consensus movements. Because the goals and values of a consensus movement are widely supported, gaining validation through the state is more likely. The Medicare Hospice Benefit was also noted as legitimizing hospice in the healthcare system, which led to its ultimate incorporation. Although this three-stage trajectory was developed based on this study of the hospice movement, this theoretical model has potential for application to other consensus movements.

Co-option of Hospice Ideology

The three-stage trajectory of the hospice movement is one element in understanding the relationship between hospice and traditional medicine. This model places each stage of the development of hospice in relation to traditional medicine. The oppositional stage can be seen as a reaction to traditional medicine. The institutional stage creates an organization that mirrors traditional medicine due to the implementation of the Medicare benefit. Finally, the incorporated stage demonstrates the integration and collaboration between hospice and traditional medicine. This model explains the changes

of the relationship between hospice and traditional medicine from the viewpoint of hospice. Examining the co-option of the hospice philosophy provides understanding from the perspective of traditional medicine.

As a consensus movement, hospice began as an alternative philosophy challenging the cure-orientation within the traditional medical model. Because of this opposition, the majority of the medical field did not recognize early hospice programs. The Medicare Hospice benefit was the beginning of the integration of hospice into traditional medicine. Medicare not only bound hospice and traditional medicine to institutional requirements such as physician referrals, but the Medicare benefit also served to validate hospice principles in the eyes of the medical community. In an article describing the history of hospice the following quote describes this validation.

The outcome was not only reimbursement for hospice care, but also ultimately, the “legitimization” of hospice care in the medical system. As hospice care was integrated into the health care system, by virtue of its reimbursement, the medical community finally began to accept hospice (Article 107 Tehan 1999:224).

As hospice care was integrated and accepted within traditional medicine, a closer examination of the hospice philosophy occurred. The philosophy of the hospice movement served as a starting point for the development of palliative care. Over the time span of this study, traditional medicine is more critical of its own practices and created the new philosophy of palliative medicine. Like hospice, palliative care includes compassion and comfort in end of life care and utilizes a multi-disciplinary medical team. In an article published in 1999, the connection between hospice and the development of palliative care is clearly established.

The Hospice movement serves as the template for effective and compassionate end-of –life care. Hospice philosophy and principles provide the foundation for the emerging specialty of palliative care, which has taken a broader perspective in addressing the comprehensive needs of patients along all points of the illness trajectory (Article 104 Sherman 1999:110).

Through this understanding of the influence of hospice ideology and philosophy on the creation of palliative medicine, the need to examine the discussion of ideology within the sample emerged.

The variable created to analyze this relationship is “ideology” and is the combination of the discrete variables ideology/philosophy, pain management, multi-disciplinary team, holistic care, and family as care unit. This combined variable represents the discussion and definition hospice philosophy and ideology and includes discussion of the specific foundational elements within the hospice ideology.

Like the variables representing the different stages of development, “ideology” was first tested for significant variation for each individual year. The results of this ANOVA were not significant. A second ANOVA was completed using the same “time” variable which produced significant results. Table four describes the statistical findings for this variable.

Table 4. Co-option of Hospice Ideology

		Mean	Standard Deviation	F	Significance
Ideology		0.6109	0.48978	3.352	0.039*
	Time 1	0.7073	0.46065		
	Time 2	0.4474	0.5039		
	Time 3	0.6765	0.47486		

*p<.05

Analysis of variance found significant difference in “ideology” across time periods ($F= 3.352, p<.05$). Post-hoc analysis Tukey reveals that the significant difference occurs between the first and second time period at a level of .046 and the second time period experiences the lowest level of discussion as illustrated by the means in the table. This u-shaped curve in the discussion of ideology and philosophy could be the result of the increase in discussion of hospice philosophy with the development of palliative medicine. The division of the third time period in 1997 is due to NHO’s acknowledgement of the importance of hospice philosophy in palliative care at this time. As the official journal of NHO, the articles published after 1997 may reflect this awareness. An article written in 1998 highlights this increase in discussion of changes in end of life care.

In the past year, major institutions around the country have awakened to the need to provide better end-of-life care to patients regardless of the setting. NHO has helped lead that discussion and welcomes the interest in better pain and symptom management, an interdisciplinary approach to comprehensive services and continuity of care (Article 94 1998:143).

Analyzing this u-shaped pattern from the hospice perspective does not provide an explanation for this trend. If the sample only reflected the discourse from the hospice movement point of view, discussion of ideology should have decreased over time. The resurgence of discussions of ideology speaks to the environment within traditional medicine. The need to change end of life care in all medical settings is influenced by the existing hospice philosophies.

Examining the relationship between hospice and traditional medicine from this point of view allows for a better understanding of the true importance of the hospice

movement. Although the unique trajectory of hospice from movement to formal organization offers insights into understanding the relationship between hospice and medicine, the development of palliative medicine and the co-option of hospice philosophy capture the deeper interplay between hospice and medicine. Palliative medicine represents the integration of hospice ideology into the medical model.

CHAPTER IV

DISCUSSION

The hospice movement presents as an interesting case within the field of social movements. As a movement quickly accepted within the larger society, hospice's development takes a unique trajectory into a formal organization within traditional healthcare. While the findings in this study offer empirical data on the stages of hospice development, perhaps the more intriguing finding is the co-option of hospice ideology in the development of palliative medicine. The concepts of structuration and reflexive modernity can provide a deeper understanding of the relationship between hospice and traditional medicine

Theoretical Explanations of the Relationship between Hospice and Traditional Medicine

Anthony Giddens develops a theory of society based on the concept of stucturation. Stucturation is defined as the "modes in which social systems, grounded in the knowledgeable activities of situated actors who draw upon rules and resources in the diversity of action contexts, are produced and reproduced in interaction" (Giddens 1984:25). Giddens creates a dichotomy of structure and agent that resembles the classic divide between macro and micro, but also contains important differences. As conceptualized by Giddens, structure is not something fixed or external to the acting agents (Ritzer 2004). Structure is the "underlying codes to be inferred from surface manifestations" through social action (Giddens 1984:16). Structure is not a physical entity, but is formed virtually through the rules and resources in society. Rules are the

different procedures and practices agents develop and agents utilize material and nonmaterial resources. Agents are the actors within society, which resembles classic understanding of the individual. Giddens deviates by emphasizing the consciousness of the agent. Actions should be seen as both purposeful and based on an individual's power to act (Ritzer 2004). In classical functionalist theory, structure is understood as constraining the actions of individuals. The external institutions of society limit the potential actions of individuals. Giddens makes the distinction that structure can be both constraining and enabling to the agent. The agent has the knowledge and power to work with or against structural properties within society. The final aspect important to the theory of structuration is the duality of structure. Giddens' conceptualization of structure and agent seem to logically lead to his definition of the duality of structure:

The constitution of agents and structures are not two independently given sets of phenomena, a dualism, but represent a duality. According to the notion of duality of structure, the structural properties of social systems are both medium and outcome of the practices they recursively organize (Giddens 1984:25).

The duality of structure does not allow structure and agency to be understood independently by connecting the development of structure to the action of the agent and the location for social action as bound to structure.

The emergence and changes within the hospice movement reflect Giddens' theory of structuration. The development of hospice can be conceptualized in terms of structure and agent. The current state of hospice within medicine can be understood through defining the biomedical model as the dominant structure under which hospice emerged.

The hospice movement can be understood as a collective agent. Hospice acted purposefully and knowingly within the structure of traditional medicine. Although

medicine seems to be a physical entity through classical conceptions of institutions, traditional medicine also can be conceptualized as structure in Giddens' terms. In that regard, traditional medicine as a structure is continually manifested in the actions of medical professionals, administrators, and patients. Medicine provides rules and resources for agents to draw upon including medications, technology, procedures, and hospital policies. In the case of hospice, the structure of traditional medicine was viewed as constraining to dying patients. The dehumanizing practices within hospitals removed autonomy from the individual by limiting goals within a cure-orientation. As a knowledgeable agent, hospice was able to strive for different outcomes that would not be constrained by the existing structure. By choosing to focus on maintaining dignity and comfort instead of cures and prolonging life, hospice was able to alter the goals of end of life care.

This application of agency and structure to the hospice movement and traditional medicine provides for a unique analysis of the emergence of the movement. Social movements are typically conceptualized as reformative or revolutionary. Reform movements aim to change policies and practices within an existing system whereas revolutionary movements attempt to completely alter the current system. The hospice movement most commonly falls into the reform category (Wald 1983). Hospice does offer an alternative to traditional medicine's treatment of the dying, but it does not attempt to revolutionize medicine as a complete system clearly placing the hospice movement in the reform classification. Using Giddens' theory of the duality of structure

the relationship between the reformative actions of hospice within the structure of traditional medicine can be more fully understood.

The duality of structure maintains that agency and structure can only be conceptualized in relationship to one another. The agent's actions continue to manifest structure while at the same time structure provides the rules and resources for agents. Agents produce structure while structure enables action. Duality of structure is crucial in understanding the development of the hospice movement. Because of the success of modern medicine, cure based practices were central to patient treatment and care. Medication and technological development within traditional medicine created a structure defined by attempting to save lives and cure diseases. As life expectancy was prolonged, the traditional practices of medicine were not successful in saving lives indefinitely, leading to dehumanizing treatment of dying patients. Using these shortcomings in the rules and resources of the medical structure, the hospice movement was able to act toward a different outcome. Without the structure provide by traditional medicine, the hospice movement would not have been able to develop. That is, hospice had a relationship with traditional medicine that was at once dialectical and dependent.

The continuation of the hospice movement also shapes the structure of traditional medicine. The actions of hospice bring dignity and comfort into the structure of traditional medicine. The duality of structure allows for an understanding of the hospice movement's actions within the structure of traditional medicine as dialectical instead of purely oppositional.

This understanding of the early relationship between hospice and traditional medicine provides an explanation to hospice's eventual incorporation. Giddens' understanding of the interplay between agent and structure highlights the connection of hospice and traditional medicine. Viewing this relationship as a dialect rather than an opposition allows the co-option of the hospice philosophy to seem logical. One final concept helps to more completely explain this co-option.

The concept of reflexive modernization is developed by Giddens and is further explained by Ulrich Beck. For Giddens, one of the characteristics of modernity is reflexivity meaning "social practices are constantly examined and reformed in the light of incoming information about those very practices, thus constitutively altering their character" (Giddens, 1990:38). Through reflexivity, society and its social organizations are constantly open for critique and reinvention.

Beck further expounds upon the idea of reflexivity. "This concept does not simply imply (as the adjective 'reflexive' might suggest) reflection, but (first) self-confrontation" (Beck, 1994). Post-industrial societies must increasingly confront the limitations within their own logics and structures, which leads to a systematic transformation of society. Beck also argues that this transformation can also result from confrontation with society victories. Successes within society produces their own set of new problems and issues that need to be addressed.

The development of palliative care within allopathic medicine can be understood through the concept of reflexive modernization. The introduction of palliative care teams within hospitals reflects a self-critique of the purely curative treatment plans for terminal

patients. Medical professionals observed their own limitations and created new orientations in end-of-life care. This process can also be seen as a result of the successes in the biomedical model. As discussed earlier, advances in vaccines and antibiotics have increased life expectancies and have altered the common causes of death. This success also produced new limitations and raised new questions about medical practice. Curative treatments were not an effective plan for terminal patients. The evolution of palliative medicine can be viewed as a result of the initial victories of the biomedical model and a response to the ultimate limitations of this same model. Self-confrontation and the concept of reflexive modernization provide theoretical depth to this occurrence within the medical field.

The hospice movement was led by medical professionals who observed problems in the biomedical model. Even in its oppositional stage, hospice philosophy was a self-critique. Over time as hospice was formally organized into a medical service provider, traditional medicine was able to accept the changes in end of life care philosophy. The reframing of the philosophy into “palliative care” separates the ideology from its early oppositional approaches and allows traditional medicine to challenge its own logics.

Limitations and Future Research

There are two major limitations within this study that both relate to the sample of articles. The first limitation was already briefly addressed in the findings chapter. Although the total sample was large enough for statistical testing, many of the specific variables produced very low counts. This caused issues in finding significant variation

within individual years. Dividing the sampling time into three categories can be justified through events within hospice, but the findings would have been stronger if the variable year would have resulted in significant differences.

The other issue with the sample is the time of the sample. Although the selection of *The Hospice Journal* is representative of the discourse within the National Hospice Organization the oppositional stage of the movement was not included. The content analysis method allowed examination of a past time period, but *The Hospice Journal* did not provide discussion in the early stages of the hospice movement because of the sample start date. Another method, such as interviews or archival research, might have been more appropriate in capturing this data. The end point of the sample proved to be problematic as well. The rationale for concluding the sample in 2001 was the journal had changed its name and focus. This change was the integration of hospice and palliative care into one field. Continuing the context analysis to include articles after this formal change might have offered more insights into the co-option of the hospice ideology.

At the conclusion of this project, there appears to be two potential directions for future research. The three-stage trajectory of hospice development could be tested on other consensus movements. If this pattern is present in other movements, new theoretical understandings of role of structure in formalizing a movement could be added to social movement literature.

The application of reflexive modernity to the emergence of palliative medicine also offers new research areas. This study does not address how palliative care philosophies were implemented and practically organized, but speaks only to the

relationship between hospice and palliative care not the advancement of palliative medicine. Studies that examine changes in medical education and hospital policy after the development of palliative care would provide an understanding of the organizational changes of this ideological shift.

Final Remarks

The purpose of this study was to examine the development of hospice as a social movement to a formal organization in relation to traditional medicine. The two-phase content analysis allowed for an empirical study of these past transitions. Through the analysis of discourse and frame, a three-stage trajectory of the hospice movement was developed and supports theories of the consensus movement literature. The co-option of hospice philosophy in the development of palliative medicine was a surprising finding in the data. The theoretical application of structuration and reflexive modernization help explain the nuances of the relationship between hospice and traditional medicine and offer new directions for further research.

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APPENDIX A

DESCRIPTION OF CODES

Table 5. Description of Discrete Coding Scheme

Movement Strategies	
Volunteer Recruitment	Discussion of how to get and keep volunteers
Political Campaign	Placing hospice within the larger political movement
"Die with Dignity"	Use of phrase
Community Education	Spread awareness of hospice
Definition of Movement	Defines goals and objectives of hospice
Ideology/Philosophy	Explanation of the logics behind hospice views towards death
Maintenance	Discussion of how to sustain existing hospice programs
Rapid Growth	Recognition of the fast spread of hospice
"Movement"	Use of phrase in relation to hospice
Organizational Awareness	
Scope of Services	Discussion of what qualifies as hospice care
Definition of Roles	Clear definition of tasks and functions
Professionalization	Language and discussion of hospice work as a profession
Assessment	Examination of existing hospice organizations
Access to Care	Who is eligible for hospice
Costs of Dying	Role of Medicare
NHO	Mention of National Hospice Organization
"Organization"	Use of term in relation to hospice
"Program"	Use of term in relation to hospice
Hospice Assumed	
No Definition of Hospice	Philosophy and services are not explained
Role Assumed	No justification for the need for hospice
No Discussion of Hospice	Hospice is not mentioned in article
Oppositional Attitudes	
"Dehumanize"	Use of term
Role Stress	Tension between hospice and medical professionals
Hospital as Negative	Dying in hospital presented as negative
Bureaucracy as Negative	Organization in hospital as negative
"Alienation"	Use of term
Isolation from Family	Family access limited within hospital setting

Table 5 Continued

Shortcomings Med. Model	
Inability to Cure	Medical focus on curing disease
High Costs of Dying	Expenses of dying within a hospital
Power of Physician	Need for referral to enter hospice program
Fear of No Treatment	Physician feels trapped in hospice treatment plan
Defined as Different	
Family Unit of Care	Treatment of entire family in hospice care
Holistic Care	Importance of treating all needs of patients
"Alternative"	Use of term in relation to hospice
"Non-traditional"	Use of term in relation to hospice
Evidence of Co-option	
"Palliative Medicine"	Use of term
General Dying Issue	Discussion of grief and depression
Hospital Based Hospice	Presence of hospice care within hospital
"Hospice Physician"	Use of term
Multi-disciplinary Team	Holistic treatment plan including team of professionals
Pain Management	Discussion of the importance pain treatments and new drugs
Patient as Consumer	Need for patient satisfaction in services
High Technology	Use of technology in delivery hospice care
Discussion of Integration	Direct comments on blending of medicine and hospice
Cultural Acceptance	Hospice ideology accepted in larger society/"Good Death"
"Hospice Patient"	Use of term

APPENDIX B

INTER-CODER RELIABILITY SCORES

Table 6. Inter-coder Reliability Scores

Variable	Kappa
Oppositional	0.195
Movement Language	0.015
Institutional	0.068
Medicare	-0.065
Incorporation	0.372
Incorporated Language	0.233
Ideology	0.267

APPENDIX C

THREE STAGE MODEL DIAGRAM

Table 7. Three Stage of Hospice Development Model

