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DISSERTATION

A STUDY OF FOUR CASES OF PHYSICIAN PARTICIPATION IN TERMINALLY ILL PATIENTS' SUICIDES: FACTORS THAT MAY CONTRIBUTE TO A PHYSICIAN'S DECISION

Submitted by

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In partial fulfillment of the requirements

for the Degree of Doctorate of Philosophy

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Fall 2000

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November 1, 2000

WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY KIRBY L. STONE ENTITLED A STUDY OF FOUR CASES OF PHYSICIAN PARTICIPATION IN TERMINALLY ILL PATIENTS' SUICIDES: FACTORS THAT MAY CONTRIBUTE TO A PHYSICIAN'S DECISION BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

A STUDY OF FOUR CASES OF PHYSICIAN PARTICIPATION IN TERMINALLY ILL PATIENTS' SUICIDES: FACTORS THAT MAY CONTRIBUTE TO A PHYSICIAN'S DECISION

The purpose of this study was to identify and understand the factors that contribute to a physician's decision to participate in a terminally ill patient's suicide. To accomplish this, four published stories by two physicians who agreed to participate in terminally ill patients' suicides were analyzed using a cross-case study methodology.

Due to the continued advancements in medical technologies, our life expectancy has increased, causing us to suffer from more illnesses. Many of these illnesses are degenerative and debilitating over time, making people die a prolonged death. Because of the prolonged dying process and the suffering that comes along with it, people are asking their physicians to participate in helping them control their own deaths. Previous studies show that some physicians do consent to assist with their patient's suicide, and some show that a higher percentage of physicians support the legalization of physician-assisted suicide than those that do not.

Four common factors contributing to a physician's decision to participate in a terminally ill patient's suicide were identified. The four factors are: 1) Physician/patient relationship, 2) Physician/patient communication, 3) Physician/patient progression

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together through patient's disease, and 4) Physician understanding/acceptance of patient's personal definition of suffering.

Each of the four stories in this study clearly demonstrated the four identified factors. The physician and patient developed a personal and professional relationship over a period of time. Together they worked through the different stages of the patient's illness, which enabled the physicians to understand and accept the patient's definition of suffering. The trust between the physician and the patient developed because of their ability to communicate openly and honestly, leading to the accomplishment of the other three factors.

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CHAPTER I

INTRODUCTION

Fletcher (1954) found that:

> Euthanasia, the deliberate easing into death of a patient suffering from a painful and fatal disease, has long been a troubling problem of conscience in medical care. For us in the Western world the problem arises, *pro forma*, out of a logical contradiction at the heart of the Hippocratic Oath. Our physicians all subscribe to that oath as the standard of their professional ethics. The contradiction is there because the oath promises two things: first, to relieve suffering, and second, to prolong and protect life. When the patient is in the grip of an agonizing and fatal disease, these two promises are incompatible. Two duties come into conflict. To prolong life is to violate the promise to relieve pain. To relieve pain is to violate the promise to prolong and protect life. (p. 172)

Background and Context

The change in how western medicine has been practiced over the years has had an effect on the right-to-die movement in the United States. From the holistic Hippocratic approach to the Renaissance anatomists' specific body part approach to Descartes' mechanical laws of nature approach, medical practice has developed into fields of specialized medicine (Hoefler with Kamoie, 1994). A historical review shows that this progression has widened the gap between physicians and their patients.

In the late 1800s through the 1920s, physicians developed relationships with their patients by developing personal ties with them (Hoefler with Kamoie, 1994; Rothman, 1991). People often selected their physician based on similar interests such as religion, ethnicity, and socioeconomic background. A basis of trust was developed and the practice of physicians making decisions for an uninformed patient became common practice.

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Physicians made rounds to their patients' homes, not just their bedsides in a hospital. With the invention of the telephone, as well as other technological advances, the practice of house calls began to disappear.

Through the 1930s and 1940s, the communication technology advancements made it possible for patients to see their physician in the physician's office at a prearranged time (Hoefler with Kamoie, 1994). The telephone helped to make the physician's practice more efficient and more profitable by scheduling a steady flow of an increased number of patients. However, it did decrease the amount of time the physician spent with the patient, thereby making personal friendships with the patients no longer possible. As Hoefler with Kamoie (1994) express, the social distance between the physician and the patient increased, contributing to the erosion of trust patients had for their physicians.

Technological advances in diagnostic tools were the next logical step toward broadening the chasm between physician and patient. In the 1930s, conversation with patients was inseparable from diagnosis and treatment (Rothman, 1991). As more patients visited the physician in an office, diagnostic tools such as x-ray machines and now computerized scanner and magnetic imagers replaced the role of conversation as a tool physicians used to make diagnoses. This negatively affected the physician/patient relationship. The next step, acknowledgement of human experimentation, was even more devastating to this relationship.

The Nuremberg trials of 1946, brought before the public the horror of the atrocities carried out by physicians in Nazi Germany. Nazi physicians carried out numerous harmful and deadly experiments on prisoners of World War II. Then in 1966,

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Henry Beecher wrote an article published in *The New England Journal of Medicine* called 'Ethics and Clinical Research'. This article accelerated the movement that brought human experimentation under rigorous federal and institutional control (Rothman, 1987). Twenty-two examples of the endangerment of the life or health of human subjects by researchers were brought to the public's attention. Even though the intent of the research was to benefit humankind, abuses were allowed. Tests were conducted on captive populations without their consent, and at times without their knowledge. The events during this time in history also contributed to the distrust between patients and their physicians, and the distrust in the decisions physicians were once trusted to make.

Medical technology continued to advance contributing to an increase in the life expectancy of Americans. These advancements included medicine, equipment, emergency medical response systems, and community health initiatives. Over eight decades Americans' life expectancy increased from 47 years of age in 1900 to 75 years of age in 1987 (Jamison, 1995). With these advancements also comes a prolongation of the dying process and a new type of patient, a patient in a persistent vegetative state (PVS). In 1975, the case of Karen Ann Quinlan, a famous PVS patient in New Jersey being kept alive by a ventilator, came to the forefront of the American public. Shortly after being diagnosed with an irreversible coma, Karen's father Joseph Quinlan requested the ventilator be disconnected. A long court battle ensued. The physician, Dr. Robert Morse, and the hospital, St. Clare's Hospital, made the decision that no matter what state Karen lived in, she was alive; therefore, they would not disconnect the ventilator (Filene, 1998; Humphry & Wickett, 1990). As described by Rothman (1991):

> In fact, physicians shared a powerful tradition of ethical discourse that went back to Hippocrates and continued through modern times. It was at once high-minded,

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> generous, and even heroic, yet remarkably insular and self-serving too. Physicians almost exclusively defined the problems and arrived at the resolutions, giving the deliberations a self-contained quality. (p. 102)

The Karen Ann Quinlan story emphasized patients' rights, or their surrogates' rights, to be informed of their condition and, therefore, the right to make an informed decision about their medical care.

Ultimately, patient autonomy developed. This principle celebrates the value that democracies place on allowing individuals to make their own decisions (Pence, 2000). Patients and society are now in a controversial battle over the right to choose how, when, and where to die. Various religious beliefs have contributed to this battle over the years. The history and advancement of medical practice has led us to the point where patients ask their physicians for assistance in ending their lives which, patients believe, are no longer lives with quality nor with dignity and often times are not free of pain.

Problem Statement

Because of the technological and scientific advancements in the field of medicine, physicians and patients are being forced to change their approach to one another. As diagnostic tools enhance the speed and accuracy of determining a patient's illness, the physician can more readily determine the patient's prognosis and possible treatment. However, as trust in the physician/patient relationship declined over the years, the patient became more determined to be a part of deciding the plan of treatment. In addition, with today's information technology, patients are able to access more information about their illnesses and treatment, better enabling each patient to discuss the options of care with their physician. This has the potential to cause problems between a physician and his patient. As Pence (2000) explains:

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> Physicians usually believe that they are best qualified to assess risk, and they're right as far as statistical risk is concerned. But *acceptable* risk is evaluative as well as statistical, and many patients want the right to make their own judgments about what is acceptable risk. (p. 105)

This encompasses end-of-life decisions including a patient's desire to control his own death.

The right-to-die movement in America has been studied from a historical perspective by looking at the aspects of legalization of assisted dying and the acknowledgment that physician-assisted suicide exists. It is important now to study the aspects that contribute to a physician's decision to participate in an act of suicide, so that physicians and patients can better understand the concept of acceptable risk.

Purpose Statement

The purpose of these case studies is to understand the factors that contribute to physicians' decisions to participate in a terminally ill patient's act of suicide when there is a positive physician/patient relationship. This study endeavors to find answers to three basic questions: 1) Are there common factors that contribute to a physician's decision, 2) How does the physician/patient relationship affect the physician's decision, and 3) How does communication occur between the physician and patient about end-of-life choices? My intent is to discover information that will help physicians who are asked by their terminally ill patients to assist with their suicide. This information may help the physician to find a better method of addressing the topic of suicide and a better method of evaluating the decision of whether to participate or not to participate in their patient's suicide.

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Research Questions

1. What are the factors associated with the physician's decision to participate in a terminally ill patient's suicide?

2. Why and how does the physician/patient relationship contribute to a physician's decision to participate in a terminally ill patient's suicide?

3. How do the physician and patient discuss the topic and method of the terminally ill patient's suicide?

Definition of Terms

The following terms have been defined to help readers discriminate between often misunderstood terms (The Hemlock Society, 1995):

Active euthanasia – deliberate action physically carried out by a medical professional to end the life of a dying patient to avoid further suffering

Active voluntary euthanasia – a request by a dying patient for a lethal injection to be given by a medical professional to end life

Assisted suicide – providing the means (drugs or other agents) by which a person can take his or her life

Autonomy – the right to make decisions about one's own life and body without coercion by others (Pence, 2000)

Beneficence – the fact or quality of being kind or doing good (Websters New World College Dictionary, 2000)

Double effect – giving large amounts of opiate or barbiturate drugs to a patient to relieve pain while at the same time recognizing that these will hasten death

DNR – do-not-resuscitate; orders written with the knowledge and consent of the patient that authorize medical professionals not to initiate any life resuscitating procedures when the patient is found with no heart activity and/or no breathing activity

Durable power of attorney for health care provisions – is a legal document that identifies another individual to act as the incompetent patient's surrogate, also referred to as the 'health-care proxy'

Euthanasia – the act or practice of killing individuals (as persons or domestic animals) that are hopelessly sick or injured, they are killed for reasons of mercy; Greek meaning well (eu) death (thanatos)

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Health-care proxies – surrogate decision makers with the legal power to make treatment decisions and right-to-die decisions on behalf of people considered incompetent (Hoefler with Kamoie, 1994)

Incurable illness – irreversible, chronic medical conditions where death is not imminent, but the condition is painful and/or debilitating (Hoefler with Kamoie, 1994)

Informed consent – the right to be told the nature and risks of proposed treatment (Filene, 1998)

Living will – a legal document created by a person who is legally competent that contains instructions about their wishes for future medical care which includes life-sustaining measures, in the event they become incapable of making decisions (Humphry & Clement, 1998)

Medical ethics – the rules of governing the social conduct and graces of the medical professions (Fletcher, 1954)

Morality – interpersonal actions; situations where one person's actions affect other people (Pence, 2000)

Nonmaleficence – not causing harm to others

Palliative care – Latin meaning conceal, cloak; to lessen the pain or severity of without actually curing; alleviate; ease (Websters New World College Dictionary, 2000)

Passive euthanasia – deliberate disconnection of life support equipment, or cessation of any life-sustaining medical procedure, permitting the natural death of the patient

Persistent vegetative state – (PVS) people are unconscious, the higher center of the brain is permanently damaged, and the people are not capable of sensation or thought (Dworkin, 1993); characterized by massive and irreversible brain damage that leaves the individual unable to sense or respond to his or her surroundings

Physician assisted dying – a medical doctor assists with the death of a competent patient who is in unbearable pain or suffering (Pence, 2000); encompasses all forms of assistance with injection of lethal drugs, removal of life sustaining treatments, suicide

Terminal Illness – conservative definition – death is imminent with or without the continuation of life sustaining treatments; liberal definition – death is imminent without the application of life sustaining interventions (Hoefler with Kamoie, 1994)

Voluntary euthanasia – the act of passive or active euthanasia when a terminally ill patient asks for assistance to die by a medical professional's hand

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Delimitations

The focus of this study is limited to a review of published accounts of physician participation in terminally ill patients' suicides in the United States. The stories utilized were written by two physicians who had developed a relationship with certain patients over a course of time and who, after 1950, participated in their patients' suicides. The study examines the factors that physicians take into consideration when deciding whether or not to participate in their patient's suicide enabling the patient to control how, when, and where they will die.

Limitations and Assumptions

As in the qualitative paradigm, the interpretation of the documents could be viewed differently by others. This is especially true as the stories used in this study are written from the physician's perspective, which may be considered by some as second hand data. It is assumed by this researcher that the physician's perspective is accurate, and is thus, analyzed and interpreted as such. In addition, there was no attempt by this researcher to determine the level of support or lack of support by physicians or patients through an interview process. This study will not include stories of physician participation in patients' suicides in other countries nor will it consider acts of suicide participation by people other than physicians. It will be difficult to generalize the findings across all acts of suicide participation for the terminally ill.

Significance of the Research

Terminally ill and incurably ill patients currently ask their physicians, partners, families, and friends to assist them with their suicide so they can have control over how, when, and where they die. The literature and existing research surrounding physician-

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assisted suicide typically focus on the pros and cons of its legalization and the verification that the practice does currently exist. Research needs to be conducted to determine the factors that contribute to a physician's decision to participate in the suicide of a terminally ill patient. This researcher gathered and compared the documentation of two physicians who chose to participate in patients' suicides. Knowledge of these factors is needed in order to understand why a physician decides to participate in a patient's suicide. This knowledge is intended to help a physician faced with this difficult question to identify and evaluate the factors that would enable him to make the best possible decision for himself and his patient.

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CHAPTER II

LITERATURE REVIEW

Overview

The purpose of this chapter is to provide a synopsis of the changes in medical practice by physicians and how these changes have affected their relationships with patients. This review will give us a good basis to address the research question of why physicians decide to participate in a patient's decision to control their own death through assisted suicide. First, I examined beliefs as they have been interpreted from Plato to Hippocrates' holistic approach to today's practice of specialization. Second, I looked at how physicians' practice of medicine contributed to the relationships they had with patients. Third, I reviewed how technological changes affected the physician/patient relationship. Fourth, I looked at the practice of decision making by physicians through the viewpoint of human experimentation to extraordinary life extending measures. Fifth, I examined the change in the role patients have regarding their own medical treatment, nontreatment, and desire for controlling how they die. Sixth, I reviewed the perspectives of various religious beliefs and the effect of these beliefs on society and the right-to-die movement. Finally, I looked at the documented acts of assisted suicide and euthanasia and the resulting court cases.

Research Tools

Many research tools are available and easy to access in today's era of high

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technology. They provide a wide spectrum of topics and professional knowledge at the touch of a finger. The following database research engines have been put to great use:

- LEXIS/NEXIS – Academic Universe and Congressional Universe
- ABI/Inform – OCLC/FIRSTSEARCH
- SAGE
- PubMed
- MEDLINE – OCLC/FIRSTSEARCH
- World Wide Web – Right-to-die organizations, book searches, state and federal legislative sites

Early History of Medical Practice

Medicine and euthanasia have been practiced for centuries. Plato believed that people should contribute to society and if they were unable to contribute due to illness they should die. Death at this point would be acceptable by either suicide or euthanasia.

> Then will you not establish by law in your city an art of medicine as we have described in conjunction with this kind of justice? And these arts will care for the bodies and soul of such of your citizens as are truly wellborn, but those who are not, such as defective in body, they will suffer to die, and those who are evil-natured and incurable in soul they will themselves put to death.
> This certainly, he said, has been shown to be the best thing for the sufferers themselves and for the state. (Shorey, 1961, p. 654)

As emphasized in Plato's Republic for all well-governed people each man was assigned work that needed to be performed in order to keep the state functioning in an efficient and productive manner. If a man was unable to perform his work either due to physical illness or mental illness, he was considered no use to himself or to the state. "...if a man was incapable of living in the established round and order of life, he did not think it worth while to treat him, since such a fellow is of no use either to himself or to the state"

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(Shorey, 1961, p. 652). Though there is some disagreement, there is support for this translation of Plato's work that euthanasia and suicide under these circumstances was acceptable and even expected (Fletcher, 1954; Humphry & Wickett, 1990; Uhlmann, 1998).

Hippocrates lived around 450 BC and is considered the father of modern medicine (Hoefler with Kamoie, 1994; Lowes, 1995). He taught his students to treat their patients in a holistic manner, to view the body as a whole, and to believe in the sanctity-of-all-life. Hippocrates believed that no physician should assist a patient to die. However, the naturalistic Greek physicians used a scientific approach to medicine. They believed that they could treat based on what they saw and felt. They were trained to help their patients in the here-and-now, which often meant helping their patients to die; it was even considered a noble act (Lederer, 1996; Pence, 2000).

In the fifteenth and sixteenth centuries, anatomists began to dissect human cadavers as a way to understand diseases. Leonardo da Vinci, for example, graphically depicted the human body. "Anatomists of this period began to perceive disease as a malfunction of the body at a localized site, and they tried to understand in detail the operation and malfunction of various sites within the whole" (Hoefler with Kamoie, 1994, p. 74).

In the seventeenth century, people began to perceive the body in a mechanistic approach, which began the specialization paradigm in medical practice. The French philosopher Rene' Descartes believed that the mechanical laws of nature could impact the human body. "No longer would the body be viewed in holistic terms; instead, it would be seen in mechanistic terms, as a collection of separable, identifiable, and dissectable parts"

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(Hoefler with Kamoie, 1994, p. 74). These all represent the growth in medical practice, which led to the development of and the changes in physician/patient relationships.

Physician/Patient Relationships and the Effects of Technology

The core of medical practice is the physician/patient relationship (Humphry & Clement, 1998). Over the years, there have been many changes in medical practice that has had an impact on this relationship – the greatest has been the continual improvement in technologies. According to Dr. Timothy Quill (1996) these advancements in medical technology can lead to extraordinary good or extraordinary harm. What Quill (1996) means by extraordinary good and extraordinary harm is best explained by one of the stories in his book, *A Midwife Through the Dying Process.* Mr. Williams was a very active, healthy man who had his first heart attack in 1975 resulting in thirty percent of his heart being damaged and irregularities in his heartbeat. Over the next few years, Mr. Williams developed a severe cardiac arrhythmia known as ventricular tachycardia. This type of cardiac arrhythmia causes fainting spells and eventually death. The only way to correct the cardiac arrhythmia was to implant into his heart a mechanical device that would interrupt the irregular heartbeat electrically causing his heart to resume a more normal rhythm. Mr. Williams agreed and the surgery was performed. For two years the implanted defibrillator stabilized Mr. Williams' condition and he was able to enjoy his life with his wife, and to spend time with his children when they would visit even though he had extreme physical limitations. During these first two years, the implanted defibrillator went off only five times correcting his arrhythmia and restarting his heart in a normal rhythm. At one point, while Mr. Williams was in the shower, he became faint due to arrhythmia in his heart causing the defibrillator to send out an electrical shock.

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Since Mr. Williams' feet were in the water, he experienced a severe electrical shock that left him unresponsive for some time. He gradually regained consciousness. Over the next six months Mr. Williams' condition deteriorated significantly and his implanted defibrillator started to go off every month or two, each time saving his life. Eventually, Mr. Williams requested that his defibrillator be turned off. After consulting with a psychiatrist and Timothy Quill, it was decided that Mr. Williams' request was rational and the defibrillator could legally be deactivated even with the knowledge that death would be inevitable. Three weeks later, Mr. Williams was found dead due to severe cardiac arrhythmia. What was considered to be 'extraordinary good' from this story was the fact that the implanted defibrillator could interpret cardiac arrhythmia and automatically correct it by sending an electrical shock into the heart muscle. The 'extraordinary bad' was the fact that Mr. Williams, no matter how much he deteriorated physically, could not die because the defibrillator would automatically restart his heart.

During the 1800s through the 1920s, physicians usually built strong, caring relationships with their patients and the patient's family. People selected physicians who had similar backgrounds, religions, and socioeconomic status (Rothman, 1991; Hoefler with Kamoie, 1994). Physicians made rounds to their patients' homes. They spent time talking to their patients and their patients' families. Typically, they knew the whole family's medical history and used this information along with their conversations with the patient as diagnostic tools (Hoefler with Kamoie, 1994; Humphry & Clement, 1998; Rothman, 1991). Along with caring for their patients, physicians also "...believed in soothing a dying patient and to best minister to patients by limiting suffering and often assist a patient's dying" (Filene, 1998, p. 4). Patients trusted and respected their

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physicians and their physicians' decisions.

Lonny Shavelson (1995) tells the story of his grandmother's death in 1949. His grandmother, a strong woman, had helped his family escape from Russia in 1910. She became ill, and in 1949 lived at home under an oxygen tent with shortness of breath caused by congestive heart failure. At night she would yell out, and during the day she would remain silent. The family physician, a Polish immigrant, had known Shavelson's grandmother for years and visited her daily for ten months. One day he came to visit and with family present filled a syringe and gave his patient the shot. A few minutes later, his mother told him, his grandmother's pulse stopped. Shavelson's uncle believed the injection was the cause of Shavelson's grandmother's death and that the doctor had done the best thing possible for her. This demonstrates the acceptance and the expectation that people be allowed to die at home with family and friends surrounding them.

In the 1930s and 1940s, a major advancement in communication technology, the telephone, affected the physician/patient relationship. The telephone made it possible for the physician to see his patients in an office at a prearranged time. This increased the number of patients that could be seen in a day and contributed to the decreased amount of time the physician spent talking with his patients (Hoefler with Kamoie, 1994; Rothman, 1991). It also led to a decrease in physician house calls, which by the 1960s represented less than one percent of a patients contact with their physician (Hoefler with Kamoie, 1994).

Advances in diagnostic technologies such as the X-ray machine, the electrocardiogram machine, and computer-assisted lab testing have taken the place of conversation as a diagnostic tool (Hoefler with Kamoie, 1994; Humphry & Clement,

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1998; Rothman, 1991). Improvements in technological and surgical techniques, and improvements in types of medication and their administration have also affected the physician/patient relationship. Physician specialization, that is, physicians who have become experts in the functioning and treating of specific body organs, continues to broaden the distance between physicians and patients. Patients no longer have close personal relationships with their physicians (Caine & Conwell, 1993; Campbell, 1992), and often see a physician only at a time of crisis. "Doctors now learn more about the patient from the available technology than from conversations with the patient or family" (Humphry & Clement, 1998, p. 37).

Another consequence of the advancements in medical care is the increase in our life-expectancy from forty-seven years of age in 1900, to seventy-five years of age in the 1990s (Campbell, 1992; Jamison, 1995). According to Campbell (1992), although we live longer, we suffer from more sickness and morbidity, which means that a majority of people will die a prolonged death due to chronic, degenerative, debilitating diseases. These diseases often mean the individual will be in some sort of an institutional setting such as a hospital or nursing home and die a solitary death in that setting (Campbell, 1992; Jamison, 1995). Eighty percent of Americans now die in such an institutional setting (Campbell, 1992; Nuland, 1993). As Hoefler with Kamoie (1994) explain the new rescue-medicine and diagnostic techniques have created an entirely new group of individuals he calls the 'would-have-dieds' – people who, earlier in the century, would have died. Some of these would-have-died people end up in a persistent vegetative state (PVS) and await an institutionalized and solitary death.

Two well-known examples of PVS patients are Karen Ann Quinlan and Nancy

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Cruzan. Both women were in their early twenties when they were taken to a hospital after being without oxygen for an unknown amount of time. They were diagnosed as PVS patients due to the irreversible brain damage caused by the lack of oxygen. Karen Ann Quinlan was kept alive for many months by a ventilator, a machine enabling her to breathe, and a feeding tube inserted into her stomach providing nourishment and hydration. Nancy Cruzan was kept alive by a feeding tube inserted into her stomach providing nourishment and hydration (Filene, 1998; Hoefler with Kamoie, 1994; Humphry & Wickett, 1990; Pence, 2000). The Quinlan family and the Cruzan family asked the medical professionals providing care for Karen and Nancy to remove the life sustaining measures. The medical professionals and/or the medical institution denied each request. Therefore, it is clear why Sherwin Nuland (1993) explains that a doctor, in an attempt to maintain control, convinces himself that he is better able to decide what type of care is best for the patient, which can include what time is best for the patient to die.

Ethics of Medical Care

Joseph Fletcher (1954) identified a very important distinction between 'medical ethics' and the 'ethics of medical care'. Medical ethics are the rules governing the business of the medical profession as it relates to the social obligation of medical professionals. The ethics of medical care stems from the patient and their right to demand knowledge about and participation in their medical care. This can be a difficult leap for many physicians to make.

> In fact, physicians shared a powerful tradition of ethical discourse that went back to Hippocrates and continued through modern times. It was at once high-minded, generous, and even heroic, yet remarkably insular and self-serving too. Physicians almost exclusively defined the problems and arrived at the resolutions, giving the

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deliberations a self-contained quality. (Rothman. 1991, pp. 101-102)

Historically physicians had a substantial amount of autonomy in deciding treatment for their patients without involving the patient. As a result, many people came to believe that doctors' decisions were made to benefit themselves or their profession. However, in the 1960s, patients and society in general began to rebel against the medical decision-making dictatorship that existed causing the chasm in the physician/patient relationship to broaden. (Filene, 1998; Hoefler with Kamoie, 1994; Humphry & Clement, 1998; Pence, 2000).

A historical contributor to the broadening chasm between physician and patient were the Nuremberg trials in 1946, also known as the Doctors' Trials. These trials brought to the attention of the public numerous atrocities carried out by German physicians in Nazi Germany. These atrocities included human experimentation and what was then termed euthanasia (Humphry & Wickett, 1990; Pence, 1995; Shuster, 1997). Pence (1995) described some of the human experiments that were conducted on prisoners during World War II. These experiments included the injection of typhus infected blood to study the effect of experimental vaccines. Bones and limbs were removed to study the regeneration of body parts. Prisoners were exposed to icy waters or blizzards to study how the body revives from freezing temperatures. Mengele, the 'angel of death', conducted some of the most gruesome experiments on children. After his experiments were completed, the children were frequently exterminated. Racial cleansing, which the Nazi propaganda referred to as euthanasia, took place in Nazi Germany.

The racial cleansing began with the killing of mentally retarded and physically handicapped people who were considered to have 'lives not worthy of living' –

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lebensunwerten Leben (Filene, 1998; Humphry & Wickett, 1990; Pence, 1995). Hitler's race-purification philosophy then expanded to include another program known as the 'final solution'. Under this program the Nazis killed approximately 6 million Jews, 600,000 Poles, thousands of gypsies and thousands of homosexuals (Pence, 1995). Even though the Germans used the term euthanasia for these acts of killing, there were no mercy killings or assisting the death of suffering, incurably ill people – the killings were unexpected and merciless (Fletcher, 1979; Humphry & Wickett, 1990). "Improperly labeled 'euthanasia,' such a practice would forever affect the meaning of mercy killing and good death" (Humphry & Wickett, 1990, p. 19).

"As a result of the Nuremberg trials, in August 1947, a very important historical document know as the Nuremberg Code was created. It served as a blueprint for today's principles that ensure the rights of subjects in medical research" (Shuster, 1997, p. 1436). The core of the Nuremberg Code is informed consent. Two aspects of informed consent are predominate in the code: 1) The physician researcher is required to protect the subjects best interest, and 2) The subject has the right to actively protect himself, typically by withdrawing from the experiment. "Unfortunately, by the year 1997 the Nuremberg Code had still not been officially adopted in its entirety as law by any nation or ethics by any major medical association" (Shuster, 1997, p. 1439). However, the informed consent principle has been universally accepted as a guideline for human experimentation. The ten points of the Nuremberg Code follow (Shuster, 1997, p. 1436):

1. The voluntary consent of the human subject is absolutely essential.

   This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit,

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duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity.

2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study that the anticipated results will justify the performance of the experiment.

4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.

5. No experiment should be conducted where there is an a priori reason to believe that death of disabling injury will occur; except, perhaps, in those experiments where the experimental physicians also serve as subjects.

6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.

7. Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.

8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.

9. During the course of the experiment the human subject should be at liberty to bring the experiment too an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.

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10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage. If he has probable cause to believe, in the exercise of the good faith, superior skill, and careful judgment required of him, that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

Then in 1966, Henry Beecher wrote an article called 'Ethics and Clinical Research' published in *The New England Journal of Medicine*. Like the Nuremberg trials, his article brought to the forefront the unethical practice of uninformed human experimentation. In this article he discussed twenty-two experiments that were conducted involving humans that were harmful or potentially harmful to the participants. "In any precise sense statements regarding consent are meaningless unless one knows how fully the patient was informed of all risks, and if these are not known, that fact should also be made clear"(Beecher, 1966, p. 1355). One of the experiments conducted was to determine if the occurrence of rheumatic fever and acute glomerulonephritis could be reduced by certain medications. A large group of hospital patients, captive subjects, were selected with the control group and the experimental group being approximately the same size. The experimental group did not receive any of the sulfadiazine drugs known to be effective, resulting in subjects acquiring rheumatic fever. A medical officer, associated with the study, admitted that none of the patients involved in the study had been informed or were aware of their participation, nor did they give their consent (Beecher, 1966). The participants were considered 'captive' groups because they were in hospitals, state institutions, military institutions, or industry. In every experiment, the participants were neither informed of the experiment nor the possible effects of the experiment.

> During ten years of study of these matters it has become apparent that thoughtlessness and carelessness, not a willful disregard of the patient's rights, account for most of the cases encountered...it is evident that in many of the examples presented, the investigators have risked the health or the life of their

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subjects. (Beecher, 1966, p. 1354)

Even though some believe there is a difference between physician researchers and physicians, the lack of obtaining 'informed consent' from a subject to participate in an experiment or a patient to participate in a treatment is not different. After being fully informed, patients need to have the opportunity to choose to participate in an experiment or medical treatment. Beecher's article demonstrates the lack of concern by physicians and physician researchers about medical ethics and the ethics of medical care.

Pence (2000) discusses four principles of medical ethics: autonomy, beneficence, nonmaleficence, and justice. "Autonomy refers to the right to make decisions about one's own life and body without coercion by others" (Pence, 2000, p. 21). This principle also reflects Fletcher's (1954) description of the ethics of medical care, the patient has the right to demand knowledge and make a decision of participation in treatment. The last three principles relate more to medical ethics, the rules governing medical practice. Beneficence refers to the physician doing good to others. Nonmaleficence refers to doing no harm to others. Justice refers to the impartial treatment of patients regardless of race, gender, sexuality, or wealth. Two famous cases, Karen Ann Quinlan and Nancy Cruzan, publicized concerns about how physicians applied the principles of medical ethics and the ethics of medical care.

In 1975, Karen Ann Quinlan turned twenty-one and became a patient in a persistent vegetative state. After celebrating a friend's birthday, Quinlan was found unresponsive and not breathing; mouth-to-mouth resuscitation was started, and Quinlan was taken to a near-by hospital. Quinlan was put on a ventilator, a machine that would breathe for her, thus keeping her alive. When her condition did not change, she was

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transferred to another hospital (St. Clare's) which employed neurologists. Quinlan was in an irreversible coma. In the past, people in comas died of starvation and dehydration, but Quinlan was supplied with nutrition and fluids through a tube inserted into her stomach. After many months, the members of Quinlan's family agreed that she would never get better and asked the hospital to remove her from the ventilator. The primary doctor providing Quinlan's care and the hospital refused to disconnect the ventilator. After a long legal battle, Joseph Quinlan, Karen Ann's father, was finally appointed the guardian. A court representative told the hospital and the doctors to comply with the guardian's wish and to disconnect the ventilator. At this point the doctors made the decision to 'wean' Quinlan from the ventilator (Filene, 1998; Hoefler with Kamoie, 1994; Humphry & Wickett, 1990; Pence, 2000). Weaning is the process of training a patient to breathe on his or her own again without the mechanical assistance of the ventilator. Quinlan was weaned and eventually transferred to a nursing home and lived as a PVS patient for the next ten years. In June 1986, eleven years after her initial hospitalization, Karen Ann Quinlan died.

In 1983, Nancy Cruzan was in a car accident, thrown from the car, and was without oxygen for approximately 15 minutes (Pence, 2000). She was revived by paramedics and taken to a hospital. Due to the lack of oxygen to her brain, Cruzan was in a persistent vegetative state. Cruzan was able to breathe on her own, but required a tube into her stomach to supply her with nutrition and fluids. After four years, her parents decided Cruzan would never improve and requested to have her feeding tube removed. Medical personnel and the nursing home in which Cruzan resided refused to remove the feeding tube (Filene, 1998; Hoefler with Kamoie, 1994; Humphry & Clement, 1998;

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Pence, 2000). Another long legal process ensued, this time focusing on the removal of the life-sustaining feeding tube. The Cruzan family won their case first in a probate court, but the ruling was immediately over turned by the Missouri Supreme Court. Cruzan's family appealed to the US Supreme Court. To Cruzan's family's relief the US Supreme Court's decision included the right of competent people to decline medical treatment, including the cessation of life sustaining intervention. The second part of the Supreme Court's decision required that there be 'clear and convincing' evidence that an incompetent patient had expressed his desire of how he wanted to live before he became incompetent. Cruzan's family, therefore, needed to continue their court battle, as the US Supreme Court's decision shifted the Cruzan case back to the lower Missouri State Court. After friends of Nancy testified about their discussions of how Nancy would want to live and not want to live, the court ruled that there was enough clear and convincing evidence and ordered the feeding tube to be removed. In December 1990, Nancy Cruzan died.

Both of these cases demonstrate the profound effect that physicians' decisions can have on their patients and their patients' families. The publicity these cases received contributed to the increased lack of trust patients have in physicians. When the physicians decided to wean Karen Ann Quinlan from the ventilator, they failed to explain that it would mean Karen would be able to breathe on her own. While patients are ordinarily allowed to accept or decline a physician's recommendation for treatment, the physician decides what treatment recommendations are made (Orentlicher, 1990). The Cruzan case demonstrates how important it is for individuals to express their wishes about how they would want to live and under what conditions they would want to live or to die. Joseph Fletcher in 1954 wrote, "Without their freedom to choose and their right to know the

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truth, patients are only puppets" (p. 33).

Religious and Societal Perspectives

The belief of the right-to-life movement is based historically on religious beliefs. Pope John II in 1978, emphasized the sanctity of life, that God entrusted the sacred reality of life to mankind, therefore, suicide is as objectionable morally as murder (Pope John Paul II, 1998). Kass (1998) believes that life is sacred in itself; "...that 'sacredness', what ever it is, inheres in life itself, and that life, *by its very being*, calls forth an appropriate human response, whether veneration or restraint" (p. 203). Many people believe the Bible itself forbids suicide and says that people who commit suicide commit a sin as severe as murder, the killing of a human.

Prior to the seventeenth century, the main influential religion was Catholicism. The Church was the driving force in the formation of a country's governance and societal norms. Then at the end of the seventeenth century the Protestant Reformation occurred, causing the unity of Christendom to be shattered. Along with this came divergent views on many issues, one of which was suicide (Uhlmann, 1998). Some of the factions still considered suicide immoral, while others started to believe suicide was acceptable under certain circumstances.

> It is also objected by religious moralists that euthanasia violated the Biblical command, 'Thou shalt not kill.' It is doubtful whether this kind of Biblicism is any more valid than the vitalism we reject. Indeed, it is a form of fundamentalism, common to both Catholics and reactionary Protestants. (Fletcher, 1954, p. 195)

Emile Durkheim in his study *Suicide* (Translated by Spaulding & Simpson, 1951) stated, "We have seen that Catholicism reduces the tendency to suicide while Protestantism increases it" (p. 353). Not until the advancement of medical technology in the mid-1900s and the Nazi atrocities did the issue of suicide, euthanasia, and the right-to-life come back

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to the forefront.

In 1957, Pope Pious XII made public the Vatican's stance on the distinction between ordinary and extraordinary measures for sustaining or pro-longing life (Hoefler with Kamoie, 1994). Ordinary measures for sustaining life were exemplified by artificial means of supplying food and water. Extraordinary measures for sustaining life were described as heroic measures and advanced medical technologies that stopped the death process. The Church took the stance that extraordinary care measures could be withdrawn from a terminal patient, without having the meaning of suicide or euthanasia. Since 1957, the Church's position has wavered on the necessity of maintaining nutrition and hydration artificially. "Ultimately, it may be that the Catholic position is simply adapting to the realities of modern medical practice" (Hoefler with Kamoie, 1994, p. 142). However, the Vatican maintains a firm stance on the immorality of euthanasia. In 1980, the Vatican made public their Declaration on Euthanasia which declares euthanasia to be a very serious crime and that suicide is as equally wrong as murder (Humphry & Wickett, 1990). "Curiously enough, there is very little about medicine and pharmacy in the Bible or in the Talmud" (Fletcher, 1954, p. 22).

The Jewish religion normally condemns both murder and suicide, with a few exceptions. The exceptions include martyrdom, killing in self-defense, and other forms of justified homicide such as religious wars. With this in mind as translated from the Talmudic text, "Active-voluntary euthanasia is prohibited but passive-voluntary euthanasia may be permitted" (Sherwin, 1998, p. 155). Judaism also believes that a terminal patient does not need to be resuscitated as the dying process and the anguish of dying would be extended. The termination of natural hydration and nutrition to hasten

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death is prohibited, but artificial hydration and nutrition are not mentioned. "Therefore, the tradition endorses *passive euthanasia* in most cases where death is imminent and inevitable and where the process of dying is accompanied by unbearable anguish" (Sherwin, 1998, p. 168).

There are many other religious groups, both Christian and Eastern, that do not oppose passive euthanasia. "Only Mormons, Evangelicals, and other strict Gospel denominations are opposed to passive euthanasia in the West, while Islam is opposed in the East" (Humphrey & Wickett, 1990, p. 288). It is believed that the right-to-life movement has been encouraged and lead behind the scenes by religious ideologies, especially by the Catholic ideology.

It is believed by some in society, that euthanasia is one of the last serious moral issues modern man needs to confront and resolve. The right-to-life, pro-life, movement initially focused the majority of their attention on abortion issues, but their focus started to incorporate end-of-life issues more in the 1970s. Living will legislation was their first real concerted effort to stop the growing emphasis on the right-to-die (Humphry & Wickett, 1990). As society's awareness and understanding of problems created by modern medical technology grew, the pro-life stance became more ambiguous. Eventually, their firm stance that ultimately life (the sanctity of life) is more important than the type of life, had to change to making a distinction between killing a person and letting a person die (Humphry & Wickett, 1990). Many pro-lifers believe in and support the hospice movement and emphasize palliative care, a successful end-of-life care system. Hospice's intent is to provide comfort care for the terminally ill at the end-of-life. This comfort care includes palliative care, a specialization in the management of pain and

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other symptoms that can occur during the dying process. With this intent for comfort care and controlling pain the issue of 'double-effect' arises. Double-effect occurs when the dosage of narcotics given to ease a patient's pain also hastens death. The less radical pro-lifers accept the concept of double-effect. Yet, it is considered to be acceptable to die from a large dose of narcotics with the intent to alleviate pain, it is not acceptable for nutrition, naturally or artificially, to be stopped to hasten death. This act could be considered as an aspect of what is known as the 'slippery slope'. The slippery slope is the main argument of opponents to the right-to-die movement.

"A slippery-slope argument can refer to predicted, disastrous consequences ensuing from a major change in morality or to a line of reasoning that will follow from acceptance of certain premises" (Pence, 1995, p. 82). The main aspect of the slippery slope argument is that if physician-assisted dying becomes a legal option for the terminally ill, that the option would then expand to include people who are not terminally ill. This argument is valid, as society ages and becomes more chronically and incurably ill, more people may choose to select when and how they will die. Opponents also argue that some patients may feel obligated, possibly forced to die because of believing to be physical, emotional, and financial burdens on their families. At this point, the slippery slope argument incorporates coercion by people other than the terminally ill patient to end their life because their life is not considered valuable or to actually take the patient's life through euthanasia. Opponents to the right-to-die movement openly compare this possibility to the acts of genocide carried out by the German physicians in Nazi Germany during World War II.

There are many religious and societal obstacles that the American Right-to-Die

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Movement has had to face in the past and continue to face now. It is only fair to be conscious of both perspectives. Fletcher (1954) helps us to think of both sides of the slippery slope argument.

> What of the common religious opinion that God reserves for himself the right to decide at what moment a life shall cease? ...Is medical care, after all, only a form of human self-assertion or a demonic pretension, by which men, especially physicians, try to put themselves in God's place? Prolonging life, on this divine-monopoly view, when a life appears to be ending through natural or physical causes, is just as much an interference with natural determinism as mercifully ending a life before physiology does it in its own amoral way. (Fletcher, 1954, pp. 192 & 193)

The Hippocratic Oath

The Hippocratic Oath is considered by many to be the foundation of medical ethics (Lowes, 1995).

> I swear by Apollo Physician and Asclepius and Hygieia and Panaceia and all the gods and goddesses, making them my witnesses, that I will fulfill according to my ability and judgment this oath and this covenant:
>
> To hold him who has taught me this art as equal to my parents and to live my life in partnership with him, and if he is in need of money to give him a share of mine, and to regard his offspring as equal to my brothers in male lineage and to teach them this art--if they desire to learn it--without fee and covenant; to give a share of precerpts and oral instruction and all the other learning to my sons and to the sons of him who has instructed me and to pupils who have signed the covenant and have taken an oath according to the medical law, but to no one else.
>
> I will apply dietetic measures for the benefit of the sick according to my ability and judgment; will keep them from harm and injustice.
>
> I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect. Similarly I will not give to a woman an abortive remedy. In purity and holiness I will guard my life and my art.
>
> I will not use the knife, not even sufferers from stone, but will withdraw in favor of such men as are engaged in this work.
>
> Whatever houses I may visit, I will come for the benefit of the sick, remaining free of all intentional injustice, of all mischief and in particular of sexual relations with both female and male persons, be they free or slaves.

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> What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must speak abroad, I will keep to myself holding such things shameful to be spoken about.
>
> If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if transgress it and swear falsely, may the opposite of this be my lot. (Anonymous, 1995, p. 201)

It originally represented a paternalistic philosophy believed to have been created from some of Hippocrates' writings by a group known as the Pythagoreans (Hoefler with Kamoie, 1994; Kevorkian, 1991). The Pythagoreans were adamantly opposed to killing or assisting in killing people. Thus, aspects of the oath prohibit physicians from assisting with abortions and from assisting with a patient's suicide. Many believe that the Hippocratic oath as originally written does not apply to today's physicians. "Ethical medicine is always in tension between remaining true to its historical roots and traditions and trying to respond sensitively and effectively to the changing values and needs of the society" (Brody, 1992, p. 1385).

Furthermore, the oath itself contains a conflict (Abrams, 1990; Anonymous, 1995; Lowes, 1995). One part of the oath promises that physicians will keep harm from their patients, while another part promises that physicians will not give a deadly drug. However, with the technological advances in medical practice today many of us will be struck by illness leaving us connected to machines and ingesting drugs which can produce a 'bad' death (Brody, 1992; Hester, 1999). Wrable (1989) believes these technological advances keep patients alive long enough that they become no more than living carcasses.

Louis Lasagna (1995) wrote a modern Hippocratic Oath that takes into account modern medicine.

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> I swear to fulfill, to the best of my ability and judgment, this covenant:
>
> I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.
>
> I will apply, for the benefit of the sick, all measures which are required, avoiding those twin traps of over treatment and therapeutic nihilism.
>
> I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.
>
> I will not be ashamed to say 'I know not', nor will I fail to call on my colleagues when the skills of another are needed for a patient's recovery.
>
> I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life: this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.
>
> I will remember that I do not treat a fever chart, or a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.
>
> I will prevent disease whenever I can, for prevention is preferable to cure.
>
> I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body, as well as the infirm.
>
> If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help. (p. 202)

In today's world of advanced life pro-longing medical practice, special attention needs to be paid to the following wording of the Modern Hippocratic Oath.

> Most especially must I tread with care in matters of life and death. If it is given to me to save a life, all thanks. But it may also be within my power to take a life: this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God. (Lasagna, 1995, p. 202)

This wording expresses the importance of caring for the person as an individual and that

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it is also important to think about the others the patient's illness may affect. When physicians take this wording to heart, it will be a step toward rebuilding the trust a patient has for a physician.

The old Hippocratic Oath and the modern Hippocratic Oath represent two conflicting theories in medical ethics: the 'curing' approach and the 'caring' approach (Mellert, 1997). The curing approach relates to the old Hippocratic Oath because it is based on the belief that the physician is the primary decision maker, that the role of medicine is to heal, and that everything reasonably possible must be done to sustain life (Mellert, 1997). The caring approach is subjective and is based on the participation of the patient. The physician is obligated to minimize pain and review all probable outcomes keeping in mind that the quality of life is the basis for moral judgment, not the sanctity of life (Mellert, 1997). The caring approach, with its emphasis on the patient's participation, can be viewed as contributing to the current patient rights movement in the United States.

Patient Rights

Patients and patients' representatives through the years have become distrustful of physicians and physicians unilateral decisions. This has been demonstrated by society's push for patient rights, especially the right to have an informed choice. Blendon, Szalay, & Knox (1992) believe that the conflict brought about by the demand for more choice from the public and the hesitation by physicians to participate in end-of-life decisions will continue and possibly escalate. "The ethics of medical care have to change, to grow, and to engage constantly in self-correction" (Fletcher, 1954, p. 26). As a result of the patient rights movement, three types of advance directives have been developed: living wills, health care proxies, and do-not-resuscitate orders. All three of these advance

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directives provide instructions or statements regarding future medical care, including the refusal of medical care. This right to refuse medical treatment can help protect a patient from unwanted treatments by shifting the power from the medical system to the patient (Anderson, 1997).

Louis Kutner first brought the concept of a living will to the public's attention in 1969 (Humphry & Clement, 1998; Humphry & Wickett, 1990). A living will is a legal document that allows a competent adult to determine in advance the type of medical care they wish to have or do not wish to have, in some states this may include nutrition and hydration (Humphry & Clement, 1998; Pence, 2000; Rothman, 1991). One drawback of the living will is that it applies only to those who are terminally ill, not to those with incurable illnesses (Filene, 1998; Hoefler with Kamoie, 1994). The definition of terminally ill can vary from state to state, but, typically, two physicians must agree that the patient is terminally ill with a prognosis of six months to live.

The health care proxy, often known as a durable power of attorney, was established to help protect an incompetent person from unwanted medical treatment. These are legal documents that allow competent adults to select someone to make medical treatment decisions in the event they become incompetent and are the most powerful tools to protect dying patients' rights (Humphry & Clement, 1998; Pence, 2000; Rothman, 1991). Filene (1998) refers to this as relatedness, the exercising of a person's autonomy through the assistance of others. Family members are often appointed to act as health care proxies because they are typically the most trusted to act according to the patients' wishes (Blendon et al, 1992).

Finally, the last type of advance directive is the do-not-resuscitate (DNR) order.

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These are orders placed on a patient's chart instructing health care professionals not to use extraordinary measures to attempt to save the patient's life (The Hemlock Society, 1995). Initially these orders were written in pencil or passed on verbally by the physicians, often times without the knowledge or consent of the patient or family (Hoefler with Kamoie, 1994; Rothman, 1991). DNR orders are now well formalized, discussed with patients, and documented in their charts. DNR orders were originally only valid within medical facilities, but have recently become valid in nonhospital settings. "This means that at home or elsewhere outside the hospital setting (including in an emergency room) emergency medical services personnel will *not* perform CPR if the requisite document has been signed by a physician" (Humphry & Clement, 1998, p. 96). The document needs to be well displayed. Twenty-nine states recognize the legal validity of DNR orders in non-hospital settings (Humphry & Clement, 1998).

> The establishment and legal acceptance of advance directives were great influences for the advancement of America's patient rights and right-to-die movements. With a growing number of individuals tethered indefinitely to pumps and monitors in intensive-care nether worlds, patient advocates and ethicists argued that patient autonomy is a primary ethical principle in medical decision making. After intense professional and public debate, a consensus emerged that a patient's normal right of self-determination entails a right to refuse medical treatment or demand that it be stopped even if death is a sure result. (Anderson, 1997, p. 60)

By 1998, forty-five states and the District of Columbia had developed legislation authorizing living wills and health care proxies (Humphry & Clement, 1998). As part of the advance directive movement, health care professionals are released of legal liability for wrongful death. However, even with legalization and public awareness, only about fifteen percent of the people have actually initiated and signed an advance directive (Humphry & Clement, 1998). More recently, Covinsky, Fuller, Yaffe, Johnston, Hamel,

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Lynn, Tene, & Phillips (2000) conducted a study utilizing the findings of the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) to determine the communication about preferences for end-of-life care between physicians and seriously ill patients. Only six percent of patients who had completed advance directives prior to the Patient Self-Determination Act had documentation in their chart representing their wishes about end-of-life care. After passage of the Patient Self-Determination Act, thirty-five percent of the SUPPORT control patients and seventy-eight percent of the SUPPORT intervention patients had documentation of their advance directives in their charts. These results, however, lead us to another trend emerging surrounding the liability issues faced by healthcare professionals – liability for providing unwanted life-sustaining treatment.

Even though the right to refuse life-sustaining treatment by either competent or incompetent individuals has been determined to be legal by the judiciary system and state legislatures, it has been demonstrated that physicians do not always abide by the individual's oral or written wishes. "Now individuals are suing physicians, hospitals, and nursing homes for money damages when treatment is provided in contravention of the right" (Rodriguez, 1999, pp. 1-2). Many times patients receive initial emergency life saving treatments without complaints. The problem occurs when the life-sustaining treatments are not discontinued when it is determined that there is no possible recovery from the patient's existing condition.

> …a young woman in Michigan, Brenda Young, had a history of progressively worsening seizures, which her doctor had warned her would eventually leave her severely disabled. Hoping to avoid precisely the situation she later faced, she signed a Living Will and a Health Care Proxy authorizing her mother to stop all life-support treatment if she became incapacitated. When she suffered a particularly severe seizure, she was put on a respirator, despite her mother's

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> insistence that she did not want this life-sustaining treatment. Young emerged profoundly disabled, thrashing and screaming for hours at a time, requiring total care. The family sued the hospital for continuing unwanted medical treatment and ultimately, in 1996, won a $16.5 million judgment. (Humphrey & Clement. 1998, pp. 22-23)

In 1990, President Bush signed the Patient Self-Determination Act, which took effect in December 1991.

> This law was designed to increase patient involvement in decisions regarding life-sustaining treatment by ensuring that advance directives for health care are available to physicians at the time medical decisions are being made and that patients who have not prepared such documents are aware of their legal right to do so. (Greco, Schulman, Lavizzo-Mourey, & Hansen-Flaschen, 1991, p. 639)

The Patient Self-Determination Act required all American health care delivery systems receiving federal funds (Medicare and Medicaid) to provide written information to patients about their right to refuse or accept medical treatment and to make advance directives available (Filene, 1998; Greco et al, 1991; Hoefler with Kamoie, 1994; Humphry & Clement, 1998). The down fall of this law is that many times when a patient needs to discuss their treatment they are acutely ill or cognitively impaired and unable to discuss their treatment options, especially those that are life-sustaining.

Right-to-Die Legislation

Bill Number 135 was introduced to Nebraska's unicameral legislature by Senator John H. Comstock in February, 1937 (Kuepper, 1981). It was the first bill presented in the United States recommending legalization of 'mercy death' for terminally ill people. The bill included the right to request mercy death for minors who were suffering and for incompetent people. These requests would be made by the families of those involved (Kuepper, 1981). Many attempts have been made in America since 1937 to legalize assisted dying.

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Washington State in 1991 successfully placed an assisted-suicide initiative, Proposition 119, on the ballot. California placed Proposition 161 on the ballot in 1992, again a public initiative. Both propositions lost by eight percentage points, fifty-four percent to forty-six percent (Campbell, 1992). The level of funding for the right-to-die movement fell thus causing the campaign to diminish. Those in opposition to the legislation, the right-to-life movement, had sustained funding. Kevorkian's actions also affected the passage of these public initiatives. In 1994, Oregon passed a public initiative called the Oregon Death with Dignity Act by a fifty-one percent to forty-nine percent vote (Filene, 1998; Humphry & Clement, 1998; Pence, 2000). The Oregon Death with Dignity Act had a rocky start. Prior to its implementation, a local judge declared that it violated the equal protection clause in the United States Constitution. The Ninth Circuit Court of Appeals repealed the lower court decision. Then in November 1997, the Oregon people again approved the Death with Dignity Act, this time by twenty percentage points – sixty percent to forty percent (Azevedo, 1998; Filene, 1998; Humphry & Clement, 1998; Pence, 1998). David Azevedo (1998) defined the qualifying criteria that a dying patient in Oregon must meet to carry out assisted dying. First, the patient must be capable and able to communicate their decisions. Second, they must be expected to die within six months. A second physician must confirm this prognosis. Once a patient qualifies by these two criteria, they must make a written request for assisted suicide to their physician. After the written request, the patient must make two oral requests. There must be at least 15 days between the first oral request and the second oral request. The final guideline is the responsibility of the physician. They are required to submit a compliance form to the Oregon health officials or allow the inspection of the relevant

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aspects of the patient's chart.

Currently, thirty-seven states criminalize assisted dying by statute, six states criminalize it by common law, six states have no law or unclear laws, and one state has legalized assisted dying. Oregon is the only state that has legalized assisted dying. Since 1988, eighteen states have attempted to legalize assisted dying through either legislation or public initiatives (Hemlock Society, 1998). Of the seventeen states in which it did not pass, five have again attempted or are attempting to legalize assisted dying in the years 1999 or 2000. New Hampshire, Vermont, Nebraska, and California all had proposed legislation for legalization of assisted dying during the 1999 legislative session. Maine's proposal is through a public initiative. Once it is put before the Maine legislature it cannot be rejected though it may be amended. The initiative will be on the ballot in November 2000. Each of these state proposals is designed around the Oregon Death with Dignity Act, though there may be some variations.

The main difference presented by the Maine proposal is that the patient will be required to see a professional licensed counselor to rule out or diagnose depression. If depression is diagnosed, treatment will be required. Nebraska's bill changes the terminology from terminal disease to terminal condition (Nebraska legislature, 1999). Vermont's bill changes the length of time prior to death from six months to one-year (Vermont legislature, 1999). California's bill follows Oregon's Act very closely (California legislature, 1999). The New Hampshire bill is also designed after the Oregon Act.

Most authors writing about assisted suicide and euthanasia agree that these are practices currently and discreetly taking place in America.

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> It is of great importance that policy makers, leaders within this country and the public be made aware of the extent to which active euthanasia and assisted suicide may be taking place, because only in this way may individuals accurately understand the dimensions of the phenomenon and make informed decisions regarding its place in American life. (Lederer, 1996, p. 15)

The Practice of Assisted Suicide and Euthanasia

Though it is not truly known to what extent assisted dying is practiced in this country (Filene, 1998; Jamison, 1995; Lederer, 1996; Quill, Cassel, & Meier, 1992), there are studies and reports demonstrating that the practice of assisted dying does exist. Many health care professionals become intimately involved with their dying patients and develop an insight to their patients suffering and anguish, enabling them to realize their own mortality and limitations (Lederer, 1996; Quill, 1993).

> On those occasions when thoughtful, reflective individuals make decisions to end their lives on their own terms through suicide, assisted suicide, or euthanasia, we who are involved with these patients run the risk of true moral peril if we simply ignore or deny their wishes, condemning them to die alone in meaningless acts of biology and medicine. (Hester, 1999, p. 113)

The New England Journal of Medicine published two surveys on the views and attitudes of physicians toward assisted suicide. Lee, Nelson, Tilden, Ganzini, Schmidt, & Tolle (1996) conducted a survey of Oregon physicians who might be eligible to prescribe lethal doses of medication. Seventy percent of the eligible physicians replied. Sixty percent of the respondents believed physician-assisted suicide should be legal in some cases; forty-six percent might be willing to prescribe a lethal dose of medication if it were legal; twenty-one percent had previously received requests for assisted suicide; and seven percent had complied with their patients request for assistance. Bachman, Alcser, Doukas, Lichtenstein, Corning, & Brody (1996) conducted a survey of Michigan physicians whose specialization would be likely to involve terminally ill patients. The

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response rate for this survey was seventy-four percent. Fifty-six percent of the respondents supported the legalization of physician-assisted suicide over a ban of physician-assisted suicide. Thirty-seven percent chose a ban of the practice and eight percent were undecided. In another part of the study forty percent selected legalization of physician-assisted suicide, thirty-seven percent preferred no law, seventeen percent selected prohibition and five percent indicated they were not certain. "Most Michigan physicians prefer either the legalization of physician-assisted suicide or no law at all; fewer than one fifth prefer a complete ban on the practice" (Bachman, et al., 1996, p. 303). Anderson (1997) reported more evidence that physicians support physician-assisted dying. A nationwide poll of oncologists showed that fifty-one percent had received requests to make suicide possible or easier and that twenty-five percent of this fifty-one percent had complied at least once.

> In our surveys, the change from 28 percent in 1990 to 48 in 1995 in the proportion of resondents who reported willingness to assist in a patient's suicide suggests that acceptance by physicians of assisted suicide is increasing over time and that resistance to assisting in suicide appears to be lessening. (Slome, Mitchell, Charlebois, Benevedes, & Abrams, 1997)

Some stories of physician-assisted suicide and euthanasia have been published. Shavelson (1995) wrote about his grandmother's death in 1949 after the family physician gave her an injection of some substance. Kuepper (1981) writes about the death of Mrs. Abbie C. Borotto after Dr. Hermann Sander injected 10 cc of air into her vein four consecutive times. Then in 1988, *The Journal of the American Medical Association* published the story of a gynecology resident who administered 20 mg of morphine sulfate to a twenty year old girl dying of ovarian cancer thus causing her respiration to slow and then stop (Anonymous, 1988). Timothy Quill (1991) published his story of prescribing

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barbiturates and providing his patient, Diane, with instructions of how much to take to induce sleep and how much to take to die. In the state of New York, the Monroe County district attorney charged Quill with manslaughter, but in July of 1991, the grand jury declined to indict Quill (Hoefler with Kamoie, 1994). Quill (1996) wrote a book about the lives and deaths of nine of his patients. The causes of death varied from natural deaths to hastened deaths to assisted suicide. Shavelson (1995) wrote about five deaths in which the patients planned their suicides, two of which he participated in by being present at the time of the suicide. Finally, Dr. Jack Kevorkian became a household name with his 'mercitron' machine that was used to assist people who chose to commit suicide. "Although helping to arrange a suicide is forbidden, and caregivers who defy the law run some real risk of malpractice and wrongful death charges, no physician has ever been strongly sanctioned for doing so" (Anderson, D. 1997, p. 61).

Physician Court Cases

Notably, since 1950, there have been three physicians who have had charges brought against them for assisting patients with their suicide. Dr. Hermann Sander was charged with first degree murder in 1950. In 1991, Dr. Timothy Quill was charged with manslaughter. Dr. Jack Kevorkian was charged with violating assisted suicide laws four times and in 1999 he was charged with second-degree murder.

Dr. Hermann Sander was arrested for first degree murder because of causing the death of Abbie C. Borotto in 1949. (Kuepper, 1981) Borotto was a fifty-nine year old housewife who had been diagnosed with cancer and who had suffered for over a year. She had gone from 140 pounds to 80 pounds, she wasn't able to eat, and she was in constant severe pain, which the high doses of medication could no longer control. Dr.

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Sander dictated his procedure of giving the four consecutive shots intravenously of air to Borotto because he believed it was his duty as a physician (Kuepper, 1981). Many people expressed their support for and their bias against Dr. Sander's actions, both personally and publicly. Dr. Sander remained free on bond after agreeing to give up his practice until the case was decided. The murder trial started on February 20, 1950, and ended on March 8, 1950. The jury deliberated for only seventy-one minutes with the resulting verdict of not guilty.

In 1991, Dr. Timothy Quill published his account of assisting his terminally ill patient, Diane, with her suicide. Diane was a strong, determined individual who had fought and overcome previous abusive hardships and diseases that included alcoholism, depression and vaginal cancer (Hoefler with Kamoie, 1994; Quill, 1991). She was eventually diagnosed with myelomonocytic leukemia, a cancer that could be treated with only a twenty-five percent survival rate even with the required treatments. With no treatment death is guaranteed. Diane chose not to have any treatment; her husband and son were accepting of her decision. Quill also came to understand and accept Diane's decision and ultimately prescribed barbiturates with instructions for a lethal dose. Quill's case eventually was taken before the grand jury by the Monroe County, New York, district attorney. In July 1991, the grand jury declined to indict Quill on the charges pressed by the district attorney (Hoefler with Kamoie, 1994; Humphry & Clement, 1998).

Dr. Jack Kevorkian is probably the physician that is best known for his part in assisting patients with their suicides. Janet Adkins, who had been diagnosed with Alzheimer's disease, was the first patient Kevorkian assisted with suicide. In 1990, Adkins and her husband flew to Detroit to meet with Kevorkian to discuss her suicide.

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Adkins used Kevorkian's 'mercitron' machine to administer, through an IV, a dose of a barbiturate that rendered her unconscious followed by a lethal dose of potassium chloride (Hoefler with Kamoie, 1994; Humphry & Clement, 1998). Adkins' death resulted in the first charge of criminal homicide against Kevorkian. He was acquitted of this charge by the decision of a jury. Kevorkian was tried three more times for either murder or assisted suicide. In two of these cases he was also acquitted, the fourth case was declared a mistrial. Then in March of 1999, Kevorkian was convicted of the second-degree murder of Thomas Youk, a fifty-two year old man suffering from Lou Gehrig's disease (Hyde, The Denver Post, March 27, 1999).

Dr. Kevorkian

> The only son of Armenian immigrants, Kevorkian was born in Pontiac, Michigan in 1928. He attended the University of Michigan, as an undergraduate and as a medical student, interned at the Henry Ford Hospital in Detroit, and then spent more than a year as an army medical officer in the Korean War. Back in civilian life, he did residencies at Pontiac General Hospital and Detroit Receiving, where his interest in the final moments of dying people developed. (Humphry & Clement, 1998, pp. 127-128)

Jack Kevorkian became a licensed medical doctor with specialized training as a clinical pathologist. He became extremely interested in potential methods of human experimentation to broaden the knowledge and capabilities of medical practice. A great interest of Kevorkian's was the potential of utilizing death row inmates, with their informed consent, to partake in medical experimentation and the organ donor program. To investigate this possibility, he first went to the Ohio State Penitentiary to interview men on death row to determine their feelings about partaking in medical experimentation (Humphry & Clement, 1998; Kevorkian, 1991). Kevorkian's research regarding death row inmates' attitudes toward medical experimentation included the potentiality of

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participating in organ donations. In 1991 Kevorkian wrote:

> So we sanctimoniously keep snuffing out the lives of criminals, many of who acknowledge their transgression and sincerely desire to somehow make amends. They are eager to give society *real* retribution by donating their organs and by helping science unlock some of nature's deepest secrets by submitting to otherwise impossible experimentation. (p. 70)

None of Kevorkian's ideas about utilizing death row inmates for experimentation or allowing them to donate organs has come to fruition.

Kevorkian also did extensive historical research on man's methods of execution. His findings include the condemned being buried alive, being burned alive, being drawn and quartered, and now, being put to death by lethal injection (Kevorkian, 1991). Through Kevorkian's research on lethal injections, he came to invent his infamous 'mercitron' machine. There are normally three drugs utilized in a lethal injection: 1) Thiopental sodium – a fast acting barbiturate, 2) Succinylcholine – drug that paralyzes muscles, and 3) Potassium chloride – a drug that paralyzes the heart muscle (Kevorkian, 1991). Kevorkian's mercitron machine utilizes the three drugs previously listed, which are then mixed with a saline solution in three separate bottles. At the appropriate time each solution containing the different medications are released into an intravenous line that has been inserted into the vein of a person. The mercitron machine is a device that enables a person to commit suicide by the flip of a switch (Hoefler with Kamoie, 1994; Humphry & Clement, 1998; Kevorkian, 1991). Kevorkian's, mercitron machine was first utilized in 1991 by Janet Adkins, a woman diagnosed with Alzheimer's disease. After Adkins' death, Kevorkian was charged with criminal homicide. The charges were dismissed because of the lack of evidence and the fact that Michigan, at that time, had no law forbidding assistance with a suicide (Hoefler with Kamoie, 1994; Humphry &

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Clement, 1998). Kevorkian did not stop there.

In October 1991, he assisted two women in committing suicide at the same time and location with the use of carbon dioxide. Again, Kevorkian was charged with murder, and again the charges were dismissed. He became known as 'Dr. Death' as he continued his attempts to advance the acceptance of assisted suicide (Hoefler with Kamoie, 1994). Eventually, the Michigan Board of Medicine suspended Kevorkian's medical license in 1991, and also rejected his appeal to have his license re-instated. Kevorkian did not stop believing in his goal of making assisted suicide acceptable.

> Kevorkian claimed the alleviation of suffering as his overriding motive, and he has never been shown to accept a penny from his patients. He also aimed to change the way the leaders of medicine viewed assistance in dying. (Humphry & Clement, 1998, p. 126)

As a result of Kevorkian's acts of assisted suicide, several bills were presented to the Michigan State Senate to make a law to forbid the practice of assisted suicide. Finally, a bill was passed in 1992 that would make assisting in a suicide illegal and the act of assisting a suicide punishable by a sentence in prison up to four years and a $2000 fine. The law was originally to take effect on April 1, 1993, but due to Kevorkian's continued assistance with seriously ill patients' suicides the act was amended to take effect the day it was signed by the Governor, December 15, 1992.

Kevorkian challenged the new law by committing his sixteenth suicide on May 16, 1993. He was arrested and charged with violating the ban on assisted suicide. However, "...Judge Cynthia Williams of the Wayne County Circuit Court found the Michigan law to be unconstitutional on procedural grounds" (Hoefler with Kamoie, 1991). Kevorkian was released. He, again, continued his practice of assisting seriously ill people with their suicides and was again arrested on November 22, 1993, for his

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participation in the suicide of Ali A. Khalili. This time Judge Richard C. Kaufman released Kevorkian because the Michigan law had no substantive grounds.

> In his first year of activity, Kevorkian helped only one person to die; he assisted two in his second and six in his third year. But in 1993, even as legal pressures on him escalated, he helped twelve people. The next year he helped only one person to die and then five the year after that. In 1996 he was extremely busy helping nineteen people to their ends. His activity increased in 1997 to twenty-nine people. In the early months of 1998, eighteen people received his help to die, making a total of ninety-three recorded deaths. He had a waiting list of hundreds of patients. (Humphry & Clement, 1998, p.134)

The end of Kevorkian's career assisting with suicides was approaching. In 1999, he sent a video tape to '60 Minutes' showing himself giving Thomas Youk, a 52 year-old accountant suffering from amyotrophic lateral sclerosis, a lethal injection (The Denver Post, March 31, 1999). With this act of euthanasia being publicized in front of millions of people via television, Kevorkian was again charged with murder. This time he was convicted of second-degree murder and sent to prison. Even with this sordid history, Kevorkian helped to advance American's knowledge of the right-to-die movement. "Kevorkian injected life and action into the smoldering right-to-die debate. It needed a maverick like him to do so" (Humphry & Clement, 1998, p. 127).

Summary

The literature surrounding medical practice helps provide a clear understanding of the historical changes that have contributed to the rift in the physician/patient relationship. At one point in time, patients personally knew and trusted their physicians. People relied on their physician to make knowledgeable and caring decisions about their care, including their ability to ease and at times hasten a death. Then the act of human experimentation on non-consenting, captive populations came to the forefront at the Nuremberg trials. The Nuremberg Code was created to provide guidelines to physician

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researchers about acceptable methods and practices for human experimentation (Shuster, 1997). Unfortunately, many physician researchers who conducted human experiments believed that 'the greatest good for the greatest number' outweighed the rights of an individual (Humphry & Clement, 1998). This lack of regard for an individual's right to informed decisions for experimentation carried over to medical treatment. As in the Quinlan and Cruzan cases, the medical professionals determined which treatments were necessary for the patient to live, no matter what the patient's life was like. Again, adding to the lack of trust in the physician/patient relationship.

As the physician/patient relationship is the core of medical practice, it is also an important aspect in the American Right-to-Die Movement. It is desirable for physicians be aware of their patients' expectations at the end-of-life. A step toward this was the creation and legalization of advance directive documents that enable an individual to express in writing their choices about end-of-life care. These documents may help mend the physician/patient relationship by opening the door to necessary communication about personal choices. Factors such as communication and understanding in a physician/ patient relationship have inspired this research project.

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CHAPTER III

METHODOLOGY

The purpose of this study is to understand the factors that contribute to a physician's decision to participate in a terminally ill patient's suicide. Even though physician-assisted suicide is illegal, except in the state of Oregon, it is an act that is known to occur. This study focuses on three research questions:

1. What are the factors associated with the physician's decision to participate in a terminally ill patient's suicide?
2. Why and how does the physician/patient relationship contribute to a physician's decision to participate in a terminally ill patient's suicide?
3. How do the physician and patient discuss the topic and method of the terminally ill patient's suicide?

Four stories written by two different physicians were studied using a qualitative case study approach to analyze and understand why physicians participate in a terminally ill patient's suicide. Understanding why these two physicians agreed to participate in a patient's suicide may help other physicians work through the decision process when they are approached by a patient asking for their assistance. This chapter explains the research approach used in the study, the researcher's perspective, the research process, the data selection and analysis, and the verification of the study.

Research Approach and Rationale

This study is based on the qualitative research paradigm, a paradigm that is known for its inductive and emergent process of analysis. Creswell (1998) defines

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qualitative research as:

> ...an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

A qualitative case study design was selected for this research project. The case study design comes from the desire to add to our knowledge base because of our need to understand complex social phenomena (Yin, 1994). The research questions for this study focus on the cultural phenomenon of physician participation in a patient's suicide. Since assistance with suicide is illegal, except in Oregon, there is a need to better understand why and how a physician decides to risk the legal ramifications associated with their participation.

Merriam (1998) believes the most distinctive aspect of a case study is the delimitation of the case and that the case is an entity with boundaries, a bounded system. To test for boundedness, the researcher needs to determine if the data collected is from a limited number of people or that the time to collect the data is finite. Since the availability of documented stories about physician participation in a patient's suicide is very limited this study meets Merriam's (1998) criteria of a case study. Four published stories were identified for this research project. As Miles and Huberman (1994) express, "Multiple cases not only pin down the specific conditions under which a finding will occur but also help us form the more general categories of how those conditions may be related" (p. 173).

Creswell (1998) identifies four basic types of data collection: observations, interviews, documents, and audiovisual materials. For this study, published documents in the form of stories about a physician's decision to participate in a patient's suicide were

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analyzed.

Researcher's Perspective

After working in the health care industry for more than twenty years, I do have a personal bias and believe that an individual should have the right to choose the time of their death. During that twenty years, I have worked in long term care facilities as a nursing assistant, as a licensed practical nurse, and as a health care facility administrator. The focus of the care I provided during this time was based on a variety of end-of-life issues. After receiving a master's degree in gerontology my interest in end-of-life issues was even stronger. It can be very emotionally turbulent caring for people with incurable and terminal illnesses. Some of these people are your own age and are not able to care for themselves. These illnesses eventually leave people totally dependent on others for feeding, bathing, toileting, dressing, and even turning over in bed. There have been many times patients have asked me the question, "Why can't I die? I don't want to live like this." How do I answer that question?

Research Process

The research process involves the selection of the documents to be studied and the methods used in analyzing the documents.

Selection of documents. A review of the American Right-to-Die Movement literature has provided the names of two physicians, Timothy Quill and Lonny Shavelson, who have written about their participation in a terminally ill patient's suicide. Timothy Quill (1991) published his first story about Diane, one of his terminally ill patients, in *The New England Journal of Medicine.* His case was brought before a grand jury which in July of 1991 declined to indict him, and three judges from the New York Health

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Department announced that there would be no charge of misconduct brought against him (Hoefler with Kamoie, 1994). Timothy Quill's book (1996), *A Midwife Through the Dying Process*, tells the stories of the deaths of nine patients, one of which he assisted with her suicide. Lonny Shavelson's book (1995), *A Chosen Death: The Dying Confront Assisted Suicide*, tells the stories of the deaths of five people he came to know, for two of which he was present at the time of their suicide. Part of the intent of this research is to determine how the physician/patient relationship contributes to a physician's decision. A strong physician/patient relationship was also used in the selection of the stories. This sample limits the published documents to two physicians in the United States from 1950 to 1998. Strauss & Corbin (1990) describe this nontechnical literature as "...biographies, diaries, documents, manuscripts, records, reports, catalogues, and other materials that can be used as primary data..." (p. 48). Copies or originals of these documents were obtained through libraries and bookstores.

Data analysis procedure. A case study is a research strategy that is comprised of the logic of the design which includes specific approaches to data collection and data analysis (Yin, 1994). Since this study utilizes four individual cases, a cross-case methodology was used. This process requires that each case be analyzed individually to determine the theme of the case, within-case analysis, followed by a thematic analysis across the cases, cross-case analysis (Miles & Huberman, 1994). The coding process used in this study incorporated the three typical levels of coding (open, axial, and selective) plus an additional level identified as pre-axial. The pre-axial coding was developed as a result of coding the pilot case.

A story about the terminal sedation of a terminally ill patient from Timothy

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Quill's 1996 book, *A Midwife Through the Dying Process*, was selected as a pilot case study, the first step in this study's analysis. "The pilot case study helps investigators to refine their data collection plans with respect to both the content of the data and the procedures to be followed" (Yin, 1994, p. 74). As a result of this pilot case study an additional level of coding, labeled pre-axial, was utilized. According to Miles & Huberman (1994), "Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during the study" (p. 56). The pre-axial code was a step utilized between the open coding and axial coding levels that created clusters of categories that ultimately contributed to the sub-categories used in the axial codes. Once the pilot case study was completed, the four selected stories were coded and analyzed.

The first step of coding followed was open coding. Open codes are labels that have been assigned to parts of a case with the intention of developing concepts, categories, and properties (Pandit, 1996). An inductive process was used to assign descriptive codes to the identified unit of analysis. The unit of analysis for this study varied in size from phrases to partial phrases. Miles & Huberman (1994) describe this as attaching codes to 'chunks' of various sizes of information.

The open codes were then assigned to a list of pre-axial codes. These pre-axial codes segmented the open codes into predominate categories with a broad range of possible sub-categories. The sub-categories then became the basis for the next level of coding, known as axial coding.

Axial coding was then used to find the relationship between the pre-axial codes. As Pandit (1996) explains axial coding is used to develop a connection between

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categories and their sub-categories. Through the process of reassembling the data that had previously been broken down, some original open codes were dropped or reassigned. Miles & Huberman (1994) expect codes to change through the process of coding.

Selective coding was the final level of coding utilized in this study. This level of coding leads to the point of analysis that a researcher uses to integrate categories enabling him to build a theoretical framework (Pandit, 1996). To accomplish this, a central phenomenon was identified by analyzing the interrelationships of the axial codes. Creswell (1998) recommends that some form of a visual aid be used to better understand the interrelatedness of the categories as they relate to the central phenomenon. The visual aid used in this study was a wall chart meta-matrix. This representation then became instrumental in generating a theory that connected all the categories and patterns to the central phenomenon.

From the analysis of the data through the various levels of coding, the researcher can start to learn from the case. As a part of the qualitative paradigm, a case study can create an empathetic understanding for the researcher through 'thick description' of what the actual experience would convey (Stake, 1995).

To initiate the research process each story was transcribed into the computer program Word ©. From here the researcher was able to develop the open codes for each story. Next, predominate pre-axial categories were created for each case. Third, a re-building of these codes for each case was done during the axial coding. A with-in case analysis was the first step completed in this study. Each story's pre-axial and axial codes were entered and displayed in a matrix. The axial code matrix displayed the themes identified for each story by researcher observations. After the completion of the with-in

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case analysis, a cross-case analysis was done. The research process used for this study is shown below in Figure 1.

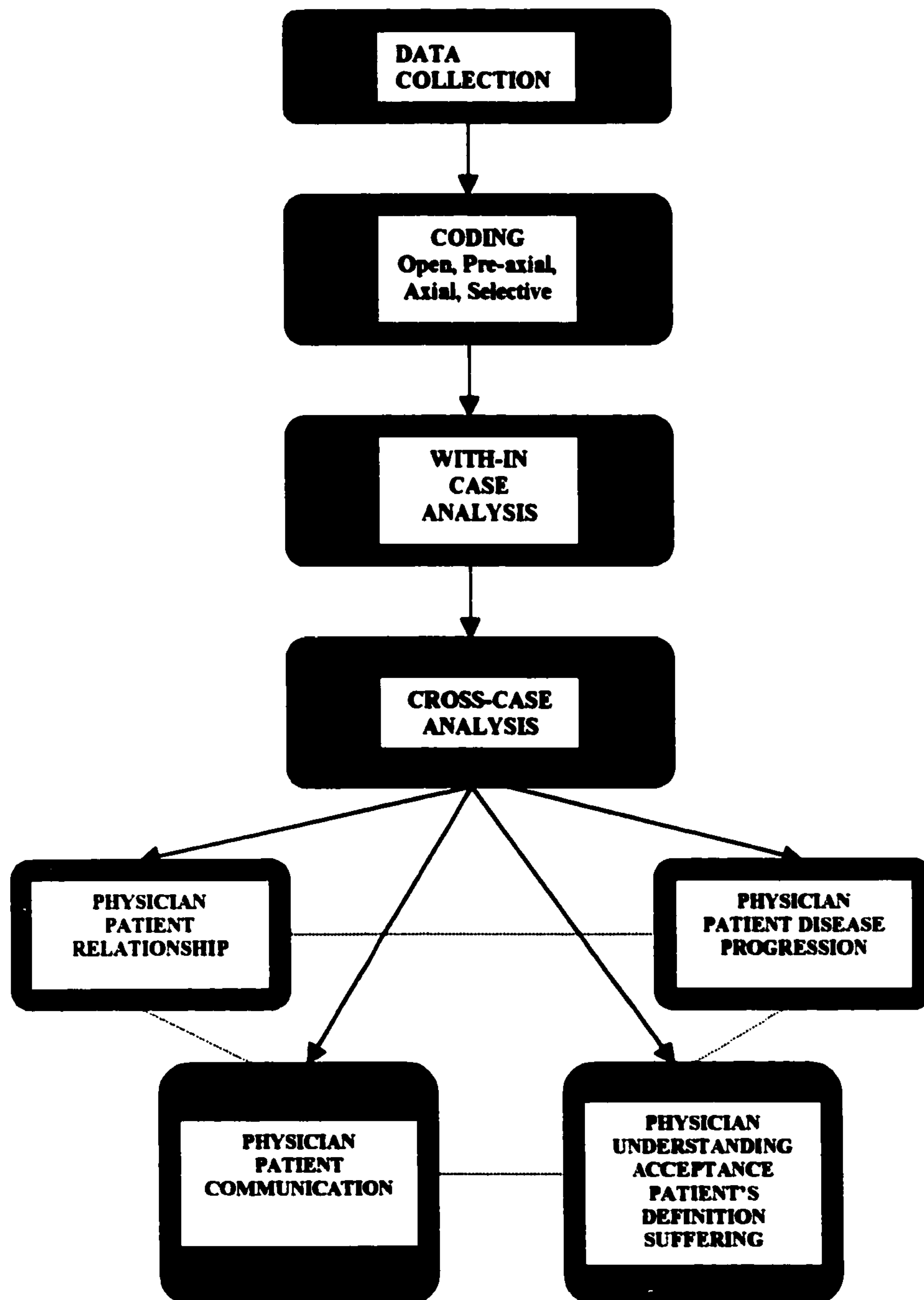

Figure 1. Research Process

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The purpose of a cross-case analysis is to enhance generalizability. People learn by receiving generalizations from others and forming generalizations from their own experiences. Stake (1995) views this as a naturalistic generalization. "Naturalistic generalizations are conclusions arrived at through personal engagement in life's affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves" (Stake, 1995, p. 85). Cross-case studies help researchers and readers learn vicariously to broaden our knowledge and our ability to understand specific phenomenon.

To initiate the cross-case analysis, the information from the axial codes was entered into a wall chart meta-matrix, which allowed for the stacking of the individual story's axial codes (Miles & Huberman, 1994). This table then enabled the researcher to better understand the themes common throughout each individual story. A sample of the wall chart meta-matrix is shown below in Table 1.

Table 1. Wall Chart Meta-Matrix

Categories from pre-axial coding	Mary	Jane	Renee	Diane	*Across-case Themes*
Who is pt.	*Sub-categories from axial coding*				
Aspects physician, patient relationship					
Aspects disease, diagnosis					
Aspects treatment					
Aspects decision suicide					

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The analysis used at this point of the cross-case study enabled the researcher to look at each story's predominate categories and to distill further the cell information into what Miles & Huberman (1994) call 'category-grounding phrases'. These category-grounding phrases provided the with-in case category themes that were then used to develop the across-case themes. This process enabled the researcher to understand the similarities and differences between the cases. A sample of the grounding-phrase matrix, Table 2, is shown below.

Table 2. Grounding-Phrase Matrix

Categories	Jane	Mary	Diane	Renee	Common Themes
Who is pt.	*Grounding-phrase*				*Across-case grounding-phrases theme*
Aspects physician/pt. relationship					
Aspects disease/diagnosis					
Aspects treatment					

Next, the themes pertinent to the research questions were identified and clustered across the cases. As Miles & Huberman (1994) explain, cross-category clustering is a variable oriented display that goes beyond a case-by-case fragmented account of the study's subject to a more focused and integrated cross-case depiction that retains much of the case-specific individuality. After analyzing the clustered across-case themes for patterns, four common themes were developed as factors that contribute to a physician's decision to participate in a terminally ill patient's suicide. The four common themes developed emphasize the interaction between the physician and his patient. The four themes are as follows:

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1. Physician/patient relationship

    - Know who patient is
    - Growth together – respect, learn from each other
    - Awareness family, friends relationships

2. Physician/patient communication

    - Open communication
    - Honest communication
    - Trustworthiness

3. Physician/patient progression together through patient's disease

    - Diagnosis
    - Treatment choices
    - Treatment effects
    - Inevitable death

4. Physician understanding and acceptance of patient's personal definition of suffering

    - Patient fears
    - Patient quality
    - Patient dignity
    - Physician commitment

These themes were then compared to the limited research findings surrounding physician/patient relationships and physician/patient communication at the end-of-life. These areas, which became the researchers deductive codes, include:

1. Direct, honest, timely communication

2. Insightful physician/patient relationship

The deductive codes used for the factors contributing to a physician's decision to participate in a terminally ill patient's suicide seemed to fit the stories used in this study. The researcher was able to see the effect that an insightful physician/patient relationship and the open, honest communication between the physician and his patient has on a physician's ability to decide to partake in his terminally ill patient's suicide.

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Verification

The verification of a study emphasizes that qualitative research is a distinct approach with a legitimate mode of inquiry (Creswell, 1998). The following steps were taken by this researcher to ensure the verification of this study.

1. *Clarification of researcher bias* – the researcher's bias about a patient's right to choose the time of their death was clearly stated.

2. *Peer review* – the coding and analysis process used by the researcher in this study was reviewed and verified by other experienced researchers.

3. *Audit trail* – a detailed description of the data collection process, the development of the main categories and sub-categories, and the analysis process were laid out in the methodology section of this study.

4. *Rich, thick description* – an in-depth description of the factors that contribute to a physician's decision to participate in a terminally ill patient's suicide was provided.

"*Reader or user generalizability* involves leaving the extent to which a study's findings apply to other situations up to the people in those situations…a common practice in law and medicine…" (Merriam, 1998, p. 211).

Two specific criteria were utilized to select the documents used for this study, a form of purposive sampling. First, the documents had to be published accounts of a physician's participation in a terminally ill patient's suicide in the United States between the years 1950 and 1998. Second, the physician and patient had to have a positive relationship that had developed over time. Merriam (1998) believes the most appropriate type of sampling in qualitative research is nonprobability sampling. This study is strengthened by the use of a purposive sampling technique.

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CHAPTER IV

RESULTS

The purpose of this study is to analyze the factors that contribute to a physician's decision to participate in a terminally ill patient's suicide. Four published stories of two physicians in the United States who participated in the suicide of terminally ill patients were studied. These stories were analyzed using the qualitative case study approach.

The research questions used for this study are:

1. What are the factors associated with the physician's decision to participate in a terminally ill patient's suicide?
2. Why and how does the physician/patient relationship contribute to a physician's decision to participate in a terminally ill patient's suicide?
3. How do the physician and patient discuss the topic and method of the terminally ill patient's suicide?

Each story was individually coded using open coding, pre-axial coding, axial coding, and selective coding. A cross-case analysis was then completed resulting in a theory about the factors a physician considers in making a decision about his participation in a terminally ill patient's suicide.

The results of this study are presented in the following order. First, a summary of each story will be presented followed by a detailed description of the with-in case analysis. Then, the cross-case analysis will be described with its identification of four common factors. Finally, the factors will be explained and supported.

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With-In Case Analysis and Results

Each story utilized in this case described a terminally ill patient, her battle with a terminal disease and her relationship with her physician. A summary of each story is presented below.

Jane

Jane lived alone with no close relatives, but she had many good friends and an active social life. She loved being outdoors and played tennis and golf. Jane had two professions. First, she was a nurse with a great interest in palliative care. Later, she became a teacher who enjoyed challenging all students. Jane was a smoker and was very proud of the fact that she was able to quit. She had high blood pressure and respiratory problems that included asthma and pre-mature emphysema. In 1982, she was diagnosed with breast cancer. Over the years Timothy Quill provided medical care to Jane and they developed a personal and professional relationship, creating a strong bond.

Multiple medications were required daily to maintain Jane's several health problems. When she was diagnosed with breast cancer, Jane chose to have a mastectomy. As a precaution for limiting the chance that the cancer might spread to the other breast, her hormone replacement therapy was stopped. Unfortunately, her hot flashes returned with a new intensity. Jane chose to risk the small chance of the spread of breast cancer and resumed her hormone therapy. Since her active lifestyle was being curbed by multiple health problems, she chose to have a better quality of life without the intense hot flashes. Jane was hospitalized at different times for severe lung infections that compromised her already limited breathing ability. Increased steroid and inhaler therapies were prescribed to ease her difficulty with breathing. Over time, the effect of the multiple

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medications contributed to more medical problems. At one point her condition was so weakened she was unable to catch her breath; she was taken to the hospital and was admitted to the intensive care unit. She survived this bout, but felt exhausted and defeated.

The next time Jane went to the doctor's office, she was tired and frustrated that there was no prospect of her condition improving. Her mind was still very active, but her body was deteriorating. She did not like the idea of depending on others, especially her friends. Jane was terrified of suffocating. As a nurse she had seen people die from suffocation, drowning for days in their own body fluids. Jane said she had exceeded her own limits of suffering; she was ready to die. Timothy Quill committed to providing her with enough morphine to keep her comfortable when she began to struggle with her breathing. Jane asked for a prescription for secobarbital to help her sleep. Since she had a long history of insomnia with little relief of sleeping medications previously, Quill asked her to be more specific about her request. Jane explained that her life no longer had meaning or joy, that she was not living anymore, that she did not want to become any more of an invalid than she was already, and that she knew there was no chance of her getting better. Quill finally prescribed the secobarbital in an amount that was not lethal. On three follow-up visits, Jane told Quill the secobarbital was helping her to sleep and requested refills. Quill was sure Jane had enough for a lethal overdose at this time, and asked Jane if she had a plan. Jane had no plan, but reassured Quill that she had friends that had committed to support her to the end. They parted saying a tearful good-bye. Since assisted suicide was illegal, Quill was not able to be present when Jane died, leaving him with many unanswered questions and unresolved feelings (Quill, 1996).

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Mary

Mary was 56 years old when she was diagnosed with breast cancer. The cancer was fairly advanced as it had already spread to her bones. She was a journalist and the author of mystery novels. Mary loved life, her family, and her friends. She was a down-to-earth, pragmatic person with a sense of humor and a mischievous streak. Mary contacted Lonny Shavelson, a physician doing research on people choosing suicide, to discuss and explore her decision to control her death through suicide. Their talks about Mary's planned suicide over the next two years led to the development of a close, caring relationship. Mary also shared her suicide plans with her family believing it would protect them from her dying process.

Mary chose several different types of treatments over five years, each extending her life a little longer. One treatment she chose, a bone marrow transplant, kept her in the hospital in isolation for six weeks. The staff became very concerned when all Mary did was lie in bed and look at the ceiling – they called in a psychiatrist. Mary was having a wonderful time creating a complex murder mystery. With her mischievous side emerging, Mary never told the psychiatrist that she was writing a new mystery in her mind, leaving his questions unanswered. Fighting to continue living, Mary fought her way into an experimental treatment program with a drug called Taxol. The Taxol reversed the cancer tumors that had appeared on her skin, but had the bad side effect of making her violently ill. After thirteen months of the Taxol treatments, the skin tumors started to grow again with a vengeance. She found another experimental treatment program with the drug RU-486 in which she wanted to participate, but was unable to qualify because her cancer had progressed too far. Mary was now very ill, the cancer had

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again invaded her bones causing them to leak calcium into her blood.

Mary's body started to make decisions for her and her dying process began. Mary was admitted to the hospital to treat the high blood calcium level. Wanting to maintain her independence, on her first night in the hospital, Mary attempted to get out of bed by herself falling and hitting her head. The hospital staff tied her to the bedrails to prevent her from doing it again. Tying Mary down killed her fighting spirit. Mary's personal dignity and quality of life were extremely important to her, but these too disappeared while she was in the hospital. Her most humiliating experience was being picked up by her youngest son, unable to control her bowels, and 'shitting' in front of him. Mary decided it was her time to die. Mary's family and friends came to be close to her and to be present during her final hours. During this time of reminiscing, all of Mary's relationships were closed with no loose ends. Shavelson and Mary's family, because of this special time with her, came to understand and accept her decision to take her own life. Mary reminded Shavelson that he had 'signed up' a long time ago, and asked him to stay with her while she took the Seconal to end her life. Mary died peacefully. (Shavelson, 1995)

Diane

Diane was not an ordinary person. She had overcome alcoholism, vaginal cancer, and depression. She had taken control of her life and had become independent and confident. Diane was a very clear thinker and communicator, sometimes overly honest. She had developed very deep connections with her husband, son, and many friends. Diane's life was full. Timothy Quill, providing her medical care through these times, had come to know and understand Diane.

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When Diane complained of feeling tired and having a rash, Quill checked her blood count. The results were unusual and the test was redone. Diane was diagnosed with myelomonocytic leukemia. This type of leukemia was treatable, but only 25% of those treated had long-term cures. The treatment itself was horrific due to the severe side effects, and death resulted in approximately 75% of the people receiving the treatment. An oncologist confirmed the findings and planned to initiate the treatment. Diane was devastated by the finality of the diagnosis, but chose not to be treated. She went home to be with her family, to discuss her options and feelings. Diane had fought through other illnesses, but chose not to fight this one. She wanted to be at home with her family for the remainder of her time. Diane spoke with a psychologist. Quill came to understand Diane's feelings and to support her decision. Her family was also supportive of her decision. They planned for hospice care at Diane's home, and Quill promised to keep her as comfortable as possible. Diane had another idea. She had known people who had lingered in 'a state of relative comfort' and wanted nothing to do with it. Diane wanted to take her own life when the time came.

Quill and Diane discussed her idea of suicide in length. When Quill was convinced this was the best option for Diane, he informed her of the Hemlock Society. A little later, Diane called Quill and requested a prescription for barbiturates. They scheduled an appointment and discussed her plans. After being sure Diane was thinking clearly, Quill gave Diane a prescription for barbiturates with instructions on how much to take for her to sleep and how much to take for a lethal dose. Diane spent several important months with her family. Eventually fatigue, bone pain, and fevers dominated her life. Diane started to tell everyone good-bye. She met with Quill as promised telling

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him she was more terrified of staying and suffering than of dying. Two days later Diane died with her husband and son nearby, but not with her. Quill went to their house. Diane was seemingly at peace. Quill was left with many unanswered questions – "I wonder..." (Quill, 1991).

Renee

Being conceived and raised by Jewish, middle aged parents in postwar Germany, Renee learned to be self-sufficient and independent. She moved to California when she was twenty-one. Renee worked with the government in the area of emergency disaster planning which bolstered her love for a good fight. She loved adventure and thrills – flying small aircraft, sky diving, and driving a small sports car. Renee had many friends, though she enjoyed the private side of her life. At 36 Renee experienced a sharp, sudden headache. This began her battle with brain cancer.

Renee's first battle was with her HMO. Several of the HMO doctors told her that her headache was nothing; she was fine. The pit-bull in Renee came out. She called the public relations officer of the HMO and threatened to inform all her friends in the legislature of their denial for her to be thoroughly examined. She was given an appointment at 8:00 the next morning and was diagnosed with brain cancer. Renee chose a variety of treatments including neurosurgery and radiation, halting her cancer for two years. The cancer returned and Renee found her way into an experimental program in Europe. She flew to Sweden and under went the new treatment in which a 'gamma knife' sent an intense slicing beam of radiation through the cancer. The cancer then virtually disappeared. Even though the cancer had disappeared, Renee still thought about planning for her suicide. The cancerous tumor returned.

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The cancer grew again, this time spreading to a lymph gland in Renee's neck. The growth of the tumor in her neck made it difficult for Renee to swallow, so she started to drink fewer fluids resulting in dehydration. When she was finally found at home, Renee was barely conscious and extremely confused. She was taken to the hospital and admitted to the hospice unit. Shavelson visited her in the hospice unit and found her strapped to the bedrails. Because of her confusion the hospice staff had tied Renee to the bed. Even though the hospice staff was able to rehydrate Renee, her confusion continued intermittently and her weakness progressed. Renee went home a few days later, barely able to walk and against medical advice. Her friends took turns staying with her and caring for her. Eventually her intermittent confusion turned into hallucinations of crashing in a small aircraft and scorpions all around her. Shavelson and her friends were helpless to comfort her. During a time of lucidity, Renee realized she really was dying and there was nothing that could keep it from happening. She then selected the day she was going to die. After talking with her friends, they acknowledged her decision and they told each other good-bye. Not wanting to die alone, Renee asked Shavelson to stay with her. She ingested liquid morphine and vodka. Her respirations slowed. After several hours Renee died (Shavelson, 1995).

Coding process. Once each story was transcribed into the computer program Word ©, the researcher inductively provided open codes for varying chunks of data. Appendix A shows a sample of one of the story's transcription and the open coding for that transcription. Each story's open codes where then clumped into several major pre-axial categories. Appendix B shows a sample of one of the story's pre-axial codes. Since the pre-axial codes were cumbersome to work with, they were then inductively broken

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down into subcategories, which is the initial step of this study's axial coding. Each story's initial axial codes are found in Appendix C. The second step in axial coding was rebuilding the individual study's subcategories into nine major categories on a wall chart meta-matrix as displayed in Table 1 of Chapter III. As the wall chart contained voluminous information, the subcategories were then entered into a partially ordered meta-matrix as displayed in Appendix D. Category grounding-phrases were then developed from the wall chart meta-matrix to create the with-in case category themes. A sample of this method is shown below in Table 3.

Table 3. With-In Case Category Grounding-Phrases

Categories	Jane	Mary	Diane	Renee
Who is pt.	Content with life – strong willed, spiritual person, teacher.	Creative, mischievous, strong willed person – fulfilled relationships.	Extraordinary, confident, living life fully – deep connections others.	Self-sufficient, adventurous, determined – carefully controlled life.
Aspects physician/pt. relationship	Strong personal and medical relationship based on commitment, honesty, and openness of communication.	Demonstrated with two physicians: Respectful relationship developed through communication and awareness commitment to each other.	Long-standing relationship developed due to admiration and commitment – physician learned from pt..	Friendship developed through open, honest communication, growth from mentoring.
Aspects disease/diagnosis	Chronic respiratory disease and breast cancer – eventually no improvement, no future, terminal.	Breast cancer spread bones and visible skin, numerous treatments – body makes decision death imminent.	Leukemia's rapid progression requires rapid decisions.	Cancer spread brain effect mind – took choice for life away.

The researcher was then ready to move on to the next level, the across-case analysis.

Across-Case Analysis and Results

The first step of the across-case analysis was to find across-case themes utilizing the with-in case category grounding-phrases. The complete grounding-phrase matrix is exhibited in Appendix E. Using the grounding-phrase matrix to find the commonalties across the stories, the researcher was able to identify six categories that related to the study's research questions. These categories are as follows:

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1. Who is patient
2. Physician/patient relationship
3. Aspects of end-of-life friends, family, physician
4. Aspects of disease/diagnosis
5. Aspects of treatment
6. Aspects of decision about suicide

Upon further analysis of these categories, the researcher found that these six categories developed into four common factors that contributed to a physician's decision to partake in a terminally ill patient's suicide. The four common factors are:

1. Relationship
2. Physician/patient communication
3. Physician/patient progression together through patient's disease
4. Physician understanding and acceptance of patient's personal definition of suffering

With even further analysis by this researcher, subcategories were identified for each factor. The results of this analysis are as follows:

1. Relationship
    - Know who patient is
    - Growth together – respect, learn from each other
    - Awareness family, friends relationships
2. Physician/patient communication
    - Open communication
    - Honest communication
    - Trustworthiness

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3. Physician/patient progression together through patient's disease

   - Diagnosis
   - Treatment choices
   - Treatment effects
   - Inevitable death

4. Physician understanding and acceptance of patient's personal definition of suffering
   - Patient fears
   - Patient quality
   - Patient dignity
   - Physician commitment

A clustered summary table was utilized to explain and support these findings. Appendix F displays this clustered summary table.

Explanation and Support

With the use of the cluster summary table this researcher was able to explain and support the four common factors contributing to a physician's decision to participate in a terminally ill patient's suicide.

Relationship. Even though each patient is an individual, they each developed a strong and confident character. In each story the physician/patient relationship developed over time enabling the physician to truly know who his patient was as a person. They respected and learned from each other and their relationships grew. While Quill was a patient's primary physician, Shavelson was not. They still each developed a very special bond with the terminally ill patient each one wrote about. In three of the stories Quill and Shavelson interacted with friends and family of the patients prior to the patient's death. In the fourth, Quill talked with one of the patient's friends after her death. Examples of this relationship factor are illustrated below:

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1. Know who patient is

    - Spiritual ~ "...confident about the existence of a beneficent God" (Jane)
    - Mischievous ~ "...ornate fountain began to spout water in elaborate colors" (Mary)
    - Extraordinary ~ "Diane was no ordinary person..." (Diane)
    - Loved adventure/thrills ~ "...Learning to fly small aircraft and sky diving" (Renee)

2. Growth together – respect, learn from each other

    - Personal and medical relationship ~ "...immediate connection ten-year relationship" (Jane)
    - LS caring close to pt. ~ "...sat down on edge of Mary's mattress – holding her hand" (Mary)
    - Taught TQ inner strength & risk-taking ~ "She taught me about life, death, and honesty..." (Diane)
    - Pt. friend and mentor ~ "...My mentor at thriving in the face of adversity" (Renee)

3. Awareness family, friends relationships

    - Friends committed to end ~ "...good friends who would support her to the end" (Jane)
    - Timing death important – not mode ~ "...important question wasn't suicide – it was the timing" (Mary)
    - Family/TQ remember remarkable person ~ "...talked about what a remarkable person she had been" (Diane)
    - Surrounded by friends ~ "...cluster of friends surrounding her bed" (Renee)

Physician/patient communication. Both Quill and Shavelson were able to communicate with the terminally ill patients. The physicians and their patients had grown to trust each other encouraging open and honest communication throughout their relationships. Even though the method of communication was different, each patient was able to express her own thoughts and feelings without fear. Examples of the physician/patient communication follow:

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1. Open communication

    - Open communication ~ "...discussed our common interests – wide ranging conversations" (Jane)
    - Talk about plan suicide ~ "...we began to talk about her plans for suicide" (Mary)
    - Pt. testing doctor commitment ~ "...she opened up another area that would stretch me profoundly" (Diane)
    - Share reality of cancer ~ "Maybe through me...you'll get a good hit of what it's really like" (Renee)

2. Honest communication

    - Honest relationship – communications ~ "...our relationship honest – conversation out in open" (Jane)
    - Couldn't lie to doctor ~ "...didn't think it would work to lie to him – we knew each other too well" (Mary)
    - Committed open – regular communication ~ "We agreed to meet regularly – promised to meet me before taking life" (Diane)
    - Described possible death scenarios ~ "...hope I was fair in my description" (Renee)

3. Trust in each other

    - TQ question reason for request ~ "...take request face value – too important decision to make without direct conversation" (Jane)
    - Be clear – direct ~ "Don't be so eloquent..." (Mary)
    - Informed pt. Hemlock Society ~ "...I told Diane that information available from the Hemlock Society" (Diane)
    - Discussed suicide and how to do it ~ "She asked me how she might do it..." (Renee)

Physician/patient progression together through patient's disease. The process of a terminal disease begins with the diagnosis. Each physician and his patient progress through the disease process in different ways and in different time frames, but they progress as a team. Three of the stories describe the various treatments chosen by the terminally ill patient and the effects of treatments on the patient, good and bad. Only one patient chose no treatment. The survival rate from the treatment for this patient's type of disease was only twenty-five percent. Finally, with or without treatment, the disease from

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which each patient suffered took choice for life away – death became inevitable. Both physicians partook in the different phases of the patent's disease process, the chosen treatment or non-treatment of the disease, the various effects on the patient of both the treatments and the disease, and finally the time when the disease won the battle. Examples of the disease progression process follows:

1. Diagnosis

   - Breast cancer – respiratory problems ~ "…biopsy determined breast cancer", "…given her problems with asthma" (Jane)
   - 56 – dx breast cancer ~ "…breast cancer – already spread to bones" (Mary)
   - Definite dx leukemia ~ "…acute myelomonocytic leukemia" (Diane)
   - Diagnosis brain cancer ~ "…cancer in her brain" (Renee)

2. Treatment choices

   - Selected mastectomy ~ "…chose invasive surgery – no confidence in radiation" (Jane)
   - Visible skin tumors – experimental ~ "…very visible skin tumors – became her saving grace" (Mary)
   - Physical symptoms treated ~ "…emotional and physical hardships – transfusions – antibiotics" (Diane)
   - Endured treatments and side effects ~ "…endured painful neurosurgery, radiation, and the nausea, vomiting" (Renee)

3. Treatment effects

   - Bad side effects – medical complications increased ~ "The steroids were associated with all the predictable complications…" (Jane)
   - Cancer spread – chemotherapy depleted resistance ~ "…bones riddled with cancer, and the chemotherapy – susceptible to infections" (Mary)
   - Attempt minimize suffering – comfort measures ~ "…tried our best to minimize the suffering and promote comfort" (Diane)
   - Treatment stopped cancer two years ~ "…halted the cancer for two years" (Renee)

4. Inevitable death

   - Disease only get worse ~ "She was hovering on the edge of dying…" (Jane)
   - Body making decisions ~ "Your body is making the decisions…" (Mary)

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- No treatment – certain death ~ "...outcome no treatment – certain death" (Diane)
- Tumor spread in brain ~ "...the tumor had also spread inside her brain" (Renee)

This progression together through the progress of a terminal disease has a very personal effect on each person. It provides the physician the opportunity to start to understand the patient's personal definition of suffering.

Physician understanding and acceptance of patient's personal definition of suffering. As each stage of the patient's disease is experienced, the patient is able to share his feelings and his fears about suffering. All of the patients expressed a fear of the dying process, not of death itself, to Quill and Shavelson. Even though each patient's disease causes different ways of dying resulting in different fears, all the patients expressed a fear of the loss of dignity and quality at the end of their life. Due to this ability of the patients to share their fears with Quill and Shavelson, Quill and Shavelson were both able to commit to not abandoning their patient either by prescribing a medication that was lethal at a certain dose or by being present when the patient committed suicide. Examples of the physicians understanding and acceptance of the patient's definition of suffering follow:

1. Patient fears

    - Terrified suffocation ~ "I am terrified of waiting to suffocate..." (Jane)
    - Tied down worst fears ~ "Tied down, Mary faced her worst fears..." (Mary)
    - No desire existence relative comfort ~ "...lingering in relative comfort – wanted no part of it" (Diane)
    - Terrified dying process ~ "I'm terrified of...Pain – Delirium – Hopelessness – Dependence" (Renee)

2. Patient quality of life

    - Not want be more invalid ~ "This is not living any more – only get worse" (Jane)

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- Wait – shit bed ~ "...wait forever shit in this bed – before I'll let them tie me up again" (Mary)
- Suffering during dying process real ~ "...to think people do not suffer in the process of dying is an illusion" (Diane)
- Hates dependence ~ "I abhor dependence" (Renee)

3. Patient dignity

- Hated dependence on others – scheduled care ~ "...hated being in hospital and depending on others" (Jane)
- Incontinent bowel – loss dignity ~ "...the foul smell of feces filled the room as she lost control" (Mary)
- Lack control – dignity wants death ~ "...no longer possible – clearly wanted to die" (Mary)
- Due to confusion – pt. choice taken away ~ "I wake up in the middle of the night – yelling to let my dog in – insisted to go home – they tied me down" (Renee)

4. Physician commitment

- Guarantees enough medicine comfort ~ "...not afraid to give enough medicine once start to suffocate" (Jane)
- Requested LS stay – agreed not abandon ~ "You stay – you signed up a long time ago" (Mary)
- TQ committed pt. good death process ~ "...felt strongly that I was setting her free to get the most out of time left" (Diane)
- LS reached decision ~ "From some mysterious merger – I had reached my decision" (Renee)

Summary of Decision Factors

This research revealed four major decision factors, which these two physicians took into consideration when deciding to participate in a terminally ill patient's suicide. The four factors found are communication, relationship, disease progression, and definition of suffering. A model of the interaction of the decision factors was developed to help explain how the factors are intertwined and result in a physician's decision.

The core of this interaction model is the level of communication between the physician and the terminally ill patient. A relationship is built best when people have the ability to communicate openly, honestly, and in a trustworthy manner. This study

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revealed that in each physician/patient relationship communication enhanced how they related to each other. First, because of the openness of their communication the physician was able to identify who the individual patient really was. They came to know the strengths and special gifts of each patient from the spiritual, to the mischievous, to the confident, to the adventurous. Second, communication enabled their relationship to grow over time, both personally and professionally. As between Shavelson and Mary, their initial verbal sparring turned into a close personal friendship. Diane taught Quill not to fear the need to talk openly and honestly with patients. Finally, because Quill and Shavelson developed a personal relationship with their patients, they also came to know their patients' families and friends either vicariously or personally.

Communication is, again, the key to how a physician and their patient progress through the process of a terminal illness. With the development of such a special physician/patient relationship, honest communication is essential. This is extremely important when the physician informs their patient of a terminal diagnosis. Once the patient is aware of the diagnosis, they need to be informed of their options for medical treatment so they can make an informed decision. The physician ought to be honest about the potential outcome of the treatment and the possible side-effects associated with the treatment. This was best evidenced by Quill and his patient Diane who decided that the horrific side-effects and the limited survival rate of the treatment was not worth going through the treatment. At each phase of the disease and the treatment for the disease the physician and the patient discussed how the patient felt about the process. As Renee tells Shavelson, "Maybe through me…you'll get a good hit of what it's really like." (Shavelson, 1995, p. 20) Finally, the physician and patient can discuss the time that death

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is inevitable when there is a high level of trust between them. Just as when Shavelson (1995) told Mary "…your body is making the decisions for you" (p. 186).

A physician ought to be able to understand and accept the patient's personal definition of suffering. This is accomplished throughout all levels of communication: 1) openness, 2) honesty, and 3) trustworthiness. A terminally ill patient should be comfortable enough to be able to clearly explain to their physician their fears of dying. Each of the patients in these stories expressed their fear about the dying process, not death itself. Jane was terrified of suffocation. Mary feared deterioration and a loss of dignity in front of her family. Diane feared living the end of her life in relative comfort provided by medication and other comfort measures. Renee feared pain, delirium, hopelessness, and dependence on others. The loss of the quality of life and the loss of personal dignity contributed greatly to the patients' definitions of suffering. This is best described by Mary (Shavelson, 1995) "…I will not be dragged to the bathroom to shit in front of my son" (p. 191). A physician can best exhibit their understanding and acceptance of a patient's personal definition of suffering by committing not to abandon their patient at the end-of-life. In these four stories, neither Quill nor Shavelson abandoned the terminally ill patient. Quill provided his two patients, Jane and Diane, with a prescription for a barbiturate. For Diane he told her how much of the medication would help her sleep and how much would be lethal. Jane was given a prescription only for enough secobarbital to sleep, but through subsequent visits and refilling prescriptions she would obtain enough for a lethal dose. Shavelson, not being Mary's or Renee's primary physician, did not write any prescription for medication, but was present when each took a lethal overdose of medication.

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This model, shown in Figure 2 below, provides a physician with four factors to consider when making a decision about his possible participation in a terminally ill patient's suicide. It also depicts, as discussed within this chapter, how communication is the core factor causing each of the other factors to interact with each other.

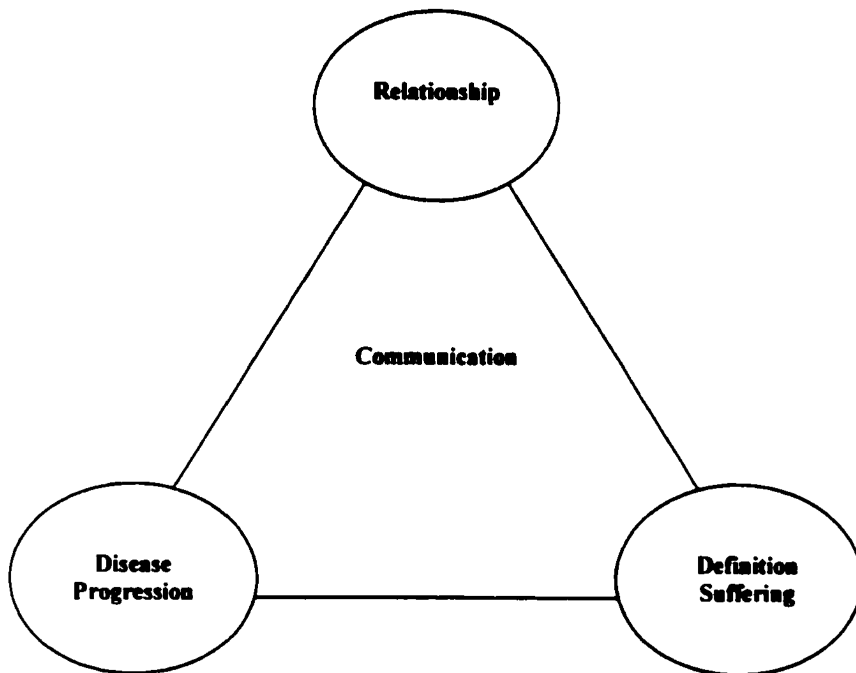

Figure 2. Model Interaction Decision Factors

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CHAPTER V

DISCUSSION

This research project analyzed the factors that contribute to these physicians' decisions to participate in a terminally ill patient's suicide. The results of this analysis revealed four common factors. A model was developed based on these factors that illustrates the interaction between the factors as they contribute to a physician's decision process. The four factors are: 1) Relationship, 2) Physician/patient communication, 3) Physician/patient progression together through patient's disease, and 4) Physician understanding and acceptance of patients' personal definition of suffering. This chapter discusses these findings as they relate to current literature and suggests areas for further research.

Relationship

> Ego strength is the vital factor which determines how sturdily the fortress of self is built – how well it can endure the psychic shock, physical disability, pain and other eroding aspects of fatal illness. Ego strength represents the sum total of intellectual and emotional maturity of an individual. (Verwoerdt, 1966, p. 15)

The relationship between a physician and his patient is something that grows over time. It includes a deep understanding of each other as individuals. Charon (2000) describes it as "...a relation between two human beings, two selves" (p. 39). Physicians and patients go through a great deal together. The patient may go through acute or chronic illnesses while the physician goes through diagnostic uncertainties, some therapeutic victories, and some therapeutic defeats (Charon, 2000). Through this process,

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the physician and patient learn from each other and develop a certain level of trust. Jecker (1991) believes Quill's story of 'Diane' is a true representation of his understanding of Diane as an individual and relays his special relationship with her. Special relationships between a physician and his patient need to include an awareness of the dynamics of patients' relationship with their families and friends (Jamison, 1997).

The stories used in this study clearly demonstrate the development of special physician/patient relationships. Quill and Shavelson describe each terminally ill patient with insight, they know the personality of each patient and how it carries over into their everyday lives. Shavelson came to know Mary very well, especially her mischievous side. He wasn't surprised by her rebellious act at the rest home in which she resided for a short time during her illness. "Soon after Mary moved in, the ornate fountain at the entrance to the lodge began to spout water in elaborate colors. Someone, it seemed, was putting food dye in the recirculating water, a different color each day" (Shavelson, 1995, p.173). Through their patients, Quill and Shavelson came to know the patient's family and friends, either vicariously or personally. Quill knew that Jane had a very social life prior to her limiting illnesses and through their conversations knew she had some very close friends. "Jane reassured me that she had good friends who would support her to the end" (Quill, 1996, p.167). The physicians understand the importance of these relationships, especially at the end of life. "The greatest dignity to be found in death is the dignity of the life that preceded it" (Nuland, 1993).

"Framing the doctor-patient interaction within a context of intimate human relationships rather than within a context of technical interchange provides a deep and rich tradition of knowledge and experience as background and inspiration" (Charon,

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2000, p. 40). This is explanatory of the relationship aspect, 'growth together', between the two physicians and their patients. Quill talks about how Diane taught him to realize his own inner strength thus giving him the ability to be better at what he does personally and professionally. "Diane taught me about the range of help I can provide...She taught me about life, death, and honesty...She taught me that I can take small risks for people..." (Quill, 1991, p. 694). Jecker (1991) corroborates Charon's sentiments by believeing it is the physician's responsibility to avoid depersonalizing either the physician/patient relationship or the patient.

Unfortunately, in the growth of America's Right-to-Die Movement, we have run into a physician that has depersonalized the importance of an intimate human relationship between physician and patient. Dr. Jack Kevorkian has become well known for his participation through assisting numerous people with their suicides. His assistance with Janet Adkins suicide exemplifies his lack of a personal, long-standing relationship with this patient. Kevorkian, after examining Adkins medical records, met with both her and her husband for a detailed interview about her understanding of her condition (Alzheimer's Disease) and the finality of her decision to commit suicide. "Next day he helped her die with his suicide machine" (Humphry & Clement, 1998, p.130). The other suicides Kevorkian assisted with resembled this very impersonal type of physician/patient relationship. In contrast to Kevorkian, Jecker (1991) believes Dr. Timothy Quill exemplifies the need for a personal quality and deep understanding of a physician/patient relationship in his story about Diane.

Opponents to the right-to-die fear the possible effect managed care may have on the abuse of assisted-suicide (Azevedo,1997). Their fear is that physicians who have

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received a capitated rate to provide care for their patients may consider the option of assisting a patient to die at a time earlier than expected. "...a physician should make an effort not to succumb to temptation, pressures, and impulsive or selfish desires that might betray the patient's trust" (Jecker, 1991, p. 833). However, proponents believe a close personal and meaningful physician/patient relationship could be used as a criteria for a physician to legally assist an incurably ill patient with their suicide (Jecker, 1991; Quill, Cassel, & Meier, 1992).

Physician/Patient Communication

Communication is the key component to any physician/patient relationship because it enables both the physician and the patient to openly discuss what they each go through, especially when it relates to end-of-life issues (Jamison, 1997; Morrison, 1998).

> Physicians do not like to give bad news. Almost universally, end-of-life discussions contain bad news. Doctors working with terminally ill patients experience several feelings – for example, helplessness, guilt, and anger about not being able to offer more. (Morrison, 1998, p. 124)

Though many years apart, Verwoedt (1966) and Morrison (1998), have both identified three important characteristics of good physician/patient communication. These characteristics do not resolve the issue of having to deliver 'bad news', but they can help the physician to know better how to deliver bad news. First, they believe that direct communication best helps the patient to understand their illness and encourages them to ask questions about what they don't understand. Second, honesty and respect are of the utmost importance. There are times that a physician doesn't have all the answers, and it strengthens the bond between the physician and patient when they are honest about their own limitations. Timeliness is the final characteristic of good physician/patient communication. As the physician and patient have already developed a strong, special

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relationship, the physician can use some judgment about how and when it is the best time to discuss end-of-life choices with his patient. Even with these characteristics in mind, it is never easy to discuss end-of-life issues. "Unfortunately, physicians' responses to the dying patient are often strained and characterized by either distancing from the patient or engaging in high-tech responses instead of providing palliative or comfort-directed care" (Kvale, Berg, Groff, & Lange, 1999, p. 691).

Both Quill and Shavelson demonstrated their ability to communicate openly and honestly with the patients in the stories analyzed for this study. They each knew and understood the terminally ill patients well enough to know how to talk to them. There was also a high level of trust that enabled Quill and Shavelson to discuss the patients' plans for suicide. Quill's relationship with Jane had grown to be comfortable enough that he made sure their conversations about 'self-deliverance' were open and honest. "I chose to keep our relationship honest and our conversation out in the open…I made her be more explicit about what she was asking" (Quill, 1996, p. 165). The communication between a physician and patient is not one-sided; the physician must be open to listening and learning from what the patient has to say. "Maybe through me, Lonny, you'll get a good hit of what it's really like" (Shavelson, 1995, p. 20).

The open discussion and willingness to listen between a physician and a patient helps them each explore and understand the differences in their perceptions enabling them to find the common ground needed to make joint decisions for end-of-life care (Quill & Townsend, 1991). This end-of-life care should also incorporate an awareness and an understanding of not only the patient's experience with the dying process, but also the family's experience with the patient's dying. A physician should realize that many

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dying patients "...want the last days, weeks, and months to pass without pain, to be spent harmoniously with family and close friends, preferably at home in familiar surroundings" (Balaban, 2000). This has been best represented by Quill's (1991) account of Diane's death. "She had said her final good-bye to her husband and son...they found her on the couch, lying very still and covered by her favorite shawl" (p. 693). With this understanding and level of communication between a physician and his patient, they are both better able to confront and discuss together a patient's desire to commit suicide.

Quill, Cassel, & Meier (1992) have developed a set of proposed clinical criteria for physician-assisted suicide. Two of these criteria can be utilized to help measure the level of communication between a physician and his patient. First, is the criteria which says, "...the physician must ensure that the patient's suffering and the request are not the result of inadequate comfort care" (Quill et al, 1992, p.1382). Second, is the criteria which says "...the patient must clearly and repeatedly, of his own free will and initiative, request to die rather than continue suffering" (Quill et al, 1992, p. 1382). Both of these criteria are demonstrated in Shavelson's story about Mary. At the end, Mary was dying of a high level of calcium in her blood, which results in a patient becoming increasingly sedated to the point of unconsciousness – then death. "You're one of the fortunate ones...it looks like you will have a comfortable death" (Shavelson, 1995, p. 184). During Mary's last days in the hospital, she spoke to her family and Shavelson of her desire to die at a time she chose; these requests were consistent with her desires expressed so many times before about wanting to die before she lost all dignity.

> Physicians must discuss the risks, benefits, and likely outcomes of assisted suicide. They must also discuss alternatives to suicide, including the possibilities of palliative care. This model assumes rational decision making and also assumes that when patients raise the possibility of assisted dying, they are, in fact, asking

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> for a hastened death rather than using the request to express unmet needs or to manipulate their situation. (Tulsky, Ciampa, & Rosen, 2000, pp. 494-495)

Physician/Patient Progression Together Through the Patient's Disease

> Dying patients need more than prescriptions for narcotics or referrals to hospice programs from their physicians. They need a personal guide and counselor through the dying process – someone who will unflinchingly help them face both the medical and the personal aspects of dying, whether it goes smoothly or it takes the physician into unfamiliar, untested ground. (Quill, 1993, p. 872)

With today's medical and technological advancements, terminally ill patients really need a physician who is committed to helping make the end of their life the best it can possibly be. "Only the inexperienced doctor expects diseases to get better, only the newly stricken patient expects the disease to ever leave him or her alone" (Charon, 2000, p. 43). The physician committed to helping ease a patient's end-of-life must include informing the patient of all the various options available to them, and, then give support for whatever decision they may make. Campbell (1992) emphasizes the importance of and respect for the patient's right for autonomy and self-determination. "Informed consent is usually invoked to protect patients' informational and decisional needs" (Tulsky et al, 2000).

In all four stories analyzed for this study, each terminally ill patient was provided the information they needed to make informed decisions. Two of the patients, Mary and Renee, conducted quite a bit of research on their own about their diseases and the various treatments available. They both found experimental treatment programs and fought their way into them. Diane, on the other hand, was informed by Quill about the treatment for her leukemia and the overall survival rate of only twenty-five percent after completion of the required treatment. Diane chose no treatment for her disease and knew that death was inevitable. Quill and Shavelson were both supportive of the patients' decisions throughout the disease process, including the patients' decision to end their own lives.

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One of the options for end-of-life care presented in three of the four stories was hospice. Hospice is a program whose philosophy about end-of-life care includes "...compassionate care and supportive services for terminally ill individuals and their families, and significant others" (Sendor with O'Connor, 1997, p. 1). Hospice is committed to caring for the whole patient – mind, body, and soul. They specialize in comfort care, which includes palliative care. Palliative care is a specialization in the medical profession that emphasizes comfort and is well known for its expertise in pain management. "Palliative medicine, as opposed to traditionally curative medicine, involves an ethos of caring instead of an ethos of curing" (Sendor with O'Connor, 1997, p. 114). There are specific criteria that a patient must meet before they can be admitted to a hospice program. These criteria include (Sendor with O'Connor, 1997):

1. The patient must be in the final stages of his illness – a prognosis of six months or less.
2. The patient must be willing to accept only comfort (palliative) care. There can be no attempts at curative or life prolonging treatments.
3. The patient, if a home care patient, must have a primary care person available to provide care.
4. The patient, if a home care patient, must live within the hospice service area – approximately one hour travel time.
5. The patient's attending physician must certify that the patient's prognosis is six months or less, and must authorize/order hospice care.
6. The patient and the patient's family must be fully informed of, understand, and consent to participation in the hospice program.
7. The patient and the physician must agree to utilize a contracted and certified hospital or nursing home for inpatient care.

Palliative care specialists, on the other hand, are committed to providing comfort in both a patient with less than six months to live without life-prolonging treatment, and patients

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with a longer prognosis and receiving life-prolonging treatments. Both the physician and the patient must have a good knowledge about and understanding of the various options available for end-of-life care to be able to make informed decisions. Without knowledge of the various options, a terminally ill patient might progress through his disease as expressed in Tolstoy's (trans., 1981) story *The Death of Ivan Ilyich*.

> Morning or night, Friday or Sunday, made no difference, everything was the same: that gnawing, excruciating, incessant pain; that awareness of life irrevocably passing but not yet gone; that dreadful, loathsome death, the only reality, relentlessly closing in on him; and that same endless lie. What did days, weeks, or hours matter? (p. 107)

Physician Understanding and Acceptance of the Patient's Personal Definition of Suffering

> Thus, the coming into sight of the inescapable limit to one's life, the end of self as a being, evokes a feeling of dread. Even though death is the only future event of which we can be completely certain, the human mind recoils from the thought. (Verwoerdt, 1966, p. 3)

There are many aspects to suffering, not all of which are pain. A study was conducted by van der Maas, van Delden, Pijnenborg, & Looman (1991) which showed that loss of dignity represented 57% of the patients requesting euthanasia and assisted suicide while 46% was because of pain. Another 33% percent requested assisted dying because of dependence on others. Some patients selected both pain and loss of dignity. Terminal pain can be controlled in approximately ninety percent of the cases (Humphry & Wickett, 1990; Jamison, 1995). However, that leaves ten percent of terminal patients with uncontrollable pain. It is also important to understand that pain control requires specialized knowledge and that two-thirds of all physicians are incompetent in the technique of managing pain (Azevedo, 1997). Lederer (1996) did another study also identifying the reasons patient's asked for assistance in dying. Part of the results of this

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study showed that 71.9% requested assistance because of the loss of control and dignity. and 71.9% resented not dying in a dignified manner. Being a burden on others represented 62.5% of those requesting assistance with dying.

> Moralists who spend little or no time in terminal wards of a modern city hospital cannot contribute much in the way of realistic opinion or relevance on the subject of euthanasia. They need to examine the facts, or to re-examine them, not only statistically but clinically. (Fletcher, 1954, p. 26)

Only when there is a close physician/patient relationship built upon open, honest communication can there be an understanding of the patient's definition of suffering. This awareness of what a patient considers suffering enables the physician to commit to be a part of the terminally ill patient's end-of-life. Unfortunately, most physician residency programs focus on the treatment of acute diseases with the intent to heal, and training surrounding end-of-life care is typically neglected (Kvale, et al, 1999). "A physicians' willingness to enter into such a vital conversation demonstrates a commitment to avoiding abandonment" (Tulsky et al, 2000, p. 497).

In the four stories written by Quill and Shavelson, each patient emphasized their fear of the dying process – not their fear of death. "In the depth of his heart he knew he was dying, but not only was he unaccustomed to such an idea, he simply could not grasp it, could not grasp it at all" (Tolstoy, trans. 1981). Two of the patients, Mary and Renee, ended up being 'tied to the bedrails' because of confusion and their desire to do things independently, which in their mind was a loss of control and dignity. Jane was terrified of suffocation and did not like being dependent on others for her care, especially when the care was on a schedule convenient to the hospital staff. Diane feared lingering in relative comfort, which in her mind was a loss of her quality of living.

Suffering is the most difficult part of end-of-life issues to define as it is so

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individualized because it encompasses physical, psychological and spiritual pain. All four women in the stories analyzed emphasized in some way that what they feared most about the suffering in the dying process was their potential loss of dignity and the lack of quality of life – ultimately the loss of self-respect. Dignity is often connected to an individual's capacity for self respect and autonomy (Dworkin, 1993; Wolfson, 1998). This idea of suffering is addressed in Quill's et al (1992) proposed clinical criteria for physician-assisted suicide. They emphasize that the patient must have an incurable condition that is associated with severe and unrelenting suffering. To assess this unrelenting suffering, a physician must have a clear understanding of and knowledge of his patient's definition of suffering. This can only be accomplished by honest, open communication and a special, personable relationship with the patient.

> Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying – the emphasis we put on dying with 'dignity' – shows how important it is that life ends appropriately, that death keeps faith with the way we want to have lived. (Dworkin, 1993, p. 199)

Summary

This chapter discussed the results of this study regarding the factors that contribute to a physician's decision to participate in a terminally ill patient's suicide. The core factor that integrates all of the factors is communication. When a physician and his patient are able to openly and honestly communicate, they can build a deep personal relationship that can be balanced with a professional relationship. The physician and the patient are then able to understand and progress through the patient's disease together. "Every life is different from any that has gone before it, and so is every death. The uniqueness of each of us extends even to the way we die" (Nuland, 1993).

The stories written by Quill and Shavelson represented the process they each went

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through as they decided to participate in a terminally ill patient's suicide. Each physician developed a special relationship with a terminally ill patient over a period of time and came to understand the essence of the patient's personality. Because of the physician's ability to communicate with the patient and the physician's awareness of the patient's beliefs and feelings about their disease, Quill and Shavelson were better able to accept the decisions each patient made about their own care. They were able to discuss the various types of treatments available, the possible effects of the treatments, and the probable side-effects of the treatment. Each patient was encouraged to make an informed decision with Quill and Shavelson ultimately understanding and accepting the patient's decision. Including the patient's decision to chose the time of their own death.

> Emphasis on the process of dying brings to light the potential for meaning that dying affords at the end of life. As a process, dying has its movement not only toward a final end – death – but it can have a movement toward a goal – namely, dying well, a movement that can be manipulated by us through our determined activities and technologies. Given the nature of the process, this can be our final opportunity for meaning in life, and our control over the means to the end shapes the very character of the end itself. (Hester, 1999, p.121)

Recommendations

Listed below are two recommendations that have resulted from this study and previous literature as it relates to the end-of-life issues faced by a physician and a terminally ill patient.

1. Enhance medical school curriculum with the inclusion of the aspects of end-of-life care: communication, palliative care, and relationships.

2. Have a group of ethicists, physicians, and patients develop a measurable group of criteria for a quality physician/patient relationship.

Areas for Future Research

Listed below are areas for future research as it relates to decisions for a physician

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to participate in assisted dying of terminally and incurably ill patients. Because euthanasia and assisted suicide are illegal acts, it may be difficult to obtain valid answers to any future research questions that relate to these acts of assisted dying.

1. A study comparing the differences between physicians assisting terminally ill patients with their suicides when there is a quality relationship as opposed to when there is a poor quality relationship.

2. A study to compare the number of terminally ill patients who meet the criteria for hospice and palliative care to the number of terminally ill patients that do not meet the criteria for hospice and palliative care.

3. A study to compare the decision process physicians go through to assist an incurably ill patient with his suicide as opposed to a terminally ill patient.

4. A study to determine the emotional effects on a physician who participates in a terminally ill patient's suicide when it is illegal as opposed to when the assistance is legal.

5. A study comparing the results of the Dutch legalization of assisted suicide and euthanasia to the legalization of assisted suicide as used in the Death with Dignity Act in Oregon.

6. A study to compare the decision process of a non-medical professional to participate in a terminally ill patient's suicide as opposed to a medical professional's decision process.

7. A study to determine what decisions patients make for treatment options when they are informed of their condition as opposed to the decisions patients make when they are not informed of their decisions.

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APPENDIX A

SAMPLE OF OPEN CODING

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Mary Open Coding

In February of 1989, fifty-six-year-old Mary Bowen Hall sat in the kitchen with Ann McGinley, her stepdaughter and closest friend. Mary had just learned that she had breast cancer and that it had already spread to her bones.	56 yr old woman, dx breast cancer spread to bones
"The last thing I learned from my mother," Mary told Ann, "was how to die. It was an important lesson. Now I can pass it on to you."	Learned how to die now pass it on
Ann was stunned by the news. "Couldn't you just teach me to crochet?" she responded.	Stepdaughter shocked
Mary laughed, then got up from the table and turned away. She wanted Ann to see only the smile, not the tears that had quickly followed.	Laughter, hid tears
A journalist and author of complex mystery novels, Mary always enjoyed the direct and straightforward manner that she and Ann shared.	Pt. journalist, mystery writer, direct/straight forward
But on that day, Mary needed to disguise her intense fear.	Intense fear
"No," she said. "I'd better teach you about dying. I don't know how to crochet."	Humor
Mary did think she knew about dying.	Pt. believed understood dying
"As I continue to deteriorate," she advised her forty-one-year-old stepdaughter, "it will be obscene to prop up what's left of me and have the family come take a look at it..."	Deterioration obscene
"...So I've arranged to die before that."	Choice control death
Ann listened intently. "I've got this planned out," said the author of The Queen Ann Killer and The Sacramento Stalker.	Pt. planned death
"I'll call 911. I will then lie down on the floor in the bathroom with a couple of towels under one side of my head, and I'll pull the trigger of the thirty-eight I just bought. I didn't get a twenty-two because I don't want to just do a lobotomy. I figure 911 will show up in a hurry, so my body won't lay around; and it will be professionals, not my family, who will deal with it. And in case I lose my nerve, I think I'll pull the trigger when I hear the sirens outside and they burst through the door."	Shoot self
Mary stared at Ann, waiting for her reaction. Her stepdaughter looked at her in disbelief.	Stepdaughter disbelief
"I just want to protect the family," explained Mary Hall, "from the suffering of my death."	Pt. protect family from her death
"Let's talk about this with your dad, and your sons" was all Ann could bring herself to say.	Need talk with rest family
But it was five years later, on the very day of her death, that Mary Bowen Hall would realize for the first time that she'd had it all wrong. On that final day, it was her family, especially her son Paul, who would teach Mary how to die.	Pt. wrong, family taught her how to die
And it is tempting to believe that such an unpredictable ending to her story was exactly the way Mary had planned it.	Desire believe unpredictable ending planned

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Mary Open Coding

"The prospect of what's going to happen seems far off right now."	End seems far off
"...said Mary when I first contacted her to see if she would talk with me about her plan for suicide..."	LS contact pt.
"But soon it's going to become very real. There are profound changes that will occur, in the way I'm going to see my life and in the way I'll confront death..."	Changes life, confronting death reality soon
Mary paused; it was the longest she could maintain any conversation on such a serious note.	Seriousness short lived
Her voice shifted from the tone of the journalist and the author to her preferred more folksy style. "So if you're weird enough to stick around while I go through this..."	Folksy tone, humor
"...well, get over here and let's have us a talk."	LS invited to discuss suicide plan
But our first meeting was delayed. "One of the neat things about having cancer," Mary told me when we tried to arrange an interview, "is that suddenly I've got more money than I've got time to spend it. So I just bought some plane tickets for my stepson and his family in Alaska to come down for the weekend. Why don't you come by after that?"	Good part cancer, closer to family
From the very beginning, Mary Hall's plans for death seemed filled with contradictions.	Pt. plans for death ambiguous
She thought she might die soon and, thus, often indulged herself in "final moments," from suddenly flying family members in for a visit, to weekly pedicures at a nearby beauty salon. She even bought herself a grand 'last gift' of a trip to a mystery writer's conference in London, then sailed there on the Queen Elizabeth 2.	Thought death close, indulged final enjoyments
But while enacting these 'final events', Mary also began researching and writing another mystery novel, a commitment of two or three years until its completion.	Contradiction, started new mystery
And she spoke frequently about other book projects, far in the future.	Planned future writing
There were other confusing paradoxes as well. Although she was adamant in the desire to protect her family by being alone at her moment of death, what upset them most was the thought of Mary's solitude, on the bathroom floor with a gun to her head.	Paradox – protect family, family not want protected
Mary planned to shelter the family from 'those dreaded emotional farewells' she was sure would take place as she approached death. Yet some of her children felt they would need exactly the emotional final leave-taking that their mother viewed with such dread.	Pt. deny family farewells, family want farewells
Mary was trying to protect her family by isolating herself from them	Pt. isolate from family
– which was the very thing that upset them the most.	Family not want isolation

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Mary Open Coding

Mary Bowen Hall, a writer who could neatly tie together the most convoluted twists and turns of her mystery novels, was having an impossible time plotting out the mysterious process of her own final days and her death.	Writes tangled plots mysteries, unable to plot own death
The scene she had outlined just didn't seem to come together into something that would work.	Plan not workable
"I think I'm in a heap of trouble," declared Mary Hall when the cancer specialist told her, in 1989, that the most she could hope for was 'remission.'	Diagnosis cancer, remission only hope
"I had thought I was in the afternoon of my life, the sun shining over my shoulder," Mary conceded. "But suddenly it was a couple of minutes before midnight, and straight ahead of me was this dark shadow…"	Plan of life cut short
"…remember thinking, I'd better make some plans."	Need to plan
Five years later, Mary was still alive, and still trying to work out the best design for her impending death.	After 5 years unable plan death
"I've always been a terribly pragmatic person," she asserted, failing to mention the strong mischievous side that filled her life as much with jest as pragmatics.	Pt. pragmatic, yet mischievous
It was this combined playfulness and pragmatism that had kept her going through five years of one different cancer treatment after another, each buying her a bit more time.	Chose numerous treatments
In one of these desperate attempts to stay alive, Mary spent six weeks in a hospital isolation room to undergo a bone-marrow transplant.	Six weeks isolation bone marrow transplant
Her doctors sent in a psychiatrist because she did nothing all day but lie in bed, staring at the ceiling. "Why won't you even turn on the TV?" they asked her. "How are you going to get through this time?"	Psychiatrist sent to evaluate pt. in isolation
"I was sorely tempted to tell them what I was doing," Mary laughed. "But it was more fun not to. So I just kept staring at the ceiling…"	Pt. teasing psychiatrist
"…I was laying there having a great time, thinking up murders, working out in my head a particular story I hadn't been able to write before. And it really got exciting. I created a lovely villain while I lay there waiting for my bone marrow to recover…"	Writing mysteries in head while in isolation
"…In fact, thinking through my mysteries has enabled me to get through some of the worst times…"	Creating mysteries gave pt. strength
"…So I just looked sternly at the psychiatrist, told him to leave, and went on with my fun."	Dismissed psychiatrist
Yet Mary never lost sight of the fact that at the end of the good she believed she could extract from the worst of times was her death.	Pt. knew death inevitable

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APPENDIX B

SAMPLE OF PRE-AXIAL CODING

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Jane Pre-Axial

Who is patient?	
Gifted teacher, challenged students	Many friends – socially and physically active
Lived alone, no close relatives	Planned for the future

Aspects physician/patient relationship	
Personal and medical relationship	Pt. no chance get better
Mutual respect	No wish compromise TQ
Open communication between TQ/pt	Question certainty and depression
Pt. stayed with TQ	TQ guarantee enough medicine comfort – not afraid to give
Strong TQ/pt. bond	TQ unable to guarantee availability or process
Medical professionals abandon at end-of-life	TQ uncertain level dosage comfort – too much/too little
Pts. shared end-of-life stories	Does pt. have plan?
TQ/pt. understanding not abandon at end	Honest communication
In-depth TQ/pt. story telling	TQ promise not to abandon, keep comfortable
Bill – story within story TQ surprised story not previously shared	Incomplete – TQ hands tied
TQ surprised story not previously shared	Question helping or abandoning
TQ understood fear suffocation greater than death	TQ unresolved feelings
TQ committed not abandon pts.	TQ hoped patient peaceful
TQ promised comfort	Hope good friends make inner peace
Pt. requested secobarbital for sleep	
TQ question reason for request	
TQ/pt. honest relationship, open communication	

Aspects disease/diagnosis	
Smoker with health problems	Breathing decreased, treatments increased
Pt. increased health problems	Condition worsened taken to hospital
Decreased physical ability	Pt. no potential to improve
1982 decreased breathing capacity	Pt. saw no future, ready to die
Diagnosed breast cancer	Pt. no chance get better
Decreased decision-making independence	Question certainty and depression
Cancer not spread, no further treatment	Pt. clear understanding – no choices
1983 – lung infection	Disease only get worse
Condition worse, possible ventilator	
5 years no hospital, increased medical problems	
TQ/pt. understanding not abandon at end	

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Jane Pre-Axial

Aspects treatments	
Numerous medications – multiple health problems	Bad side effects – medical complications increased
Selected mastectomy as treatment	Home with nursing visits
Concern cancer spread other breast – stop hormone replacement	Pt. agreed to hospital if necessary
Hot flashes returned – intense	Intensive-care, no ventilator
Various treatments unsuccessful	TQ promised comfort
Bad side effects due to medication	Comfort measures only
Tranquilizers no relief	Secobarbital unsuccessful sleep before
Most staff understanding	TQ unable to guarantee availability or process
Some staff not understanding	Secobarbital for sleep – legal
Hospitalized unfamiliar hospital	Secobarbital for security blanket – gray zone
Medications increased anxiety/fear	Enough medication for sleep, not overdose
Breathing decreased, treatments increased	

Aspects decision suicide	
Previous near-death experience	Pt. thinking clear, no signs depression
Did not fear death	Terrified of suffocation
Hated dependence on others for scheduled care	Pt. suffered beyond limits
Decreased independence = increased vulnerability	Pt. clear understanding – no choices
Bill – story within story	Pt. want control of dying
Returned home, increased dependence on others	Finality of decision, make sure 100% certain
Disliked dependence on friends	Pt. certain re: decision, saying good-bye
Pt. not want live with decreased quality of life	Pt. not exact plan
Advance directives completed	Pt. values, chose least worst option
Pt. saw no future, ready to die	Belief afterlife – fear how get there
Pt. no joy meaning to life	Pt. initially discreet re: end-of-life beliefs
Pt. not want be more invalid	Plan set, pt. open about death
Pt. thinking clear, no signs depression	Practical date/time set
	Pt. Ready
	Anticipate twilight other side

Feelings/emotions pt.	
Did not fear death	Fear hospitalization
Hated dependence on others for scheduled care	Pt. thinking clear, no signs depression
Fear of suffocation	Terrified of suffocation
Intense suffocation fears, no advocate	Pt. brighter, felt in control
	Pt. outwardly peaceful

Feelings/emotions friends-physician	
TQ surprised story not previously shared	TQ unresolved feelings
TQ unanswered questions	Friend deep feelings about story
Question helping or abandoning	Anger due to legalities making process uncaring

Contributors treatment choices	
Pt. chose hormone replacement over risk cancer spread	Pt. never wanted ventilator
Pt. informed consent for treatment/non-treatment	

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Aspects pt. fighter	
Pt. fighter	Home – aggressive search reverse condition unsuccessful
Discharged, back in control	Chose life changes to treat asthma

Aspects death process	
Fear of suffocation	Secrecy/ambiguity not good process
Decreased independence = increased vulnerability	Medicine bitter, pt. Peaceful
Intense suffocation fears, no advocate	Medicine working, good-byes said
TQ understood fear suffocation greater than death	Pt. deep sleep not arousable
What will future bring?	5 hours remained in limbo
Stop medication, slow death	Plastic bag alternative for situation (Hemlock Society)
Morphine comfort, not always successful	Plastic bag used, pt. Comfortable
Terrified of suffocation	Pt. died with committed friends present
Pt. have control, TQ support	Death consistent with person, freedom
Pt. comfort with access to secobarbital	Must be better way
No one should have to die alone	

Thoughts about way living	
Personal quality of life important	Pt. no joy meaning to life
Still enjoyed life	Pt. not want be more invalid
Returned home, increased dependence on others	Pt. suffered beyond limits
Disliked dependence on friends	Pt. values, chose least worst option
	Pt. ready

Means for suicide	
Secobarbital	TQ uncertain level dosage comfort - too much, too little
Pt. requested secobarbital for sleep	Secobarbital for overdose - legally vulnerable
Secobarbital central ingredient Hemlock Society – self-deliverance	Pt. Comfort with access to secobarbital

Aspects end-of-life friends/physician	
Questions others to help/make right choice	Another friend semi-supportive
TQ guarantee enough medicine comfort – not afraid to give	2nd friend lack belief afterlife
Finality of decision, make sure 100% certain	Friendship, support more important
Pt. have control, TQ support	Plan set, pt. open about death
Pt. certain re: decision, saying good-bye	Most convinced pt. doing right thing
No one should have to die alone	Last day spent together/friends
Friends committed to end	Friends waited for guidance
Probably last time see each other	Medicine working, good-byes said
Uncomfortable, options inadequate	Friends confused
Incomplete experience – loose ends	Would not abandon friendship
Pt. friend told TQ story	Plastic bag used, pt. comfortable
Strong supportive friendship	Pt. died with committed friends present
Belief afterlife – fear how get there	Friend deep feelings about story
	Commitment fulfilled
	Love of friendship allowed pt. escape

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Hemlock Society, plastic bag	
Pt. member Hemlock Society Secobarbital central ingredient Hemlock Society – self-deliverance	Plastic bag alternative for situation (Hemlock Society) Plastic bag negative remembrance
Effects assistance suicide on others/pt./physician	
TQ understand fear legal ramifications Pt. requested secobarbital for sleep Secobarbital unsuccessful sleep before No wish compromise TQ Secobarbital for sleep – legal Secobarbital for security blanket – gray zone Secobarbital for overdose – legally vulnerable Action of assistance hidden Ambiguity – cannot play a part Uncomfortable, options inadequate Incomplete – TQ hands tied TQ unanswered questions Question helping or abandoning TQ unresolved feelings	Secrecy/ambiguity not good process No inquiry authorities Incomplete experience – loose ends No win situation – friends burden heavy Cremation no means for follow-up Friends participation illegal, grieving difficult Must be better way Anger due to legalities making process uncaring 1 friend difficult talking about assistance Faith in self and here after less strong Inability to talk openly, injured by death process Hope good friends make inner peace

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APPENDIX C

AXIAL CODING

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Who is patient?	
1p- Physical *1pr-Personality* Lived alone, no close relatives Planned for the future Pt. fighter Spiritual person	*1ap- Activity/profession* Pt. (nurse) interested in palliative care Gifted teacher, challenged students Many friends – socially and physically active
Aspects physician/patient relationship	
2oc- Openness communication Open communication between TQ/pt. Pts. shared end-of-life stories In-depth TQ/pt. story telling Bill – story within story TQ surprised story not previously shared Pt. requested secobarbital for sleep TQ question reason for request TQ/pt. honest relationship, open communication Question certainty and depression TQ unable to guarantee availability or process TQ uncertain level dosage comfort – too much/too little Does pt. have plan? Honest communication *2r- Respect* Mutual respect TQ understood fear suffocation greater than death TQ/pt. honest relationship, open communication	*2c- Commitment* Pt. stayed with TQ Medical professionals abandon at end-of-life TQ/pt. understanding not abandon at end TQ committed not abandon pts TQ promised comfort No wish compromise TQ TQ guarantee enough medicine comfort – not afraid to give TQ promise not to abandon, keep comfortable Question helping or abandoning TQ hoped patient peaceful Hope good friends make inner peace *2tl-Type/length* Personal and medical relationship Strong TQ/pt. bond
Aspects disease/diagnosis	
3td- Type disease Smoker with health problems Diagnosed breast cancer 1983 – lung infection *3dp-Disease process* Pt. increased health problems 1982 decreased breathing capacity Cancer not spread, no further treatment Condition worse, possible ventilator 5 years no hospital, increased medical problems Breathing decreased, treatments increased Condition worsened taken to hospital Pt. no potential to improve Disease only get worse	*3il-Impact life style* Decreased decision-making independence Decreased physical ability *3kd-Knowledge disease* Pt. saw no future, ready to die Pt. no chance get better Pt. clear understanding – no choices

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Aspects treatment	
4c-Choices	*4se- Side effects*
Numerous medications – multiple health problems	Hot flashes returned – intense
Selected mastectomy as treatment	Bad side effects due to medication
Concern cancer spread other breast – stop hormone replacement	Medications increased anxiety/fear
Pt. chose hormone replacement over risk cancer spread	Bad side effects – medical complications increased
Pt. informed consent for treatment/non-treatment	*4r- Results*
Hospitalized unfamiliar hospital	Various treatments unsuccessful
Still enjoyed life	Tranquilizers no relief
Breathing decreased, treatments increased	Secobarbital unsuccessful sleep before
Pt. agreed to hospital if necessary	*4t- Type treatment*
Intensive-care, no ventilator	Home with nursing visits
Pt. never wanted ventilator	Comfort measures only
TQ unable to guarantee availability or process	Secobarbital for sleep – legal
	Secobarbital for security blanket – gray zone
	Enough medication for sleep, not overdose

Aspects decision suicide	
5d-Dignity	*5fp-Fear process, not death*
Pt. not want be more invalid	Previous near-death experience
5q-Quality	Did not fear death
Personal quality of life important	Bill – story within story
Pt. not want live with decreased quality of life	TQ understood fear suffocation greater than death
Pt. saw no future, ready to die	What will future bring?
Pt. no joy meaning to life	Advance directives completed
Pt. suffered beyond limits	Terrified of suffocation
5id-Independence/dependence	Belief afterlife – fear how get there
Hated dependence on others for scheduled care	Anticipate twilight other side
Most staff understanding	*5cd-Clarity decision*
Some staff not understanding	Pt. thinking clear, no signs depression
Decreased independence = increased vulnerability	Pt. clear understanding – no choices
Returned home, increased dependence on others	Finality of decision, make sure 100% certain
Disliked dependence on friends	Pt. certain re: decision, saying good-bye
5c-Control	Pt. not exact plan
Pt. want control of dying	Plan set, pt. open about death
Pt. values, chose least worst option	Pt. ready
Practical date/time set	

Feelings/emotions pt.	
6f-Fear	*6a-Acceptance*
Fear of suffocation	Did not fear death
Intense suffocation fears, no advocate	Pt. thinking clear, no signs depression
Fear hospitalization	Pt. brighter, felt in control
Terrified of suffocation	Pt. outwardly peaceful

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Feeling/emotions friends/physician	
See #14	
Contributors treatment choices	
See #4	
Aspects patient fighter	
9ng-Not give up Discharged, back in control Chose life changes to treat asthma	*9ng-Not give up* Home – aggressive search reverse condition unsuccessful
Aspects death process	
10gd-Good death Pt. comfort with access to secobarbital Medicine bitter, pt. peaceful Medicine working, good-byes said Pt. deep sleep not arousable Death consistent with person, freedom	*10bd-Bad death* Fear of suffocation Decreased independence = increased vulnerability Stop medication, slow death Terrified of suffocation No one should have to die alone Secrecy/ambiguity not good process 5 hours remained in limbo
Thoughts about way living	
See #5	
Aspects end-of-life friends/physician	
See #14 *12c-Closures* Pt. certain re: decision, saying good-bye Probably last time see each other Medicine working, good-byes said *12sd-Sharing death* Pt. friend told TQ story Last day spent together/friends	*12cm-Commitment* Friends committed to end Would not abandon friendship Strong supportive friendship Unconditional support, friendship Pt. died with committed friends present Commitment fulfilled Love of friendship allowed pt. escape
Hemlock Society, plastic bag, barbiturate	
13sm-Suicide means Morphine comfort, not always successful Secobarbital Secobarbital central ingredient Hemlock Society – self-deliverance Secobarbital for overdose – legally vulnerable Pt. comfort with access to secobarbital Plastic bag negative remembrance	*13sg-Suicide guidance* Pt. member Hemlock Society Plastic bag used, pt. comfortable Plastic bag alternative for situation (Hemlock Society)

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Aspects assistance suicide on friends/physician	
14ap-Awareness plans	*14a-Aftermath*
Secobarbital unsuccessful sleep before	Incomplete – TQ hands tied
Plan set. pt. open about death	TQ unresolved feelings
Friends waited for guidance	Secrecy/ambiguity not good process
14sp-Support plans	Friends confused
Finality of decision, make sure 100% certain	No win situation – friends burden heavy
Pt. have control, TQ support	Friends participation illegal, grieving difficult
No one should have to die alone	Must be better way
Friendship, support more important	Friend deep feelings about story
Most convinced pt. doing right thing	Anger due to legalities making process uncaring
Plastic bag used, pt. comfortable	1 friend difficult talking about assistance
14qp-Question plans	Faith in self and here after less strong
Questions others to help/make right choice	Inability to talk openly, injured by death process
Ambiguity – cannot play a part	Hope good friends make inner peace
Another friend semi-supportive	*14li-Legal implications*
2nd friend lack belief afterlife	TQ understand fear legal ramifications
14p-Protection	Secobarbital for security blanket – gray zone
Pt. requested secobarbital for sleep	Secobarbital for overdose – legally vulnerable
Secobarbital for sleep – legal	Action of assistance hidden
Pt. initially discreet re: end-of-life beliefs	No inquiry authorities
Cremation no means for follow-up	
No wish compromise TQ	
14uq-Unanswered questions	
Uncomfortable, options inadequate	
TQ unanswered questions	
Question helping or abandoning	
No more communication pt./TQ	
Incomplete experience – loose ends	

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Mary Axial

Who is pt.

1p – Personality

Pt. journalist, mystery writer, direct/straight forward
Seriousness short lived
Folksy tone, humor
Pt. pragmatic, yet mischievous
Pt. teasing psychiatrist
Do something to make things happen
Pt. be sure of things go after them
Pt. mother taught don't waste time, do something useful
Don't lean on others, do yourself
Pt. proud survived bone-marrow transplant
Always done everything self
No reason change now
If want something go get it
Institution rebel lose control
Mischievous rebellion, food color fountain
Beat cancer, pt. regaining control

1p- Personality (continued)

Death will come, but living now
Pt. and retired CIA to Mexico smuggle drugs to US
Pt. Remains adventurous
Pt. had not given up 1st time
Prior to loss sons pt. lovable
Pt. became impatient cuz loss
Will not put on oxygen
Pt. not admit dye in fountain

1a – Activity/professions

Pt. journalist, mystery writer, direct/straight forward
Writing mysteries in head while in isolation
Creating mysteries gave pt. strength
Quick pace, pt. test self
Today feel like walk

Decide how suicide

2sg – Suicide guidance

Important step, member Hemlock Society
Friend opened door for other methods suicide
Derek Humphry published book with names and dosages lethal drugs
Hemlock Society members crossed border, filmed for 60 Minutes
'Final Exit' drugs more difficult to get
Feels committed to Hemlock cause
2sm – Suicide methods
Shoot self
LS question pt. shoot self
Pt. can't count on pill to work
'Final Exit' plastic bag
Can't sit with plastic bag over head to die
Pragmatic – one moment pull trigger

2sm- Suicide methods (continued)

Gun only way to be alone
Pt. morphine and Darvon in freezer, plan on hold
Previously reconsidered plan gun suicide
Gun gory and gruesome
Shooting self not complete end
Pt. lethal drugs back-up plan
Pt. poor research, farce of trip
Darvon not certain to kill
Doctor told pt. morphine possessed prior prescription, more lethal
Doctor wrote prescription Seconal, pt. preparing
LS knew Seconal at bedside
Pt. reached for Seconal
Pt. took Seconal pills
Darvon lead to obtaining Seconal

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Aspects disease/diagnosis	
3dp-Disease process 56 yr old woman, dx breast cancer spread to bones Diagnosis cancer, remission only hope Cancer caused bone damage hip and spine Cancer also survived May, 1991 clear pt. lose cancer battle Cancer spread to skin Skin tumors reminder cancer winning battle 13 months treatment skin tumors returned Cancer damage bones leak calcium to blood Medication unsuccessful die soon Terrible day even though untied Pt. aged 10 years in 2 days Pt. appeared close to end High calcium not bad death No severe pain comfortable death Body making decisions for pt *3di-Disease effect independence* Doctor not want pt. left alone Pt. hospitalized Pt. strapped down prevent crawl out bed Wait, shit bed no more tie down	*3ds-Disease symptoms* Small blotches skin cancer to large visible welts Cancer visibility pt. felt death closer Skin tumors worse, painful, cancer worse rapidly Weak after doctor appointment No strength share news High calcium level dangerous High calcium cause side-effects Extremely weak, difficult move Pt. okay hard find words, fuzzy Pt. slurred speech, SOB Pt. easily exhausted Pt. pain with movement Pain on movement Panic, sudden movement extreme pain Pt. pain excruciating Pt. terror, confusion Pt. exhausted, intermittent pain

Feelings/emotions pt. experience	
4d- Denial End seems far off If only more time I'd... Don't think that way, still have responsibilities Used clothing hide tumors Denying possible sudden deterioration due to cancer Denial eliminates chance to plan death Pt. denial, go home do things *4h- Hope* Experimental drug hope, difficult accept finality death Practical realism turned to optimism Experimental drug effective pt. happy Thrilled with research and interviews Pt. still hope cancer go away totally Hoping praying get in 2nd experimental program *4t- Toward others* Pt. angry healthy people attitude In rest home during treatment, did not want staff help Pt. embarrassed poor research lethal drug in possession Surprise, doctor offer write Seconal prescription when time right Pt. committed to book audience Question decision based on expect audience want *4g- Give-up* May, 1991 clear pt. lose cancer battle Pt. gave up fight Laughter, hid tears Humor	*4a- Acceptance* Pt. knew death inevitable Pt. great sadness Pt. believes all relationships clear Appear no unclear relationships, die peaceful Say all good-byes when well, not when really sick Cancer visibility pt. felt death closer Skin tumors worse, painful, cancer worse rapidly Reality not cheery Moved to rest home medical environment Reality starts hit, no 2nd experimental treatment Saddened by rapidly worsening illness Pt. reality hits, must decide Pt. calmed, passive, cleaned up LS visit remind pt. suicide *4f- Fear, uncertainty* Intense fear Writes tangled plots mysteries, unable to plot own death Plan of life cut short Won't be easy to kill self Pt. crying, sad Time for pt. to decide suicide (yes/no) Pt. panic reality Panic, sudden movement extreme pain Pt. terror, confusion Pt. upset, confused Pt. agitated removed oxygen Pt. tension eased, oxygen refusal continued Pt. agitated, no good situation Comfortable death why suicide

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Aspects contributing to decision	
5d- Dignity	*5c-Control*
Deterioration obscene	Choice control death
Couldn't stand humiliation family caring for pt	Pragmatic – one moment pull trigger
Loose dignity, don't want family to see	Pt. need stay control
Tied to bedrails	Only pt. know specific suicide day
Strapping down prevent physical injury	Want to die near death when no longer pt.
Fighting prior tie down	Must commit suicide while strong
Wait, shit bed no more tie down	Choice must be for best way to die
Pt. not tied down	Decision must be based on current reality, not past commitment
Pt. caged by siderails	Pt. frustrated ready to die
Pt. incontinent bowel, total loss dignity	Plan do suicide when LS return
Pt. anguish, loss dignity	Pt. grateful for last days, no more wanted
Pt. believe obscene display deterioration at end	Suicide no more to do, no meaning left to live
Pt. want die before loss dignity	Pt. planned death
Pt. miserable, not pain but loss dignity	Determined suicide, plan how may change
Humiliating dying for days	*5q- Quality*
Pt. strapped down prevent crawl out bed	Darvon overdose prolonged seizures, bad death
5id-Independence:dependence	Tying pt. down killed pt. spirit
Don't want impose on people	Pt. definition comfortable not same
Tied down thought of suicide	No reason to go through misery – bad death
Called staff for help no one comes	No quality to life
Pt. strapped down prevent crawl out bed	
Do self, crawl over bedrail	
Nurse no control pt. without sedative	
Staff would take away pills and suicide precautions	

Aspects family, friends, physician assistance suicide	
6p-Protection	*6lr-Legal ramification*
Pt. protect family from her death	Asking for help while dying terrible burden put on others
Paradox – protect family, family not want protected	Doctor not allowed help suicide
Pt. deny family farewells, family want farewell	*6d-Die alone*
Why distance from family – protect them	Pt. isolate from family
No ask family help kill pt.	Gun only way to be alone
Pt. insist protecting family	Certain do suicide self
Share suicide plan, won't share when	Pt. won't allow family be present
Pt. protect doctor	*6af- Aftermath*
6a-Allow assistance	Gun gory and gruesome
Paradox – protect family, family not want protected	Family clean mess from gun
Most very ill accept help from others when near death	Kids relive pt. shooting self
Doctor wrote prescription Seconal, pt. preparing	Shooting self not complete end
Son-in-law decides guard door	Decision affects others
LS by pt. side	Pt. choice impact family
Last Seconal taken acknowledged LS not abandon	Torture to others if suicide too early
Night of suicide, young son would have helped if asked	All involved go through changes when faced with death
Pt. wanted not linger, young son would have helped	If needed to help, young son in pain for life

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Aspects physician/pt. relationship	
7oc- Openness communication	*7c- Commitment (continued)*
LS invited to discuss suicide plan	LS promised return at night
LS and pt. hike/talk	When calm talk about suicide
LS question pt. shoot self	Pt. requested LS stay – agreed not abandon long time ago
Talking about hard, want continue	LS by pt. Side
Open discussion planned suicide	Last Seconal taken acknowledged LS not abandon
Pt. told doctor possessed Darvon	*7r-Respect*
Doctor told pt. morphine possessed prior prescription, more lethal	Request pt. put oxygen back on
	Finally told doctor plan for suicide
Pt./doctor talked no prediction problem right away	Pt. ask LS come back
Doctor told pt. no chance 2nd experimental program	LS instructed pt. convince nurses untie her
Pt. address end/suicide	*7tt-Time & growth together*
LS & pt. talk about suicide	Pt. pragmatic part like LS, question how other part feels
Anticipate suicide discussion	LS/pt. close friendship 2 years
Why uncomfortable, can doctor help	Pt. couldn't lie doctor, knew each other too well
Pt. vague re: uncomfortable	LS caring, close to pt
7c-Commitment	LS thinking last 2 year relationship with pt.
Pt. protect doctor	Be clear, direct – not vague
Surprise, doctor offer write Seconal prescription when time right	Pt. requested LS stay – agreed not abandon long time ago
	Caring close to pt.
Doctor wrote prescription Seconal, pt. Preparing	
Elicit doctors assistance	
Doctor not want pt. left alone	

Family, friend, physician part in end-of-life	
8c- Closures	*8c- Closures (continued)*
Pt. aware family difficult deal with grief if relationship unclear	Important grandchildren say good-bye
	Grandson present guide to galaxy – good-bye
Make sure ready say good-bye	Granddaughter enjoy heaven grandma
Say all good-byes when well, not when really sick	Needed know last chance to end with good relationship
Family clean mess from gun	How die (suicide, natural) not important, timing important
Kids relive pt. shooting self	Pt. killed self right before death, horrible suicide
Pt. wanted no loose ends with relationships prior to death	*8qp- Question plans*
Young son not talk of times apart	Why die by gun and alone as choice
Young son wanted remember pt. only after back together	Who easier for – family or pt.
Young son unresolved relationship with pt.	Brother hope pt. death won't come to plan
Pt. need talk young son, no rest	Would family know pt. not die too soon?
Young son difficult talk	Friend pragmatic dissuaded suicide with gun
Young son upset difficult talk	Young son clearly against suicide
Young son able to close good relationship	Bad if pt. chose suicide cuz said would
Pt. strength end positive relationship young son	Permission to call off commitment good thing
Family friends tell pt. good-bye	Help pt. not obligated to prior commitment
Pt. sharing with others at end	Convince dignified to change mind
Contradiction – previous wish no bedside farewells	Young son previous lost 3 people suicide/horrible
Sudden decline people glad good-byes said	Can't accept pt. suicide
Young son by pt., then left go home	LS, pt. don't need to decide
Visits end, close family only with pt	Pt. why are others afraid of suicide
Pt. told family ready to die	LS asked pt. slow down talk to family
Farewells done	Young son would have stopped suicide while there
Question how many times say good-bye	Last night before pt. death suicide wrong
We have said everything already	Night before pt. suicide, young son would have prevented
Final good-byes	Pt. plans for death ambiguous
Stepdaughter special good-bye	
Grandchildren came to hospital	

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Family, friend, physician part in end-of-life (continued)	
8gt- Growth together	*8sp- Support plans (continued)*
Good part cancer, closer to family	Question would staff stop pt. taking Seconal
LS met young son death scene, story unclear	Young son agreed suicide gave pt. good death
Friend admired pt. strength	Young son proud of pt. act
Started to ask for some help	Pt. wanted not linger, young son would have helped
Stepdaughter opened house	*8pd-Part dying process*
Young son apologized harshness	Family not want isolation
Time spent together important	Pt. not acknowledge family want participate dying process
Pt. underestimated love & care of others	Pt. won't allow family be present
LS & young son talked, shared sorrow	Don't want impose on people
Warm greeting young son LS, sharing home	Father stay with pt. due to weakness
Young son sorry missed pt. finest hour	LS promised return at night
Young son able express anger and love	Family present wait for LS
Pt. obligated to share more with family	Young son came when mother (pt.) very sick
Pt. giving to others night before suicide	Young son close watching pt.
Young son presume LS push suicide	Young son not give up, close
Young son hesitant, allowed access pt.	Young son support, close
Hope pt. understand suffering = growth	Young son help carry pt. to commode
8au- Awareness/understanding	Young son holding pt. 'What do I do?'
Family gathered re: how pt. plan die	Young son cradled, soothed screaming pt.
One son understand pt. desire	Young son continues holding pt.
Young son mood change, accepting	Young son object IV injection sedative
Timing death important, not mode of death	Support pt. desire clarity, no IV sedative
Need talk with rest family	Young son reassuring pt.
8sp- Support plans	Young son questioned ability calm pt.
Difference between support and agree decision	Pt. asked for father at deathbed
Family understand and ready for pt. suicide	Family close by
LS saw agreement family present	Young son wouldn't want pt. alone
	Changes life, confronting death reality soon

Suicide plans ambiguity	
9y-Yes/control death	*9qt-Question timing*
9n-No/fight for life	Deprive pt., some time of good life
Contradiction, started new mystery	Snag – decide which period illness last
Planned future writing	How much good life time to lose?
Pt. not acknowledge potential snag	Pt. question time right to die
Suicide difficult while still fighting	Skin tumors disappeared, making plans for future
Fight for treatment while plan suicide	Address suicide later when need to
Practical realism turned to optimism	Suicide thoughts tucked in back of mind
Began writing non-fiction book	Pt. undecided
Experimental drug remission suicide thoughts back burner	Suicide/natural death little difference now
Pt. still hope cancer go away totally	*9p-Preparedeness*
Pt. morphine and Darvon in freezer, plan on hold	Won't be easy to kill self
Experimental treatment successful, forgot possession of means for suicide	Pt. store water, plan for earthquake
End comes fast, need more time	Pt. prepared for natural disaster, not death
	Easier plan survive earthquake than how to die
	Suicide to prove point irrational

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Mary Axial

Aspects pt. fighter

10dg- Doesn't give up

Chose numerous treatments
5 years various treatments kept death away
Desire fight cancer back
Pt. fight to get experimental drug
Doesn't give up easily
Beat cancer, pt. regaining control
Doesn't give-up, pursues 2nd experimental therapy
Pt. not want give up
Hoping praying get in 2nd experimental program

10dg- Doesn't give up (continued)

Not give up, still fighting
Pt. denial, go home do things

10tc- Treatment choices

Six weeks isolation bone marrow transplant
Experimental drug publicized
Chose to wait
Experimental drug not cure, want long remission
Experimental drug beating cancer, moved to condo
No, lower calcium and go home

Aspects treatments

11r-Results

Treatments slowed skin tumors growth, not stop spread
Treatment successful, skin tumors disappeared
Experimental drug not cure, want long remission
Experimental drug effective pt. happy
Skin tumors disappeared, making plans for future
Drug not solution, but extending life
Experimental treatment successful, forgot possession of means for suicide
13 months treatment skin tumors returned
1 out of 10 days no medical appointment
Today feel like walk
Medication can lower blood calcium level
Medication unsuccessful die soon
Calcium normal

11r-Results (continued)

Pt. decreased oxygen level
Lack oxygen unable think clear

11se-Side effects

First dose pt. violently ill
Intensive chemotherapy, bad side effects
1 dose chemotherapy = negative impact 3 weeks
Cancer spread, chemotherapy depleted resistance

11te-Traditional/experimental

Experimental drug from rare tree, pt. took personally
Visible skin tumors pass into experimental treatment
Hospital treat high calcium
Pt. connected O2 and IV
Nurse plan inject sedative IV
Oxygen replaced
Received experimental drug treatment

Aspects dying process

12bd-Bad death

Can't sit with plastic bag over head to die
Couldn't stand humiliation family caring for pt.
Suffering okay if worth it
Darvon overdose prolonged seizures, bad death
Pt. try convince untie
Tied down thought of suicide
Tied down worst fears, bad death
Wait, shit bed no more tie down
Pt. not tied down
Pt. caged by siderails
Few days left, bad days
Urgency go bathroom
Pt. pain excruciating
Break in pt. terror
Pt. clear, not want lose dignity in front young son
Pt. incontinent bowel, total loss dignity
Pt. anguish, loss dignity
Pt. believe obscene display deterioration at end
Pt. miserable, not pain but loss dignity
No comfort dying suffocation
Pt. definition comfortable not same

12bd-Bad death (continued)

Humiliating dying for days
No quality to life
Pt. killed self right before death, horrible suicide

12gd-Good death

High calcium not bad death
No severe pain comfortable death
Comfortable death why suicide
Wait, peaceful death coming
Pt. wouldn't need, going good death
Comfortable death coming
Pt. peaceful, unconscious, breathing stops
Pt. lucid not severe pain

12fp-Fear process

Death not problem
Dying process scary/unclear
Pt. really don't know how to die
Not afraid death, afraid process
Don't want to live bad death process
Pt. terror, confusion
Pt. calmed, passive, cleaned up
Reality pt. end not predicted

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Decide how suicide	
See #2	
Reminiscing	
See #17	
Things contribute to accepting/not accepting death	
See #4	
Family /friend/physician feelings	
See #8 *17r-Reminiscing* Pt. mother blind, never complained Pt. reminiscing Pt. mother taught don't waste time, do something useful Pt. 1st divorce war Reminiscing 3 sons prisoners of war Young son hit hardest Older brothers with dad Young son with pt. Young son miserable Young son finally lived with father Young son said good-bye to mother (pt.) for 9 years Pt. divorce, loss sons agonizing Traumatic to pt., deprived sons Pt. parents deprived grandchildren Reminiscing problems 1st divorce Young son felt pt. deserted him 9 years Desertion empty feeling young son Contact pt. to young son rare over 9 years Young son phoned pt. to meet after 9 years Pt. thrilled huge embrace Young son set rule, no discuss past Impact especially 2 sons LS & family good reminiscing Music box soothing when pt. young & ill Last moments with pt important Would have been angry if cheated of last moments Pt. giving to others night before suicide Timing death important, not mode of death	*17rl-Relationships* Father/daughter (pt.) close Young son came when mother (pt.) very sick Family finding peace with pt Pt. underestimated love & care of others Pt. realize important to others Young son spoke with brother re: pt. final night *17c- Commitment* Young son gentle blocking access to pt. LS persistent Young son hidden, listening Young son shouldn't leave pt. alone Time spent together important Special music box left by pt. to young son's daughter Night of suicide, young son would have helped if asked Young son try understand feelings *17cn- Concern* Young son worried, pleasant Young son calm yet tense Young son blocked door LS good-bye young son Question talking to family important Stepdaughter concerned about young son LS concern young son feeling Young son regret leaving hospital LS anticipated young son guilt not stop pt. suicide Young son crying due to missing pt Nobody wants to lose special time Young son questioned his actions Young son upset LS disturbed, shaking

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Aspects of denial	
1p-Physician	*1pt-Patient*
TQ denial test results	Pt. not want to hear diagnosis
Retest, possible leukemia	
TQ not want to tell diagnosis	
Pt. not want to hear diagnosis	
2oc-Open communication	*2rt-Respect/trust*
TQ supportive, no guarantee minimal suffering from treatment	TQ admired pt
	2c-Commitment
TQ disturbed by pt. choice	TQ advocate pt. rights
TQ/pt. talked several times	TQ understood, supportive decision
TQ/pt. planned care together	Pt. testing doctor commitment
TQ informed pt. Hemlock Society	TQ instructed barbiturate sleep and suicide
TQ concerned pt., open discussion	TQ/pt. committed open, regular communication
TQ/pt. committed open, regular communication	TQ committed to pt. good death process
2go-Growth over time	TQ committed to assist pt.
8 year relationship	
Pt. teach importance informed decision making	
Pt. taught TQ not fear open communication	
Pt. taught TQ inner strength and risk-taking	
Reminiscing	
See #6	
Pt. fighter	
4ps-Previous success	*4ps-Previous success*
Not giving up rewarded	TQ knew pt. fought previous illnesses
Aspects contributing decision suicide	
5t-Treatment	*5dq-Dignity/quality*
Intervention 25% long-term cures	Lack control, dignity wants death
Long treatment, severe side-effects, 25% survive treatment	No desire existence relative comfort
	5c-Control
Convinced treatment very bad or fatal	Pt. definite, no treatment, no hospitalization
5id-Informed decision	Pt. need control/dignity
No treatment, certain death	Choosing to take own life least painfully
Decided no treatment	*5fp-Fear process*
Informed denial of treatment and risk	Refused bad death due to treatment
Pt. clear risks of treatment, no treatment	Fear of bad death decrease possible good death
Choice pain, sedation	Pt. sad to die, terrified suffering

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Aspects family/friend/physician end-of-life	
6c-Closures	*6p-Participation*
Good-byes to friends	Be with family
Special good-bye to TQ	Husband, son deeply involved
Died 2 days after good-bye TQ	Close relationship family, friends
Good-bye husband, son – asked left alone 1 hour	Several months close relationship family/friends
6r-Reminiscing	
Family, TQ remember remarkable person	

Feeling/emotions pt.	
7a-Anger	*7f-Fear*
Pt. angry oncologist presume to start treatment	*7d-Devastation*
Life not fair	Pt. terrified, angry, sad, hopeful
Illness unfair, death final	Pt. crushed finality dx

Aspects dying process	
8cm-Comfort measures	*8bd-Bad death*
TQ knowledgeable comfort care	Bad death process started
Physical symptoms treated with relief	Bad death process continued
Attempt minimize suffering, provide comfort measures	Suffering during dying process real
Choice pain, sedation	8gd-Good death
Suffering limited, not eliminated	1 hour pt. still, peaceful
Suffering can be lessened, not eliminated	TQ arrived, pt. peaceful

Aspects assistance family, friends, physician	
9ad-Awareness desire	*9af-Aftermath*
TQ aware and explored pt. wish	TQ fearful potential outcomes on family/pt. due to suicide
Open with family, accepted choice	Authorities informed – cause death acute leukemia
9sd-Support decision	Best care possible, concern where others stand
TQ supportive, no guarantee minimal suffering from treatment	Question society understanding suffering, dying process
Family accepted decision	Pt. taught TQ not fear open communication
Barbiturates available, security blanket	Pt. taught TQ inner strength and risk-taking
TQ instructed barbiturate sleep and suicide	How many help pts. die?
Good-bye husband, son – asked left alone 1 hour	How many commit suicide die alone?
Family no doubts pt. choice and their cooperation	TQ unanswered questions about pt. dying alone
9p-Protection	*9lr-Legal ramification*
Pt. protect TQ	Outside acceptable medical practice, no promise
TQ felt protecting all	If suicide mentioned – intrusion by authorities
9qp-Question plan/competence	Legal risk supporting pt. choice
Pt. talked with psychologist	Written prescription pushed TQ (doctor) boundaries
Pt. mentally stable	

Who is pt.?	
10p-Personality	*10al-Activity/life*
Pt. extraordinary, overcame previous illnesses	Pt. deep connection with others, living fully
Pt. clear, honest, open	
Pt. independent, confident, control of life	

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Hemlock Society, barbiturate	
11sg-Suicide guidance	*11sm-Suicide method*
TQ informed pt. Hemlock Society	Barbiturate essential ingredient Hemlock Society suicide Barbiturates available, security blanket

Aspects disease	
12p-Process	*12t-Type*
Pt. tired rash More tests, rapid decisions Calm before the storm Difficulty sleeping	Definite dx leukemia

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Who is pt.	
1p-Personality	*1pb-Physical being*
Pt. survivor, persevered	LS met 5 tall, spunky pt. with cancer in remission
Pt. self-sufficient, independent	Like being just me, not me with cancer
Loved adventure and thrills	*1ap-Activity/profession*
People in life, but liked privacy	Complex government job loved a good fight
'Carefully controlled' life	Loved being active
Pt. terminally ill not quitter	Loved work
Doesn't give up, pit-bull fighter	Current life quiet, simple

Feeling/emotions friends/physician	
2i-Inadequacy	*2f-Fear*
LS unprepared	LS fearful
Thought prepared what to expect, wrong	Fear no success
LS questioned inability to offer assistance	Failed suicide, the greatest fear
LS physically, mentally exhausted	*2e-Emptiness*
2af-Anger/frustration	LS pain of loss
LS shaken	
LS frustrated	
LS distraught	
LS barbaric act	

Feelings/emotions pt.	
3d-Denial	*3f-Fear*
No Plan B (suicide) exists	Scared the hell out of me
Pt. never believed cancer would win fight	Terrifying
Pt. not ready to die	Pt. fearful
3a-Acceptance	Fear, losing thoughts
Cancer real, hold in hand	Terrified dying process
Personal belongings comforting	Fear finality, death permanent
Ready to die when accept death	Pt. not want die alone
3ag-Anger	*3al-Aloneness*
Remembered doctor statement 'Nothing more can be done'	Cancer solitary, personal experience
Hate being forced to die	

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Aspects fight by pt.	
4rt-Research treatments	*4cl-Change lifestyle*
Pt. research began	Tragedy – giving up life to live
Found experimental treatment in Sweden	Freedom and adventure gone
Knowledgeable how to die as treatments how to live	Simple things important
Searched found experimental treatment	*4ng-Not give up*
4ib-Insurance battles	Pt. did not give up before
HMO road blocks a challenge	Pt. not give up now
Pt. won HMO battle, control back in pt. hands	Pt. not ready to die
HMO bureaucracy and cancer exhausting	Doesn't give up, pit-bull fighter
4fe-Focus elsewhere	Pt. spirit still fighting
Pt. paid attention to battle, not possible diagnosis	Pt. experience trying to touch down, hard to reach goal
Obsession, working on staying alive	
Plan A, fight like hell to live	

Aspects physician/pt. relationship	
5oc-Open communication	*5c-Commitment*
LS knew pt. plans to die	Question what do if asked to help
Willing to discuss reasons why plan to kill self	LS stayed with pt.
Doing well, why talk about suicide	LS reached decision
Frequent open discussions	*5gt-Growth together time*
Pt. request LS come	Pt. LS deep friendship grew
Share reality of cancer with LS	LS tenderness, loving care
LS questioned pt. re: thoughts suicide	LS stopped being writer/physician, became true friend
LS reminded pt. previous discussions	*5rt-Respect/trust*
Pt. aware previous discussions	Pt. LS friend and mentor
LS questioned thought about suicide	Pt. asked LS for help
LS described possible death scenarios	Pt. did not ask for assistance
Pt. lucid discussed possibilities	LS/pt. choices, risks, trust
Discussed suicide and how to do it	
5la-Limit assistance	
LS unprepared to make decision	
LS not mention option of assistance	
LS questioned inability to offer assistance	
Deciding for/against assistance LS nightmare	

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Aspects decision suicide	
6cd-Control death	*6di-Death inevitable*
Pt. decided day to die	Remembered doctor statement 'Nothing more can be done'
Pt. need for control	Death sentence pronounced, embedded in mind
Won't let death surprise	No choice death eminent
Today pt. doesn't want suicide	No options left, time to quit fighting/running
Pt. expressed suicide desire	Reality death, no options
Suicide day chosen	Dying why need to wait
Pt. want to make informed decision	Pt. ready to die, suicide decided
Pt. determined control death	Remembering cancer real
Constraints force death choice, or take chance	*6qd-Quality/dignity*
6fp-Fear process not death	Pt. tied to bed
Plan B, suicide unbearable suffering	Due to confusion, pt. choice taken away
Pt. not want prolonged agonizing death	
Terrified dying process	
Refuse bad death, decide suicide	
6id-Independence/dependence	
Hates dependence	
Confusion returns, unable to make decisions	

Aspects treatments	
7r-Results	*7se-Side effects*
Treatment stopped cancer 2 years	*7ct-Choice treatments*
Tumor disappeared with experimental treatment	Endured treatments and side effects
Celebrated successful neurosurgery and birthday party	*7te-Traditional/experimental*
Long remission, death seemed far away	Pt. found at home, taken to hospice
Rehydration increased strength and clarity	

Aspects disease/diagnosis	
8dp-Disease process	*8ed-Effects disease*
Pt. terminally ill not quitter	Sudden HA changed life at 36
Cancer returned nothing could be done	Cancer real, hold in hand
Cancer spread	Pt. aware, weak
Tumor spread in brain	Tumor difficulty swallowing, dehydration
Pt. fading quickly	Hallucinations took control
No possible improvement condition	Hallucinations returned
Cancer took choice for life away	Unable to swallow, choke saliva
8td-Type disease	
Diagnosis brain cancer	

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Hemlock Society, plastic bag, 'Final Exit'	
9sm-Suicide means Liquid morphine available, prescribed hospice doctor High dose morphine fatal 'Final Exit' suggests lethal morphine dose Morphine and vodka ingested Plastic bag = peaceful death	*9sg-Suicide guidance* Hemlock Society – 'Final Exit' 'Final Exit' plastic bag back-up
Aspects change quality/dignity	
See#6	
Aspects denial	
See#3	
Aspects friends/physician end-of-life	
12pp-Participation/presence Friends at bedside Old friend came to visit Pt. surrounded by friends LS taking care of pt. LS didn't leave alone Friends scheduled to come LS stayed with pt. Pt. not want die alone	*12c- Closures* Friend wishes pt. die, fall asleep Good-byes done *12gt- Growth together* *12so- Support each other* LS believed pt. needed pt's. friends confirmation *12r- Reminiscing* Miracle, pt. recognized friend, coherence won Friendship, reminiscing important
Friendship importance	
See #12	
Aspects death process	
14gd-Good death Sudden death possible Morphine death, sleep then breathing stops *14bd-Bad death* Coma, hallucinations, pain possible Inappropriate dose, brain and body damage without death Waiting – did not work No death yet Failed suicide, the greatest fear Oxygen deprivation to brain not peaceful	*14pu-Process uncertain* No exact prediction how die Suicide scene inexact Sleep and slowed breathing occurred rapidly Heart continued pumping Lethal dose to brain takes time Question pt. live or die Lips blue, question peaceful coma
Means suicide	
See #9	

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Aspects assistance suicide friends/physician	
16a- Aftermath	*16lr- Legal ramifications*
Friends need to know pt. wishes how to die	Friends unable to help
Assisted suicide paradox – possess lethal drug security blanket	Toxic dose advice legal
	Direct assistance murder
LS offer to assist potential prolong life with no suicide	LS assistance personal and professional damage
Difficult part assistance is loneliness	LS protect other friends
Assistance is Catch 22	Injection detectable, legal jeopardy
LS not alone in experience/choices	LS/pt. choices, risks, trust
16qp- Question competence	Deciding for/against assistance LS nightmare
Friends not convinced pt. wants suicide	Scenario described illegal act – murder
Question doing suicide because committed to	Legalities force secrecy/aloneness
Pt. intellectually committed to suicide	*16sp- Support plan*
Pt. lucid discussed possibilities	Important for others to understand why
Pt. clear thought process	Friends agreed, pt. ready to die
Pt. decision not supported when confused	No interference pt. choice
LS questioned pt. desire	Pt. decision supported when clear headed
16ap-Awareness plan	
Discussed suicide and how to do it	

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APPENDIX D

PARTIALLY ORDERED META-MATRIX

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Partially Ordered Meta-Matrix

Categories	Jane	Mary	Diane	Renee
Who is pt.	1pb - physical 1 pr - pesonality 1 ap - activity/professional 9 ng - not give up	1 pb - physical being 1 p - personality 1 a - acitivy/professions 9 p - preparedness	4 ps - previous success 10 p - personality 10 al - activity/life	1pb - physical being 1 p - personality 1 ap - activity/profession
Aspects physician/patient relationship	2 oc - openness communication 2 c - commitment 2 r - respect 2 tl - type/length	7 oc - openness communication 7 c - commitment 7 r - respect 7 tt - time & growth together	2 oc - open communication 2 rt - respect/trust 2 go - growth over time 2 c - commitment 1 p - physician	5 oc - open communication 5 c - commitment 5 rt - respect/trust 5 gt - growth together/time 5 la - limit assistance
Aspects disease/diagnosis	3 td - type disease 3 dp - disease process 3 il - impact lifestyle 3 kd - knowledge disease	3 dp - disease process 3 ds - disease symptons 3 di - disease effect independence	12 t - type 12 p - process	8 dp - disease process 8 ed - effects disease 8 td - type disease
Aspects treatments	4 c - choices 4 se - side effects 4 r - results 4 t - type treatment	10 tc - treatment choices 10 dg - doesn't give up 11 se - side effects 11 r - results 11 te - traditional/experimental	8 cm - comfort measures	4 rt - research treatments 4 ib - insurance battles 4 fe - focus elsewhere 4 cl - change lifestyle 4 ng - not give up 7 ct - choice treatments 7 se - side effects 7 r - results 7 te - traditional/experimental
Aspects decision suicide	5 d - dignity 5 q - quality 5 id - independence/dependence 5 fp - fear process, not death 5 cd - clarity decision 5 c - control 10 gd - good death 10 bd - bad death	5 d - dignity 5 q - quality 5 id - independence/dependence 5 c - control 9 n - no/fight for life 9 qt - question timing 12 gd - good death 12 bd - bad death 12 fp - fear process	5 t - treatment 5 dq - dignity/quality 5 c - control 5 id - inform decision 5 fp - fear process 8 bd - bad death 8 gd - good death	6 cd - control death 6 fp - fear process not death 6 di - death inevitable 6 qd - quality/dignity 6 id - independence/dependence 14 gd - good death 14 bd - bad death 14 pu - process uncertain

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Partially Ordered Meta-Matrix

Feelings/emotions pt.	6 f - fear 6 a - acceptance	4 g - give up 4 f - fear, uncertainty 4 d - denial 4 h - hope 4 a - acceptance 4 c - cover-up 4 t - toward others	7 a - anger 7 f - fear 7 d - devastation 1 pt - patient	3 d - denial 3 a - acceptance 3 f - fear 3 al - aloneness 3 ag - anger
Aspects end-of-life friends/physician	12 c - closures 12 cm - commitment 12 sd - sharing death	8 gt - growth together 8 pd - part dying process 8 au - awareness/understanding 8 sp - support plans 8 qp - question plans 8 c - closures 17 r - reminiscing 17 rl - relationships 17 c - commitment 17 cn - concern	6 c - closures 6 p - participation 6 r - reminiscing	12 pp - participation/presence 12 c - closures 12 gt - growth together 12 so - support each other 12 r - reminiscing
Hemlock Society, plastic bag, barbiturate ***Aspects assistance suicide on* friends/physician**	13 sg - suicide guidance 13 sm - suicide means 14 ap - awareness plans 14 sp - support plans 14 qp - question plans 14 a - aftermath 14 li - legal implications 14 p - *protection* 14 uq - unanswered questions	2 sg - suicide guidance 2 sm - suicide methods 6 p - protection 6 a - allow assistance 6 lr - legal ramification 6 d - die alone 6 af - aftermath	11 sg - suicide guidance 11 sm - suicide method 9 ad - awareness desire 9 sd - support decision 9 af - aftermath 9 lr - legal ramification 9 p - protection 9 qp - question plan/competence	9 sg - suicide guidance 9 sm - suicide means 2 i - inadequacy 2 af - anger/frustration 2 f - fear 2 e - emptiness 16 ap - awareness plan 16 sp - support plan 16 qp - question competence 16 a - aftermath 16 lr - legal ramifications

APPENDIX E

GROUNDING-PHRASE MATRIX

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Grounding-Phrase Matrix

Categories	Jane	Mary	Diane	Renee	Common Themes
Who is pt.	Content with life – strong willed, spiritual person, teacher.	Creative, mischievous, strong willed person – fulfilled relationships.	Extraordinary, confident, living life fully – deep connections others.	Self-sufficient, adventurous, determined – carefully controlled life.	**All are content with their lives and who they are as a person. A strong character for each is evident.**
Aspects physician/pt. relationship	Strong personal and medical relationship based on commitment, honesty, and openness of communication.	Demonstrated with two physicians: Respectful relationship developed through communication and awareness commitment to each other.	Longstanding relationship developed due to admiration and commitment – physician learned from pt..	Friendship developed through open, honest communication, growth from mentoring.	**Relationships, professional and personal, have developed over time through communication and willingness to learn from each other. Respectful awareness and commitment is an important aspect in the relationship.**
Aspects disease/diagnosis	Chronic respiratory disease and breast cancer – eventually no improvement, no future, terminal.	Breast cancer spread bones and visible skin, numerous treatments – body makes decision death imminent.	Leukemia's rapid progression requires rapid decisions.	Cancer spread brain effect mind – took choice for life away.	**All the diseases progressed, treated or untreated, to the point where the disease took the choice for life away – death was imminent.**

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Grounding-Phrase Matrix

Categories	Jane	Mary	Diane	Renee	Common Themes
Aspects end-of-life friends/physician	Strong unconditional, committed friendship gives ability for good-byes, closures.	Close relationship with friends and family enable sharing of suicide plan with ultimate acceptance of decision. Deep commitment from family and friends, Allow successful closures, good-byes.	Closeness with family, friends allows ability for special closures.	Patient does not want to die alone. Friends reminiscing, close-by enabling closures to relationships.	**Friends and family were committed to a close relationship with the dying person. Successful closures, good-byes were an extremely important aspect of the end-of-life.**
Aspects, assistance suicide on friends/physician	All aware suicide plan after initial protection, at some point question plan then accept and support plan. Aftermath greatest impact due to incomplete, unresolved feeling, and unanswered questions.	Initial intent to protect family and physicians from legal ramifications and willing to die alone. Decision affects others – torture for other if suicide too early and lose time shared.	All aware of plans and support decision, patient want protect physician and family from legal ramifications. Aftermath, unanswered questions, concern patient had to die alone.	Sharing plan for suicide with questioning about timing and ultimately support. Aftermath is fear legal ramifications and incomplete unsatisfied feelings.	**Suicide plans were shared with family, friends, and the physician. At times the plans were questioned, but the final result was acceptance and support from all concerned. The aftermath had the greatest impact on all. The suicide decision effects all concerned and questions each one's ability to cope with the incompleteness, the empty feelings, and the unanswered questions.**

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Grounding-Phrase Matrix

Categories	Jane	Mary	Diane	Renee	Common Themes
Aspects Decision Suicide	Fear of dying process greatest contributor to decision -fear includes loss personal quality and dignity in life. Wants good comfortable death, control of time die.	Contradiction to suicide is planning for future. Greatest fear dying process – deterioration obscene, loss dignity and quality demonstrated being tied to bed.	Informed 75% fatality rate even with treatment and severe side effects. Fears dying process, terrified suffering and lack of control.	Terrified dying process with unbearable suffering, decreased dignity and quality life – tied to bed and hates dependence on others. As life wants to control death chose day.	**The greatest fear is of the dying process – not death itself. Suffering consists of the loss of quality of life and dignity in the living of life – evidenced by two being tied to the bed, all with a loss of control ultimately.**
Feelings/Emotions Patient	No fear of death, terrified process of suffocation.	Anger, panic, and denial because life unexpectedly cut short, eventually accept inevitable death.	Devastated and angered by finality of diagnosis – life not fear.	Denied cancer win battle, terrified finality death, cancer is a solitary experience.	**Anger, denial and fear were present because of the finality of the diagnosis. Inevitably death cuts life short.**
Hemlock Society, plastic bag, barbiturate	Member Hemlock Society and aware of recommendations for comfortable self-deliverance, Secobarbital choice, not successful plastic bag used.	Member Hemlock Society, gun was initial choice for suicide, then open to other options. Seconal was final choice as method for suicide.	Doctor informed pt., Pt. became aware barbiturate main ingredient suicide for self-deliverance.	Aware Hemlock Society and guidance plastic bag can be used if drug, not successful. Morphine and vodka means available – questionable use plastic bag at end.	**The Hemlock Society information was a guide for methods to use for self-deliverance. Lethal drugs, barbiturate or analgesic, are ingredients for self-deliverance with a plastic bag recommended if the drugs are not successful.**

Grounding-Phrase Matrix

Aspects treatment	Numerous treatments tried with some bad side effects and initial success, ultimately no relief treatments = comfort measures only.	Numerous treatments including experimental expanded life 5 years, treatments no longer effective or advisable.	Chose comfort measures only.	Chose numerous treatments including experimental with reprieve for two years, then no treatment to help – death inevitable.	**All but one chose numerous treatments to try to beat death until there was no treatment that would stop death. Comfort measures at the end were provided for two patients.**

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APPENDIX F

CLUSTERED SUMMARY TABLE

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Clustered Summary Table

Category	Factor	Illustration
Who is patient Physician/patient relationship Aspects end-of-life family, friends, physician	Relationship 1. Know who patient is 2. Growth together - respect, learn from each other 3. Awareness family, friends relationships	Spiritual person, fighter, gifted teacher, many friends (Jane) "...confident about the existence of a beneficent God", "Struggling for her life...", "...gifted teacher who enjoyed engaging students...", "...had a full social life and many good friends" (Jane) Personal and medical relationship, strong bond (Jane) "...immediate connection ten-year relationship", "...several severe bronchial infections-formed a strong bond" (Jane) Friends committed to end, last day spent together/friends, died with committed friends present (Jane) "...good friends who would support her to the end", "On the day she had chosen...", "...did not have to die alone" (Jane)
		Mischevious rebellion, do something make things happen, journalist/mystery writer, do things yourself (Mary) "A journalist and author of complex mystery novels...", "...ornate fountain began to spout water in elaborate colors", "...many things to work out...make it happen", "...take care of yourself" (Mary) Close friendship 2 years, ask LS come back, LS caring close to pt. (Mary) "...next two years verbal sparring- into close friendship", "Can you come back?", "...sat down on edge of Mary's mattress-holding her hand" (Mary) Family/friends tell pt. good-bye, timing death important-not mode, family close by (Mary) "...one by one we filed in to visit-wish her good-bye", "...important question wasn't suicide-it was the timing", "The family stood around the bed" (Mary)
		Extraordinary, deep connection others, independent/confident (Diane) "Diane was no ordinary person...", "...established deeper connections-living fully", "...took control of her life" (Diane) 8 year relationship, taught TQ inner strength & risk-taking, taught no fear open communication (Diane) "...come to know, respect, admire over previous eight years", "She taught me about life, death, and honesty...", "...taught me range of help I can provide" (Diane) Husband/son deeply involved, good-byes to friends, family/TQ remember remarkable person (Diane) "...talked extensively about the problem", "She called her closest friends...", "...talked about what a remarkable person she had been" (Diane)
		Self-sufficient, loved adventure/thrills, pit-bull fighter, spunky (Renee) "...developed self-sufficiency and independence," "...learning to fly small aircraft and skydiving", "...pit-bull personality - come back kicking and screaming", "...5 foot tall - argue her way out of a New York cab fare" (Renee) Deep friendship grew, pt. friend and mentor, LS tenderness/loving care (Renee) "...our friendship grew to include other parts of our lives", "...my mentor at thriving in the face of adversity", "I smoothed the hair back - cradling her head..." (Renee) Surrounded by friends, good-byes done, friendship reminiscing done (Renee) "...cluster of friends surrounding her bed", "No more good-byes...", "It was a pajama party..." (Renee)

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Clustered Summary Table

Physician/patient relationship	Physician/patient communication 1. Open communication 2. Honest communication 3. Trustworthiness	Open communication, honest relationship - communication, TQ question reason for request (Jane) "... discussed our common interests - wide ranging conversations", "... our relationship honest - conversation out in open", "... take request face value - too important decision to make without direct conversation" (Jane) Talk about plan suicide, couldn't lie to doctor, be clear - direct (Mary) "...we began to talk about her plans for suicide", "...didn't think it would work to lie to him - we knew each other too well", "Don't be so eloquent ..." (Mary); Pt testing doctor commitment, committed open - regular communication, informed pt Hemlock Society (Diane) "...she opened up another area that would stretch me profoundly", "We agreed to meet regularly - promised to meet me before taking life...", "...I told Diane that information available from the Hemlock Society" (Diane), Share reality of cancer, described possible death scenarios, discussed suicide and how to do it (Renee) "Maybe through me ... you'll get a good hit of what it's really like", "...hope I was fair in my description", "She asked me how she might do it..." (Renee)
Aspects disease/diagnosis Aspects treatment Aspects decision suicide	Physician/patient progression together through patient's disease 1. *Diagnosis* 2. Treatment choices 3. Treatment effects 4. *Inevitable death*	Breast cancer - respiratory problems, selected mastectomy, bad side effects - medical complications increased, disease only get worse (Jane) "... biopsy determined breast cancer", "...given her problems with asthma", "...chose invasive surgery - no *confidence in radiation*", "*The steroids were associated with all the predicatable complications* ...", "She was hovering on the edge of dying..." (Jane) 56 - dx breast cancer, visible skin tumors - experimental, cancer spread - chemotherapy depleted resistance, body making decisions (Mary) "... breast cancer - already spread to bones", "... very visible skin tumors - became *her saving grace*", "...bones riddled with cancer, and the chemotherapy - susceptible to infections", "Your body is making the decisions ..." (Mary) Definite dx leukemia, physical symptons treated, attempt minimize suffering - comfort measures, no treatment - certain death (*Diane*) "... *acute myelomonocytic* leukemia", "... emotional and physical hardships - transfusions - antibiotics", "...tried our best to minimize the suffering and promote comfort", "... outcome no treatment - certain death" (Diane) Diagnosis brain cancer, endured treatments and side effects, treatment stopped cancer two years, tumor spread in brain (Renee) "... cancer in her brain", "... endured painful neurosurgery, radiation, and the nausea, vomiting", "... halted the cancer for two years", "...the tumor had also spread inside her brain" (Renee)

Clustered Summary Table

Aspects decision suicide Aspects physician/patient relationship	Physician understanding, acceptance of patient's personal definition of suffering 1.Patient fears 2.Patient quality 3.Patient dignity 4.Physician commitment	Terrified suffocation, not want be more invalid, no joy meaning to life, hated dependence on others - scheduled care, guarantees enough medicine comfort (Jane) "I am terrified of waiting to suffocate...", "This is not living anymore - only get worse", " hated being in hospital and depending on others", "...not afraid to give enough medicine once start to suffocate" (Jane) Tied down worst fears, wait - shit bed, incontinent bowel - loss dignity, no quality to life, requested I.S stay - agreed not abandon (Mary) "Tied down, Mary faced her worst fears...", " wait forever shit in this bed - before I'll let them tie me up again", " the foul smell of feces filled the room as she lost control", " no quality left to my life", "You stay - you signed up a long time ago" (Mary) Lack control - dignity wants death, suffering during dying process real, no desire existence relative comfort, fear of bad death decrease good death, TQ committed pt. good death process (Diane) "...no longer possible - clearly wanted to die", "...to think people do not suffer in the process of dying is an illusion", " lingering in relative comfort - wanted no part of it", "fear of a lingering death interfere - getting most out of time left", "...felt strongly that I was setting her free to get the most out of time left" (Diane); Terrified dying process, hates dependence, no options left - time to quit, due to confusion - pt. choice taken away, I.S reached decision (Renee) "I'm terrified of...*Pain - Delirium - Hopelessness - Dependence*", "*I abhor* dependence", "Three separate terminal diagnoses - I can't focus my eyes - I can't drive ", "I woke up in the middle of the night - yelling to let my dog in - insisted to go home - they tied me down", "From some mysterious merger - I had reached my decision" (Renee)

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