This dissertation used Q methodology to measure and analyze the moral and political positions of various actors who have an interest in the issue of physician aided dying. The population studied included health care professionals, legal professionals, members of the clergy and religious orders, social workers, caregivers, ethicists, the aged and infirm, all of whom comprised the primary decision making group for end of life issues. There were 41 participants in this study. 36 of the 41 participants who completed the Q-sorting portion of the study also completed a public policy survey. A factor analysis was performed and a judgmental rotation of the factors from which a three-factor solution emerged (referred to in the text as Factor A, Factor B, and Factor C). Factor B, the only Q factor that correlated significantly with a policy factor, supports a policy program that would reform the existing legal system in order to accommodate its moral reasoning.

Factor A is distinguished by its belief that PAS and euthanasia are inimical to physicians’ moral duty and fundamentally wrong. Factors B and C believe that physician assisted dying can, for some patients, increase the prospects for dying well and that the medical and legal system should evolve to accept that perspective. Factor C is also more
focused than Factor B on emphasizing that PAS and euthanasia do not signify a failure of physicians to follow their moral duty towards their patients and society.
LINKS BETWEEN ETHICS AND PUBLIC POLICY:
A Q METHODOLOGICAL STUDY OF PHYSICIAN
ASSISTED SUICIDE AND EUTHANASIA

A dissertation submitted
To Kent State University in partial
Fulfillment of the requirements for the
Degree of Doctor of Philosophy

by
Timothy D. Newman

May, 2005
## TABLE OF CONTENTS

LIST OF FIGURES ............................................................................................................... v

LIST OF TABLES ................................................................................................................ vi

ACKNOWLEDGEMENTS ................................................................................................. vii

Chapter

I. INTRODUCTION .............................................................................................................. 1

  Physician Aid in Dying: Physician Assisted Suicide and Euthanasia Defined .......................................................... 4
  PAS and Euthanasia: Pre-modern Developments ....................................................................................... 10
  PAS and Euthanasia: The Modern Context ....................................................................................... 23
  How We Die .................................................................................................................................. 26
  Choosing PAS .................................................................................................................................. 35
  Method .......................................................................................................................................... 43

II. THE POLICY CONTEXT ............................................................................................... 44

  Public Interest ..................................................................................................................... 45
  Autonomy .................................................................................................................................. 52
  The Legislature .................................................................................................................. 49
  State-Wide Initiatives ...................................................................................................... 61
  The Right to Die and the Courts ...................................................................................... 64
  Conclusion ......................................................................................................................... 71

III. RESEARCH DESIGN .................................................................................................... 76

  Q Methodology ................................................................................................................ 76
  Concourse and Statements ............................................................................................ 79
  Policy Statements ........................................................................................................... 86
  Participants ....................................................................................................................... 88
  Procedure ........................................................................................................................ 91
# TABLE OF CONTENTS (Continued)

IV. ANALYSIS OF THE FINDINGS..............................................................95

- Theoretical Rotation...............................................................95
- Factor A.............................................................................102
- Factor B.............................................................................116
- Factor C.............................................................................123

- Returning to the Design of the Concourse and the Selection of the Q Statements..........................................................130
- Policy Analysis ......................................................................133
  - Policy Factor I ..............................................................134
  - Policy Factor II ..............................................................137

V. CONCLUSION.........................................................................141

APPENDICES

A. FACTOR Q SORT VALUES FOR EACH STATEMENT..................150

B. PARTICIPANTS’ FACTOR LOADINGS AND DEMOGRAPHIC DATA ....154

C. POLICY FACTOR SCORES..........................................................156

D. CONSENT FORM.................................................................160

REFERENCES ............................................................................161
LIST OF FIGURES

Figure

1. Policy Statements ............................................................................................................... 87
2. Policy Questionnaire ........................................................................................................ 94
3. Graph of Two Unrotated Factors ..................................................................................... 97
4. Graph of Factors after Judgmental Rotation ................................................................. 100
LIST OF TABLES

Table
1. Q Statement Categories ........................................................................................................... 80
2. P-Set Structure ......................................................................................................................... 88
3. The Influence of Ethics and Valence on the Q Factor Scores .................................................. 131
4. Correlation of Q Factors and Policy Factors ............................................................................ 134
ACKNOWLEDGMENTS

Thanks to all of the participants in this study. Without the generous contribution of their time and insights, this study would not have been possible. I also want to thank my co-directors, Steven Brown and Jennifer Maxwell for their essential advise on this project. Finally, I thank my partner, Patricia Fridrich and my parents, David and Judith Newman for their support and patience.
CHAPTER 1

INTRODUCTION

Physician assisted suicide (PAS) and euthanasia have been important policy issues in recent years. Physician assisted suicide and euthanasia are not new issues and, for that matter, neither are most of the arguments that have ensued from the consideration of these issues. According to Stoffell (1998), “there is no bioethical issue with a longer philosophical lineage” (p. 272). The ethics of euthanasia and PAS were discussed from antiquity to modernity (Emanuel, 1994). PAS raises arguments about such issues as personal autonomy, liberty, and the value and sanctity of human life. PAS also raises practical questions regarding the proper applications in a clinical setting, the physician-patient relationship, and the problems of regulating a practice that has been referred to as a “well-kept” secret.

In the past decade, several state referenda, important Supreme Court cases, a new openness in the medical community, and the well-publicized actions of Jack Kevorkian, the “suicide doctor”, have stimulated renewed public interest in these issues. Kevorkian had, in all likelihood, ended his career as America’s most well known, or infamous, spokesman for assisted suicide and euthanasia when he was recorded on video while injecting Thomas Youk, a victim of amyotrophic lateral sclerosis (ALS) with lethal
drugs. This video, which also showed the victim’s approving family, was subsequently aired on CBS’s 60 Minutes on November 22, 1998 (Cohen-Almagor, 2001; Kastenbaum, 2004). Reformers from "right to die" advocacy groups like Hemlock Society USA and Compassion in Dying have cautiously maintained their distance from Kevorkian as have other proponents of legalization in the medical and legal professions. During the 1990s, ballot initiatives in California, Maine, Washington, and Michigan failed to garner enough support to pass legislation legalizing the practices of medical suicide and euthanasia. At the same time, many states, in an apparent reaction to Dr. Kevorkian’s actions and other widespread public interest in legal PAS, have quickly changed ambiguous or common law based regulations into criminal statutes.

In the United States, decisions concerning end-of-life treatment are influenced by a wide range of factors, among which are the current ethical guidelines of the medical profession as a whole, the personal principles and inclinations of the attending physician and other surrounding caregivers, the character of the relationship between patient and physician, the legal dictates of the particular state in which the dying are treated, and the technical skills of the professionals who work through the dying process (Kastenbaum, 2004). Even in an era in which patients’ rights rhetoric is commonplace, the desires and wishes of the dying are only a part of the landscape of the modern death.

With the exception of the state of Oregon, physician assisted suicide is prohibited by law throughout the United States and euthanasia is prohibited without exception. Federal courts have left it to the states to determine policy for the most part. Physician assisted dying remains subject to a double standard. The laws that prohibit the practice
are ostensibly recognized, but not necessarily enforced or enforceable, and many
physicians think that they are justified, under certain conditions, to ignore the legal
impediments to assisted dying (Nuland, 2000). As will be shown, PAS is practiced
regardless of the law and the American Medical Association's prohibitive stance
(American Medical Association, 2002). As long as physician assisted dying remains
illegal, but nonetheless occurs, it will be a private issue between doctor and patient or
surrogate. For better or worse, prohibiting PAS rather than regulating it places the
"responsibility for ensuring morally justified processes of decision making" solely with
the physician and patient (Blank, 1988, p. 115).

This dissertation is a study of the political and moral dimensions of PAS and
euthanasia from the vantage point of the subjectivity of various actors who have a
professional or personal interest in end of life issues. Subjectivity in Q methodology
refers to self-referential and communicable attitudes, beliefs and experiences surrounding
a particular subject matter of interest (Stephenson, 1981). There is a long history of
debate in Western ethics about what constitutes the best foundation for ethics and
whether ethics can be true or false independent of subjective beliefs and preferences
(Toumlin, 1950; Midgley, 1981; Carlson & Moser, 1997; Arrington, 1998). This study
presumes that ethics is, at least in part, “open to change in feeling and conduct” and
therefore, “conditional on self-reference,” and in this respect, can be affected by emotion,
intuition, reason, facts and logic in various combinations (Stephenson, 1987, p.13).

The purpose of this study is to identify and analyze different subjective positions
on the ethics of PAS and euthanasia and the relationship between these positions and
public policy preferences. This study, utilizing the contemporary literature on PAS and euthanasia debates, experimentally reproduces the ethical reasoning that occurs in such contexts as ethics review boards, physician-patient encounters, legislatures, and courtrooms, among other loci. Q methodology makes it possible for participants in this study to arrange various approaches to PAS and euthanasia in the literature into self-referential categories (Stephenson, 1981; Brown, 2002). These categories, expressed in Q factors, are analyzed, compared and contrasted. Finally, implications for future public policy innovation relating to PAS and euthanasia are discussed with respect to each Q factor. Policy preference and the relationship between policy preference and ethics in a complex ethical issue like PAS and euthanasia may be useful to the construction of legislation and policy either for or against assisted suicide and euthanasia. The empirical study of links between ethics and policy preference may extend beyond the issue of PAS and euthanasia to other contentious policy areas that involve complex ethical reasoning.

Physician Aid in Dying: Physician Assisted Suicide and Euthanasia Defined

Euthanasia derives from two Greek words, eu (good or happy) and thanatos (death). According to Kastenbaum (2004), the term euthanasia originally referred to “dying without pain and suffering,” but has evolved to mean the intentional ending of another’s life in order to put an end to pain and suffering (p. 277). Euthanasia is defined by the American Medical Association (2002) as “the administration of a lethal agent by another person to a patient for the purpose of relieving the patient’s intolerable and incurable suffering,” (p. 83) and this is the definition of euthanasia that is used in this
study. Euthanasia is voluntary in cases where persons give informed consent to the practice. According to Blank (1988), euthanasia is “speculative,” when consent to euthanasia is given by proxy (Blank, 1988, p. 118). According to Materstvedt et al. (2003), euthanasia must be either voluntary or nonvoluntary; euthanasia cannot be involuntary as “the medicalized killing of a person without the person’s consent, whether nonvoluntary (where the person is unable to consent) or involuntary (against the person’s will), is not euthanasia: it is murder. Hence, euthanasia can be voluntary only” (p. 98).

According to Kamm (1998), active euthanasia is a practice that "involves a death that is intended (not merely foreseen) in order to benefit the person who dies" (p. 28, italics in original). Withholding or withdrawing life support and thereby letting the patient die without intervention is sometimes referred to as passive euthanasia and is acceptable to the courts and common law in the United States (Rachels, 1986). According to Rachels (1986), “in passive euthanasia we simply refrain from doing anything to keep the patient alive – for example, we may refuse to perform surgery, administer medication, give a heart massage, or use a respirator – and let the person die of whatever ills are already present” (p. 38). In 1991, the American Medical Association formally accepted the position that physicians can, with informed consent, withhold or withdraw life-sustaining medical treatment, which is “any treatment that serves to prolong life, without reversing the underlying medical condition” including artificial nutrition and hydration (American Medical Association, 2002, pp. 65-66). In addition, the AMA makes no ethical distinction between withdrawing and withholding life sustaining treatment. Terminal sedation or TS refers to a relatively common practice in
the United States, in which a terminally ill person is rendered unconscious or semiconscious with large doses of drugs while nutrition and hydration are withheld. In so doing, death is hastened either by the suppression of respiration, dehydration, or starvation (Quill, Lo & Brock, 2003). Courts have routinely allowed terminal sedation even though death occurs sooner than it would if the terminal disease ran its course. Both withdrawing and withholding life sustaining treatment and terminal sedation are accepted based upon the principle of double effect. The double effect doctrine in this context determines that the morality of the use of potentially toxic drugs in the course of managing severe physical distress at the end of life, if the intent of the physician and the result of the physician’s action is only the management of pain and physical distress, is acceptable. The morality of an unintended second effect, foreseen or not, of the physician’s actions is also acceptable even if the second effect is the patient’s death (Brody, 1993; Veatch, 2003; Quill, Lo & Brock, 2003). According to Quill, Lo and Brock (2003):

As long as the physician’s intentions are good, it is permissible to perform actions with foreseeable consequences that it would be wrong to intend. In this view, intentionally causing death is morally impermissible, even if desired by a competent patient whose suffering could not otherwise be relieved. But if death comes unintentionally, as the consequence of an otherwise well-intentioned intervention, even if foreseen with a high probability, the physician’s action can be morally acceptable. The unintended but foreseen bad effect must be proportional to the intended good effects. (p. 255)

Physician assisted suicide (PAS) refers to the voluntary termination of life with the help of a physician who prescribes the lethal means, usually a barbiturate or an opioid or sometimes a combination of drugs (Groenewoud et al., 2000; McKhann, 1999). In a
groundbreaking article (also see Quill, 1993) on PAS published in the *New England Journal of Medicine*, Quill, Casell, and Meier (1992) offered clinical criteria for the care of terminally ill patients that included guidelines for the proper clinical practice of PAS. Quill, Casell and Meier (1992), prefaced their criteria for PAS with the statement that PAS should not be a substitute for comprehensive palliative care and adequate psychological counseling. However, these physicians also argued that palliative care would be neither feasible nor desirable for every patient. Ideally, patients would have the option to seek PAS because they have a right to the aid of a physician if they can demonstrate their rational belief that suicide is their only path to a dignified death. The authors of this article argued for the legalization of PAS and against the legalization of euthanasia. This position, they maintained, offers a balance between the needs of the patient and the protection of society from potential abuses. For PAS, patients must be physically able to act on their own. The essential difference between PAS and euthanasia depends on who commits the final act, the patient who takes the lethal medication supplied by the physician, which is PAS, or the physician who administers the immediate means of death, which is euthanasia. Emanuel, Daniels, Faircloth and Clarridge (1998) noted that about a third of the oncologists (a total of 355 oncologists participated in the survey) who reported that they have participated in euthanasia or PAS did not appear to understand fully the difference between PAS and euthanasia or between euthanasia and letting die.

Euthanasia and PAS were made legal in the Netherlands and Belgium in 2002, (Materstvedt et al., 2003). The legality of PAS and euthanasia in the Netherlands is the
result of several decades of tradition in Dutch jurisprudence. The legality of PAS in Oregon and the Netherlands has meant that the practice of PAS and euthanasia has been well documented (Admiraal, 1996b; Groenewoud, et al., 2000). In Oregon, the PAS law is specific regarding the difference between PAS and euthanasia, allowing the former while prohibiting the latter. In the Netherlands, the choice of who administers the lethal drug is made by the patient with the advice of the attending physician. There is evidence that complications are more likely to occur with PAS than euthanasia (Groenewoud et al., 2000; Nuland, 2000). A study of the Dutch experience with PAS and euthanasia during 1999 reported that in 21 of 114 cases in which the original intention of the patient was PAS, the attending physician had to intervene with a lethal injection because of complications (Groenewoud et al, 2000). In the Netherlands, it is customary for a physician or licensed caregiver to be either in attendance or nearby during the suicide and immediately available to intervene and perform euthanasia should any complications occur (Emanuel et al., 1998). In Oregon, the law allows physicians to be present when the patient takes the prescribed medication, but it is not a requirement of the law and physicians may not legally intervene should complications occur (Smith, 1996). In general, physicians in the Netherlands have had considerable experience with PAS and euthanasia and probably are more knowledgeable about the most effective drug combinations than American physicians are (Emanuel, 1994; Groenwoud et al., 2000). A study by Emanuel et al., written prior to legalization of PAS in Oregon, reported that 15% of all attempts at PAS failed. Emanuel et al. (1998) also found that there was “inconsistent adherence to well-accepted safeguards” (p. 511). Although Sullivan,
Hedberg and Fleming (2000) reported that there were no instances of failure in two years of legal PAS in Oregon, Nuland (2000) suggests that there may have been problems with reporting in Oregon and that the relatively small numbers of people who received PAS is too small to be conclusive. Further, if there were complications with PAS in Oregon, the fact that it would be illegal for a physician to intervene and perform euthanasia may have dissuaded physicians and family members of patients who received euthanasia due to a failed attempt at PAS from reporting any problems.

The difference between PAS and euthanasia has important policy implications. The Oregon Death with Dignity Act limits the action of the physician to prescribing an oral medication, which in turn limits eligibility to patients who are able to swallow large doses of effective oral medication. Many end-stage cancers and neurological diseases such as ALS make the ingestion of oral medications difficult or impossible. “A Model State Act to Authorize and Regulate Physician-Assisted Suicide” (Baron et al., 1996) would permit physicians to prescribe a lethal medication or a device to patients receiving PAS. Such devices may include a machine that enables the patient to self-administer a lethal intravenous drug. The Hemlock Society’s proposed policy plan was designed to include precautionary measures that would largely dissolve the difference between PAS and euthanasia and allow an attending physician to administer injected drugs. The provisions in the Oregon law were designed to provide safeguards for patients receiving PAS. Many of these provisions were included in the Oregon law in response to critics of proposed bills and referenda in other states that failed to become law (Smith, 1996). However, Nuland (2000) argues that problems inherent in PAS in both legal and illegal
settings reveal a need to reevaluate public policy that permits PAS by oral medication exclusively. Nuland suggests that the safeguards in the Oregon policy may actually harm patients rather than protect them from abuse and that if PAS is going to be practiced, which evidence suggests is the case, legal or not, physicians should be educated about the best available methods.

PAS and Euthanasia: Pre-modern Developments

Suicide has been a topic for philosophical discussion and moral deliberation since the time of Plato, and has produced a wide range of opinion regarding the moral permissibility of suicide. The word “suicide” entered the English lexicon in the 17th century. Classical Greek and Roman philosophers relied on noun and verb phrases such as “self-killing” or “self-murder” to describe suicide (Cooper, 1999, p. 516). Plato (trans. 1980; trans. 1955) and Aristotle (trans. 1999) were against suicide in most cases, and suicide was generally illegal in the Greek city-states at the time of their writing (Cooper, 1999). Notably absent from both Plato’s and Aristotle’s writing on suicide is sensitivity to the suffering that often accompanies suicide. Plato writes in the Laws (trans. 1980), voluntary suicide in most cases is indicative of a “lack of effort and unmanly cowardice” (p. 269). Plato (trans. 1980) recommends that suicide be discouraged by leaving the corpses “off by themselves without a single companion tomb; then they should be buried without any name, in uncultivated and nameless boundary regions of the twelve districts, without tablets or name markers indicating the tombs” (Plato, trans. 1980, pp. 269-270). In Phaedo, Plato (trans. 1955) suggests that suicide is unwise despite its misleadingly
logical appeal in certain circumstances. Plato seems to suggest that naturally, we are attracted to the afterlife as we desire to be in the presence of the Gods and significant (mortal) others who have died before us. However, our fate belongs not to us, but solely to the Gods themselves “to the effect that we mortals are in a kind of prison, and that a man must not, apparently, free himself from it or try to run away” (Plato, trans. 1955, p. 44). However, Plato (trans. 1980) suggests that in certain circumstances, death could be an attractive alternative to a bad life, in which case suicide is a permissible and even optimal course of action. Plato (trans. 1980) concedes that suicide is appropriate as a method of capital punishment, as a release from extreme and unavoidable misfortune, or as a means to destroy persons perpetually unable to control their wicked habits. Aristotle (trans. 1999) also considers suicide to be generally illegal, depraved and an injustice to the polis, and suggests that those who die by suicide should be punished by the loss of their status as citizens (p. 84).

Physician assisted dying was never addressed directly in Greek philosophy as a subject requiring special study or deliberation (Cooper, 1999). This probably had to do with the fact that the prevailing state of medicine in ancient Greece and Rome did not allow for accurate prognosis or a prolonged dying process. As Calahan suggests (1999),

> When physicians could do nothing to stop death, they were not held responsible for it. When, with medical progress, they began to have some power over death—but only its timing, and circumstances, not its ultimate inevitability—moral rules were devised to set forth their obligations. (p. 329)

According to Cooper (1999), the people of antiquity were well aware that there was a great deal of uncertainty in medical knowledge, and thus, the conditions that tend to give
rise to demands for euthanasia were too rare to warrant a systematic philosophical examination of the morality of euthanasia. There is no discussion of euthanasia or PAS in the writings of Plato or Aristotle (Cooper, 1999). However, the withholding of medical care from people afflicted with incurable disease or chronic injury would be sanctioned in Plato’s ideal city-state (Plato, trans. 1985, pp. 104-106). With the general exception of the elderly, who are to be honored and respected in Plato’s *Republic*, physicians would not care for incurable patients so as not to prolong their pointless lives. The withholding of medical care is not voluntary for the patient, but rather is prescribed based on the physician’s objective evaluation of the patient’s physical condition and prognosis for recovery. Plato wants physicians to deny treatment to hopeless patients irrespective of the patient’s personal wishes as the severely ill and infirm, unable to perform any of their useful functions, would be a burden to the community and to themselves:

> But for those whose bodies were riddled by disease he [Asclepius, the god of healing] did not try to prolong a wretched existence with diet or infusions or evacuations and so increase the likelihood that such patients would beget similarly wretched offspring. He did not think it worthwhile to treat a man incapable of living a normal life since such a one is of no use to himself or to the state. (Plato, trans. 1985 p. 105)

In defense of this point, Plato takes a position that we would probably find unacceptable today based on his essential moral principle that maintains that one ought to act according to what is best for the good of the community. The decision to withhold medical care is for Plato a community decision that should be respected insofar as all right-minded
people would accept as their duty to die under certain circumstances because dying would be the right thing to do for the community.

The Stoic philosophers, who generally had much more to say about suicide than Plato and Aristotle, accepted and even encouraged suicide to end the suffering of the painfully ill, partly because there was a cultural premium placed on living and dying in accordance with the Stoic conception of nature and the good life (Choron, 1984). The Stoics essentially deify nature such that their concept of God is virtually interchangeable with nature (Arlington, 1994; Cooper, 1995; Seneca, trans. 1997; Cicero, 44/2001). A basic feature of Stoic philosophy is that events in life are predetermined by nature, but nature endows people with a rational capacity to find the appropriate way to live in harmony with nature. By utilizing their natural capacity for rational planning and reasonable decision making, people can live a good and happy life, but only if they attain the requisite wisdom to adjust to their experience by taking the right attitude to any situation (Arlington, 1994; Cooper, 1995; Seneca, trans. 1997; Cicero, 45/2001). The Stoic conception of the good life is one that is lived wisely in accordance with nature, i.e., the natural and naturally inevitable course of events, and the natural human capacities, as opposed to a bad life, which is a life that is lived in futile resistance to nature (Cicero, 45/2001; Arlington, 1994). Stoic wisdom involves a combination of reason and disciplined control of the emotions such as anger and despair (Arlington, 1994; Seneca, trans. 1997).

The Roman Stoic Cicero (45/2001) suggests that in order to live well people require “advantageous items” among which are “well-functioning senses” and “good
health” (p. 82). People can attain the wisdom to respond appropriately, with reason rather than emotion, when the body becomes too unhealthy to support a good and happy life.

It is appropriate to live when most of what one has is in accordance with nature. When the opposite is the case, or is envisaged to be so, then the appropriate action is to depart from life. (Cicero, 45/2001, p. 84)

For the Stoics, unlike Plato and Aristotle, suicide has nothing to do with personal or public virtue (Cicero, 45/2001; Cooper, 1999; Choron, 1984). According to Cicero (45/2001), “one who is endowed with virtue need not be detained in life, nor need those without virtue seek death. . . . The Stoics hold that living happily—that is, living in harmony with nature, is a matter of timeliness” (p. 84). In his essay, On Anger, the Roman Stoic, Seneca (trans. 1995), who would eventually find himself forced to commit suicide at the hands of the Roman state, suggests, perhaps with an air of smugness, that as a practical matter, suicide is an ubiquitous cure for unbearable pain or ignominy.

Wheresoever you cast your eyes there lies an end to affliction. Look at that precipice—down it runs the way to freedom. Look at the sea there, the river, the well—at its bottom lies freedom. Look at that tree, short and shriveled and barren—there on it hangs freedom. Look at your throat, your windpipe, your heart—all are ways of escape from slavery. But perhaps the ways out which I have shown are too toilsome for you, too demanding on spirit and strength. Are you asking for the road to freedom? Take any vein you like in your body! (Seneca, trans. 1995, p. 92)

The Roman Stoics’ position on suicide was congruent with Roman law and culture. Roman citizens were entitled to have their slaves assist them in the act of suicide, and the Roman city at Marseilles had supplies of poison for any citizen who made a case before the Senate (Battin, 1996, p. 174).
State sanctioned suicide ended with the conversion of Rome to Christianity and Christian philosophers ceased to justify suicide as a rational act. Choron (1984) states that "the permissiveness of ancient philosophers towards suicide was completely obliterated by the uncompromising attitude of the Christian Church" (p. 348). St. Augustine of Hippo (trans. 1950), in *The City of God*, advocates an explicit prohibition of suicide in his writings and is representative of early Christian writers who view suicide as inherently sinful and an affront to the will of God. Augustine (trans. 1950) bases his argument on his reading of God’s Sixth Commandment, “Thou shalt not kill,” which he takes to imply that God considers suicide to be effectively equivalent to homicide:

> It is not without significance, that in no passage of the holy canonical books there can be found either divine precept or permission to take away our own life, whether for the sake of entering in the enjoyment of immortality, or of shunning, or ridding ourselves of anything whatever. Nay, the law, rightly interpreted, even prohibits suicide, where it says, ‘Thou shalt not kill.’ (p. 26)

In *The Summa Theologica*, (1272/2003) theologian and philosopher St. Thomas Aquinas argues that suicide is “always a mortal sin, as being contrary to natural law and to charity” (question 64, article 5). For Aquinas, God’s will is invariably good and the natural law is always in accordance with God’s will; therefore, living and dying according to natural law is always morally right and reasonable. Suicide is against the natural law and an affront to God, who wills us to live, and so leads to damnation of the soul in the afterlife. Aquinas seems to recognize a need to reconcile Christianity’s absolute prohibition of suicide and the condemnation of the souls of those who die by suicide with the notion that God endows people with reason and free-will. Like Plato
(trans. 1955), for Aquinas, the notion, however intuitively appealing, that free-will allows for the voluntary exchange of a bad life on earth for a good afterlife in heaven rests on a deceit. Free-will enables people to live responsibly and morally according to natural law, but it does not permit mortal sin. Souls belong to God and may enter heaven by God’s invitation only.

Man is made master of himself through his free-will: wherefore he can lawfully dispose of himself as to those matters which pertain to this life which is ruled by man’s free-will. But the passage from this life to another and happier one is subject not to man's free-will but to the power of God. (Aquinas, 1272/2003, question 64, article 5)

Aquinas makes an additional argument against suicide, which refers to Aristotle’s thoughts on the subject, by saying that the harm that suicide does to other people, the state and the greater society outweighs any good that it does for the individual. As evidenced by a contemporary exposition of orthodox Christian ethics, the attitude towards suicide or physician aided dying has not changed. Breck (1995) argues that Christian ethics are grounded in the principle of the sanctity of life. Suffering may be beneficial or even redemptive according to this principle. Christians can accept in good faith pain management regimens for the terminally ill, but they cannot condone suicide or euthanasia in violation of the sanctity of life principle.

Modern Catholicism bases its prohibition against euthanasia and suicide on the sanctity of life principle that maintains that innocent human life is a gift from God and as such is a basic good that affords unconditional protection (Odenberg, 2000). According to Calahan (1992):
One important intent of the Christian understanding [of the sanctity of life] is to remove the ultimate source of the sanctity of life from any dependence on human experience and judgment; this is accomplished by locating the source of the sanctity of life outside man. (p. 130)

According to this view, suicide and euthanasia are essentially instances of self murder and cannot be morally justified under any conditions (Grisez & Boyle, 1979). Although Catholicism opposes euthanasia and suicide of any kind, it generally accepts the doctrine of the double effect and allows for the withdrawal of life support technology under conditions in which death is imminent (Boyle, 1998). The perspective on suicide and euthanasia found in Judaism and Islam is generally similar to the Christian perspective. Jewish tradition is similar to the Christian tradition in that it “emphasizes that the Creator should decide matters of life and death” (Resnicoff, 1998). Jewish law considers all innocent life sacred and forbids suicide and mercy killing of any kind (Resnicoff, 1998). There is general acceptance of the double effect in Jewish law (De Lange, 2000). However, there is some difference of opinion among interpreters of Jewish law regarding the right of a suffering patient to refuse life-sustaining treatment (Resnicoff, 1998; De Lange, 2000). According to De Lange (2000), in the Jewish tradition,

> euthanasia is considered to be murder, although some Rabbis have argued that there is no obligation to keep someone alive mechanically who is not capable of independent life, particularly if the patient is in pain. It is also widely accepted that pain-killing drugs may be administered even if they have the indirect effect of hastening death.” (p. 114)

According to Resnikoff (1998), Jewish law prohibits advising or otherwise helping another to commit suicide even if the person whose suicide is assisted is suffering and imminently dying. Islamic tradition also posits that all innocent life is sacred and
forbids all forms of suicide and euthanasia as these are unacceptable reasons for killing. The Koran states that Allah must decide the exact time of death. Paralleling Christian and Jewish traditions, Muslims believe that all innocent human life is sacred because it is a gift of Allah and that intentionally killing persons can only be acceptable as a means of meting out justice for heinous crimes.

The influential 18th century philosopher Immanuel Kant’s opposition to suicide is based on a deontological argument, which posits that there is an absolute duty to respect human life. For Kant (1785/1959), right actions are actions that are derived from a priori principles discernable through reason and motivated by a good will rather than the hope or desire for a preferred outcome. According to Kant (1785/1959), “the moral worth of an act does not lie in the effect which is expected from it or in any principle of action which has to borrow its motive from this expected effect” (p. 17). Tannsjo (2002) suggests that “the truth about Immanuel Kant is that he holds an ethical theory with two very different tenets” (p. 57). One of these tenets is that moral agents should be motivated to perform morally obligatory actions by the right reason, namely, that which Kant refers to as a good will, which, being something that is possessed by the moral agent, implies that virtue or character is of central importance to Kant’s theory.

Nothing in the world—indeed nothing even beyond the world—can possibly be conceived which could be called good without qualification except a good will. Intelligence, wit, judgment, and the other talents of the mind, however they may be named, or courage, resoluteness, and perseverance as qualities of temperament, are doubtless in many respects good and desirable. But they can become extremely bad and harmful if the will, which is to make use of these gifts of nature and which in its special constitution is called character, is not good. (Kant, 1785/1959, p. 9)
Although universality and impartiality are features of Kantianism, Kant’s theory suggests both that “the virtues [a good will] are objectively good,” which is a central claim of virtue ethics (Oakley, 1998, pp. 90-91). The other tenet of Kant’s ethical theory is deontological, that is, right actions are governed by a set of obligatory duties or commands. According to Callahan (1999), Kant’s absolute duty to avoid killing and suicide parallels the Judeo-Christian sanctity of life principle. In a passage resembling both Plato and the Catholic law tradition on suicide, Kant states:

We have been placed in this world under certain conditions and for specific purposes. Thus, suicide opposes the purpose of his creator; he arrives in the other world as one who deserted his post; he must be looked upon as a rebel against God. (Kant, 1775/1980, p. 154)

However, Kant does not argue that divine retribution or any other consequence of suicide provides grounds for its prohibition. For Kant (1785/1959), the sanctity of life is grounded not on God’s will or natural law, but rather on what Kant refers to as the categorical imperative, which is the moral law. Kant (1785/1959) distinguishes a categorical imperative, which is a command that must be followed without exception and with the right motive, regardless of the consequences, from a hypothetical imperative, which is a command that impels the requisite action for achieving a valued end. Kant (1785/1959) states the categorical imperative in several different ways, which are meant to be actionably equivalent. Two of the more frequently quoted versions are as follows,

Act only according to that maxim by which you can at the same time will that it should become a universal law. (Kant, 1785/1959, p. 39)
Act so that you treat humanity, whether in your own person or in that of another, always as end and never as a means only. (Kant, 1785/1959, p. 59)

The first statement of the categorical imperative indicates that morality must be made universal and impartial, i.e., treating like cases alike without exception. The second statement points to the centrality in Kant’s theory of general respect for human dignity as well as respect for individual persons as autonomous—willful—agents who are both moral agents and objects of moral consideration (Beauchamp & Walters, 2003, pp. 14-17; Neumann, 2000; Glover, 1999). Kant deduces from the categorical imperative that suicide and killing of innocents is immoral. Suicide is forbidden since the destruction of one’s self is an instance in which one is using one’s self as a means only, i.e., as a self-killer, rather than as an end in itself. Death, which is the unimaginable annihilation of reason and good will, from which all morality is derived, cannot be an end for moral beings. Suffering and happiness, both of which are consequences of being alive, are irrelevant to moral duty.

First, according to the concept of necessary duty to one’s self, he who contemplates suicide will ask himself whether his action can be consistent with the idea of humanity as an end in itself. If, in order to escape from burdensome circumstances, he destroys himself, he uses a person merely as a means to maintain a tolerable condition up to the end of life. Man, however, is not a thing, and thus not something to be used merely as a means; he must always be regarded in all his actions as an end in himself. Therefore, I cannot dispose of man in my own person so as to mutilate, corrupt, or kill him. (Kant, 1785/1959, p. 47).

Although the Christian, Jewish, and Islamic traditions have had, in general, a long history of opposition to suicide, there have been notable exceptions among Christian
thinkers. The Catholic philosopher, Thomas Moore, in *Utopia* (1516/1949), argued that in an ideal society, suffering, terminally ill patients would be provided assisted suicide and euthanasia. As it happens in Moore’s imaginary city-state of Utopia, following “the advice of the priests, who are interpreters of God’s Will,” dying Utopians can choose suicide by starvation or “with the aid of an opiate, die painlessly” (Moore, 1516/1949, p. 57). Although suicide is generally disdained in Utopia, voluntary suicide for the dying is considered to be virtuous and respectable. Utopians are never forced to commit suicide and, if they are not interested in suicide, they continue to receive care. *Biathanatos* (1608/1984) was the first broad and explicit defense of suicide written in the English language (Donne, 1608/1984, p. xii). In *Biathanatos*, Donne (1608/1984) argues, in contrast to the absolutism of Christian doctrine, that suicide is not necessarily sinful or otherwise inconsistent with God’s design or the laws of nature. By way of analysis of numerous cases of suicide among historical figures as well as characters from the bible and other literature, Donne argues that God gave mankind reason, which should extend to the control of the timing and manner of one’s death. Donne’s reasoning on suicide was shared by many Enlightenment philosophers, among them David Hume.

In his essay, *On Suicide* (1777/1993), Hume expresses his belief that suicide can be voluntary, rational and morally permissible. Hume rejected the prevailing absolutism of Christian doctrine, which considered suicide to be a mortal sin, and points to important reasons why autonomously chosen suicide can be both morally permissible and compatible with religious faith (Frey, 1999; Urofsky, 2000). Hume argues that the rejecting suicide on religious grounds is based not on reason, but on superstition and
misunderstanding of God’s design. Voluntary suicide is not an affront to our duty to
God, nature, or society, and those who commit suicide need not fear any sort of divine
retribution in the afterlife. Hume also suggests that the prohibition of suicide is not
necessary to public health and safety, as people are naturally averse to death under all but
the most extreme conditions. Hume finds it appropriate that some people, even those
who today would likely be diagnosed with mental illness, when confronted with dire
circumstances will conclude that committing suicide is the right thing to do. For Hume,
like the Stoics’ wise man, the permissibility of suicide ultimately rests on the individual’s
preference for death over an unbearable life.

That suicide may often be consistent with interest and with our duty to
ourselves, no one can question, who allows that age, sickness, or
misfortune may render life a burden, and make it worse even than annihilation. I believe that no man ever threw away life, while it was
worth keeping. For such is our natural horror of death, that small motives
will never be able to reconcile us to it; and though perhaps the situation of
a man’s health or fortune did not seem to require this remedy, we may at
least be assured, that any one who, without apparent reason, has had
recourse to it, was curst with such an incurable depravity or gloominess of
temper as must poison all enjoyment, and render him equally miserable as
if he had been loaded with the most grievous misfortunes. (Hume,
1777/1993, p. 201)

This brief historical survey of attitudes towards the ethics of suicide and
assistance in dying suggests that the essential ethical positions have changed little over
the centuries. The sanctity of life and possibility of redemption and enlightenment
through suffering as well as the potential for abuse of euthanasia is repeatedly countered
by the demand for individual autonomy and the right to avoid unnecessary and useless
suffering. However, while ethical arguments may remain fairly consistent, the legal and
medical contexts that accompany death and dying in the United States have changed considerably.

PAS and Euthanasia: The Modern Context

Jessica Mitford in *The American Way of Death* (1963), a humorous and critical look at the funeral industry in America, argued that the business of death in America was made possible by the desire of modern Americans to deny death and avoid serious thought on the subject of death and bereavement. Funeral industry euphemisms like “grief therapy” (the cost of a funeral), “cremains” (the remains of a cremation), “eternal slumber” (death), and “slumber room” (the room in which the corpse is viewed) all exemplify the effort of Americans and the American funeral industry to avoid the uncomfortable topic of death.

Elizabeth Kubler-Ross’s *On Death and Dying* (1969) used the framework of psychoanalytic theory and presented five stages of dying that began with denial and ended with acceptance. In so doing, Kubler-Ross introduced many readers to the emotional and psychological needs of the dying and the bereaved. Kubler-Ross argued that denial of death was the result of a mostly unconscious defensive avoidance mechanism, which, although a natural response to the ever-present possibility of annihilation, could and should be overcome with therapy and insight in order to improve the dying process. Kubler-Ross (1969) states:

> When we look back and study old cultures and people, we are impressed that death has always been distasteful to man and probably always will be. From a psychiatrist’s point of view this is very understandable and can

23
perhaps best be explained by our basic knowledge that, in our unconscious, death is never possible in regard to ourselves. (p. 2)

*On Death and Dying* was not an ethical argument about euthanasia or PAS.

Kubler-Ross, a long-time advocate for hospice and palliative care for the dying, has never advocated euthanasia and has claimed that none of her patients requested euthanasia once death had been accepted (Singer, 2000). Although neither text deals with the issue of PAS or euthanasia, the popularity of *On Death and Dying* and *The American Way of Death* among the American public and critics alike suggests that there was a growing interest in the 1960s in confronting and understanding death and dying. Renewed interest in death and dying probably evoked interest in suicide and euthanasia.

The politicization of PAS and euthanasia in the United States during the period following World War II derived from popular interest in death and dying and patients’ rights. The broader civil rights movement of the 1960s was driven by the same concerns for personal freedom and autonomy (Glick, 1992, p. 76; Urofsky, 2000). In the 1960s and 1970s, a culture of individual autonomy, demanding new “rights” for Americans, sought to change laws that govern the body (see Foner, 1998 for a study of manifestations of freedom that surfaced prominently in 1960s America). This liberalism of the body extends to the rights of women to choose safe and legal abortion and the rights of the hopelessly ill to have some control over the manner of their deaths (Wald, 1996, pp. 82-84). Glick has suggested that the phrase “right to die” surfaces prominently during the 1960s and that “right to die laws,” advanced care directives, “do not resuscitate orders,” slow codes, passive euthanasia, withholding and withdrawing extraordinary means of life
support reflect the evolution of other civil rights in the post war period in the United States. The patients’ rights movement of the 1960s essentially sought choice and control for patients, more honesty and information from physicians so that patients could make informed choices about their treatment, an end to gender and racial discrimination in health care and a return to the premodern concept of treating the patient as a whole person with particular needs and desires rather than as a disease to be conquered by the latest technology (Wald, 1996).

A related development was the introduction of hospice care in the United States. In 1963, a new palliative therapy for terminally ill patients, called hospice care, now common throughout the United States, was first introduced at the Yale University Medical Center by British pioneer in the field, Dr. Cicely Saunders (Wald, 1996). Hospice is a technique for dying well that entails using a variety of therapies, either in an institutional setting or at the patient’s home, to provide physical and emotional comfort for the terminally ill patient without necessarily rendering the patient unconscious or stupefied. The success of hospice care may signify a victory for patients’ rights activists and a further extension of freedom because patients can choose how they die to a certain degree. However, the new liberalism of the body and ethic of care for the dying does not enable the terminally ill to control the precise time of their death. Only suicide, assisted or otherwise, or active euthanasia can do this.

In order to understand how a renewed interest in death could become a need for a “right to die,” an expression that began to be used widely in the 1960s, it is necessary to
consider the modern medical context of dying and, in particular, the role of technology in the dying process.

How We Die

The legal and medical context in which death occurs has altered considerably since the beginning of the twentieth century. Medical interest in euthanasia and suicide to end the life of a suffering patient existed in the eighteenth and the nineteenth century. By the end of the nineteenth century, physicians possessed both the skills and the means with which to bring permanent relief to terminally ill patients (Vanderpool, 1997). Debate over the morality of physician induced death or euthanasia ensued for much of the nineteenth and the twentieth century, and, at the same time, euthanasia societies formed in Europe and the United States. Unlike many modern counterparts, these societies focused largely on the needs and demands of dying rather than the practice of medicine per se. Euthanasia societies probably reached the height of their popularity during the years immediately preceding World War II, but faded after the holocaust when the euthanasia policies of Nazi Germany became widely known.

With the discovery and invention of effective analgesia and anesthesia came controversy over the use of these substances in euthanasia and end of life care. Vanderpool (1997) explains that the physicians who founded the American Medical Association in 1847 accepted the role of what would be called comfort care providers today. However, physicians also believed that they had the responsibility to use all the means at their disposal to extend life. Physicians "wrestled with a question that continues
to plague modern medicine: By what means and to what extent should the physician try to prolong life?” (Vanderpool, p. 36). Thus, the dual role of the physician as the source of lifesaving technology and knowledge and as the comforter to the dying can be contradictory and has always been a part of modern medicine in the United States.

Fanu (2000) notes that “[t]he history of modern medicine starts sometime in the 1830s, when a few courageous physicians acknowledged that virtually everything they did—bleeding, purging, prescribing complicated diets—was useless” (p. 3). At the beginning of the twentieth century, the average life expectancy for Americans was 46 years. The typical American died at home, not always with an attending physician, and usually surrounded by family members. A physician or a pharmacist might have provided some palliative measures, usually in the form of an opiate drug. Until 1906, when narcotic control legislation was enacted, pain relief medication was often self-prescribed (Vanderpool, 1997, p. 34). Before the invention and widespread use of antibiotics such as penicillin in 1941 and vaccines such as the Salk polio vaccine that are commonplace today, people who were gravely ill would often decline rapidly. Death was frequently caused by secondary infections, sepsis, and pneumonia: "Less than fifty years ago there were relatively few serious illnesses that health care professionals could effectively treat, let alone cure" (The Hasting Center, 1987, p. iii). Fanu (2000) further states:

The history of medicine in the fifty years since the end of the Second World War ranks as one of the most impressive epochs of human achievement. So dramatically successful has been the assault on disease that it is now impossible to imagine what life must have been like back in 1934, when death in childhood from polio, diphtheria and whooping
cough were commonplace, when there were no drugs for tuberculosis, or schizophrenia, or rheumatoid arthritis, or indeed for virtually every disease the doctor encountered; a time before open-heart surgery, transplantation and test-tube babies. These and a multitude of other developments, have been of immeasurable benefit, freeing people from a range of illness and untimely death, and significantly ameliorating the chronic disabilities of aging. (p. xv)

In the 1960s, the new technologies that were employed to extend human life altered the context of death and dying in the United States. By 1970, the developed countries of the world were experiencing an "epidemiological transition" that has led to the "Age of Delayed Degenerative Diseases" that radically changed public health (Battin, 1996, p. 178). Parasitic and infectious diseases are rarer. Improvements in sanitation and in public health in general have changed the way people typically die in the developed world. Relatively rapid deaths from infection are no longer the norm. Chronic, degenerative diseases that require long-term care have become, more often, the cause of death (Webb, 1997, p. 33). In 2001, the average life expectancy in the United States was 77.2 years (CDC, 2004a). Many people are living longer because of the advances and benefits of modern medical technology that can sustain the life of the very ill for longer periods of time than ever before. According to Peterson (2001), “over the next several decades, countries in the developed world will experience an unprecedented growth in the number of their elderly and an unprecedented decline in the number of their youth (p. 458). Between 1950 and 2000, the elderly population of the U.S. (65 years of age or older) grew at twice the rate of the total population (CDC, 2003, p. 7). The elderly population grew from 8% of the population in 1950 to 12% in 2000, while the percent under 18 years of age declined during the same period from 31% to 26% (CDC, 2003, p. 7).
While the overall population growth rate in the U.S. is projected to decline, the aging trend is projected to continue when the baby boom generation reaches 65 in 2011 (CDC, 2003, p. 7). According to the Centers for Disease Control (2003), the increase in the elderly population of the U.S. means that “there will be more elderly Americans living longer, many with chronic health conditions or functional limitations” (p. 4). Extending life with the modern medicine chest often means extending suffering as well, and the final days of life for the patient can become painful and undignified (Englehardt, 1996, pp. 341-354).

According to the Centers for Disease Control, in 2001, 72% of all deaths in the United States occurred in a hospital, a medical center or a nursing home, 23% of deaths occurred in a residence (CDC, 2004b). According to a report by the advocacy group Last Acts (2002), in the United States, although more than 70% of Americans say that they would prefer to die at home, approximately 24.9% of all deaths occur at home (p. 13). Dying at home today is the exception and not the rule because long term and chronic illnesses require long-term care, which is often unavailable for patients who wish to remain in their homes. According to Last Acts (2002):

Where people die—and what kind of end-of-life care they receive—may be less of a reflection of their wishes and more influenced by local doctors’ practice habits, the availability of hospice services and the proportion of open hospital beds in the community. People use hospice earlier in the course of their illness if they live in areas that have more hospital beds, more hospice services and more general practitioners. They are less likely to die in hospitals if they live in areas where nursing homes and hospices are more available. Patients’ preferences are often not the deciding factor in where they die. (p. 23)
Modern diagnostic technology contributes further to this phenomenon. People can be diagnosed at relatively early stages of disease and consequently can receive medical treatment for a long time. Many diseases that advanced rapidly in the past now can be managed for extensive periods of time before death occurs. HIV and AIDS, heart disease, Alzheimer's disease, diabetes and many types of cancer fall into this category. The dying experience is longer today than in the past and it is also more complicated. Many patients will undergo intensive, invasive and expensive treatment at the end of their lives. For some patients, the extended care may be a burden rather than a blessing. Further, the dying patient may be subjected to considerable loss of autonomy in such situations, as stated in Englehardt (1996):

Technologies that extend our lives and postpone death underscore the need to decide when to accept death and prolong life no longer. They raise the ancient questions of whether and when individuals should take their own lives or be aided in the commission of suicide. (p. 341)

It is ironic that exhaustive and sometimes futile medical practices that prolong the dying process may also be a way for professional health care providers and their patients to avoid the legal and ethical responsibilities of making difficult end-of-life decisions. Englehardt (1996) further argues that the notion that physicians should extend life at all costs and by any means necessary is a relatively modern phenomenon and without historical precedent. Only since the advent of modern medical technologies and the culture that evolved around these technologies has prolonging life at all costs been standard procedure.
End-of-life care and critical care are part of a broader health care culture with rules and cues that influence the conduct of patient and physician. Both patients and physicians may share responsibility for the problem of too much or overly aggressive treatment. An unreflective reliance on technology can function as an avoidance mechanism for both patient and caregiver. Technologies have changed the cultural perception "of human illness with all its intricate physical, social, emotional, and cultural aspects to the biological problem of disease" (Cassell, 1996, p. 179). Health care, in this light, becomes a mechanistic practice, the clear and simple goal of which is to harness the appropriate technology and cure the disease. Cassell suggests that this goal simplifies the role of both patient and caregiver because of the combination of "wonder and wonderment" and "the lure of the immediate" (p. 181). Wonder and wonderment describes the often irrational belief that problems can be solved if only the latest technology and the smartest physicians were available. Technology also offers immediacy insofar as computer generated imagery and the skilled handling of medical devices facilitates an immediate response to the problems of the infirm. Cassell suggests that technology can become a barrier to good patient care because of the incongruity of the simplicity of the machine and the complexity of the patient. Immediacy and wonder are problematic because the cultural and psychological parameters of illness are too complex for automated responses that are governed solely by technology, particularly at the end of life. Cassell is not suggesting that technology be abandoned, but that technology can be a way to avoid and obstruct honest and clear communication between patient and caregivers.
Another important component in the modern experience of dying that illustrates the role of technology and culture in medical practice is prognostication. In *Death Foretold*, Christakis (1999) argues that physicians may neglect or avoid predicting the outcome of fatal diseases. The problem, according to Christakis, is not so much that physicians are unable to predict outcomes with a high degree of accuracy, but rather that modern physicians are unwilling to make predictions and unable to communicate effectively with their patients so that they fully understand all the important details of their options for treatment and care. Modern physicians have come to avoid prognostication:

> Both consciously and subconsciously they [do] not want to deal with its unpleasant aspects or to think about it because they [want] to deceive themselves about their ability to change the future. But they also [avoid] it because they [want] to deceive themselves about death, as if in not predicting it, they could avoid causing it or witnessing it. (Christakis, 1999, p. xii)

Put simply, evidence suggests that physicians do not like to tell their patients that they are going to die soon and that there is nothing more that can or should be done to prolong their life. Christakis (1999) suggests that the broader culture of medical knowledge combined with modern life sustaining technologies as well as patients’ own denial also influence the physician. This failure to communicate may lead patients to seek and often receive painful, expensive and futile treatment rather than accepting palliative care and dying comfortably with some degree of control over the manner of their death. The fear of painful and ultimately futile therapy as well as indignity and loss of control are commonly expressed in explanations that patients give for requests to die.
Incomplete or unclear information may exacerbate these fears. Thus, the modern propensity to avoid clear and precise communication about the dying process may lead to more demand for assisted dying.

Byock’s (1997) recounting of his experiences with critically ill and dying patients as an emergency physician in a teaching hospital during the 1970s serves to illustrate the role of technological thinking in modern medicine and how this thinking can lead directly to patient requests for PAS and euthanasia:

In the teaching hospital death was always treated as a problem . . . . A strong presumption throughout my medical career was that all seriously ill people required vigorous life-prolonging treatment, including those who were expected to die, even patients with advanced chronic illness such as widespread cancer, end stage congestive heart failure, and kidney or liver failure. It even extended to patients who saw death as a relief from suffering caused by their illness. (p. 27)

Byock (1997) also describes an experience with a family that brought their dying father to the hospital's emergency room despite the fact that they were aware that he was not suffering and that any medical intervention would be futile. They had brought their father to the emergency room because they thought that it was illegal to allow a family member to die at home rather than in a hospital. The story reveals that many dying people and their families are part of a culture that has learned to believe that there are no alternatives to dying in a hospital environment. However, according to Byock, it is this pervasive cultural ignorance of the needs of the dying that leads to an interest in PAS and euthanasia rather than technology per se. In other words, technological approaches to death and dying, like the euphemistic language of the funeral industry, can serve as
avoidance and ignorance on the part of health care professionals, which do a disservice to
dying patients who need physical and emotional support.

Emanuel (1994) argues that public interest in PAS and euthanasia is not linked
with advances in medical technology. He bases his argument on the fact that euthanasia
and PAS have been debated and practiced since ancient times and have been of interest to
physicians since the discovery of ether and other anesthetics and analgesics such as
morphine. Further, the arguments both for and against euthanasia in the nineteenth
century are virtually identical to contemporary arguments. In 1906, an Ohio bill to
legalize euthanasia was defeated after 35 years of heated debate. Emanuel points to the
physician's role in the overall culture as an influential factor in determining public
interest in the issue. That is, public interest in euthanasia increases when the authority of
physicians is challenged. However, Emanuel, in his dismissal of medical technology,
may be overlooking the fact that medical technology could be a crucial factor influencing
medical decisions and may be linked to challenges to the authority of physicians.
Physicians may be guided more by what they can do for their patients than by what they
should do for them. Patients may fear that physicians will let technology determine the
course of treatment, which in turn can lead the patients to challenge medical authority.

A study by Singer, Martin, Levery, Kelnor and Mendelssohn (1998) that
documents opinions of patients who are critically ill, but have not requested assistance in
dying, suggests that patients are afraid of a protracted, painful death and do not want to
be kept alive in a persistent vegetative state. Participants in the survey were suffering
from a range of illnesses and included patients with HIV infection, patients undergoing
kidney dialysis, and patients in long term care facilities. The participants claimed that they only wanted life sustaining technology if there was a chance for recovery and a reasonably normal life.

Choosing PAS

As it was for philosophers and theologians, the possibility of a rational request to die is a contentious issue for present day medical professionals. Part of the policy debate about PAS and euthanasia will concern who should decide and by what criteria, and what, if any, requests to die are rational. As will be shown in the next chapter, legal arguments in the United States, which are generally based on the assumption that there is a liberty interest in PAS, require that a rational decision to die be realistic. However, some physicians and psychiatrists do not believe that an expressed desire for PAS would exist if patients received adequate palliative care and psychological counseling. Whether such a view is based entirely on objective clinical criteria rather than a covert attempt to deny any autonomy-based ethical argument for the moral permissibility of PAS is difficult to determine. Nonetheless, evidence suggests that palliative measures and psychological care can deter some but not all patients from requesting an assisted death.

Why do gravely ill patients want to die and what can be done to control this desire? The loss of autonomy, the desire for control over the circumstances of one’s death, the inability to engage in enjoyable activities, becoming a burden on caregivers and family, the loss of a personal sense of dignity and the futility of suffering for no apparent reason are the most common reasons that patients give to explain their desire to
seek medical assistance in dying (Byock, 1997; Sullivan, Hedberg & Fleming 2000; Webb, 1997; Wineberg & Wirth, 2003). According to Admiraal (1996b), empirical evidence suggests that the most important physical causes of suffering in terminally ill patients that may lead to requests to die are loss of strength, shortness of breath, nausea and vomiting, incontinence, and pain (pp. 116-117).

A narrative approach to conveying the reasons that some patients choose to seek PAS was conveyed in the story of Diane’s suicide, assisted by Timothy Quill, published in the *New England Journal of Medicine* in 1991, and later reprinted in Quill’s (1993) *Death and Dignity*. Quill has since become an important advocate for legalizing PAS. Diane was diagnosed with acute myelomonocytic leukemia. With a combination of painful and expensive therapies administered immediately after diagnosis, including a series of chemotherapy treatments, radiation and a bone marrow transplant, it was estimated that Diane had a 25% chance of survival. Without treatment death was certain within months of the diagnosis. Diane chose to refuse treatment. According to Quill:

She remained very clear about her wish not to undergo chemotherapy and to live whatever time she had left outside the hospital. As we explored her thinking further, it became clear that she was convinced she would die during the period of treatment and would suffer unspeakably in the process (from hospitalization, from lack of control over her body, from the side-effects of chemotherapy, and from pain and anguish). Although I could offer support and my best effort to minimize her suffering if she chose treatment, there was no way I could say any of this would not occur. In fact, the last four patients with acute leukemia at our hospital had died very painful deaths in the hospital during various stages of treatments (a fact I did not share with her). Her family wished she would choose treatment but sadly accepted her decision…. I had her repeat her understanding of the treatment, the odds, and what to expect if there were no treatment. I clarified a few misunderstandings, but she had a remarkable grasp of the options and implications. (pp. 11-12)
Quill accepted Diane’s decision and arranged for her hospice care. Diane also requested that Quill prescribe barbiturates, following the method recommended by Humphry (1985) and the Hemlock Society. After a conversation with Diane, Quill wrote her a prescription:

It was important to me to know how she planned to use the drugs and to be sure that she was not in despair or overwhelmed in a way that might color her judgment…. [T]he security of having enough barbiturates available to commit suicide when and if the time came would leave her secure enough to live fully and concentrate on the present. It was clear that she was not despondent and that in fact she was making deep personal connections with her family and close friends. I made sure that she knew how to use the barbiturates for sleep, and also that she knew the amount needed to commit suicide. (Quill, 1993, pp. 13-14)

Quill goes on to tell the story of Diane’s final months, which according to Quill were “intense and important” for Diane. Diane’s health eventually declined to the point where she chose to commit suicide alone in her bedroom after saying her final goodbyes to her husband. The cause of Diane’s death was reported as acute leukemia rather than suicide because assisted suicide was illegal. Quill argues that PAS can be an appropriate response to terminal patients who wish to control the time and manner of their death.

Byock (1997), a leading advocate for hospice care, is against PAS and concludes that PAS is unnecessary when the dying process is handled properly by both the patient and the caregiver. Byock suggests that, in fact, the expressed desire on the part of the patient for PAS or euthanasia should be understood as a sign that the patient is not receiving adequate palliative care and emotional support. In effect, Byock does not accept the idea of a reasonable request to die. Byock blames the failure on the American
medical culture that does not adequately attend to the special needs and requirements of
dying patients. Physicians are not trained adequately in palliative care, pharmacists are
hesitant to carry the necessary analgesics, and insurers do not want to pay for hospice and
other forms of comfort care. Byock's argument suggests that the context of end of life
care is the principal reason that patients request PAS and euthanasia. Byock argues that
changing the context of end of life care by ensuring that all patients receive adequate
palliative care and that the patient's psychological needs are met will result in fewer
requests for PAS and euthanasia. Byock’s argument against PAS and euthanasia places
demands upon the dying that they may not want to meet. Byock, in effect, offers a
 secular version of the Judeo-Christian notion that all innocent human life is good and that
there is potential for value, dignity and enlightenment in suffering the final stages of a
painful, protracted death. Byock also suggests that patients dying from a protracted
illness must learn to accept care because both the patient and caregiver benefit from being
allowed to care for a dying loved one:

Caring for a dying loved one is a powerful way to express love, devotion
and reverence. Allowing a spouse or grand child to care for one becomes
a final gift from the person dying. The physical acts of caring can help
family members in their own grief. (p. 160)

Loss of control over bodily functions and the inability to engage in activities that were
once enjoyable, which in turn, leads to experiencing a loss of one’s sense of dignity appears to be
a major reason that people request assistance in dying. According to Hammer (2000), “the desire
for control is understandable, the important question is what type of control is appropriate and
how that control can be manifested” (p. 263). However, Hammer suggests that the loss of
control is inherent to the dying process, and our definition of dignity must change as dying proceeds. Hammer, like Byock, is, in effect, arguing that dying people must learn to accept loss of control. Hammer (2000) suggests that redefining dignity and delimiting the appropriate level of control over end of life care will improve the dying process while maintaining what Hammer refers to as a “reverence for life,” which does not sanction suicide:

Participation can help people distinguish those parts of dying that are controllable from those that are not and help them to accept the inevitable loss of control they have over their bodies and existence. Dying must involve an appropriate combination of taking charge and letting go, engagement and resignation.

Just as the desire for control requires a balanced understanding of what can and cannot be influenced, so the desire for dignity requires an understanding of different forms of dependence. (p. 263)

Hendin (1997), a psychiatrist, surveyed the Dutch experience with physician aided dying and concluded that both patients and physicians were being subtly coerced into choosing suicide over palliative care. Hendin suggests that the toleration of euthanasia in the Netherlands has created an environment in which the medical culture fails to interpret subtle signals from patients. These signals can mean that the patients are incapable of making rational decisions because they are depressed and anxious for a quick solution to their troubles. Hendin, like Byock (1997), believes that rational suicide is unrealistic and that the desire to commit suicide can be ended with counseling and adequate palliative care in virtually every case.

Muskin (1998), a psychiatrist, offers a middle ground in the clinical debate about rational suicide. Muskin argues that many but not all patients who request assistance in dying are suffering from pain, depression or inadequate social support, much of which
can presumably be ameliorated with better care. Muskin offers empirical evidence that suggests that depression and lack of social support are more highly correlated with a request to die than pain (1998, p. 323). However, Muskin is not emphatically against the notion of the possibility of a rational suicide and he does not believe that physicians should automatically turn down a request for PAS, but that a request for PAS should be met with a professional evaluation of the patient’s emotional state. Muskin acknowledges that psychodynamics, anxiety and depression may play a role in a request for PAS, but that physicians who automatically reject patient requests for PAS may actually be harming the patient insofar as such a response may signify to the patient that the physician does not accept that the patient’s experience is valid and that the patient’s request is rational. An automatic “no” answer can serve to cut off further communication between the physician and patient (Muskin, 1998, p. 327). Not all patients who request PAS should be allowed to receive it:

Not every request for physician-assisted suicide indicates complex unspoken dynamics, but that cannot be known until physician and patient talk. The request for suicide may be found to be “rational” but not until there has been an adequate exploration of its meaning. The willingness of a physician to enter into such a dialogue is not without an emotional impact on the physician, but it is what is required if physicians are to appropriately respond to such requests. (Muskin, 1998, p. 327)

Characteristics of patients who died after ingesting a lethal dose of medication legally prescribed by a physician under Oregon’s Death with Dignity Act and interviews with their family members and physicians show some of the reasons for requesting to die (Ganzini et al., 2000; Sullivan et al., 2000). In 1998, 73% of patients who died with PAS were enrolled in hospice care immediately before death and in 1999, 78% of patients
were enrolled in hospice care immediately before death. All but one had insurance
coverage for both years (Sullivan et al., 2000, p. 600). In their analysis of PAS in
Oregon, from 1998 through 2001, Wineberg and Wirth (2003) conclude that:

Contrary to the fears of many, members of disenfranchised and disempowered
groups are not disproportionately using the Death with Dignity Act, according to
the official statistics reported by the State.

Similarly, it is of great importance that the desire for PAS does not appear
to be inversely related to quality of end-of-life care. There has been speculation
that improved care near the end of life would eliminate the desire and need for
PAS; however, this does not seem to be the case for the vast majority of people
who have died under the Death with Dignity Act. Most of the participants were
receiving hospice care and all of them were living in the state that, arguably, has
the best end of life care in the country. (p. 514)

In the Netherlands, hospice care is widely available for all at no cost to patients
(Admiraal, 1996b). However, Ganzini et al. (2000), report that two-thirds of requests for
PAS and euthanasia in the Netherlands are rescinded, presumably after palliative
interventions. Further, Ganzini et al. found that, in Oregon:

Substantive interventions by the physicians led many patients to change
their minds about assisted suicide. However, some patients who wanted to
obtain a prescription were very determined to do so, despite palliative
interventions. (p. 562)

The role of depression in influencing the desire for PAS is unclear. Ganzini et al.
(2000) found that physicians suspected depression in 20% of requests for PAS in Oregon,
but found that 93% of patients were mentally competent to make an informed choice (p.
559). However, many physicians in Oregon expressed doubts about their ability to detect
depression. Treatment of depression with medication had a limited effect on patients
seeking PAS. Only 11% of patients who received medication to alleviate depression or
anxiety changed their minds about PAS (Ganzini et al., 2000, p. 562). According to
Wineberg and Wirth (2003), analysis of reports from nurses, physicians and social workers in Oregon suggest that depression can sometimes influence a patient’s decision to seek PAS, but the data overall “contribute to a conclusion that desire to have PAS is not necessarily a product of depression” (p. 512).

Families of patients reported in 2000 that the concerns that were important factors in the patients’ decisions to end their lives were (1) loss of control of bodily functions (68%), (2) loss of autonomy (63%), (3) inability to participate in activities that make life enjoyable (47%), (4) burden on family, friends, or other care givers (47%), pain and physical suffering (40%), and (6) expense of treating end-of-life issues (5%) (Sullivan et al., 2000). Of course, these concerns are interrelated. Physical suffering, loss of autonomy, including “the feeling of being trapped by the disease,” and the inability to enjoy life were all features of many terminal illnesses. The ability to choose the time and manner of their death and the belief in the futility of suffering throughout their remaining time when death was imminent was also important to patients who died with PAS. While the Sullivan et al. study is limited to two years and a total of only 43 patients, the data suggest that patients may have rational reasons for their requests to die and that hospice care, health insurance and the social support of family and physicians will not prevent all imminently dying patients from desiring PAS or euthanasia. Statistical surveys and subjective narrative accounts of the contemporary dying process in the United States provide us with similar insights about the reasons that some people seek assistance in dying. The fear of being kept alive under intolerable circumstances is causing many Americans to think seriously about the level of dependence on medical technology with
which they are willing to live. Open dialogues between physicians and their patients about the dying process have been taking place more regularly. For Americans with access to health care, options have increased and palliative care has improved. As we have seen from empirical surveys of the Dutch and Oregon experiences, even with improvements in end of life care, there remains a persistent demand for assistance in dying.

Method

This dissertation will use Q methodology to measure and analyze the moral and political positions of various actors who have an interest in the issue of physician aided dying. The population studied is comprised of health care professionals, legal professionals, members of the clergy and religious orders, social workers, caregivers, ethicists, the aged and infirm, all of whom comprise the primary decision making group for end of life issues. A survey of the policy preferences of this primary decision making group with regard to legislation for or against physician assisted dying and the enforcement of such legislation is also included. The relationship between the Q factors and policy preferences revealed by the survey may provide a link between ethical positions and policy preference. The design for this study was reviewed and accepted by the Kent State University Human Subjects Review Board in 1999. All participants in this study signed a consent form explaining the study and their role in it. The full text of the consent form is in Appendix D.
CHAPTER 2
THE POLICY CONTEXT

In the United States, the legalization of PAS has been sought in state legislatures, state and federal courts, and through ballot initiatives. In this chapter, the history of public policy concerning PAS in the United States will be reviewed. McKhann (1999) states that “the inexorable changes that are taking place in our society and its medical needs” make it inevitable that laws will be enacted to deal with assisted dying (p. 224). However, the fact that some Americans will, against their expressed wishes, experience a protracted and miserable death does not mean that physician assisted dying will become a legally sanctioned course of action in the United States anytime soon. Many ethicists, theologians, and professional medical organizations like the American Medical Association have resisted the legalization of PAS or euthanasia in the United States and elsewhere (Hillyard & Dombrink, 2001; also see American Medical Association, 2002). Traditional religious views about the sanctity of innocent human life persist. A commitment to public safety seems to influence all policy decisions that involve PAS and biomedical issues in general, but with PAS, many other interests are evident as well. Beyond public safety, the courts and policy makers must balance powerful sectarian and secular commitments to the sanctity of human life, the integrity of professional healthcare, the lobbying power of professional health care associations and disability advocacy groups.
Public Interest

No serious discussion of policy debates surrounding PAS and euthanasia can avoid the problem of potential abuse. Opponents of legalized PAS and euthanasia point out that under certain circumstances, some patients may avoid alternatives to suicide. These opponents claim that if PAS or euthanasia were legally and clinically acceptable practices in the United States, it could prove difficult to protect patients with treatable depression or cognitive impairments from impulsive decisions or even subtle coercion. Patients could be subtly coerced to seek PAS or euthanasia, perhaps because of their reluctance to become burdens to their families. Financial difficulties also may have a coercive effect on the dying, particularly since there are so many Americans who lack adequate health insurance. In 1994, the New York State Task Force on Life and the Law published a report warning that legalized PAS and euthanasia could cause great harm to certain individuals. The report states:

The risk of harm is greatest for the many individuals in our society whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, advanced age, or membership in a stigmatized social group. The risk of legalizing assisted suicide and euthanasia for these individuals, in a health care system and society that cannot effectively protect against the impact of inadequate resources and ingrained social disadvantages, would be extraordinary. (New York State Task Force on Life and the Law, 1994, p. 120)

The European Association for Palliative Care (EAPC) issued a report in 2003, which also points out the risks involved in legalizing PAS and euthanasia. According to the report:

If euthanasia is legalized in any society, then the potential exists for: (i) pressure on vulnerable persons; (ii) the underdevelopment or devaluation
of palliative care; (iii) conflict between legal requirements and the personal and professional values of physicians and other healthcare professionals; (iv) widening of the clinical criteria to include other groups in society; (v) an increase in the incidence of nonvoluntary and involuntary medicalized killing; (vi) killing to become accepted within society. (Materstvedt et al., 2003, p. 98)

A major concern of opponents and skeptics of legalized PAS and euthanasia is that PAS and euthanasia will lead to a lack of interest in and resources dedicated to improving end of life care. Another concern is that physicians may be pressured to compromise their ethical principles in order to serve their patients who request assistance in dying. Worse still is the fear that assisted dying may desensitize society to its aversion to killing innocent people, which in turn can lead to the lawful killing of undesirable individuals or even populations (Brock, 2001). This is a component of the slippery slope argument. Frey (1998) suggested that slippery slope based moral arguments are a mainstay in our "ethical landscape" and have been used as the basis for arguments covering a wide array of moral issues (p. 43). McKhann (1999) summarized the slippery slope argument as follows:

Legalization of voluntary assisted dying, which in itself might be harmless, would be followed by nonvoluntary euthanasia, involving patients whose current personal desires could not be evaluated. From there it would be a short step to involuntary euthanasia, where death was forced upon people who understood perfectly well what was going on and did not want to die. This process could be expanded in any direction, to eliminate the incompetent, the elderly, people with disabilities, racial minorities – any group that society deemed an unwanted burden. (p. 179)

However, Brock (2001) suggests there is no reason to assume based on available data that people are more likely to be coerced into PAS than to voluntarily forego life support, which is rare but not without precedence (p. 69). Brock (2001), referring to
research by Emanuel and Battin (1998), suggests that “the savings would be negligible and insufficient to create strong incentives, for example within managed care plans, to pressure patients to accept physician-assisted suicide” (p. 70).

Smith (1999), an attorney for the International Anti-Euthanasia Task Force, uses the slippery slope argument when he points out that legalization of PAS in Oregon has changed the criteria for which PAS may be legitimately used. PAS is now sought by those with uncomfortable conditions as well as unlivable conditions. After reviewing the first year of PAS cases under the Oregon Death with Dignity Act, Smith (1999) concluded that the recipients of PAS had opted for PAS not because of unbearable pain, but for what in Smith’s view are lesser medical conditions, such as incontinence, loss of control of bodily functions, and loss of personal autonomy.

Slippery slope arguments often raise the specter of Nazi death camps or other cases in which a policy of euthanasia is actually a euphemism for state sanctioned murder (McKhann, 1999; Singer, 2000). According to Singer, "for fifty years Adolf Hitler has cast a long and dark shadow over discussions of euthanasia. His shadow still persists, to the extent that every time euthanasia is debated, the slippery slope appears beneath our feet, and the Holocaust lies at the bottom of it" (p. 201). Nazi Germany and other regimes that have had policies of destroying whole nations of people based on their religion, race, ethnicity, disabilities, sexual orientation or political ideology have rationalized their killing by deeming these people not worthy of life. Lifton and Marcusen (1990) have referred to such policies as genocidal projects that, in their view, demand a total ideological, psychological and spiritual commitment on the part of the
architects and perpetrators of such projects. According to Lifton and Marcusen, the Nazi doctors at the Auschwitz concentration camp who tortured and murdered prisoners in their "experiments" generally believed that what they were doing had therapeutic value to themselves and the Nazi regime. Nazi ideology held that German society had suffered from defeat, humiliation, weakness, and general malaise, which could only be ameliorated by the sometimes unpleasant but necessary procedure of destroying the contaminating elements of society (Lifton, 1986; Glover, 1999). Thus, the Nazi doctors’ mission was effectively incorporated into the mission of the entire Nazi regime, which came to act on the belief that killing undesirables would heal Germany at the societal level (Lifton, 1986). However, Glover (1999) suggests that for the Nazis, killing was more than just a means to the desirable end of societal improvement. Nazi ideology also incorporated a variant of Kantian deontology (one that, as Glover points out, would have appalled Immanuel Kant), which made torturing and killing an absolute duty and concern for the suffering of others a moral mistake.

There is a side of Kant to which the Nazis could claim a sort of adherence: the emphasis on obedience to rules for their own sake. Kantian rules are supposed to be generated purely rationally, in a way that is independent of their impact on people. And they should be obeyed out of pure duty, rather than out of any sympathy for people. For Kant, to act out of any sympathy for others is to act on a mere inclination rather than out of duty, and so to do something without moral worth. The Nazis produced a grim variant of this austere, self-enclosed morality. (Glover, 1999, p. 357)

It is not clear that Nazi Germany provides the appropriate context to establish an association between assisted dying and the slippery slope problem. The Nazis established a brutal totalistic state combined with a complex and elaborate array of
bureaucratic procedures, public officials, publicists, propagandists and medical professionals involved in genocidal projects (Lifton, 1986). The Nazi state imposed a wide range of restraints on both political and moral opposition that might have limited its brutality (Glover, 1999). In a comparatively open democratic society like the United States, it may be possible, and even likely, that with appropriate safeguards in place, the kinds of abuses that occurred in genocidal regimes like Nazi Germany can be prevented. Brock (2001) argues that the climate of rights and protections of patients that has evolved in the United States has constructed a “formidable bulwark against movement down the feared path” towards the erosion of protections for patients against medicalized killing (p. 72). A case study more appropriate than Nazi Germany for cautionary advice about slippery slopes and euthanasia would probably be the Netherlands, a modern industrial democracy, which openly practiced PAS and euthanasia for 25 years or so before legalization, and about which there is a great deal of available data as discussed in the previous chapter. The Netherlands policy on assisted dying is certainly not without its critics, but clearly, there has been no slide down the slippery slope into genocide as a consequence of legalized assisted dying.

Singer (2000) suggested that Nazi ideology, which held that there were certain lives that were not worthy of life, must be distinguished from the belief that certain lives are not worth living (p. 203). According to Singer, courts and policy makers in many countries have determined that certain lives are not worth living. According to Winkler (1995), in modern medicine
We have abandoned the idea that life is always a benefit to its possessor. On the contrary, the continuation of life for a patient in a permanent vegetative state for example, does not serve the patient’s interest. Therefore, death, for such a patient, may itself be seen as a benefit. (p. 323)

Legal decisions that allow withdrawal of artificial life support and the harvesting of organs from persons in persistent vegetative states and that allow women to abort fetuses with severe mental retardation or other birth defects support this view.

Determining whether a life is worth living can be morally problematic, but is nonetheless routinely done in medical practice and law. Lavi (2001) argues that there has been a marked change since 1985 in the rationale used to determine and measure quality of life with respect to end of life policy. From 1976 until 1985, state supreme courts addressed the legal permissibility of withholding or withdrawing respirators and other life sustaining medical treatments of terminally ill patients, incompetent patients or patients in permanent vegetative states (PVS) “on the basis of the principle of self-determination as expressed by the patient or his surrogate in cases in which the patient could not express his own wish” (p. 142). According to Lavi, based on his analysis of the 1985 New Jersey Supreme Court decision in *In the matter of Conroy*, there has been a shift from concern about the subjective wishes and desires of the patient to concern about an objective measurement of a reasonable and humane threshold for a patient's pain and discomfort behind such legal decisions. Lavi maintains that in recent decisions, the courts have routinely utilized a deceptively "simple calculus of pain," which involves an assessment of the patient’s suffering. In this way, a kind of cost benefit analysis determines when a patient’s suffering has reached an unbearable level. Within this legal framework, it has
been determined that under certain conditions, a life is too painful to be worth living. In most cases, three basic principles guide the court’s decision. These principles are the following: pain is measured by intensity and is understood primarily as a bodily sensation, pain and pleasure are opposites, pain is to be diminished, and pleasure is increased and life is worth living only when the balance of pleasure outweighs the balance of pain (Lavi, 2001, p. 143).

Adding complexity to the concern over potential abuse is the fact that PAS and euthanasia are practiced both in clinical settings by medical professionals and by unlicensed practitioners. In other words, assisted suicide and euthanasia are common practices that occur regardless of the law. For example, in a survey of the attitudes of 228 physicians in the San Francisco Bay area about using PAS for patients infected with the HIV virus, Slome, Mitchell, Charlesbois and Abram (1997) found that 53% of the physicians surveyed had, at some time, granted the request of a patient for PAS and they had done so an average of 4.2 times. Slome et al. (1997) also concluded that acceptance of PAS among physicians had increased between 1990 and 1995. In a survey of 355 oncologists, Emanuel (1994) found that 53 had participated in “clearly defined” euthanasia or PAS under illegal or unclear legal circumstances. Shavelson (1995), a physician and journalist, reported several cases of euthanasia and PAS performed by unlicensed “freelance” euthanasia providers as well as by licensed physicians. Shavelson also noted that freelance euthanasia was prominent within the gay community in the San Francisco Bay area. Shavelson writes about the case of a partially paralyzed stroke victim in his fifties who committed suicide with the help of a "free-lance" euthanasia
provider. The president of a local chapter of the Hemlock Society and a student of Derek Humphry's popular and controversial manual on suicide and euthanasia, *Final Exit* (1991), the euthanasia provider had an apparently compulsive desire to help people die. The euthanasia provider and the patient formed a kind of symbiotic relationship. There have also been well-documented cases of freelance euthanasia providers in the San Francisco gay community who help people dying from AIDS to commit suicide.

Why is there a need to legalize PAS and/or euthanasia when physicians can help people to die, regardless of existing laws? Haber (1996) suggests that keeping PAS medicine's "poorly kept secret" is a violation of patients' rights and harms the physician-patient relationship. If PAS is illegal, physicians cannot be held accountable to their patients. Keeping PAS a secret facilitates self-deception and violates the basic principles of honesty, integrity, and full disclosure between physicians and patients. Those who seek assisted dying from unregulated nonprofessionals may face many other types of abuses such as coercion from others, unnecessary pain and discomfort, botched attempts or inadequate psychological and emotional support.

**Autonomy**

The potential for abuse of legalized PAS and euthanasia must be weighed against the ethical principle of autonomy and the related legal argument that people have a liberty interest in legalized PAS and euthanasia. Autonomy also must be weighed against the principle of avoiding killing, which states that intentionally killing an innocent person is always wrong. Autonomy-based arguments have been central to legal and ethical...
decisions regarding end of life care, PAS, and euthanasia. Beauchamp (1986) describes respect for personal autonomy as follows

The autonomous individual is capable of deliberations and of actions based on such deliberations. To respect such self-determining agents is to recognize them as entitled to their considered evaluations and view of the world, even if it is strongly believed that their evaluation or their outlook is wrong or even potentially harmful to them. To grant such persons a right is to say that they are entitled to autonomous expression without external constraint. It follows that to show a lack of respect for an autonomous agent is either to show disrespect for that person’s deliberative choices or to deny the individual the freedom to act on those choices when such interference would affect in important ways the person’s present and future interests. (p. 80)

With respect to the selection of end of life care options autonomy can be understood to be associated with practical features of individual free will. Kane (2002) suggests that free will from a practical and subjective standpoint evokes in people the feeling of “up to us-ness” when they act (p. 5). According to Kane (2002)

We feel it is “up to us” what we choose and how we act; and this means that we could have chosen or acted otherwise…. This “up to us-ness” also suggests that the origins of our actions are in us and not in something else over which we have no control—whether that something else is fate or God, the laws of nature, birth or upbringing, or other humans. (p. 5)

Kane (2002) points out that against the notion of free will are conflicting views on human activity referred to as doctrines of determinism or necessity. These various doctrines consider free will to be subsumed by forces that we cannot control such as physical forces, divine will, social conditioning, unconscious motives and other automatic psychological processes, inherited genetic traits or biochemical processes involving hormones and neurotransmitters (Kane, 2002). Debates over free will may influence the degree to which respect for personal autonomy can be utilized to determine
the available options for medical treatment. Arguments based on the principle of personal autonomy stress that, within limits, it is up to individuals to make their own decisions about their medical treatment. Thus, autonomy can be defined as self-determination, in contrast to coercion. According to Brock (1993), respect for self-determination has instrumental value as it can serve the patient’s well-being, the determination of which, under normal conditions, is for the most part subjective, i.e., up to the patient (p. 31). Respect for patient self-determination also has intrinsic value as an ideal of respect for the patient as a person “who is capable of determining and taking responsibility for his or her destiny” (Brock, 1993, p. 32). In the context of end-of-life care, autonomy requires complete disclosure from physicians about the prognosis of an illness and relevant health care options. The failure to have a clear and accurate exchange between patient and physician can obstruct the ability of patients to make autonomous decisions (Brock, 1993).

The doctrine of informed consent and the right to refuse unwanted medical procedures are ethical and legal principles that reflect respect for autonomy and patient self-determination (Veatch, 2003; Brock, 1993). However, PAS and euthanasia are procedures that can require that the autonomy of an individual other than the patient be compromised. Physicians must be involved in PAS and euthanasia at many levels. The experience in the Netherlands and Oregon suggests that any policy sanctioning PAS and euthanasia would be based on strict guidelines and qualifications that must be met before a person may be aided in dying by a physician. Among these guidelines is the requirement that physicians involved in assisted dying must make assessments of their
patients’ level of suffering and psychological state and use these assessments to
determine if their patients may receive assistance in dying. This can be a determination
that many physicians do not feel qualified to make regardless of the informed consent of
the patient. According to Calahan (1999)

The doctor would have to decide, on her own, whether the patient’s life
was “no longer worth living…” Euthanasia is thus no longer a matter
only of self-determination, but of a mutual, social decision between two
people, the one to be killed and the other to do the killing. (p. 382)

Whereas there is general agreement among ethicists, physicians, and legal
scholars that respect for autonomy supports the permissibility of letting patients die under
prescribed circumstances through omissions, there is disagreement as to whether respect
for autonomy can lead to the right to PAS or euthanasia. There is also disagreement over
the value of the distinction between omission and commission, otherwise known as the
active-passive distinction.

According to Veatch (2003), respect for autonomy understood in light of the
ethical and legal distinction between omissions and commissions leads to the following
premise

Letting die at the request of the patient surrogate is always required by
respect for autonomy. By contrast, autonomy never requires that a
physician kill a patient. Autonomy is an ethical principle requiring the
noninterference with the life plans of others. It does not require that one
facilitate those plans. (p. 94)

Tannsjo (2002) suggests that the active-passive distinction is really derived from
“linguistic intuitions,” which is to say that our actions are active, if we describe them as
such. According to Tannsjo (2002)
Each concrete action can be described in some way which makes it active…. And killing is indeed another example of this. There are clear-cut cases of active killing and there are clear cut cases of passive killing (of allowing nature to take its course). No criterion can be formulated here, I submit, but no criterion is needed. Our linguistic intuitions are clear enough. In particular situations we can say of an act of killing if it is active or passive, and we can state our reasons for this assessment (although these reasons cannot always take a quite general form).

(p. 62)

Winkler (1995) considers such linguistic distinctions between active and passive actions or intended and foreseen consequences, which in effect presume distinct psychological states, to be dubious. According to Winkler (1995)

Unless we postulate incredible stupidity on the part of the agent, we cannot make sense of this separation of psychological states because we cannot conceive enough causal separation between what is said to be intended and what is said to be merely foreseen. (p. 324)

Legislation that distinguishes between killing, which is commission, and letting die, which is omission, has a long and established history in Western law and ethics and the controversy over this distinction is at the core of the legislation debate (Neeley, 1996; Quill, Lo & Brock, 2003). Physicians who want to help their patients die more comfortably often cannot do so without the doctrine of the double effect and the passive-active distinction, if they do not wish do break the law. However, according to Glover (1999)

One question about the doctrine of the double effect is about how to decide whether the consequences of an act are intended and which are merely foreseen. One possible test is whether the consequences in question are wanted. . . . A more demanding test is that you still intend even unwanted consequences if they are so close to the act as to be inextricable from it. . . . There is a problem of how close or how inextricable actions and consequences have to be for consequences to
count as intended. What reasons can there be given for drawing the boundary in one place rather than another, and what is the moral case for regarding the boundary as so important? (p. 108)

Actions and consequences become inextricable when action causing death is the only available means to prevent the consequence of remaining alive, which is further suffering. Kuhse (1999) refers to the argument that there is a significant moral difference between intending death (deliberately killing) and foreseeing death (letting die) as the “Moral Difference Myth,” that supports the essentially religious ideal of the sanctity of innocent human life (p. 255).

According to Kuhse (1999)

Both the intended and foreseen consequences of an agent’s action share a feature which any system, such as the law, concerned with assigning responsibility for prohibited consequences, must treat as crucial: that the agent could have refrained from bringing the prohibited consequence about, but nonetheless chose to bring it about. (p. 260)

According to McKhann (1999) there is little difference between euthanasia and letting a person die by withholding or withdrawing life sustaining treatment because in both cases "death is central in both intent and result" and that the common practice of terminal sedation is really "a backdoor to euthanasia" (p. 101).

According to Frey (2001), in cases of withdrawal of food and hydration, physicians are actively helping their patients commit suicide, and therefore, to refer to withdrawal as passive and PAS as active is a matter of arbitrary linguistic determination since in both withdrawal and PAS, the physicians’ actions are causally equivalent and thus morally equivalent.
What is not true is what opponents to physician-assisted suicide want in this case, namely, that the doctor be held to be neither legally or morally responsible for the patient’s death because they want to hold that this act of withdrawing feeding tubes is not a cause of the patient’s death. For starvation only gets into a position to kill the patient as a result of the feeding tubes being withdrawn. There is no difference between the withdrawal and lethal medication cases on this score: if the doctor withdraws feeding tubes, if he prescribes the pill, he is a cause of death….

Withdrawal of feeding tubes is not an alternative to physician-assisted suicide, so far as causality is concerned. The doctor takes the essential step involved in enabling starvation to kill his patient. To say in the pill case that the doctor also takes an essential step in enabling his patient to kill himself does not show any causal difference between the withdrawal and pill cases. (Frey, 2001, p. 52)

In addition, according to Quill, Lo and Brock (2003) voluntarily stopping eating and drinking (VSED) has disadvantages over PAS and euthanasia:

VSED may last for weeks and may initially increase suffering because the patient may experience thirst and hunger. Subtle coercion to proceed with the process may occur if patients are not regularly offered the opportunity to drink, yet such offers may be viewed as undermining a patient’s resolve. (p. 253)

Neeley (1996), a legal scholar, and other legal scholars, physicians, ethicists and "right-to-die activists" argue that the traditional distinction between omission and commission is unconstitutional, unethical, and impractical in a clinical setting. The right to be free from unwanted medical intervention is a negative right associated with the right to privacy. Neeley argues that the correct reading of case law and the Constitution demands a positive right to PAS and euthanasia. According to Neeley (1996), under current conditions

At best, the individual could request medication for relief of pain while refusing nourishment or other medical treatment until he eventually succumbs to his disease or starvation. Forcing persons to stay alive against their wishes and best interests—even if only for a short period of
time—is not optimally humane and violates the right to personal autonomy, which lies at the heart of the Constitution. (p. 22)

Frey (1998) argues that the active-passive distinction, regardless of its merits, is the "dividing line universally drawn in the literature" of end of life ethics and law (p. 27). This dividing line, although challenged in federal courts, has been maintained by law in the United States. Brody (1993) suggests that the failure of the active-passive distinction “does little to illuminate what public policy ought to be on physician-assisted suicide or active euthanasia” (p. 112).

Dworkin (1993) argues that the constitutional protection that guarantees the liberties of a patient in end-of-life care coincides with an ethic of autonomy. However, arguing that there exists a moral right to PAS and euthanasia based on the principle of autonomy is not the same as arguing that the right to PAS and euthanasia is a constitutionally protected right. In order to guarantee the right to PAS, a court would have to agree that the protection of the right to make difficult moral choices in private outweighs the state’s need to protect society as a whole from suicide and the potential abuses of legal euthanasia.

The Legislature

PAS and euthanasia can be characterized as morality policies (Mooney, 2000; Glick & Hutchinson, 2001). Morality policies are policies that reflect, and to some extent define, the moral values of a society (Mooney, 2000). Morality policies can lend themselves to a high level of public involvement because they provoke intense moral controversies and vigorous debate. Morality policies can involve many types of issues,
but they tend to center on questions of deeply held values that are often rooted in religious doctrine. Morality policies include policies that deal with issues such as when life begins, gay and lesbian rights, or whether individuals have the right to assistance in dying. Like other morality policies such as abortion and gay and lesbian rights, debates over PAS and euthanasia often elevate questions of good, evil and sin over cogent analysis of the effectiveness of the policy, and, in so doing, there is little room for compromise among contending viewpoints (Meier, 1994; Mooney, 2000).

Blank (1988) argues that the federal legislature is "not designed to handle the kinds of issues raised by biomedical technology" (p. 15). Congress is often too slow to recognize policy issues and even when an issue gets on the policy agenda, Congress is slow to act. Not recognizing the policy issue is only one of the barriers to effective biomedical policy. Federal and state legislators may be aware of contentious biomedical issues like PAS, but will nonetheless tend to avoid issues like assisted suicide and euthanasia that generate complicated ethical arguments and require a high level of moral reasoning. Further, election pressures tend to persuade legislators at both the state and federal levels to avoid controversial issues "that may trigger single-issue group action against them" (Blank, 1988, p. 16). Proffered opinions on biomedical issues do not necessarily follow political party lines. Most of the laws regulating death and dying are state laws that vary from state to state. However, state legislators, pressured by interest groups and the potential for harmful publicity, have been reluctant to go against the political consensus and to support laws that legalize PAS and euthanasia.
State-wide Initiatives

Mobilization of citizen based issue advocacy groups can be especially important in determining policies like PAS and euthanasia. However, policies that involve conflicts over deeply held values and morality are seldom resolved, even when one group succeeds with passing new legislation because the opposition often remains mobilized in order to seek its repeal (Mooney, 2000). Regardless of public officials who seem to avoid addressing assisted dying, the issue is still important to advocacy groups like the Hemlock Society and Choice in Dying as well as many voters, physicians and their patients. Left without any viable alternative to change the legal status of PAS and euthanasia, voters in several states have turned to the statewide initiative and referendum process for public policy-making. Several states, including Washington in 1991, California in 1992, Oregon in 1994, Michigan in 1998, and Maine in 2000, have attempted to pass state-wide referenda for legalization and regulation of both PAS and euthanasia. In 1991, two right to die advocacy groups, the Hemlock Society and Citizens for Death with Dignity, pushed successfully to get Issue 119, the first of its kind in the United States, on the ballot in Washington. Issue 119 was to enable physicians to administer lethal injections to their terminally ill patients legally. A number of precautions were written into Issue 119 that were designed to prevent abuse and were consistent with the Hemlock Society's general policy approach to physician aided dying. The media were used to communicate emotionally charged messages from interest groups on both sides of the issue. Issue 119 failed by 46% to 54%, but its popularity
encouraged the Hemlock Society to try a similar ballot initiative, also unsuccessful, in California (Hillyard & Dombrink, 2001, p. 53).

The only state that has succeeded in passing a ballot initiative for legalizing PAS is Oregon. The Oregon policy, called the Oregon Death with Dignity Act, or Measure 16, passed in 1994 with 52% of the vote, but was not implemented until 1997 because of legal challenges in court (Battin, Rhodes & Silvers, 1998, p. 327). In 1997, voters in Oregon voted against the repeal of Measure 16 by 60% to 40% (Battin et al., 1998). In March of 1998, the first patient received physician assistance to suicide in Oregon under the new legal guidelines. The Oregon policy is limited only to PAS as defined in chapter 1, and contains several safeguards designed to prevent abuse. Under the Oregon Measure 16, patients must be fully informed of their diagnosis, prognosis, risks associated with the prescribed drugs and feasible alternatives such as hospice and palliative care. Patients must also make two oral requests, 15 days apart from each other and a written request at least 48 hours before receiving a prescription. Patients also have an opportunity to rescind the request at any time. Physicians that prescribe lethal medication under the Death with Dignity Act must be licensed in the state of Oregon (Hillyard & Dombrick, 2001).

As with other public policies, the route to legal PAS through public initiatives is contentious. According to Tolbert (2001):

In the U.S. context, states with the initiative process have a built-in mechanism for increasing citizen participation in politics and policy-making. Groups, citizen and economic, can place a policy question on the state ballot through the initiative process without delays or legislative intermediaries. State legislatures under direct legislation threats are also more likely to adopt proposed legislation. The
initiative process, or the threat of pending circulating initiatives, is often necessary to translate citizen preferences into policy, especially over the resistance of powerful economic interests, such as the tobacco or car insurance industry. The process is often used to adopt policies resisted by elected officials, corporate interests and established political parties, but supported by a majority of the public. (p. 38)

Blank (1988) thinks that, in general, public initiatives are problematic because they are costly and may end up shifting the burden of making complicated ethical choices from the legislature to an ill informed public. Another concern is that the more democratic public initiatives are something of a last resort and may not be the best forums for developing policy concerning complex and morally charged issues like PAS and euthanasia (see Waters, 2001). The public is also affected by pressure from media campaigns funded by interest groups. This type of pressure is expensive and the interest groups with the most money to spend often have the advantage (Garett & Gerber, 2001; Tolbert, 2001). Interest group pressure certainly has played a role in the defeat of public initiatives to legalize PAS, particularly in California and Washington. In California, the California Medical Association (CMA), the Roman Catholic Church and the National Conference of Catholic Bishops used a variety of tactics to campaign successfully against the passage of a public initiative called the Humane and Dignified Death Act that would have legalized euthanasia (Hillyard & Dombrink, 2001). Moreover, a policy adopted by public initiatives may not have benefited from the required expert knowledge needed to meet ethical guidelines. Once passed, public initiatives cannot be amended though they may be repealed or held unconstitutional (Qvortrup, 2001). However, this was not the case with the Oregon Death with Dignity Act (1995) that has passed constitutional
muster. Jacob (2001) suggested that citizens are capable of making good public policy through the initiative and referendum process, but legislators are resistant to the process. Jacob claimed that legislators caught in a “power struggle” with citizen groups try to “silence, not enhance usage” by regulating the initiative process in order to retain control over the public policy-making process (p. 97).

The demand for public initiatives that would legalize and regulate PAS could be an indicator of the public's demand for access to safe, legal PAS. Officially, the state of Oregon has not reported any problems with PAS but the policy is still contentious. Advocacy groups on both sides of the issue appear to be dissatisfied with the Oregon policy. The Hemlock Society considers the Oregon Death With Dignity Act to be a step forward, offering more legal options to patients than any other state does, but prefers a more comprehensive approach to medically aided dying that will be applicable to patients for whom PAS is not possible. The anti-PAS advocacy group for people with disabilities, Not Dead Yet, considers the Oregon policy to be a dangerous step down the slippery slope to coerced suicides and involuntary euthanasia.

The Right to Die and the Courts

A similar lack of expertise to that found in policy by public initiative is also found in policy derived from decisions made by judges who are inexperienced or ill-informed about biomedical matters (Blank, 1988). Blank suggested that judges should either be more capable of dealing with scientific matters or, alternatively, less willing to make policy about issues they do not adequately understand. The courts are primarily
responsible, by default, for making biomedical policy because other branches of government fail to do so. In the matter of PAS and euthanasia, the courts are usually approached by interest groups or patients seeking PAS and/or euthanasia and physicians who wish to avoid prosecution under pre-existing criminal statutes (Urofsky, 2000). The result of a series of lower court and United States Supreme Court decisions has been the maintenance, in law, of the official position of the medical community in the United States that accepts the validity of the passive/active distinction, allowing the withholding or withdrawing of life support when death is imminent, but not allowing PAS or euthanasia.

There is no part of the United States Constitution that explicitly guarantees a right to die, nor, for that matter, is there a specific definition of the concept of rights in the Constitution. Several Supreme Court decisions have been based, in part, on the interpretation that the Constitution guarantees the right to privacy and this interpretation has been expanded to include the right to refuse medical treatment. A notable case in this matter is *Union Pacific Railroad v. Botsford* (1891), a personal injury case in which the Supreme Court decided not to force the plaintiff to submit to a pretrial physical examination against his wishes. According to the precedent set in this case, the United States Constitution guarantees the right of privacy in medical matters that in effect means being left alone, free from unwanted medical intervention (Clark, 1997, p. 39). Through a series of court decisions based on common-law rules of self-determination and the constitutional right to privacy, this right was further expanded to include the doctrine of informed consent (Urofsky, 2000, pp. 54-55). According to this doctrine, patients have
the right not only to refuse medical treatment but also to be provided with adequate information about other available options so that they can make rational decisions about their medical treatment.

Another important and well-documented court case that strengthened the right to privacy is *Griswald et al. v. Connecticut* (1965) (O'Brien, 1996, p. 312). In this case, the Court ruled that states could not prohibit the sale of contraceptives to married couples. In *Roe v. Wade* (1973), one of the more famous decisions, the Court ruled that states could not prohibit a woman from having an abortion. Both of these cases strengthened the right to privacy, based on the First, Fourth, Fifth and Fourteenth Amendments to the Constitution (Clark, 1997; Dworkin, 1993).

Arguably, the most important case in the modern history of end-of-life law in the United States is *Quinlan v. New Jersey* (1976). Other cases dealing with situations that were similar to *Quinlan* were seldom heard by the Appellate Court, and therefore, did not set legal precedent (Meisel, 1998, p. 235). In March 1976, the New Jersey Supreme Court decided that Joe and Julia Quinlan could remove their 21 year old comatose daughter, Karen Ann Quinlan, from a respirator. Karen Ann had been in a persistent vegetative state since April 1975, probably as a result of a combination of alcohol and three common prescription drugs. Karen Ann Quinlan had stopped breathing for an unknown period of time and as a result, she sustained severe brain injuries without any chance of recovery. She continued to live in a comatose state until 1985 because her physician did not remove her respirator abruptly to allow her to die quickly, but instead slowly weaned her from her respirator so that she was able to resume breathing on her
own. The question posed and answered by *Quinlan* is to what extent and to what end should life saving technology be used to prolong life and who decides? *Quinlan* initiated an extensive public debate in the United States about end-of-life decisions and broke the mantle of secrecy surrounding discussion of issues that were previously either taboo or occurred so infrequently that public discussion and debate were not required.

*Quinlan v. New Jersey* (1976) represents "a paradigm shift" in end-of-life case law for many reasons (Meisel, 1998, p. 236). *Quinlan* sets a legal precedent that enables physicians to withdraw extraordinary means to keep a patient alive in a persistent vegetative state. Although earlier Court decisions had an influence on end-of-life decisions, *Quinlan* is the first case that deals specifically with the issue of omission and the distinction between passive euthanasia (omission) and active euthanasia (commission). Omission of treatment by withholding or withdrawing life-sustaining or life-supporting technology does not subject physicians to criminal liability but active euthanasia is illegal in every state. The *Quinlan* decision is based on the right to refuse treatment as part of the constitutional right of privacy established by the Fourteenth Amendment and the common-law notion of informed consent that has been incorporated into medical case law since 1956 (Webb, 1997).

*In re Quinlan* (1976) and other similar cases that followed would determine the rights of patients who are too incapacitated to give informed consent to the refusal or withdrawal of unwanted medical interventions. *Quinlan's* influence extends to advanced care directives and do-not-resuscitate (DNR) orders. DNR orders and unwritten "no codes" have become common practices in hospitals and long-term care centers (Blank,
Proposals for formal advanced directives had begun in 1969, but the momentum for nationwide acceptance of advance directives was not feasible prior to the legal precedent established by the *Quinlan* case (Urofsky, 2000, pp. 54-55). By 1992, advance directives had been accepted in some form by every state legislature and the District of Columbia.

*Cruzan v. Director, Missouri Department of Health* (1990) is another important case in the history of end-of-life law. Nancy Beth Cruzan was in a persistent vegetative state (PVS) as a result of a car accident and required a feeding tube inserted in her abdomen to stay alive. The parents of Nancy Cruzan petitioned the courts to allow the feeding tube to be removed in order to end Nancy’s life, but the State of Missouri refused the request. The request was denied because the court claimed that the family did not have enough evidence to show that the removal of the feeding tube was what Nancy Cruzan would have wanted. The decision was upheld by the United States Supreme Court. This case is significant because, based on the opinion of the Supreme Court, it is assumed that a competent person has a constitutionally protected liberty interest in having the right to reject life preserving measures. Although the *Cruzan* decision strengthened the liberty interest by affirming the right to be free of futile and unwanted medical intervention, the decision did not alter the common-law distinction between omission and commission that was affirmed by *Quinlan*, nor did the decision confirm a constitutional right to die.

In 1997, the Supreme Court upheld New York and Washington State laws that criminalize PAS. This was the culmination of two cases that sought to extend the right of
privacy to the right to PAS, based on the Fourteenth Amendment's liberty and equal protection guarantees. In *Quill v. Vacco* (1996), the Court of Appeals for the Second Circuit decided that because patients who were on life-support systems had the right to have their treatment discontinued, which would result in their deaths, those without such life-support systems should have the same option based on the equal protection guarantee in the Constitution. In *Vacco v. Quill* (1997), the Supreme Court by a 9-0 vote reversed the decision of the Court of Appeals for the Second Circuit.

In *Compasion in Dying v. State of Washington* (1996), the Ninth Circuit Court of Appeals decided that ending life by withdrawing life-support systems, affirmed in the *Cruzan* case, was equivalent to physician assisted suicide, and therefore there is an equivalent liberty interest in physician assisted suicide guaranteed by the due process clause of the Constitution. The conclusion of the court opinion in *Compasion in Dying v. State of Washington* stated that:

> There is one final point we must emphasize. Some argue that decisions regarding matters affecting life or death should not be made by the courts. Essentially, we agree with that proposition. In this case, by permitting the individual to exercise the right to choose we are following the constitutional mandate to take decisions out of the hands of government, both state and federal, and to put them where they rightly belong, in the hands of the people. We are already allowing individuals to make the decisions that so profoundly affect their very existence—and precluding the state from interfering into that critical realm. *(Compassion in Dying v. State of Washington, 1996)*

In *Washington v. Glucksberg* (1997), the Supreme Court in a 9-0 vote reversed the decision of the Ninth Circuit Court of Appeals. It was argued, albeit unsuccessfully by Rawls et al. (1997) in the Philosophers’ Brief of the *amici curiae* in *State of*
Washington v. Glucksberg and Vacco v. Quill (1997), that the opinion in Cruzan (1990) implies that there is a constitutionally protected right to choose the “timing and manner” of one’s death, which would override the state’s interest in preventing physician assisted dying:

If a competent patient has a constitutional right to refuse life-sustaining treatment, then, the Court implied, the state could not override that right. The regulations upheld in Cruzan were designed only to ensure that the individual's wishes were ascertained correctly. Thus, if Cruzan implies a right of competent patients to refuse life-sustaining treatment, that implication must be understood as resting not simply on a right to refuse bodily invasions but on the more profound right to refuse medical intervention when what is at stake is a momentous personal decision, such as the timing and manner of one's death. In her concurrence, Justice O'Connor expressly recognized that the right at issue involved a "deeply personal decision" that is "inextricably intertwined" with our notion of "self-determination." (Rawls, et al. 1997, p. 44)

In Vacco v. Quill (1997) and Washington v. Glucksberg (1997), the Supreme Court essentially opined that there is no constitutional right to suicide implied by Cruzan (1990) or any other case, for that matter, and that states are free to enact legislation to regulate PAS. By reversing the decisions of the two appellate courts, the Supreme Court maintained the validity of the omission and commission distinction and in so doing, also maintained the legal distinction between PAS and the withdrawal and withholding of life-sustaining treatment. However, the Court's decision did not prohibit states from allowing PAS and euthanasia as a matter of state policy. The general opinion of the Court was that the issues surrounding assisted dying should be decided in the state legislatures. The following statement by Justice Kennedy summarizes the view of the Court with respect to public policy:
This matter of defining a liberty…. is a question of ethics and of morals and of allocation of resources and of our commitment to treat the elderly and infirm. And surely legislators have much more flexibility and a much greater capacity to absorb these kinds of arguments and make those decisions than we do. You’re asking us in effect to declare unconstitutional the law of fifty states. (Washington v. Glucksberg, 1997; Vacco v. Quill, 1997, cited in Hilyard and Dombrink, 2001, p. 151)

Conclusion

Behuniak (1999) argues that the official position of the American Medical Association, many physicians, and American health care law experts had a greater impact on the decisions and the corresponding written opinions of the justices than the testimony of patients, families, physicians and right-to-die advocacy groups seeking a constitutional right to PAS. The differences in opinion between the appellate courts and the Supreme Court reflect the lack of consensus in the United States regarding PAS and euthanasia. “In the foreseeable future the debate about physician assisted suicide will be principally a moral and policy, not a constitutional debate.

The following is list of medical, legal and moral concerns over which the current lack of consensus with respect to the appropriateness of existing legislation covering PAS and euthanasia in the United States has settled for the time being.

The interest in public policy prohibiting PAS and euthanasia encompasses the following concerns and issues:

- Protecting the sanctity of innocent human life.
- Protecting those who may be suffering from depression or other mental illnesses from suicide and euthanasia.
• Protecting the ethics and integrity of the American medical profession.

• Protecting vulnerable groups such as the poor, elderly, and disabled from abuse and coercion.

• Protecting the chronically and terminally ill from neglect, and promoting a stronger interest in improving pain management and other forms of palliative care.

• Protecting the chronically and terminally ill and their significant others from the loss of the benefits of giving and receiving end of life care.

• Preventing the slide down the slippery slope from PAS and euthanasia to medicalized homicide.

The interest in legalizing PAS and euthanasia encompasses the following concerns and issues:

• Terminal sedation as well as withholding and withdrawing of life support and are morally and legally equivalent to euthanasia.

• In some cases, unbearable physical distress and suffering can only be alleviated by death.

• Choosing the timing of one’s death is an essential reflection of personal autonomy, which should be respected by the medical profession and the law.

• There is a liberty interest in physician assisted dying that is protected by the Constitution and implied by case law in the United States.
• As many as 1 in 5 physicians has assisted a patient in suicide, yet there has never been a successful prosecution in the United States of a licensed physician for PAS (see *Compasion in Dying v. State of Washington*, 1996). In addition, terminally ill patients can and do stockpile prescription pain medicine and tranquillizers in order to commit suicide. Physicians who write prescriptions for terminally ill patients are, in effect, knowingly and unknowingly, assisting their patients in suicide. Legalizing PAS and euthanasia with appropriate safeguards would improve the safety and comfort of terminally ill patients who intend to end their lives.

• Legalizing euthanasia in addition to PAS would enable patients who are too physically incapacitated to ingest lethal medication orally to have the same freedom to end their lives as those who can ingest lethal medication orally.

• Experience with euthanasia and PAS in the Netherlands suggests that PAS can result in complications that may require the help of an attending physician. Therefore, the option of euthanasia improves the safety and comfort of patients who wish to end their lives.

The interest in legalizing PAS, but not euthanasia encompasses the following concerns and issues:

• The experience with the Oregon Death with Dignity Act offers experimental evidence that a public policy, which allows PAS with
appropriate safeguards, can be effective without harming vulnerable populations.

- PAS offers a “conservative” middle ground between allowing euthanasia and prohibiting all forms of assisted dying, which protects the ethics and integrity of the medical profession, the safety of vulnerable populations and the autonomy of patients (Lee, 2003).
CHAPTER 3

RESEARCH DESIGN

PAS and euthanasia are clearly contentious, emotive, and provocative issues that generate a wide range of personal reactions and rigorous ethical arguments. Gutman and Thompson (1997) argue that bioethics has been built on conflict. Like other issues such as abortion, medical research using human subjects, and genetic engineering to name a few, physician assisted suicide and euthanasia are, and probably always were, contentious issues that have raised effective arguments both for and against. PAS and euthanasia are practices that provoke discourse on spirituality, autonomy, personal liberty, the value of human life, the authority to determine the disposition of our own bodies, the proper role for public policy and the correct conduct for physicians and other health care professionals. The subjective nature of the reactions to these end-of-life issues makes Q methodology an effective research tool with which to analyze, in a systematic and rigorous manner the perspectives of the participants.

Subjectivity is defined as “nothing more than a person’s communication of his or her point of view” (McKeown & Thomas 1988, p. 12). This study uses Q methodology, which Dryzek and Berejikian (1993) have called "the most fully developed paradigm for the investigation of human subjectivity" (p. 50). Q methodology has been used in other studies exploring subjective aspects of death and dying. Metzger (1979-80) used Q
methodology in a study of Kubler-Ross’s (1969) stage-theory of dying. Hurd (1999) used Q methodology to explore subjective understandings of death and dying in adults with childhood bereavement experiences. In a follow-up study, Hurd (2002) used Q methodology to explore the bereavement experiences, emotional support systems, and mutual interactions of two groups of adult sisters who had experienced the death of their father during childhood. Stephenson (1987; 1988) used Q methodology to explore the possibility of the scientific study of the psychology of ethics.

Q Methodology

In a Q study, participants are required to respond to a set of statements that “may involve innumerable possibilities of thought and feeling” (Stephenson, 1978, p.23). Participants rate this set of statements along a continuum to the extent they like or dislike them. The Q sorts are then factor analyzed. The term sample that is used in R methodology to denote the participants in a study is used in Q methodology to denote this set of statements, which in this study deals with PAS, euthanasia and other related issues. In a Q study, the participants are variables, not a sample chosen from a population (Brown, 1980). The theoretical considerations for the selection of the statements and the structure of the distribution do not impose any problematic restrictions on the outcome of the Q sort because an a priori meaning of a statement does not necessarily enter into Q sorting consideration (Brown, 1980). Participants are free to interpret statements in any way they see fit, and there are no correct or incorrect responses. The concourse, which is analogous to the population in R methodology, is the universe of conversational
statements in which the Q sample statements are selected (Brown, 1980). The concourse in this study consisted of a range of literature including published interview, judicial opinion and commentary, and formal philosophical treatments of the issues of PAS and euthanasia. In this way, the Q study “proceeds from definition of a concrete situation, to its concourse, and from this to a sample drawn from the concourse. With this a person represents his subjectivity by Q sorts” (Stephenson, 1978, p. 28).

The scientific study of the subjectivity of the participants in bioethical debates can inform the process of applying bioethical reasoning to public policy related issues. Q methodology is well suited for exploring the debate over PAS and euthanasia, which, like other bioethical issues, can lead to conflicts that cannot be resolved by referring to objective facts alone. Experience, logic, moral intuition, and emotion among other factors, also play a role in moral decision making. According to Brown (1980)

Wherever individuals are involved and can be expected to entertain viewpoints with respect to things going on around them, however subjective these viewpoints may be, Q technique and its methodology can illuminate in broad outline the major effects that are operating. (p. 58)

This is not to take the position that ethical reasoning is by nature inherently subjective, in the sense that ethics is entirely a relativistic matter of cultural mores, emotions or personal taste, even though this view, referred to as moral relativism, is commonly held (Baergen, 2001). However, even if moral relativism is rejected, there are many approaches to and elements involved in ethical reasoning that reflect diverse traditions with conflicting positions regarding right conduct, and this is especially the case with the ethical reasoning concerned with PAS and euthanasia (Baergen, 2001).
End of life issues like PAS and euthanasia typically invoke what Tannsjo (2002) refers to as practical questions. The answers to practical questions involve applied ethics (Tannsjo, 2002). When we want to know what to do about ethical problems in a practical situation, we ask practical questions and we apply ethical reasoning in order to answer them. Answers to practical questions are typically political as they indicate the right action to take in a practical situation and thus, they may indicate public policy problems and what to do about them. Practical questions and answers may indicate a need or desire for change in the ethics of a community and a concomitant mobilization of political pressure to that end or they may indicate a desire to retain the current status quo with respect to ethics and public policy. According to Toumlin (1950),

In any particular community, certain [ethical] principles are current—that is to say, attention is paid to certain types of argument, as appealing to accepted criteria of “real goodness”, “real rightness”, “real obligation”, etc. . . .

When it is recognized that the members of a community have a right to criticize the existing practices, a new phase in the development of ethics begins. (pp. 140-141)

Stephenson (1987) suggests that Q methodology can be effectively used to measure and analyze the subjective responses to ethics and moral problems. According to Tannsjo (2002), when we apply ethics “in order to gain knowledge about what to do in a practical situation, we need true or reasonable moral principles to apply to the case under scrutiny” (p. 4). From the subjective vantage point, the truth or reasonableness of ethics and moral principles can be exhibited as a measure of their subjective truth-value, which in Q methodology is an explicit measure of their relevance to the person doing the Q sort (Stephenson, 1987, 1988). According to Stephenson (1988), the truth-value of
morals and ethics is self-referent in nature and must be “discovered in psychological experience,” which is expressed in operant factor structures (p. 38). With Q methodology, it is possible to discover “how it is that ‘different moral principles’ have such different degrees of conventionality” (Toumlin, 1950, p. 143). The subjective psychological experience of ethical reasoning can also indicate subjective preferences for political action that follows from that experience. A physician who believes that PAS is a morally correct action probably would like it to be the case that public policy facilitates PAS or at least does not prevent PAS. According to Stephenson (1988), “Operant factors are decision structures, pointing to possible courses of future action. The essential matter is to look for discovery, not determinism, for answers to ethical problems” (p. 42). Q methodology can aid in the discovery of answers to practical ethical questions and indicate both divisive and consensual components of a public policy agenda with which to deal with these answers.

Concourse and Statements

A summary of the literature that influenced the design of the Q statements used in this study was provided by Fins and Bacchetta (1994). The theoretical framework for the design of the concourse was based on Fins and Bacchetta (1995), “Framing the Physician-Assisted Suicide and Voluntary Active Euthanasia Debate: The Role of Deontology, Consequentialism, and Clinical Pragmatism.” Fins and Bacchetta (1995) attempted to create a comprehensive classification scheme for their review of the literature on PAS and euthanasia. The literature on PAS and euthanasia has, of course,
burgeoned since 1995, but the initial framework has remained an effective basis upon which to organize the statements for this study. The framework used by Fins and Bacchetta (1995) and adapted to this study include three basic categories: (1) deontology, (2) clinical pragmatism, and (3) consequentialism (see Table 1). Each of the three basic categories is represented by 12 statements, making a total of 36 statements. These statements comprise the sample for this study. Although a systematic bias (pro or anti) was not included in the theoretical framework provided by Fins and Bacchetta (1995), in the present study, each of the three basic categories was evenly divided into six pro and six anti statements.

<table>
<thead>
<tr>
<th>(A) Deontology</th>
<th>6 (pro), 6 (anti)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(B) Clinical Pragmatism</td>
<td>6 (pro), 6 (anti)</td>
</tr>
<tr>
<td>(C) Consequentialism</td>
<td>6 (pro), 6 (anti)</td>
</tr>
</tbody>
</table>

Deontological ethics are based on the acceptance of an a priori duty or obligation that determines the rightness of our actions irrespective of the consequences of our actions. The intentions or will, derived by reason, intuition or whatever, of the moral agent are what determines the relevance of the action rather than the consequences (Honderich, 2003; Tannsjo, 2002). Thus, deontological ethics provide a basis for moral actions, which are non-consequentialist. Deontological ethics are expressed in terms of universal and invariant rules or maxims for right action (Boyle, 1998). Examples of
deontological ethical traditions in bioethics include Kantianism and the Catholic natural law tradition (Boyle, 1998). There are two types of deontological statements in the sample used in this study. The first type is based on both religious and secular concepts of duty that stress the intrinsic wrongness of killing (anti). This type of deontological arguments is reflected in the following Q statements that were used in this study.

(4) To attempt to deny the distinction between active euthanasia and allowing to die is mistakenly to impute more power to human action than it actually has, and to accept the conceit that nature has now fallen wholly within the realm of human control.

(7) We are not authorized to make comparative judgments about the worth of lives, or to cut short the years that have been given us.

(14) A decent society should favor preserving life even when things seem extremely bad, especially in view of the fact that suicide seems remarkably contagious. Highly publicized suicide can cause bandwagon effects.

(24) Euthanasia is an affront to our Judeo-Christian tradition, which places a consistent and primary emphasis on the supreme value of life.

(29) Although I empathize with the despondency that suffering creates for both patient and family, physician-assisted suicide are an evasion of moral duty.

(35) Euthanasia trespasses on the bounds of self-determination: Persons cannot consent to be killed.

The second type of deontological argument is based on the philosophical and legalistic concepts of duty arising from moral principles of liberty and personal autonomy (pro). The following statements were based on this type of argument.

(1) If at the heart of our constitutional rights is our ability to act on our deepest beliefs about life, then the right to suicide and the right to assistance to suicide are the prerogatives of every adult.
(12) Our body is our own, and our life should be subject to self-determination. We have then, the right to end our own life, and if we cannot accomplish this on our own, another person has a right to end it for us, as an act of compassion.

(18) Choice and control are distinctly human qualities.

(21) The patient’s values should form the basis for the regimen to treatment.

(27) People of faith have a right to follow their own creed, but they are not free to force their religious convictions on all the other members of a democratic society, and to compel those whose values differ with theirs to die painful, protracted and agonizing deaths.

(31) The suffering of a terminally ill person cannot be deemed any less intimate or personal, or any less deserving of protection from unwarranted government interference, than that of a pregnant woman. If the abortion choice is a fundamental constitutionally protected right, so too is the decision to commit suicide.

Respect for personal autonomy has been central to legal decisions involving end of life care, PAS, and euthanasia. Arguments based on the ethical principle of personal autonomy stress the right of individuals to make their own decisions about what physical treatments they receive. Autonomy can be defined as self-determination, as opposed to coercion. The moral principle of autonomy can be extended to allow individuals to choose assisted suicide and euthanasia. In health care settings, respect for personal autonomy requires full disclosure of relevant information so that patients can make informed decisions about their own course of treatment. As previously discussed in Chapter 2, personal autonomy is relevant to the framing of issues and the construction of public policy relating to the end of life. For example, under the Oregon Death with Dignity Act (1995), patients who request PAS must be informed about the availability of
alternatives to PAS such as hospice and palliative care. Although critics (Foley & Hendin, 2002) suggest that the Oregon Death with Dignity Act does not guarantee that patients will make fully informed decisions due to the possibility that physicians dispensing information may be ignorant about the management of the physical and emotional pain of dying patients, the basis of the requirement is respect for autonomy.

Consequentialist ethical arguments are based determining the rightness of an action after it has occurred. Consequentialist ethics judge an action based upon the effect of the action. According to Singer (2000),

Consequentialists start not with moral rules, but with goals. They assess actions by the extent which they further these goals. The best known, though not the only consequentialist theory, is utilitarianism. The classical utilitarian regards an action as right if it produces as much, or more, of an increase in the happiness of all affected by it as any alternative action and regards the action as wrong if it does not. (p.8)

Consequentialist arguments are concerned with slippery slope problems (anti), the proper role of the physician (anti and pro), the ability of the state to protect the lives of its citizens (anti) and the merciful relief of intolerable pain and suffering (pro). Fins & Bacchetta (1995) note that the bulk of the literature on both sides of the debate falls into the consequentialist category. In this study, the anti consequentialist arguments are represented by the following statements:

(6) If euthanasia were made legal, it would complicate the process by bringing in a whole new set of actors – prosecutors, police, and other agents of criminal law.

(10) The greatest danger is not that patients will be over-treated or their lives to long extended, but that socially burdensome patients – the poor, the elderly, and others without access to good health care – will become sacrificial victims on the alter of cost-benefit analysis.
(15) Good hospice care can relieve all unpleasant symptoms and remove any incentive to die.

(22) Legalizing physician-assisted suicide would mean that patients could never truly trust their doctors again.

(26) The doctor who has the authority to end life, even under carefully regulated conditions, will be more apt to do so in ambiguous situations.

(36) The prohibition against euthanasia has strengthened physicians’ commitment to supporting those who face death, has led to more attention to the complexities of care, and has overall improved attention to patients’ pain and suffering.

The pro statements that were used are as follows:

(3) The voluntariness associated with doctor-assisted suicide or euthanasia is apt to be less voluntary when decisions are made by patients’ surrogates, such as relatives, than when it is made by doctors.

(9) Only the acceptance of active euthanasia will prevent the possibility of over treatment.

(17) A society that does not confront or accept death creates a fear in many that when the end comes they will be kept alive – comatose or tethered to a respirator or in excruciating pain against their will.

(19) A decision against assisted suicide risks cutting the roots out from under the tree of liberty.

(30) There is no evidence that euthanasia will have any harmful consequences.

(33) Physicians forced to act in secret would become isolated and unable to consult colleagues or ethics committees for confirmation that their patient has made a rational decision.

Pragmatism is a school of philosophy commonly associated with a philosophical movement founded by Charles Peirce, which included philosophers William James and John Dewey and among others, and is a mode of inquiry concerned with knowledge that
can be usefully put into practice in the conduct of day to day life (Peirce, 1905/1970; Watson, 2001; Smith, 1997). According to Smith (1997) pragmatism is a theory of knowledge which treats “experience as a form of truth if it acts as a guide to life—even if the experience involves apparently unscientific beliefs” (p. 487). Clinical pragmatism is an application of philosophical pragmatism to medical practice in everyday health care settings and deals with the actual conduct and experience of physicians, health care professionals and patients in a clinical setting. Clinical pragmatism emphasizes realism and clinical experiences over abstract philosophical arguments. The arguments begin with understanding the context in which physicians and their patients make decisions. Thus, an informed clinical pragmatist demands thorough and up to date information about the actual practices of physicians in end of life situations. The pro clinical pragmatism statements used are as follows:

(5) Physician-assisted suicide can be an appropriate response to desperate clinical situations.

(11) There should be a panel, like an institutional review board which regulates biomedical research, to regulate euthanasia.

(13) It is ethical for physicians to provide effective pain medication, even if the medication may have the side effect of suppressing respiration and hastening death.

(23) Withholding and withdrawing treatment is far more cruel than the ways physicians kill patients with euthanasia or assisted suicide.

(28) There is need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.
(34) Driving physician-assisted suicide underground, to be practiced by
people like Dr. Kevorkian, creates more risk for vulnerable patients than
would be the case with a clearly articulated public policy sanctioning the
practice.

The anti clinical pragmatism statements used are as follows:

(2) Modern medicine has come to see a patient’s death as a failure and the
unavoidable approach of death as a reason to back off rather than as a call for
even more intensive medical management. But this is wrong-headed: all
patients eventually die.

(8) The management of pain through drugs only leads to addiction, and can
often hasten death. In a way, the chemical control of pain is a form of
euthanasia.

(16) Walking away from a dying patient and denying that medicine can do
anything to help is an immoral abrogation of medical power.

(20) There is no morally significant difference between omission and
commission within the context of withholding and withdrawing life-sustaining
therapy and letting die.

(25) As a minimal standard of acceptable care, physicians should discuss issues
of life-sustaining treatment with their patients during routine, nonemergency
practice.

(32) The same elements that mark good clinical practice throughout the life
cycle should remain available to patients at the end of life.

Policy Statements

In addition to the 36 Q sort statements described above that were used for this
study, a set of 35 policy statements (see Appendix C) was used to determine the policy
preferences of the Q sort participants. The statements include a broad range of elements
that would likely be included in any public policy regulating legalized PAS and
euthanasia. The survey instrument includes several policy statements that would
criminalize PAS and other policy statements that would leave PAS unregulated and not a crime. There are also statements that allow for a choice of legalizing PAS but not euthanasia. The framework for the content of the policy statements was derived in part from Dworkin (1998). The source for the content of the policy statements about the format for the regulation of PAS was Baron et al. (1996). The responses to statements were factor analyzed, and the policy factors were correlated with the Q factors in order to show the relationship between the ethical positions revealed in the Q factors and the policy preferences that are revealed in the policy factors. Examples of the policy statements are shown in Figure 1.

<table>
<thead>
<tr>
<th>Criminalize</th>
<th>Use the United States Drug Enforcement Agency to control physician’s use of lethal doses of drugs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legalize</td>
<td>Insure that individuals be permitted a PAS if they suffer from an illness that is intractable or unbearable.</td>
</tr>
<tr>
<td>Decriminalize</td>
<td>Retain the status quo—that is, do not legalize PAS, but do not prosecute physicians who assist in dying either.</td>
</tr>
</tbody>
</table>

Figure 1: Policy Statements
Participants

When R methodology is utilized for a study, large numbers of subjects are needed for an adequate sample, but Q methodology requires only enough participants “to establish the existence of a factor for purposes of comparing one factor with another” (Brown, 1980, p. 192). There were 41 participants in this study. What is of interest in a Q study is the relationship between and among individual Q sorts, not the correlation between responses to isolated statements (for a discussion see Brown, 1980, pp. 191-194). The participants in a Q study (P set) are chosen on the likelihood that their Q sorts will be theoretically relevant to the study. The theoretical considerations that guide the development of the Q statements are not imposed upon participants because they may sort the statements in any manner they like. Theoretical relevance is revealed statistically in the “objective operant” factor loadings, the meanings of which are interpreted and explicated by the analyst. There is no guarantee of an automatic fit between the theoretical premise with which the study begins and the reality of the subjectivity that is revealed in the factors. The P set in Table 2 shows the categories that were used for the selection of participants, and an explanation is given for each of these categories in the following sections.

Table 2. P-Set Structure.

<table>
<thead>
<tr>
<th>Effects</th>
<th>Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interest</td>
<td>Experts, Authorities, Special</td>
</tr>
<tr>
<td>Age</td>
<td>Young, Middle, Elderly</td>
</tr>
</tbody>
</table>
Following Thompson’s (1966) essay on “The Evaluation of Public Opinion” Brown (1980, pp. 61-62, 192-194) and Stephenson (1964a, 1964b) suggest that for studies of public opinion, participants should be chosen for their expertise, their authority and their interest. Participants were chosen for their expertise, their authority and their interest. These categories need not be mutually exclusive. Although this study is not specifically interested in measuring public opinion, this framework is suitable because PAS and euthanasia is a public issue with policy implications. Experts are people who have special knowledge due to formal training or experience. Authorities are participants whose opinions are solicited because of their standing in society. While policy regulating PAS and euthanasia will affect everybody, the arguments that surround the ethics and practical clinical applications are usually made by professional health care providers, ethicists, hospital administrators, and attorneys.

Philosophers, legal scholars, physicians, members of ethical review boards, health care professionals, and social workers experienced in the area of end of life care are considered to be experts in this study. Among the participants who were considered to be experts were two professors of philosophy who specialize in ethics, research ethics and bioethics, a chief executive officer of a hospital who is also an attorney, two members of a human subjects review board, two hospice social workers and a funeral director. There was particular emphasis placed on selecting physicians and nurses to participate because they tend to have more direct experience with the dying process than others. As Nuland (1994) suggests, "poets, essayists, chroniclers, wags, and wise men write often about death but have rarely seen it. Physicians and nurses who see it often rarely write about it"
Many health care professionals will work with dying patients and it would be useful for the policy making process to understand the perspectives of these professionals on aid in dying. Physicians and nurses who see death often but rarely write about it would be able to utilize Q technique to communicate their personal perspectives.

Authorities may also be clergy or other spiritual leaders as well as political and community leaders who may not have any particular expertise in the field but whose opinion is nonetheless valued. Spiritual leaders included a Catholic priest, a Catholic nun, a Jewish rabbi, a Jewish cantor, a Protestant minister, and a Zen Buddhist priest. Some of the spiritual leaders in this study also had considerable direct experience with dying patients and their families and in so doing had become experts as well as authorities. Community leaders included a city attorney and a chairman of a major political party at the county level.

The age range in the P-set is from age 19 to 79, including 1 under 20, 2 between 20 and 29, 4 between 30 and 39, 12 between 40 and 49, 12 between 50 and 59, 7 between 60 and 69, and 3 between 70 and 79 (see Appendix B). Perspectives on death and dying tend to vary with age (Battin, 1984). There also may be important differences in the education and experiences of health care professionals over time due to the fact that medical technology and the culture of medicine change over time, and professionals learn from experience. Educational curricula may also have changed over time. In addition, the fact that PAS and euthanasia have become prominent issues over the past decade may have made these issues more prominent to younger physicians and other health care professionals who were educated during this period than those educated in the past. For
this reason, participants in the study were at different points in their careers including some who were still in school and some who were retired.

Those people with special interests include hopelessly ill patients and family members or companions. While there were no hospice patients included in the study, there were participants with family members who had received hospice care. Patients and families who are living with hopeless illnesses may have special interests in assisted dying and may also be able to provide unique perspectives on this issue of which physicians are often unaware (Byock, 1997).

Additional information about the participants can be useful in the interpretative phase of the study. In this study, participants were asked to provide basic information, which included, gender, religion, professional role, age, race, political philosophy (liberal, conservative, moderate), and political party preference (Democrat, Republican, Independent).

Procedure

The participants in this study were asked to begin the procedure by writing a short response (about 100 words) to the following essay:

Charles is a middle-age man who is dying of an incurable disease. Although some days are better than others, pain is never far away and on some days it is unbearable. His condition is getting progressively worse, and his physician, after consulting with specialists, has informed Charles that the situation is hopeless and that he will die in six months to a year. Although not wealthy by any stretch of the imagination, Charles has managed to provide his family with a comfortable life, and now he worries that a prolonged and expensive illness will consume the family’s resources, making it difficult to keep his youngest child in college and to
continue making payments on the modest home, which he and his wife had hoped to pay off before they retired. The family’s material well-being has already begun to deteriorate in the face of heavy medical bills, some of which are not covered by insurance.

Anticipating Charles’ worry, his physician has confided that he knows another physician experienced in physician aided dying, who would be willing to help Charles end his life, painlessly and with dignity, if that were an option that he wished to consider. This proposal initially bothered Charles, and still does: He does not consider himself to be overly religious, but he finds the idea of voluntarily ending his life to be ethically and spiritually troublesome. He and his wife have had long agonizing discussions about this matter, and it bothers her deeply that he would consider ending his life because he believes that his illness is a burden to her. As his illness becomes progressively worse, Charles worries that he will eventually lose the capability to make a rational decision. This dilemma recently led Charles to seek the advice of a psychologist and he is now more comfortable at least talking about physician assisted dying. Charles is aware that the moment of decision is closing in, and that soon he will no longer be able to delay choosing.

This essay, entitled “The Case of Charles,” is about a dying man who must choose whether or not to seek relief from his pain. He is torn between his values and his family’s welfare. The inspiration for this essay came from Fishkin’s (1984) *Beyond Subjective Morality*, an empirical study of ethical reasoning and moral development. The purpose for using this essay was twofold: (1) to serve as a priming device to focus the participants on the subject and to evoke their reactions, (2) to contribute additional information for the interpretive phase of the study. After reading the essay, the participants were given the following instructions: Please write a short response to this essay in which you consider what action Charles should take and whether it was appropriate for Charles’ physician to suggest the option of physician assisted dying.

After writing the response to the essay, the participants were instructed to sort the 36 statement Q sample. Using the standard procedure for participation in Q methodology
studies, the order of the sort was determined by each participant according to how much
the participant agreed or disagreed with each statement. The statements were rated by the
participant using a scale from +4 for most agree to 0 for no opinion to -4 for most
disagree. When possible, the Q sorting procedure was followed by a short interview
during which participants were asked to elaborate on their interpretation and ordering of
the Q statements, and anything else that they considered relevant to the study.
Information derived from these interviews contributed to the interpretation of the factors.
The participants who completed the procedure on their own through the mail were not
interviewed. Following the completion of the Q sort and the interview, participants
completed the final phase of the procedure by rating a set of 35 policy statements on a
visual analog scale indicating the extent to which they opposed or favored each proposal
(see Figure 2).
Policies Concerning Physician-Assisted Suicide

Inside is a series of policies concerning physician-assisted suicide that have actually been proposed in various political jurisdictions in the United States and in other countries.

- Read each policy proposal, and then through the line above it place a vertical line (|) at that point which indicates the degree to which you would favor or oppose enactment of such a policy.

Example:  

Oppose | _______________________ | Favor  
Use the United States Drug Enforcement Agency to control physicians’ use of lethal doses of drugs.

- If you are unsure about a particular policy or have no opinion about it one way or another, then place your vertical mark as close as possible to the center of the line.

- You might find it useful to read through several of the policies first, before reacting to any of them, so as to get an idea of the range of policies which have been proposed.

Figure 2. Policy Questionnaire.
CHAPTER 4

ANALYSIS OF THE FINDINGS

The 41 Q sorts in this study were analyzed using the PQMethod software program (Schmolck & Atkinson, 2002) that facilitates data entry, correlates the Q sorts, performs a factor analysis (principal components or centroid) and rotation of the factors (varimax or theoretical rotation), and calculates the factor scores. The 41 Q sorts in this study were factor analyzed using the centroid method and a judgmental rotation of the factors was performed, from which a three-factor solution emerged. The three factors are referred to in the text as Factor A, Factor B, and Factor C.

Theoretical Rotation

The theoretical rotation of factors has rarely been employed in the history of factor analysis and its contemporary usage has been almost entirely within Q methodology. Although Stephenson discussed factor rotation in his The Study of Behavior (1953), his most thorough treatment appeared in a later paper (Stephenson, 1956). In the 1956 paper, Stephenson reanalyzed data that previously had been factor analyzed in conventional ways to demonstrate that a repositioning of the factors based on theoretical considerations led to a more insightful solution. Shortly thereafter, Thompson (1962) examined various approaches to factor rotation as recommended by Cyril Burt, R. B. Cattell, Hans Eysenck, and other prominent factor analysts and concluded that
Stephenson’s approach could never be standardized (e.g., in the way that the varimax solution is) because his approach involved scientific judgment. Theoretical rotation has recently been explicated by Brown and Robyn (in press) who review the main issues and clarify the foundation of theoretical rotation found in the philosophical writings of Egon Brunswik (1947), J. R. Kantor (1959), Charles Peirce (1958), and Michael Polanyi (1966).

There are several other recent examples of theoretical factor rotation in Q methodology to which reference can be made (e.g., Aalto, 2003; Brown, in press; Kramer, de Hegedus, & Gravina, 2003; Robyn 2000). In this study, the main ideas of theoretical factor rotation are illustrated. Figure 3 displays the original (unrotated) Factors 1 and 7, with each Q sort located by a point that shows the position of the Q sort in terms of the factor loadings. Q sort no. 1, for example, has a loading of .33 on Factor 1 and a loading of .04 on Factor 7. These loadings express the degree of correlation between Q sort 1 and the two perspectives represented by the factors. (By analogy, the loadings of Factors 1 and 7 can be equated with latitude and longitude that serve to pinpoint the location of the Q sorts in attitudinal rather than geographical space.) Q sort no. 25, which has loadings of .39 and .04 on factors 1 and 7 respectively, is in close proximity to Q sort no. 1. This proximity is a spatial representation of the similarity between the two Q sorts; i.e., the more similar the Q sorts, the closer they will be in two-dimensional factor space.

Conventional factor rotation automatically proceeds to determine a solution based on the mathematical features of the data. In R methodology, factor analysts who use
Figure 3. Graph of two unrotated factors.
theoretical rotation typically defend their views in terms of statistical criteria. For example, Comrey and Lee (1992) note that “computer methods of rotating factor axes by means of analytic criteria … cannot replace intelligent judgment by the investigator as to what kind of rotational solution is appropriate” (p. 113). They justify their rotations on statistical grounds in terms of improving positive manifold, moving closer to simple structure, and reducing excess variance. This is in contrast to Aalto’s (2003) use of theoretical rotation in Q methodology “to pursue hypotheses, hunches and guesses” and to rotate the factors to probe the data, “[making] use of my knowledge of the participants … to see whether some of the Q sorts in which I had a prior interest, actually were related in any theoretically interesting way” (p. 86, n51). It is this controversial use of discretion by the researcher that has led most factor analysts, including those who employ Q methodology, to abandon graphical rotation in favor of varimax (orthogonal), oblimin (oblique), and other determinant procedures.

Within the context of this study, the literature review and the experiences of the many Q sortings and post-sort interviews as well as the reactions to the essay, “The Case of Charles,” led to greater appreciation of the role of religion in individuals’ thinking about PAS, and several participants appeared particularly salient. Participants 27, a 58-year-old Jewish rabbi, and 18, a 43-year-old Catholic professor of philosophy, not only displayed contrasting views, but also were exceptionally articulate about their experiences counseling those involved in end-of-life decisions. A third participant, no. 14, a 42-year-old Catholic nurse, whose Q sort and post-sort interview indicated that her life experiences with dying patients had led her to adopt a pro-PAS position contrary to
both the mainstream of her religious upbringing and the dominant ethical ethos of her profession, also was of note. Other participants were interesting as well, given the wide variety of outlooks and experiences purposely gathered in terms of the P-set structure shown in Table 2.

What is involved in theoretical rotation can be made clearer in reference to Figure 3 above, and particularly in relation to participants 27 (the Jewish rabbi) and 14 (the Catholic nurse), both of whom are located near the top of the figure and to the left. (Participant 27’s loadings are .77 and -.36 on Factors 1 and 7, respectively, whereas participant 14’s are .86 and -.20.) As McKeown and Thomas (1988) point out, the value of judgmental rotation arises “on those occasions where a particular Q sort holds … special interest” (p. 52), in which case a Q sort such as no. 27 becomes a “reference variate” (p. 53) in repositioning the factors, in this case highlighting Q sorts 27 and 14.

This repositioning is shown in Figure 4 and was effected (using the rotational phase of the PQMethod program) by rotating Factors 1.0 and 7.0 by 22° counterclockwise. As is apparent, the rotation in Figure 4 in no way alters the data configuration itself, which remains identical to what it is in Figure 3, but the repositioned reference vectors have now changed all of the factor loadings. (No. 27’s loadings are now .85 and -.05 on Factors 1.1 and 7.1, respectively, whereas no. 14’s are .87 and .14.) It is important to note that varimax and other automated rotational procedures can only respond to the surface of the data, but cannot distinguish the quality of thinking among participants, e.g., between someone who might have responded stereotypically from others who might have
Figure 4: Graph of factors after judgmental rotation.
reasoned their way to a particular position based on scholarship, experience, insight and generally more sustained interest in the subject matter. Theoretical rotation enables the investigator to take advantage of the additional knowledge available (i.e., over and above the statistical features of the data) and to adjust the analytical perspective accordingly. Initially, judgmental rotation provides the analyst with some confidence that whatever form Factor 1 takes, it will likely reflect a coherence that has emerged from a composite of wide experience.

Figure 4 shows only one of a series of five rotations eventually carried out that were aimed at maximizing the rabbi and nurse on Factor 1 and the Catholic philosopher on Factor 2—participants on neither 1 nor 2 were then maximized on Factor 3—and the final factor solution is shown in Appendix B. The three factors (relabeled A, B, and C) represent a composite of all of the Q sorts significantly loaded on them rather than any specific Q sort, and it is the factors that are of concern to this study. Factors are, therefore, constructions of statistically and theoretically meaningful arrangements of information about a given subject. According to Brown (1980), factor scores “reflect an attitude in operation” (p. 247). Factor A, Factor B, and Factor C each represent a shared understanding of the ethics of PAS, euthanasia and other aspects of end of life care. Appendix A shows the scores given to each of the 36 Q statements by Factors A, B, and C. Of the 41 participants, 10 were purely loaded on Factor A, 1 was negatively associated with Factor A, 21 were purely loaded on Factor B, 3 were purely loaded on Factor C, 1 was significantly loaded on both Factor A and Factor B, 1 was significantly loaded on both Factor B and Factor C, and 4 were not significantly loaded on any factor.
A complete listing of the factor loadings of each participant in this study is shown in Appendix B. Factors A, B, and C are presented individually, followed by a discussion of the policy survey and relationship between the Q factors and policy preferences.

*Factor A*

It appears from the responses to the Q sort statements that Factor A’s approach to PAS and euthanasia is based on prioritizing good clinical practice and routine discussion of end of life care issues while rejecting the moral permissibility of physician assisted suicide and active euthanasia. Factor A would not agree to further expansion of the legal sanctioning of PAS, currently a state-level public policy in the United States. Factor A believes that intentionally ending one’s own life or the life of another is intrinsically and invariantly unethical. Both physician and patient have the moral duty to refrain from active participation in either PAS or euthanasia, according to Factor A. Factor A accepts the moral permissibility of withholding and withdrawing life sustaining treatment and the doctrine of the double effect, but Factor A rejects the validity of a person consenting to death, regardless of whether that consent is granted autonomously or heteronomously.

The scoring of statements 32 and 29 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>32</td>
<td>+4</td>
<td>+2</td>
<td>+1</td>
</tr>
<tr>
<td>29</td>
<td>+3</td>
<td>-2</td>
<td>-4</td>
</tr>
</tbody>
</table>

(32) The same elements that mark good clinical practice throughout the life cycle should remain available to patients at the end of life.

(29) Although I empathize with the despondency suffering creates for both patient and family, physician assisted suicide and euthanasia are an evasion of moral duty.
Factor A’s response to statements 32 (+4) and 29 (+3) indicates that Factor A’s moral foundation is based on an essential and inviolate moral duty with respect to PAS and euthanasia. Based on the score given to statement 29 (+3), indicating a belief that PAS and euthanasia are an “evasion of moral duty,” it is clear that Factor A considers PAS and euthanasia to be incompatible with the elements of good clinical practice. Factor A’s strong emphasis on the importance of guaranteeing the availability of good clinical care throughout the life cycle clearly does not extend to the sanctioning of physician-assisted dying. It is clear from the score given to statement 29 that Factor A believes that active killing and aiding self-killing are morally unacceptable and incompatible with both physicians’ “moral duty” toward their patients and good clinical care in general. This principle, referred to as the principle of avoiding killing (Kass, 1989; Veatch, 2003), must be followed without exception at every stage of the life cycle, including the final stage. For Factor A, the principle of avoiding killing is an “absolute, exceptionless” duty (Veatch, 2003, p.168), and as such, it cannot be compromised.

Factor A finds that there are no fundamental moral differences between the “elements that mark good clinical care” at the end of life and the clinical care that accompanies other stages in the life cycle. End of life care can, indubitably, pose specific challenges and difficulties to both physicians and patients. Nonetheless, the ethics of good clinical care and the doctor-patient relationship must remain invariant throughout the life cycle. Resnik (2001) puts the goals of medicine into three broad categories: curative (treating, curing, and preventing disease and injury), palliative (relieving pain and suffering), and social (promoting public health and the advancement of knowledge,
social justice and economic prosperity) (p. 132). Curative and social goals, such as curing opportunistic infections and providing a national health care service, may be relevant to end of life issues; however, patient care will mostly involve palliative care once a terminal diagnosis is made. Factor A’s Q statement scores reveal sensitivity to the need for good palliative care, the specifics of which will be discussed later in this section. However, it is also evident, both in the factor scores and in the following written responses to “A Case of Charles” (by participants in factor A), that the principle of avoiding killing is salient and absolute:

Charles should involve his wife in his discussions with the psychologist so that together they can discuss their feelings with an objective party. Talking together with the physician or pastor may also benefit them. In discussions with the physician, Charles should identify which components of care or treatment are futile (and likely expensive) and establish advance directives so that these things do not occur. Also, seeking the help of a Hospice organization may provide Charles and his wife with reassurance that, while comfort care only will be chosen, Charles will not suffer. Symptoms could be managed by hospice nurse and physician, so that Charles can be guaranteed a pain free death with dignity. I do not think it was appropriate for Charles’ physician to suggest he see a physician who can help with assisted suicide. Charles’ concerns should be able to be managed in such a way that he can be kept comfortable, and the appropriate response would be to optimize his management at home, with Hospice. Physician assisted suicide is not compatible with physicians’ obligations to first do no harm. Since this matter has not been fully addressed by the medico-legal system as a potentially legal option under described circumstances, physicians should not be advocating this. There is a potential that this method of relieving pain and suffering, in the long run, could impart more pain and suffering for the family. (Participant 25, Appendix B)

As a physician, I feel strongly that I should not be involved in causing death in any active manner. Life is not that simple. Charles should think about a positive way of life. He should get advice from his priest. There are many options other than physician assisted dying. (Participant 22, Appendix B)

As a physician-to-be (3rd year medical student), I am concerned with 3 aspects of patient care.
I. Above all, “non-nocere” or do no harm
II. Autonomy
III. Beneficence

Of these 3 principles, I am more strongly governed by beneficence which is the physician’s duty to do his/her utmost to maintain the patient’s quality of life and the tenet that “Above all a physician shall do no harm.” I therefore do not feel that it was appropriate for Charles’ physician to suggest terminating his life, but rather feel that a more appropriate course of action would have been supportive therapy, or making the patient comfortable in his last phase of life. Lastly, I feel that in this instance, termination of life is not medically indicated and seems more elective, thus I believe that patient autonomy should guide Charles’ decision. (Participant 34, Appendix B)

Was it appropriate for the physician to suggest this [physician assisted dying]? The term appropriate would need some definition here. But I will take one interpretation of it. Namely, is it appropriate or consistent for someone who has taken the Hippocratic Oath—which the physician presumably has—to intend directly to kill a patient? I would say that this is an inconsistency and thus, presumably, inappropriate. It is considered merely that the physician is most efficient at the killing, it seems. Technically, in terms of the brief argument here, apart from considerations of efficiency, the wife should do it! (Participant 18, Appendix B)

Charles’s actions in this case are well-validated; he is a person who knows his end is near and is thinking of all the possible outcomes of what could happen to him and his family when he does die. It is only natural for Charles to be “bothered” by the proposal his physician suggested. I do not believe that it was appropriate for the physician to have suggested the option of physician assisted suicide to Charles. It is basically saying that his life right now is not worth living. I also feel that the physician was wrong in suggesting because Charles didn’t even ask him about it. (Participant 36, Appendix B)

The scoring of statements 5 and 15 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-4</td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>+1</td>
<td>-1</td>
<td>0</td>
</tr>
</tbody>
</table>
Factor A understands that suffering can occur at the end of life when pain, physical and emotional distress, unwanted dependency and other types of suffering are present. Factor A’s scoring of statement 5 (-4) indicates a negative reaction to the assertion that “desperate clinical situations” can give license to physicians to kill their patients or aid in their suicide in order to end their suffering. Factor A is aware that situations can occur in which the option to pursue physician assisted death can present itself to the patient as a reasonable means to accelerate impending death. Nonetheless, neither the desire of a terminally ill patient to live or die, nor the desperation of the situation is relevant to the morality of the prohibition against physician assisted dying.

Factor A’s scoring of statement 15 (+1), “Good hospice care can relieve all unpleasant symptoms and remove any incentive to die,” indicates that Factor A is comparatively unsure about the prospect of good end of life care ending all demand for assistance in dying. The scoring of statements 23 and 13 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

(23) Withholding and withdrawing treatment is far more cruel than the ways physicians kill patients with euthanasia or assisted suicide.

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+2</td>
<td>+3</td>
<td>+2</td>
</tr>
</tbody>
</table>

(13) It is ethical for physicians to provide effective pain medication, even if the medication may have the side effect of suppressing respiration and hastening death.

Factor A’s negative scoring of statement 23 (-3), “Withholding and withdrawing treatment is far more cruel than the ways physicians kill patients with euthanasia or assisted suicide,” indicates that withholding and withdrawing treatment is the preferred method. Factor A’s scoring of statement 13 (+2) indicates moderate agreement with the claim that “it is ethical for physicians to provide effective pain medication, even if the
medication may have the side effect of suppressing respiration and hastening death.” The implication is that Factor A accepts terminal sedation and the doctrine of the double effect. The scoring of statements 25 and 28 is shown as follows:

\[
\begin{array}{ccc}
A & B & C \\
+4 & +3 & 0 \\
\end{array}
\]

(25) As a minimal standard of acceptable care, physicians should discuss issues of life-sustaining treatment with their patients during routine nonemergency care.

\[
\begin{array}{ccc}
+3 & +4 & +2 \\
\end{array}
\]

(28) There is a need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.

Factor A finds discussion between physicians and patients to be important. This is indicated by the scoring of statement 25 (+4), “As a minimal standard of acceptable care, physicians should discuss issues of life-sustaining treatment with their patients during routine nonemergency care.” Patients must have adequate information and be able to process that information in order for them to make effective, appropriate, and ethical plans for their care. This is consistent with the principle of veracity, which supports full disclosure and truthfulness on the part of physicians, who have a duty to keep their patients fully informed of their diagnosis, plan of treatment, and prognosis (Veatch, 2003).

Factor A emphasizes that discussion of end of life issues is part of good clinical practice and can help physicians and patients make the best decisions about the plan of care. According to Siegler (2001), “Reaching a right and good decision has pretty much been the central concern of medical ethics for the past thirty years” (p. 175). Discussion is considered to be not only a normal and practical part of clinical care, but discussion
can also be the means by which both doctors and patients can allay “desperate clinical situations,” which can corrupt ethical decision making.

Routine discussion between doctors and patients about end of life issues can be a source of death education that can help patients and doctors become more comfortable with discussion of patients’ needs (Kastenbaum, 2004). The avoidance of discussing death can result in the undertreatment of pain and physical distress and inadequate psychological support. This can create a deadly combination that promotes demand for assistance in dying. Demand for PAS or euthanasia might be a sign that the patient’s needs are not being met and, for most patients, those needs that lead to a desire for PAS or euthanasia can be met if patients receive adequate professional care (American Medical Association, 2002). Providing adequate information to patients can help them make appropriate decisions about their plan of care. This reduces the uncertainty that patients, their families, and even their caregivers have about the physical and emotional aspects of the dying process. This may also lower the anxiety of all people involved in the dying process, leading to more reasonable, less impulsive decision-making that, in turn, can lead people away from the desire for PAS or euthanasia and towards other types of end of life care.

The issue of pain poses a dilemma to patients as well. Resnik (2001) finds that patients suffering from severe pain sometimes withhold information about their pain from their physicians because they believe that tolerating pain is a sign of strength and stoicisim, or they believe that attention to treating their pain will detract their physicians
from treating their “real” disease, which they believe is more important (Resnik, 2001, p. 129). The scoring of statement 8 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-3</td>
<td>-2</td>
</tr>
</tbody>
</table>

(8) The management of pain through drugs only leads to addiction, and can often hasten death. In a way, the chemical control of pain is a form of euthanasia.

Factor A’s scoring of statement 8 (-3) indicates that Factor A rejects the contention that “the management of pain through drugs only leads to addiction,” and that the “chemical control of pain” amounts to “a form of euthanasia.” Inadequate pain management can lead to the anticipation of a painful death, which can contribute to the demand for PAS and euthanasia. Promoting effective pain management instead of PAS or euthanasia neutralizes the “argument from mercy,” as stated in the following passage from Rachels (1986):

> Terminally ill patients sometimes suffer pain so horrible that it is beyond the comprehension of those who have not actually experienced it. Their suffering can be so terrible that we do not even like to read about it or think about it; we recoil from even descriptions of such agony. The argument from mercy says euthanasia is justified because it puts an end to that. (p. 49)

The reduction of suffering to tolerable levels by effective pain management can dissuade patients from considering PAS or euthanasia. Factor A’s negative reaction to statement 8 may relate to the specter of drug addiction that, even in the context of chronic pain management, is probably related to pervasive cultural attitudes that associate drug addiction with criminality, depravity and weakness of the will (Foreman, 2003; Byock, 1997). Patients sometimes underreport pain because they fear addiction (Resnik, 2001). Addiction and drug craving are actually more prevalent when patients are under treated
for pain. Under treatment can result in drug-seeking behavior, self-medicating and the ingestion of dangerous doses and dangerous combinations of drugs (Byock, 1997). The scoring of statement 8 may indicate an awareness of the need to rectify the antipathetic cultural attitudes towards the use of analgesics in pain management, particularly in the context of end of life care. According to Byock (1997) patients afflicted with pain sometimes deny themselves relief because they want to punish themselves for being bad patients. These are people who essentially feel guilty for getting sick and letting themselves and others down, including their physicians, believing that their self-indulgent and reckless behaviors, such as smoking, drinking, over-eating, avoiding exercise or whatever, contributed to their illness. The scoring of statements 35, 28 and 21 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+3</td>
<td>-4</td>
<td>-3</td>
<td></td>
</tr>
<tr>
<td>(35) Euthanasia trespasses on the bounds of self-determination: people cannot consent to being killed.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>+3</td>
<td>+4</td>
<td>+2</td>
</tr>
<tr>
<td>(28) There is a need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>+2</td>
<td>+3</td>
<td>+2</td>
</tr>
<tr>
<td>(21) The patient’s values should form the regimen to treatment.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Many of the Q statements used in this study deal with issues related to personal autonomy. Factor A believes that the permissibility of assisted suicide and euthanasia cannot be justified by the expressed will of individual patients even though there is approval of statement 28 (+3), “There is a need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care,” and moderate agreement with statement 21 (+2), “The patients’ values should form the
regimen to treatment,” both of which indicate support for autonomy and self-determination as a general principle guiding patient care. For Factor A, the incorporation of the patients’ values into their plan of care may only be partly realized as it is a process that is always governed, in part, by an external locus of control, which in the case of PAS and euthanasia is the adherence to the general principle of avoiding killing and self-killing, which is upheld by law. If patients’ values condone PAS and euthanasia, the principle of avoiding killing will limit the extent to which patients’ values may be realized in their plan of care. The scoring of statements 29, 12 and 23 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>29</td>
<td>+3</td>
<td>-2</td>
<td>-4</td>
</tr>
<tr>
<td>12</td>
<td>-4</td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>23</td>
<td>-3</td>
<td>-2</td>
<td>0</td>
</tr>
</tbody>
</table>

(29) Although I empathize with the despondency suffering creates for both patient and family, physician assisted suicide and euthanasia are an evasion of moral duty.

(12) Our body is our own, and our life should be subject to self-determination. We have then, the right to end our own life, and if we can’t accomplish this on our own, another person has a right to end it for us, as an act of compassion.

(23) Withholding and withdrawing treatment is far more cruel than the ways physicians kill patients with euthanasia or assisted suicide.

Factor A believes that patient choice must be limited if a choice could include physicians’ involvement in killing or aiding in suicide. Factor A indicates by its scoring of statement 29 (+3) that, for this factor, physician assisted suicide and euthanasia are an “evasion of moral duty.” The relevant moral duties are respect for personal autonomy, the Hippocratic tradition of beneficence and nonmaleficence, and the principle of avoiding killing. Factor A’s strong rejection of statement 12 (-4), “We have, then the
right to end our own life, and if we can accomplish this on our own, another person has a
right to end it for us, as an act of compassion,” indicates that the principle of avoiding
killing takes precedence over other duties. The relevance to Factor A of the intent of
physicians and the degree of their involvement in shortening the lives of their patients is
also indicated by the scoring of statement 23 (-3), “Withdrawing and withholding
treatment,” a procedure that presumably does not require that physicians intend to kill
their patients, “is far more cruel than the way physicians kill their patients with assisted
suicide and euthanasia,” a procedure that requires that physicians intend to kill their
patients or help their patients who intend to kill themselves. The scoring of statement 35
is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+3</td>
<td>-4</td>
<td>-3</td>
</tr>
</tbody>
</table>

(35) Euthanasia trespasses on the bounds of self-determination: people
cannot consent to being killed.

Factor A’s scoring of statement 35 (+3), “Euthanasia trespasses on the bounds of
self-determination: people cannot consent to being killed,” shows that euthanasia is
rejected by Factor A as a reasonable expression of self-determination. According to
Kastenbaum (2004), “how we interpret the state of death can influence our thoughts,
feelings and actions” (p. 62). Disassociating assisted dying with autonomy and self-
determination has to do partly with Factor A’s interpretation of the death state. One view
of the death state is that it is essentially unknowable and that lack of knowledge about
death means that it cannot be freely chosen. This view that death is unknowable is found
in Socrates’ address to his fellow Athenians in Plato’s *Defense of Socrates* (399/1997):
After all, gentlemen, the fear of death amounts to thinking one is wise when one is not: it is thinking one knows something one does not know. No one knows, you see, whether death may not prove to be the greatest of all blessings for mankind; but people fear it as if they knew it to be the greatest of all evils. And yet to think that one knows what one does not know must surely be the kind of folly that is reprehensible. (p. 42)

Jaspers (1962) refers to Socrates’ view of the death state as “nonknowledge” of death, which “is the ground and end of all speaking about death” (p. 14). This view of death and its consequences are expressed in the following response to the essay, “The Case of Charles,” by a participant on Factor A, who is also, incidentally, a professor of philosophy:

It is highly unclear as to whether one can form an intention to end one’s life. One can certainly imagine such a possibility. But one can also imagine many impossible things: that one can fly, run a mile in three minutes, and so forth. Forming an intention to end one’s life would take some sort of resolution: and resolutions always have to have future referents of some sort. Since presumably Charles is not thinking of another life (at least from what the description gives us), he is forming an intention without a referent. Thus he would not really be acting in any philosophical sense of the term. He would be, instead, re-acting. (Participant 18, Appendix B)

According to the view expressed in this passage, autonomy and respect for autonomy do not play a role in the permissibility of assisted suicide or euthanasia. A patient can express consent to death, but that consent is invalid because one cannot intend to be dead since intent implies that foreknowledge of what is being intended is possible, i.e., one cannot intend to be dead as the state of being dead is an unknown and unknowable state. People who demand assistance in dying are actually trying to avoid pain and suffering, either their own or that of their significant others, which is something
that they can be reasonably sure of, but they are not consenting to death, of which they have no knowledge.

It is unclear from this study whether other participants on Factor A would attribute their rejection of the notion that people can reasonably consent to death to their understanding of the death state. Another source of Factor A’s rejection of consent to dying has to do with religious conviction. In the following responses to the essay, “The Case of Charles,” two on Factor A exclusively and one loaded significantly on both Factor A and Factor B, convey the influence of their religious views on their views of physician assisted dying,

Although I understand Charles’ dilemma on a human level, I believe that Charles needs to trust in the Lord’s timing of his end of life. I feel it would be helpful for Charles to spend time with a chaplain. I know that it states that he is not overly religious. However, it has been my experience that at this time in an individual’s life, they are not only more receptive to the spiritual journey, but they are also functioning in a deeper level. (Participant 41, Appendix B)

Religious considerations are of paramount concern to me. I cannot accept the idea of one person taking another’s life. The dilemma is that the worry of the family is great and I’m sure bears heavily on the ill person as well as his spouse and children. Perhaps a living will would be of some help with the withdrawal of extraordinary means of maintaining someone’s life. It also talks about withdrawal of food. (Participant 36, Appendix B)

While this is a difficult situation, Charles should not consider physician assisted dying. It is a tremendous burden to bear when you know your illness will cause a financial burden on the family. It is, not, however, up to man to determine when a person should die. This is left to God. Charles should consider the unbelievable grief that would be placed on his family knowing that he committed suicide. I am sure that Charles’ family would rather bear the financial woes than lose their beloved father and husband sooner.

A physician’s duty is to save and promote life, not to determine when it should end. Charles’ physician should not have suggested
physician assisted dying as an option. All the physician has accomplished was to place a great deal of stress in Charles’ remaining life. The physician should help a terminally ill patient live as comfortably as they can in their remaining time. (Participant 13, Appendix B).

Charles does have a dilemma but he does have choices. Whatever choice he makes, he must be completely satisfied with it. I am not in a position to pass judgment on what he should do. I could not do that for someone else’s life. I suggest that he take it one day at a time and pray for answers and the help he will need to get through the next day. Things have a way of resolving themselves if you give them enough time. (Participant 21, Appendix B)

There are two aspects of religious conviction related to death and dying that are apparently at play in the preceding passages. One is based on with what Rachels (1986) refers to as “the idea of God’s dominion,” which implies that only God can rightfully determine the timing of death (p. 55). The other conviction is that euthanasia and PAS are self evidently forbidden because God forbids killing of innocent human beings.

The following response to the essay, “The Case of Charles,” comes from a participant with a significantly negative loading on Factor A,

Charles is a burden on himself and his family. Dying is no big deal when it is inevitable in a short period of time. Do it with dignity. Public health policy should strongly favor persons who make this decision. It is good public policy to end the lives of terminally ill so that limited medical resources can be used to aid the living. All participants would benefit from private decision making if it was given the protection of public law. (Participant 3, Appendix B)

For whatever reasons, it is clear that Factor A believes that it cannot be up to the patient to choose assistance in dying. Factor A believes that people who consent to PAS or euthanasia are understandably reacting to pain and suffering, either their own, or that of their significant others, but consent is nonetheless effectively invalid because death is
not amenable to personal consent. Factor A’s belief, exhibited in its scoring of the proposition that “Euthanasia trespasses on the bounds of self-determination,” suggests that for Factor A, the prohibition against physician assisted dying is not actually an affront to the autonomy of patients who demand assistance in dying. Respect for patients’ values is important to Factor A, but Factor A’s understanding of respect for patients’ values does not mean that patients can consent to death or that physicians must compromise their values and moral duty.

Factor B

In this analysis, it is evident that Factor B believes that PAS and euthanasia are morally permissible. Factor B supports an expansion of the legal sanctioning of PAS and euthanasia. Factor B does not advocate physician assisted dying as the only solution to the suffering and other problems that can occur during the dying process. Factor B believes that it is essential to listen to patients and to offer them a manifold of care options that enable, to the extent possible, patients’ values and wishes to determine their plan of care. Factor B bases its position on a strong belief in prioritizing patients’ personal control over their end of life care. The scoring of statements 28, 25 and 27 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+3</td>
<td>+4</td>
<td>+2</td>
</tr>
</tbody>
</table>

(28) There is a need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.

+4 +3 0  (25) As a minimal standard of acceptable care, physicians should discuss issues of life-sustaining treatment with their patients during routine, nonemergency practice.
People of faith have a right to follow their own creed, but they are not free to force their religious convictions on all the other members of a democratic society, and to compel those whose values differ with theirs to die painful, protracted and agonizing deaths.

Euthanasia trespasses on the bounds of self-determination: people cannot consent to being killed.

Factor B’s scoring of statement 28 (+4) indicates the importance of the “need to listen to patients” so that caregivers can understand their patients’ values and their patients’ assessment of their situation and “incorporate their values into their plan of care.” Listening to patients and offering them options is an expression of respect for personal autonomy because it can allow patients’ autonomy in decision-making to be realized. Factor B’s scoring of statement 25 (+3) indicates approval of discussing end of life issues “during routine, non-emergency care.” Like Factor A, Factor B believes that more reasonable decisions can be made when anxieties are reduced among all actors involved in the decision-making process, and routine discussion of end of life issues can contribute to this goal by making end of life issues a routine and ordinary part of clinical care. Discussion can also convey information to patients about the prognosis of their illness and available options for care. However, unlike Factor A, Factor B does not view the choice to pursue PAS or euthanasia as an inherently unreasonable or reactive decision. For Factor B, informing patients of their care options and reducing anxiety through routine discussion of end of life care is an integral part of a process by which patients can make informed choices that enable their values to be more fully realized, whatever course of treatment is desired by the patient.
With respect to the moral permissibility and appropriateness of assisted dying, Factor B believes that a determining factor should be patients’ values and their own assessment of their condition. In extreme situations, as described in statement 27 (+4), when patients are “compelled” to experience “painful, protracted and agonizing deaths,” Factor B indicates a strong concern that the patients must be protected from those persons with differing values, particularly when “people of faith” would “force their religious convictions” on them. Factor B’s strong reaction to statement 27 (+4), which contains the words “force” and “compel,” indicate that, for Factor B, the general prohibition of PAS and euthanasia is, in effect, an unjustifiable attack on personal freedom and an act of religious intolerance that is unacceptable “in a democratic society.” Factor B believes that despite advances in palliative therapy and end of life care generally, dying can involve what some people will consider intolerable suffering that cannot be completely controlled or alleviated. This point is reinforced by Factor B’s strong negative scoring of statement 35 (-4) that indicates that Factor B believes that euthanasia does not “trespass on the bounds of self-determination” and that people can, in fact, reasonably “consent to be killed.” For Factor B, the consequence of prohibition is a high price to pay in order to respect a form of religious essentialism that claims that the intentional killing and self-killing of innocent human beings must always be intrinsically immoral acts. In such a society, a public policy that enables assistance in dying may be necessary in order to protect patients’ autonomy in determining the course of end of life treatment. The scoring of statements 22, 26 and 28 is shown as follows:
Legalizing physician-assisted suicide would mean that patients could never trust their doctors again.

The doctor who has authority to end life, even under carefully regulated conditions, will be more apt to do so in ambiguous situations.

There is need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.

Factor B’s scoring of statement 22 (-4) and 26 (-3) indicates the belief that legalizing PAS would not negatively affect patients’ trust in their physicians, nor would legal PAS pose a greater risk for abuse of vulnerable patients “in ambiguous situations” by their physicians. Factor B’s scoring of statement 22 (-4) also indicates that Factor B does not believe that legalizing PAS would undermine doctor-patient trust, but that withholding the option of PAS in some circumstances would be an act of paternalism, unauthorized by the patient, that could diminish this trust. If PAS and euthanasia were to be made legal, this could lead to improved relationships between physicians and patients because providing assistance in dying could be an expression of compassion and respect for personal autonomy. In order for patients to trust their physicians, physicians must also trust their patients’ ability to make the right decisions for their plan of care. Factor B’s position on statement 28 (+4) suggests that doctor-patient trust improves when patients are allowed to make values-based decisions for end of life care. The scoring of statements 8 and 13 is shown as follows:
A  B  C  
-3  -3  -2  (8) The management of pain through drugs only leads to addiction, and can often hasten death. In a way, the chemical control of pain is a form of euthanasia.

+2  +3  +2  (13) It is ethical for physicians to provide effective pain medication, even if the medication may have the side effect of suppressing respiration and hastening death.

+1  0  -1  (15) Good hospice care can relieve all unpleasant symptoms and remove any incentive to die.

Factor B indicates that statement 8 (-3) and statement 13 (+3), both of which deal with pain management, are important. Like Factor A, Factor B also rejects the association between effective pain management, drug addiction and euthanasia. Statement 8, “The management of pain through drugs only leads to addiction,” may be problematic for Factor B because obstacles to effective pain management can lead to unnecessary suffering, and pain and physical distress make autonomous decision making more difficult. If manageable pain and suffering are left unmanaged, decisions are more likely to be impulsive and reactive. However, the availability of palliative care cannot eliminate every patient’s desire to die. Factor B is unsure about statement 15 (0), “Good hospice care can relieve all unpleasant symptoms and remove any incentive to die.” Factor B believes that patients’ desire to die should be respected.

Statement 13, which states, “It is ethical for physicians to provide effective pain medication, even if the medication may have the side effect of suppressing respiration and hastening death,” is important to Factor B, because relieving severe pain and physical distress is believed to be an important part of physicians’ professional responsibilities.
Statement 13 evokes passive euthanasia and the doctrine of the double effect. It is unclear from the results of this study whether Factor B agrees with the doctrine of the double effect or believes that there is a morally relevant distinction between active and passive euthanasia. However, there will be patients that do believe in a morally relevant distinction between active and passive euthanasia. For these patients, the availability of passive euthanasia as described in statement 13 can be a valuable asset to end of life care because it offers an additional option with which to deal with intolerable suffering that may be more congruent with their values than PAS or euthanasia. The scoring of statement 9 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-3</td>
<td>-3</td>
<td>-3</td>
</tr>
</tbody>
</table>

(9) Only the acceptance of active euthanasia will prevent the possibility of over treatment.

Factor B rejects the claim in statement 9 (-3) that “only the acceptance of active euthanasia will prevent the possibility of over treatment,” which indicates that Factor B firmly believes that there are viable alternatives to PAS and euthanasia. Further, the knowledge that pain and suffering, no matter how severe, will be relieved, even if doing so must cause death, can also reduce anxieties and thereby contribute to autonomous decision-making based on personal values rather than an impulsive reaction to extreme suffering and duress.

A sample of Factor B’s responses to “The Case of Charles” illustrates this factor’s emphasis on the importance of patient autonomy in determining a patient’s plan of care:

It was fully appropriate for his physician to suggest as an “option,” provided the physician offered a whole tableau of options for Charles. A physician is a professional resource, and ought to expand the care options available to patients,
not unilaterally restrict them. As for what “action” Charles should take, no one but Charles can know. (Participant 40, Appendix B)

My reaction to Charles, if he is in all apparent respects, in command of his faculties, [is that he] should make up his own mind. To me religious beliefs would be no barrier to asking for assistance in suicide. However, if such considerations are important to Charles, and his family, he must give them some weight. How much religious reservations should count, only he can decide. (Participant 31, Appendix B)

First, I believe that Charles should continue to collect data and support as he makes his decision. He did well to seek multi-discipline opinions and consulting his family as he chooses what he wants. I believe that Charles’ physician was wise to offer options to Charles. However, unless the physician is operating in a society that allows physician assisted suicide, he is being unethical. A physician must weigh the risks of unethical practice against his own moral fiber. It is the measure of an action in that balance which determines if a physician’s actions/suggestions are appropriate. (Participant 2, Appendix B)

I don’t care which [choice] Charles makes—either is fine with me. It is his choice! There is nothing wrong with Charles’ physician providing Charles with assisted suicide as an option. The physician should not, however, be an advocate for the option. (Participant 20, Appendix B)

I would question what other options Charles was offered. End of life care need not be expensive if palliation is the goal. Most insurances pay for hospice at 100% and if there is no insurance coverage, hospice care is provided free of charge. What drives up the cost of “end of life care” is needless invasive, expensive treatments.

Advanced directives should be completed when Charles is still able to think rationally so there is no uncertainty on the part of his family regarding artificial feeding or hydration.

Symptom management (while not 100%) can be addressed with good medical management through something like hospice care. Hospice care which is holistic in approach would also provide support to the family as well as Charles.

I don’t think the doctor should have brought up the topic of physician assisted suicide unless first brought up by the patient—might reinforce Charles’ concern of being a burden etc. However, if the topic is first mentioned by the patient, the physician should respond. I would hope the physician should address the underlying concerns that make physician assisted suicide a consideration. (Participant 8, Appendix B)
Charles might want to speak with the pastoral support staff at the hospital or with the pastoral staff at a local hospice, might be good to include his wife and kids in some of these conversations. Charles’ physician did well to advise him of this option, but hopefully he also advised him of all the options that might be open to him, hopefully his physician might have provided referrals for Charles to talk with about this and other options. (Participant 30, Appendix B)

Factor B resolves ethical conflicts by maintaining that it is, ultimately, the patient’s decision that should determine the course of treatment and decide whether PAS or euthanasia is an appropriate option. The role of the physician is to assist the patient in making the right decision regarding PAS or euthanasia based on assessment of the patient’s condition and of the patient’s values.

Factor C

In this analysis, it is evident that Factor C believes that PAS and euthanasia are morally permissible. Factor C believes that assistance in dying is a right, deserving of constitutional protection, and an act of compassion that can be compatible with both the Judeo-Christian tradition and physicians’ professional duties and responsibilities to their patients. Factor C is also distinguished from Factor A and Factor B by its concern for patients made vulnerable to unwanted and pointless medical treatment imposed upon them by a medical system that refuses to allow patients to die on their own terms. Factor C believes that the legal and moral prohibition of PAS and euthanasia can also contribute to pointless suffering at the end of life. Factor C believes that continuing to live under conditions that are replete with suffering can be more harmful than death for some
patients and their significant others. Factor C further implies that there can be a duty to die under these circumstances (Hardwig, 2000). The scoring of statement 17 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>0</td>
<td>+4</td>
</tr>
</tbody>
</table>

(17) A society that does not confront or accept death creates a fear in many that when the end comes they will be kept alive—comatose or tethered to a respirator or in excruciating pain—against their will.

Factor C’s scoring of statement 17 (+4) indicates a strong concern that the medical and legal system, propelled by a combination of technological determinism and a refusal to “confront and accept death,” might force people to experience the end of their life “comatose or tethered to a respirator or in excruciating pain—against their will.” In “a society that does not confront or accept death,” technology can be used to keep people alive beyond the point where their life has any value. In such circumstances, misapplied technology becomes a chimerical solution to dying that is actually a means by which to avoid confronting the reality of death. Factor C may be challenging the broader medical culture that places the authority on physicians and the law to determine the course and timing of their patients’ deaths. The following two written responses to “The Case of Charles,” the first from a participant significantly loaded exclusively on Factor C, the second from a participant significantly loaded on both Factor B and Factor C are illustrative of Factor C’s concern about dying under conditions of which one disapproves.

In discussions with the physician, Charles should identify which components of care or treatment are futile (and likely expensive) and establish advance directives so that these things do not occur. (Participant 12, Appendix B)

I agree with the steps Charles has taken so far. I think Charles should agree to physician assisted suicide. His situation is hopeless. PAS is one
aspect of ensuring that everyone has the quality of life he or she wants. Whereas I don’t see suicides as an out for all of life’s difficulties, Charles’ situation is beyond being one of life’s difficulties. Voluntarily taking one’s life to minimize suffering and to add to the financial security of family is a compassionate act and when done with care and ritual can be a moving and spiritual act.

The physician was right to offer assisted suicide as an option. It’s technically a medical treatment. His appraisal of Charles’ condition is accurate (I assume), and he is offering an opportunity to end the suffering with dignity. (Participant 19, Appendix B)

The scoring of statements 1, 29 and 12 is shown as follows:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>-2</td>
<td>+2</td>
<td>+4</td>
</tr>
</tbody>
</table>

(1) If at the heart of our constitutional rights is our ability to act on our deepest beliefs about life, then the right to suicide and the right to assistance to suicide are prerogatives of every adult.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-2</td>
<td>-4</td>
</tr>
</tbody>
</table>

(29) Although I empathize with the despondency suffering creates for both patient and family, physician assisted suicide and euthanasia are an evasion of moral duty.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>-4</td>
<td>+2</td>
<td>+3</td>
</tr>
</tbody>
</table>

(12) Our body is our own, and our life should be subject to self-determination. We have then, the right to end our own life, and if we can’t accomplish this on our own, another person has a right to end it for us, as an act of compassion.

Factor C’s reaction to statement 1 (+4) indicates that Factor C believes that the right to assistance in dying is “at the heart of our constitutional rights” that protect “our ability to act on our deepest beliefs about life.” Factor C believes that assistance in dying is a moral right that needs constitutional protection, especially “in a society that does not confront and accept death.” The existence of an absolute or inalienable moral right generates corresponding absolute moral duties to uphold and protect that right (Tannsjo, 2002). The implication of statement 1 and statement 12 is that there is a right to assisted suicide, which implies that there is a person who has a duty to assist a person to suicide.
Presumably, physicians are best suited to provide assisted suicide, and therefore, have a moral duty to provide assisted suicide to their patients. Factor C believes that the prohibition against physician assisted dying is a violation of an absolute, moral right and a symptom of the inability of society to deal appropriately with death and dying.

Factor C’s strong negative reaction to statement 29 (-4), “Although I empathize with the despondency suffering creates for both patient and family, physician assisted suicide and euthanasia is an evasion of moral duty,” indicates that Factor C believes that PAS and euthanasia can be expressions of care, bolstered by empathy for others and, as such, are fully compatible with both physicians’ and patients’ moral duty. This suggests that Factor C also believes that physicians evade this moral duty when they refuse or are unable to offer PAS or euthanasia to patients who request it. Physicians have a duty to benefit their patients, which can include reducing their suffering. Factor C believes that patients have a moral right to decide the amount of suffering they wish to endure and impose upon others. Factor C may be proposing that there are reasonable circumstances where patients and their physicians have a moral duty to consider PAS or euthanasia when discussing end of life issues. Hardwig (2000) extends this idea in the form of a moral argument to establish that there can be a “duty to die” (p. 88), and that there are clear circumstances, specific to each person, where the duty to die is evident. These decisions must be made multilaterally with the patient’s family providing vital input. Hardwig argues that a duty to die indicates that a person must reflect upon the amount of emotional and financial hardship the dying process will create for family members and significant others, and decide whether this outweighs the benefits which extended life can
bestow upon one’s self and others. A person has a moral duty to die when life-extending measures impose an undue burden on the family, does not improve the patient’s quality of life, and when the “part of you that is loved will soon be gone or seriously compromised” (p. 90). Hardwig is alluding to the loss of personhood, which implies loss of consciousness, loss of a sense of past, present, or future, and the loss of communicative ability and other cognitive processes (see Singer, 2000 for a discussion of the concept of personhood). The scoring of statements 22 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-2</td>
<td>-4</td>
<td>-4</td>
</tr>
</tbody>
</table>

(22) Legalizing physician-assisted suicide would mean that patients could never trust their doctors again.

Factor C fears that physicians will fail to provide assistance in dying, and this failure contributes to patients feeling vulnerable to unwanted suffering at the end of life. Like Factor B, Factor C indicates a strong negative reaction to statement 22 (-4), “Legalizing physician-assisted suicide would mean that patients could never trust their doctors again,” which further demonstrates that Factor C believes that assistance in dying is compatible with physicians’ duty to help their patients and need not provoke a breach of trust between patients and their physicians. Factor C is concerned that current legislation against PAS is what leads to mistrust, and legalizing PAS may actually improve the trust between physicians and their patients. Factor C may be considering that the non-option of PAS is what creates mistrust between doctor and patient, at a crucial point at the end of a person’s life. However, Factor C believes that not only is physician assisted dying a moral right, but also an important expression of care and
compassion for others that is consistent with physicians’ moral and professional duty to respect the wishes of their patients, to gain and maintain their trust, and to prevent or reduce harm to their patients. The scoring of statements 10, 5 and 12 is shown as follows:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>+2</td>
<td>0</td>
<td>+3</td>
<td></td>
</tr>
</tbody>
</table>

(10) The greatest danger is not that patients will be over treated or their lives too long extended, but that socially burdensome patients—the poor, the elderly, and others without access to good health care—will become sacrificial victims on the altar of cost-benefit analysis.

-4 +2 +3 (5) Physician assisted death can be an appropriate response to desperate clinical situations.

-4 +2 +3 (12) Our body is our own, and our life should be subject to self-determination. We have then, the right to end our own life, and if we can’t accomplish this on our own, another person has a right to end it for us, as an act of compassion.

Factor C’s strong concern that patients will be kept alive through extraordinary, costly measures is also reflected in their response to statement 10. Although Factor C puts its strongest emphasis on the problem of unwanted life-extending measures, as in statement 17, “being tethered to a respirator…against their will,” Factor C is also concerned that the medical system will give preferential treatment to those who can afford it. Although statement 10 does not specifically mention PAS or euthanasia, it may evoke worries about a slippery slope that leads the “socially burdensome” to be pressured to choose PAS or euthanasia when methods of extending life are no longer cost-effective. Factor C may also be expressing a concern that some patients, particularly patients made vulnerable by lack of access to adequate health care, or lack of necessary information and
understanding about end of life care, can put them in a position in which they experience
dying in a way that they do not wish to and should not have to. However, it is unclear
whether or not Factor C is concerned that “socially burdensome” patients will be more or
less vulnerable to abuse in a regime of legal PAS and euthanasia, as opposed to the
existing legal climate, where PAS and euthanasia occur, but are unregulated. Factor C
may also believe that the problem of socially burdensome patients made vulnerable to
abuse or neglect by the medical system requires special attention and vigilance in general,
and in particular, when dealing with end of life care.

Clearly, Factor C has two conflicting worries relating to PAS and euthanasia.
One is that patients may suffer “against their will” at the end of life, and the other worry
is that vulnerable patients may be at risk due to an inability to afford life-extending
measures. Factor C places the priority on the personal plight of the patient in relation to
“desperate clinical situations,” as stated in statement 5. In so doing, Factor C addresses
the conflict by placing the locus of the decision for or against PAS or euthanasia with the
patient. Factor C may be suggesting in statement 5 that there are “desperate clinical
situations” where life can be preserved at a tremendous financial and emotional cost to
the patient and the patient’s significant others, but do not add to the quality of life for the
dying patient. Factor C suggests in statement 12 (+3) that self-determination should be
the final arbiter for the formation of professional ethics and public policy related to PAS
and euthanasia. The scoring of statement 24 is shown as follows:

A  B  C
+2  -1  -3 (24) Euthanasia is an affront to our Judeo-Christian tradition.
Factor C believes that patients need not relinquish their religious viewpoints in order to accept euthanasia as an appropriate option for those facing terminal illness. In addition, it may be the case that since Factor C believes that assistance in dying is an expression of care and compassion, it also believes that euthanasia is substantively consistent with the Judeo-Christian tradition. Factor C considers religious convictions to be based upon “our ability to act on our deepest beliefs about life,” as stated in statement 1. Factor C believes that in a society in which religion is essentially a private matter and the freedom to practice religion is constitutionally protected, the permissibility of assistance in dying is not an “affront” to another’s religious convictions. Thus, it appears that there is an important distinguishing feature of Factor C with respect to the role of religion in shaping end of life choices. Whereas Factor B believes that oppositional religious zealotry can present the greatest obstacle to patients exercising their personal autonomy and dying well, Factor C believes that euthanasia can be consistent with those who hold to a Judeo-Christian ethic.

Returning to the Design of the Concourse and the Selection of the Q Statements

The theoretical design of the concourse is based on the framework provided by Fins and Bacchetta (1995), which organizes the literature of PAS and euthanasia around three categories: deontology, consequentialism and clinical pragmatism. Using this framework, 12 statements from each of the three categories were selected, half of which were pro statements and half of which were anti statements (see Table 1). An analysis of variance was performed to determine whether the ethical categories or valence, which
influenced the design of the Q statements, had also significantly influenced the factor scores. The results of the analysis of variance are shown below in Table 3.

The results of the analysis of variance reveal that the ethical categories, each equally represented in the Q statements, had no significant effect on the Q factor scores for any of the three Q factors, Factors A, B, or C. This result is consistent with Fins and Bacchetta’s (1995) views about the debate over PAS:

> If we hope to reach some societal consensus on this issue, it is critical that the scholarly debate reflect the rich range of views and arguments that surrounds this confounding issue. Neither deontology, consequentialism, nor clinical pragmatism alone will satisfy our expectations or respond to our concerns. Instead it will be the mix of these arguments that will lead to the good care of the dying patient and the crafting of responsible public policy. (p. 567)

### Table 3. The influence of ethics and valence on the Q factor scores.

<table>
<thead>
<tr>
<th>Source of Variance</th>
<th>df</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics (E)</td>
<td>2</td>
<td>0.30</td>
<td>2.47</td>
<td>0.85</td>
</tr>
<tr>
<td>Valence (V)</td>
<td>1</td>
<td>5.56</td>
<td>9.48</td>
<td>4.32</td>
</tr>
<tr>
<td>(p=.025, anti&gt;pro)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E × V</td>
<td>2</td>
<td>0.13</td>
<td>2.52</td>
<td>1.27</td>
</tr>
<tr>
<td>(p=.046, pro&gt;anti)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>30</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Probabilities in parentheses are for Tukey’s test, followed by mean differences.
However, the valence of the Q statements, i.e., whether the Q statements expressed a pro or an anti PAS/euthanasia sentiment, did have a statistically significant effect on the factor scores for all of the three factors. Factor A preferred Q statements that were anti PAS/euthanasia, while both Factor B and Factor C preferred Q statements that were pro PAS/euthanasia. What this result suggests is that the framework that Fins and Bacchetta (1995) used to categorize the extant literature on PAS and euthanasia was less important to the participants in this study than the core belief in the rightness or wrongness of PAS and euthanasia. Each of the three factors drew upon a mix of moral sentiments, ethical precepts and ideas about the risks and benefits of PAS and euthanasia expressed in the Q statements to communicate its own position. Each of the three factors was guided by a general feeling about the rightness or wrongness of PAS and euthanasia, and the individuals comprising the factors constructed what they believed was the best expression of their position available within the parameters of the design of the Q statements.

For Factor A, it is the very notion that a competent person can voluntarily receive assistance in suicide from a physician that is forbidden irrespective of whatever safeguards are in place. Factor A is unconvinced by arguments about the moral equivalency of PAS and other commonly used means of accelerating the dying process, such as terminal sedation or withholding and withdrawing food and hydration. This finding is consistent with Frey’s (2001) argument that for some opponents of PAS, worries about slippery slopes and other forms of abuse “are not the essence of the matter: even though some people will make very extensive uses of them in their cases against
physician-assisted suicide, such worries are not the ground of their complaint against physician-assisted suicide” (p. 44). Factor B and Factor C similarly may have concerns about the safety of PAS and euthanasia, but what is most important for both Factor B and Factor C, although communicated in distinctive ways, is that physician assisted dying be made available for people who want it.

Policy Analysis

In this section, the participants’ public policy preferences and the relationship between the Q factors and public policy factors are analyzed and discussed. Participants in this study were asked to rate a set of 35 public policy related statements shown in Appendix C. Thirty-six of the 41 participants who completed the Q-sorting portion of the study also completed the public policy survey. The public policy survey scores were factor analyzed using SPSS 9.0 for Windows. A principal component analysis and varimax rotation was used resulting in a two factor solution. The two factors derived from the policy survey (referred to in the text and tables as policy Factors I and II) were then correlated with the three Q factors, referred to in the text as Q factors A, B and C. The correlation between the two policy factors and the three Q factors is shown in Table 4. The factor loadings of each participant in this study on the Q factors and policy factors as well as demographic and other relevant information about each participant is shown in Appendix B.
Table 4: Correlation of Q Factors and Policy Factors

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>-0.394</td>
<td>0.628</td>
<td>0.312</td>
</tr>
<tr>
<td>II</td>
<td>0.294</td>
<td>-0.029</td>
<td>-0.070</td>
</tr>
</tbody>
</table>

Boldface significant (p<.01).

Policy Factor I. The policy statement scores for Factor I show support for public policy that legalizes PAS with appropriate safeguards. Factor A and Factor C are not significantly loaded with either Factor I or II. Factor I is significantly correlated with Q Factor B (see Table 4), which had endorsed making PAS available for patients under certain conditions as one of their end of life care options. The association between Factor B and policy Factor I shows that there is a relationship between Factor B’s ethical disposition and its policy preferences. Participants on Factor B exhibit like mindedness in their public policy preferences similar to that which they exhibit in their Q statement scores.

Factor I supports a policy that legalizes and regulates PAS based on several requirements. These requirements define the parameters in which PAS should be permitted, including who should administer PAS, how the doctor-patient relationship is affected, and the role of federal insurance programs in PAS. The scoring of statement 18 is shown as follows:
Factor I’s response to statement 18, “Insure that individuals be permitted PAS if they suffer from a terminal illness that is intractable or a bodily illness that is unbearable,” indicates that Factor I does not limit PAS to terminal illness. Rather, it allows for the permissibility of PAS in cases in which individuals suffer an unbearable bodily illness. It is unclear whether this may include chronic illnesses that while not imminently life threatening, can still cause unbearable suffering. Statement 18 specifies that PAS is to be limited to bodily illness, which may indicate that Factor I is unclear about expanding the availability of PAS to individuals suffering from mental illness.

The scoring of statements 16 and 6 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>+1.21</td>
<td>-0.16</td>
</tr>
<tr>
<td>(16) Limit authorization for PAS to responsible physicians licensed to practice medicine in the state.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>+1.18</td>
<td>+0.32</td>
</tr>
<tr>
<td>(6) Make every effort to keep the physician-patient relationship confidential.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Statements 16 and 6 deal with who should administer PAS and how relationships with practitioners are defined. Factor I indicates that PAS should be regulated and the appropriate safeguards should be in place. Factor I believes in its response to statement 16 that there is a need to “limit authorization for PAS to responsible physicians licensed to practice in the state.” This safeguard would reduce the potential for abuse of assisted suicide, since physicians are bound by legal, professional, and ethical guidelines. Legalization of PAS would require the same standards be applied to PAS that are
currently applied to other medical procedures. The need for safeguards that protect both patients and physicians involved in PAS is consistent with Factor B’s belief that PAS is ethical and appropriate to a physician’s scope of practice. Restricting PAS to licensed practitioners can reduce the potential for harm to patients caused by non-physicians who do not have a formal code of professional ethics and legal responsibilities and may not have the requisite skills to assist patients in dying.

The scoring of statements 34, 9 and 33 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>34</td>
<td>-1.69</td>
<td>-1.43</td>
<td>Prevent PAS by instituting severe penalties (including fines, decertification, and imprisonment) that punish physicians for assisting a patient to commit suicide.</td>
</tr>
<tr>
<td>9</td>
<td>-1.39</td>
<td>-0.38</td>
<td>Require physicians to indicate the purpose of the prescription that they write so that practitioners opposed to a PAS law can opt out of filling the prescription.</td>
</tr>
<tr>
<td>33</td>
<td>+2.02</td>
<td>-1.24</td>
<td>Prohibit insurance companies from voiding the policies of patients who have chosen PAS in compliance with laws which permit suicide.</td>
</tr>
</tbody>
</table>

Statements 34, 9 and 33 are concerned with legal and financial obstacles to PAS. Factor I rejects penalizing physicians who administer PAS and pharmacists who fill prescriptions from physicians who prescribe medications for PAS. In addition, Factor I wants to prevent insurance companies from refusing to pay out survivor benefits to families of persons who choose PAS. The scoring of statement 34 shows that Factor I rejects a policy that punishes physicians who would participate in PAS under prescribed circumstances. In the scoring of statement 9, Factor I dispels a requirement to indicate the purpose of the prescription so that pharmacies can refuse to fill the prescription, and thereby enable pharmacies unilaterally to deny people the option of PAS. Factor I
implies that a physician who prescribes medication to a patient is presumably prescribing that medication in an ethical manner, and a pharmacist must honor the request from the physician.

The scoring of statements 12 and 13 is shown as follows:

<table>
<thead>
<tr>
<th>I</th>
<th>II</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>-1.60</td>
<td>-0.64</td>
<td>(12) Create a law prohibiting the crossing of state lines in order to obtain PAS, so as to prevent states like Oregon from becoming Meccas for people who want to end their lives with the help of a physician.</td>
</tr>
<tr>
<td>-1.99</td>
<td>+1.00</td>
<td>(13) Institute a policy within the Department of Health and Human Services that insures that federal money is not used for PAS.</td>
</tr>
</tbody>
</table>

Factor I’s response to statement 12 raises the issue of residency requirements as a determinant for the availability of PAS. Factor I does not support restrictions on crossing state lines to obtain PAS, which suggests that Factor I may believe that legalization of PAS should be federally protected and not a state policy issue. Factor I’s response to statement 13 dispels the proposition of prohibiting federal funding for PAS and euthanasia, which further supports the belief that the federal government has an interest to allow PAS. In short, participants on Factor I reject a policy that would make PAS essentially illegal or inordinately onerous to obtain.

Policy Factor II. The policy statement scores for Factor II indicate a reluctance to accept PAS, but also indicate that if PAS were to be legalized, then it should be highly restricted. Factor II is not significantly correlated with Factors A, B, or C (see Table 3). Participants on C do not reveal a pattern of policy choices that are consistent with other
participants on the same Q factor. The scoring of statements 10, 17, 25 and 4 is shown as follows:

<table>
<thead>
<tr>
<th>I</th>
<th>II</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>-0.14</td>
<td>-2.41</td>
<td>(10) Keep PAS a “poorly kept secret,” i.e., do not regulate the practice.</td>
</tr>
<tr>
<td>+0.70</td>
<td>+1.23</td>
<td>(17) Insure that a request for PAS is fully informed, reasoned, free of influence from others, and not the result of distorted judgment due to depression or other mental illness.</td>
</tr>
<tr>
<td>-0.57</td>
<td>+1.13</td>
<td>(25) Require the presence of at least two adults—one of whom should have no affiliation with the physician and could not benefit in any way from the patient’s death—to listen to witness the discussion of options and medical information with each patient.</td>
</tr>
<tr>
<td>0.00</td>
<td>-2.24</td>
<td>(4) Extend the option of PAS to chronically-ill patients and patients with mental illness as well as terminally ill patients.</td>
</tr>
</tbody>
</table>

Factor II’s response to statement 10 indicates that Factor II is most concerned with regulating and restricting PAS. Factor II stresses the importance of informed consent in its response to statement 17, and also indicates that the request for PAS should be an autonomous decision, “free of influence from others.” The scoring of statement 25 suggests that the presence of non-involved witnesses during doctor-patient discussion of PAS may be an appropriate safeguard to ensure that patients are not pressured into choosing PAS against their will. As indicated in statement 17, Factor II is also worried that patients with depression or mental illness may be unable to grant consent to PAS as a result of their mental illness. Therefore, Factor II would not authorize extending the use of PAS to patients with mental illness, nor those with chronic but not terminal illnesses as reflected in statement 4. Factor II clearly distinguishes that PAS is reserved for terminal patients only.
The scoring of statement 30, 33 and 34 is shown as follows:

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-0.80</td>
<td>+0.99</td>
</tr>
<tr>
<td>(30)</td>
<td>Permit health care facilities opposed to PAS as a matter of policy to prohibit their personnel from providing the medical means of suicide to patients who are within their facilities or under their care.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>+2.02</td>
<td>-1.24</td>
</tr>
<tr>
<td>(33)</td>
<td>Prohibit insurance companies from voiding the policies of patients who have chosen PAS in compliance with laws which permit suicide.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>-1.69</td>
<td>-1.43</td>
</tr>
<tr>
<td>(34)</td>
<td>Prevent PAS by instituting severe penalties (including fines, decertification, and imprisonment) that punish physicians for assisting a patient to suicide.</td>
<td></td>
</tr>
</tbody>
</table>

Factor II’s response to statement 30 indicates support of the prerogative of health care facilities to choose independently whether they will permit PAS in their facilities. Factor II’s response to statement 34 is similar to Factor I in that it does not support the punishment of physicians for participating in PAS. However, it does appear that there is support for the denial of insurance benefits to survivors of persons who choose PAS. These responses indicate that Factor II is most concerned with regulating PAS and making PAS onerous, if not impossible to obtain, rather than the outright criminalization of PAS. The results of the policy factor analysis show that whether or not there is support for legalizing PAS, there is no great interest among the participants in the study who completed the survey to punish severely physicians who knowingly participate in assisting their patients to commit suicide.

Conclusion

The first part of this chapter revealed that the Q analysis resulted in the emergence of three Q factors. Each Q factor represents a distinct perspective on the morality of PAS
The results of the policy survey showed the emergence of two policy factors, each of which represents a distinctive policy program. Factor I entails a consistent preference for PAS policy that insures access to PAS for patients with appropriate safeguards and removes onerous demands that would make access to PAS difficult or impossible. The other policy factor, which was not correlated with any of the Q factors, showed an interest in regulating PAS and including elements in a PAS policy that would make it possible for those actors involved, such as physicians, pharmacists, and hospital administrators who do not approve of PAS, to exclude themselves from participation in PAS.

Factor I correlated significantly with Factor B, which suggests that Factor B has a coherent policy program. Factor A does not correlate significantly with Factor I or II, but the difference between Factor A’s correlation with Factor I and its correlation with Factor II is statistically significant (see Table 3). Although Factor A was unable to articulate its interest in a policy program within the parameters of the policy survey, which contained disparate elements of a policy that would legalize PAS, the findings of the policy survey point towards a consensual political position within Factor A. Factor A rejects PAS and euthanasia under any conditions, which is a position that would either maintain the current status quo in the United States with respect to public policy preference, or alter the status quo by actively prosecuting physicians who engage in PAS. Factor C did not correlate significantly with either of the two policy factors, which suggests that Factor C does not have a coherent policy program that corresponds to its position on the morality of PAS and euthanasia.
CHAPTER 5

CONCLUSION

Physician assisted dying continues to be a divisive issue which provokes deeply held moral convictions. These moral convictions are made operant by Q methodology. The Q factors that emerge represent a self-referential perspective on the ethics of PAS and euthanasia. The use of Q methodology allows the participants in this study to articulate their attitudes, beliefs, and feelings about PAS and euthanasia. In this way, this study is not just an amalgamation of existing ethical theories relevant to PAS and euthanasia. Rather, this study is, in effect, a real-life debate over the ethics of PAS and euthanasia among people who, due to their professions, vocations, or personal experiences with death and dying, have an interest or expertise on the matter. The three factors that emerge in this study show three different perspectives on PAS and euthanasia. Through the use of Q methodology, this study has been able to extract the operant moral and ethical principles and precepts, many of which provoke conflict in the context of end of life care. The three factors that emerged have different approaches to resolving these conflicts for themselves. Future policy debates will be influenced by these different approaches. Factors B and C are representative of people affected by PAS and euthanasia, who for different reasons, maintain an interest in reforming PAS and euthanasia policy. Factor A is representative of an alternative in American society,
which believes that there is no reason to change existing legislation to allow PAS or euthanasia.

Chapters 1 and 2 summarized and discussed the long history of debates over physician assisted dying. The context of dying in modern America, including longer life expectancies, the comparatively high percentage of deaths in hospitals or long term care facilities, the reliance on technology, and the much longer length of time in which the dying process takes place are significant changes in the way people experience dying in the United States. However, Americans and their medical system as a whole have arguably fallen short of coping with the changes that have occurred in the dying process. Dying has perhaps always been a difficult part of human existence, but dying can be made better or worse by the way that it is approached, and modern approaches to dying have not always improved the dying process (Kastenbaum, 2004; Byock; 1997; Webb, 1997).

In Chapter 1, it was shown that the available evidence suggests that there has been a limited but persistent demand for physician assisted dying in the United States and that despite legal barriers, some physicians have admitted to helping their patients to commit suicide. It appears that efforts at improving palliative care, including treatment for depression and other psychological and emotional support, do not necessarily deter all patients from wanting assistance in dying. People who received assistance in dying under the Oregon Death with Dignity Act were financially secure, had health insurance, including access to hospice, and were usually more educated than the general population (Wineberg & Wirth, 2003). In addition, the major reasons for wanting assistance in
dying was the experience of loss of dignity and the inability to be involved in activities that had once made life worth living. Some opponents of physician assisted dying maintain that depression and other mental illnesses are the primary cause of requests for assistance in dying (Hendin, 1997). Other opponents of assisted dying argue that loss of dignity and pleasure in life must be coped with through a learning process that involves rethinking the concept of dignity and accepting the value of the experience of being cared for at the end of life (Byock, 1997; Hammer, 2000). Another major reason for opposition to PAS and euthanasia is that some people, particularly the poor and historically oppressed groups, may be pressured or coerced to choose assisted dying.

In Chapter 2, there was a discussion of the philosophical and legal debate over the distinction between killing and letting die. Many opponents of PAS, including the American Medical Association, fully accept the legality and morality of the distinction between withdrawing and withholding life sustaining treatment, including the use of terminal sedation, sometimes referred to as passive euthanasia, on one hand, and physician assisted dying, including PAS and euthanasia, on the other. Proponents of legalizing PAS and euthanasia deny the validity of the passive/active distinction. In addition, worries about slippery slopes and other issues related to the potential harmful consequences of legalizing PAS and euthanasia were also discussed.

Chapter 2 discussed the role of the courts and legislatures with respect to PAS and euthanasia. Legislators have generally eschewed policy making regarding PAS and euthanasia, ultimately giving the issue to the courts to decide. In 1997, the Supreme Court decided that there was no constitutional right to assistance in dying and in so doing,
gave the issue of PAS back to the state legislatures, which may either permit or prohibit PAS. In Chapter 2 there was also a discussion of the status of PAS as a morality policy as well as the role of the initiative and referendum process in reforming the illegal status of PAS, which ultimately resulted in the Oregon Death with Dignity Act, but failed to change the legal status of PAS anywhere else in the United States.

Chapters 3 and 4 discussed the research design and methods. Chapter 4 discussed findings of the Q analysis, the findings of the policy survey and the relationship between the Q factors and the policy factors. There Q analysis revealed three factors referred to as Factors A, B, and C. Each factor represents a distinct perspective on the ethics of PAS and euthanasia. The results of the policy survey revealed two policy factors referred to as Factors I and II. Factor B was the only factor that significantly correlated with a policy factor, which suggests that Factor B has a well articulated program for the reform of existing PAS policy in the United States. Factor B’s policy program would reform existing public policy to accommodate PAS with appropriate safeguards for both physicians and patients.

A comparison between these three factors reveals agreement on certain aspects relevant to end of life care. Factor A, Factor B, and Factor C are in agreement that, besides PAS and euthanasia, other means such as effective palliative care, the withholding of nutrition and hydration, and withholding or withdrawing life sustaining technology, can be used to improve and, if need be, accelerate the dying process. All three factors are unsure as to whether or not good hospice care can eliminate any incentive to demand PAS or euthanasia, which suggests that all three factors believe that
demand for PAS and euthanasia will not go away and will require ethical responses from the medical profession and from legislators.

Factor A is distinguished from Factors B and C by its essential and uncompromising belief that PAS and euthanasia are inimical to physicians’ moral duty and fundamentally wrong. Factor A’s position incorporates views about the proper role of the clinician, the meaning and limitations of personal autonomy, the proper relationship between physicians and their patients, and the duty of physicians not to be involved in killing. All of the elements of Factor A’s position indicate the belief in the need to continue the prohibition of PAS and euthanasia in professional medical ethics and the law, while also working towards conditions in which demand for PAS and euthanasia is minimized. Factor A believes that the best way to minimize demand for PAS and euthanasia is to maintain good clinical practice throughout the life cycle. If conditions reach a point where physicians believe that pain and physical distress are otherwise untreatable and death is imminent, Factor A believes that terminal sedation is acceptable. Factor A’s position is consistent with the American Medical Association’s (AMA) Code of Medical Ethics with respect to euthanasia and physician assisted suicide (Council on Ethical and Judicial Affairs, 2002). According to the AMA code for physician-assisted suicide:

Instead of engaging in physician-assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Patients should not be abandoned once it is determined that a cure is impossible. Multidisciplinary interventions should be sought, including specialty consultation, hospice care, pastoral support, family counseling and other modalities. Patients near the end of life must continue to receive emotional support, comfort care, adequate pain control, respect for patient autonomy, and good communication. (p. 74)
Factor B and Factor C would not object to the use of various modalities listed in the AMA code such as hospice care, family counseling, and pastoral support among others. Factor B placed a high priority on discussion with and listening to patients. PAS and euthanasia are acceptable to Factors B and C, but these factors do not claim that physician assisted dying is the only approach to coping with intractable suffering at the end of life. At the same time, Factors B and C believe that none of the alternatives to PAS and euthanasia is infallible and the conditions in which assisted dying is appropriate must, with appropriate safeguards, be defined subjectively by the individual patient. Both Factor B and Factor C emphasize enabling personal choices for patients with respect to their health care options at the end of life.

Factor C expresses a sharper focus than Factor B on the plight of people made vulnerable by lack of access to adequate health care. Factor C also expresses greater concern than Factor B about a medical and legal system embedded in a society that refuses to confront and accept death. Factor C is more focused than Factor B on the need for constitutional protection of a right to assistance in dying. Factor C is also more focused than Factor B on emphasizing that PAS and euthanasia do not signify a failure of physicians to follow their moral duty towards their patients and society. Factor C may also be indicating that in some circumstances there can be a duty to die.

It does not appear from the analysis of the Q sorts in this study that any of the three factors believe that there is a relevant moral distinction between PAS and euthanasia. Factor A appears to reject both PAS and euthanasia, while Factor B and Factor C appear to accept both PAS and euthanasia. This could have important policy
implications because legalizing PAS while prohibiting euthanasia, as is the case with the Oregon Death with Dignity Act, has been suggested as a “conservative” middle-ground position between prohibiting physician assistance in dying altogether and making both PAS and euthanasia available options for patients (Lee, 2003). Thus, the differences between Factor A on one hand, and Factor B and C on the other, suggest that there will be little room for compromise among the factors over the legal and ethical basis of PAS and euthanasia with respect to the meaning and limitations of personal autonomy and its relevance to PAS and euthanasia.

Factors B and C believe that physician assisted dying can, for some patients, increase the prospects for dying well and that the medical and legal system should evolve to accept that perspective. Factor B has in mind a policy program that would reform the existing legal system to accommodate its moral reasoning. However, Factor A is currently in a stronger position than Factors B or C to have its policy preferences met. Right to die advocates failed to convince the Supreme Court of a constitutionally protected right to die. In 1997, the Supreme Court determined that states could either permit or prohibit PAS. Factor A’s position is consistent with many religious doctrines, the American Medical Association’s guidelines and existing law in 49 states.

The main division regarding PAS and euthanasia among the participants in this study has chiefly to do with the conceptualization of killing at the end of life. Factors A, B and C can agree that death is not always a bad thing and that hastening the death of a patient to die is sometimes the best option. Both Factor B and Factor C can accept that physicians’ duty to avoid killing is not inviolate, but Factor A cannot. Factor A’s
position does not rest on whether or not PAS or euthanasia can, with appropriate safeguards, be made reasonably devoid of abuse. Rather, Factor A’s position rests on maintaining that a person cannot consent to being killed and that a physician’s moral duty is to avoid killing under any and all circumstances.

Barring any major changes in the results of the Death with Dignity Act in Oregon, which as yet appears to be devoid of apparent abuse, the debate over PAS and euthanasia will ultimately rest on the morality of physicians being involved in actively killing or aiding in the self-killing of their patients. Maintaining the validity of the double effect narrative is an essential component of Factor A’s dominant position in public policy debates. Factor A accepts the double effect while rejecting PAS and euthanasia, and in so doing obstructs the potential for patients and physicians to be put in what it views as an untenable position. Administering large quantities of opioids, withholding nutrition and hydration and withholding or withdrawing life sustaining technology are procedures that can hasten death while seemingly obscuring direct responsibility for doing so in a way that PAS and euthanasia cannot. Factor A is advantaged in the debate over reforming current public policy because it does not propose any policy program that could make physicians appear to be involved in killing. There is consensus that hospice care combined with public and professional education about the dying process and the latest developments in palliative care is the best way to relieve suffering of terminal patients. The opposition to legal PAS and euthanasia can argue that physicians can put an end to intractable suffering without resorting to PAS or euthanasia by relying on effective palliative care, including, at the physician’s discretion, the administration of
quantities of opioids that would probably hasten death. The doctrine of the double effect provides its own internal safeguards insofar as the patient must be in a terminal condition and medication must be appropriate to the goal of adequate pain relief in order for the double effect to be considered plausible. The key advantage of Factor A’s position is that it maintains the integrity of the medical profession. The key drawback is that there will continue to be demand for PAS and euthanasia from people who would prefer not to live with the conditions imposed on them by their illness, their caregivers and the law.
Appendix A: Factor Q Sort Values for Each Statement, N=36.

<table>
<thead>
<tr>
<th>Statement</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) If at the heart of our constitutional rights is our ability to act on our deepest beliefs about life, then the right to suicide and the right to assistance to suicide are the prerogatives of every adult.</td>
<td>-2</td>
<td>+2</td>
<td>+4</td>
</tr>
<tr>
<td>(2) Modern medicine has come to see a patient’s death as a failure and the unavoidable approach of death as a reason to back off rather than as a call for even more intensive medial engagement. But this is wrong-headed: all patients eventually die.</td>
<td>-2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>(3) The voluntariness associated with doctor-assisted suicide or euthanasia is apt to be less voluntary when decisions are made by patients’ surrogates, such as relatives, than when it is made by doctors.</td>
<td>-1</td>
<td>-1</td>
<td>+1</td>
</tr>
<tr>
<td>(4) To attempt to deny the distinction between active euthanasia and allowing to die is mistakenly to impute more power to human action than it actually has, and to accept the conceit that nature has now fallen wholly within the realm of human control.</td>
<td>0</td>
<td>-2</td>
<td>+1</td>
</tr>
<tr>
<td>(5) Physician-assisted death can be an appropriate response to desperate clinical situations.</td>
<td>-4</td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>(6) If euthanasia were made legal, it would complicate the process by bringing in a whole new set of actors – prosecutors, police, and other agents of criminal law.</td>
<td>+1</td>
<td>-1</td>
<td>0</td>
</tr>
<tr>
<td>(7) We are not authorized to make comparative judgments about the worth of lives, or to cut short the years that have been given us.</td>
<td>0</td>
<td>-2</td>
<td>+1</td>
</tr>
<tr>
<td>(8) The management of pain through drugs only leads to addiction, and can often hasten death. In a way, the chemical control of pain is a form of euthanasia.</td>
<td>-3</td>
<td>-3</td>
<td>-2</td>
</tr>
<tr>
<td>(9) Only the acceptance of active euthanasia will prevent the possibility of over treatment.</td>
<td>-3</td>
<td>-3</td>
<td>-3</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>10. The greatest danger is not that patients will be over treated or their lives too long extended, but that socially burdensome patients—the poor, the elderly, and others without access to good health care – will become sacrificial victims on the altar of cost-benefit analysis.</td>
<td>+2</td>
<td>0</td>
<td>+3</td>
</tr>
<tr>
<td>11. There should be a panel, like an institutional review board which regulates biomedical research, to regulate euthanasia.</td>
<td>-1</td>
<td>-1</td>
<td>+2</td>
</tr>
<tr>
<td>12. Our body is our own, and our life should be subject to self-determination. We have then, the right to end our own life, and if we can’t accomplish this on our own, another person has a right to end it for us, as an act of compassion.</td>
<td>-4</td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>13. It is ethical for physicians to provide effective pain medication, even if the medication may have the side effect of suppressing respiration and hastening death.</td>
<td>+2</td>
<td>+3</td>
<td>+2</td>
</tr>
<tr>
<td>14. A decent society should favor preserving life even when things seem extremely bad, especially in view of the fact that suicide seems remarkably contagious. Highly publicized suicide can create bandwagon effects.</td>
<td>0</td>
<td>-2</td>
<td>-2</td>
</tr>
<tr>
<td>15. Good hospice care can relieve all unpleasant symptoms and remove any incentive to die.</td>
<td>+1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>16. Walking away from a dying patient and denying that medicine can do anything to help is an immoral abrogation of medical power.</td>
<td>0</td>
<td>+1</td>
<td>+2</td>
</tr>
<tr>
<td>17. A society that does not confront or accept death creates a fear in many that when the end comes they will be kept alive – comatose or tethered to a respirator or in excruciating pain against their will.</td>
<td>0</td>
<td>+1</td>
<td>+4</td>
</tr>
<tr>
<td>18. Choice and control are distinctly human qualities.</td>
<td>+1</td>
<td>+2</td>
<td>0</td>
</tr>
<tr>
<td>19. A decision against assisted suicide risks cutting the roots out from under the tree of liberty.</td>
<td>-1</td>
<td>0</td>
<td>-2</td>
</tr>
</tbody>
</table>
### Appendix A: Factor Q Sort Values for Each Statement, N=36 (cont'd).

<table>
<thead>
<tr>
<th>Statement</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>(20) There is no morally significant difference between omission and commission within the context of withholding and withdrawing life-sustaining therapy and letting die.</td>
<td>+1</td>
</tr>
<tr>
<td>(21) The patient’s values should form the basis for the regimen to treatment.</td>
<td>+2</td>
</tr>
<tr>
<td>(22) Legalizing physician-assisted suicide would mean that patients could never truly trust their doctors again.</td>
<td>-2</td>
</tr>
<tr>
<td>(23) Withholding and withdrawing treatment is far more cruel than the ways physicians kill patients with euthanasia or assisted suicide.</td>
<td>-3</td>
</tr>
<tr>
<td>(24) Euthanasia is an affront to our Judeo-Christian tradition, which places a consistent and primary emphasis on the supreme value of life.</td>
<td>+2</td>
</tr>
<tr>
<td>(25) As a minimal standard of acceptable care, physicians should discuss issues of life-sustaining treatment with their patients during routine, nonemergency practice.</td>
<td>+4</td>
</tr>
<tr>
<td>(26) The doctor who has the authority to end life, even under carefully regulated conditions, will be more apt to do so in ambiguous situations.</td>
<td>-1</td>
</tr>
<tr>
<td>(27) People of faith have a right to follow their own creed, but they are not free to force their religious convictions on all the other members of a democratic society, and to compel those whose values differ with theirs to die painful, protracted and agonizing deaths.</td>
<td>0</td>
</tr>
<tr>
<td>(28) There is need to listen to patients, to bring them into the decision-making process, and to incorporate their values into their plan of care.</td>
<td>+3</td>
</tr>
<tr>
<td>(29) Although I empathize with the despondency that suffering creates for both patient and family, physician-assisted suicide and euthanasia are an evasion of moral duty.</td>
<td>+3</td>
</tr>
<tr>
<td>(30) There is no evidence that euthanasia will have any harmful consequences.</td>
<td>-2</td>
</tr>
</tbody>
</table>
### Appendix A: Factor Q Sort Values for Each Statement, N=36 (cont'd).

<table>
<thead>
<tr>
<th>(31) The suffering of a terminally ill person cannot be deemed any less intimate or personal, or any less deserving of protection from unwarranted government interference, than that of a pregnant woman. If the abortion choice is a fundamental constitutionally protected right, so too is the decision to commit suicide.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-2</td>
<td>+1</td>
<td>+1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(32) The same elements that mark good clinical practice throughout the life cycle should remain available to patients at the end of life.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+4</td>
<td>+2</td>
<td>+1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(33) Physicians forced to act in secret would become isolated and unable to consult colleagues or ethics committees for confirmation that their patient has made a rational decision.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>+1</td>
<td>+1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(34) Driving physician-assisted suicide underground, to be practiced by people like Dr. Kevorkian, creates more risk for vulnerable patients than would be the case with a clearly articulated public policy sanctioning the practice.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>-1</td>
<td>+1</td>
<td>-2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(35) Euthanasia trespasses the bounds of self-determination: Persons cannot consent to be killed.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+3</td>
<td>-4</td>
<td>-3</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(36) The prohibition against euthanasia has strengthened physicians’ commitment to supporting those who face death, has led to more attention to the complexities of care, and has overall improved attention to patients’ pain and suffering.</th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>+1</td>
<td>0</td>
<td>-1</td>
<td></td>
</tr>
</tbody>
</table>
**Appendix B: Participants' Factor Loadings and Demographic Data, n=41.**

<table>
<thead>
<tr>
<th>P</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>I</th>
<th>II</th>
<th>Age</th>
<th>Religion</th>
<th>Sex</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>66</td>
<td>29</td>
<td>-09</td>
<td>09</td>
<td>67</td>
<td>27</td>
<td>Catholic</td>
<td>F</td>
<td>4th Year Med Student</td>
</tr>
<tr>
<td>2</td>
<td>14</td>
<td>69</td>
<td>10</td>
<td>65</td>
<td>11</td>
<td>36</td>
<td>Protestant</td>
<td>F</td>
<td>Physician</td>
</tr>
<tr>
<td>3</td>
<td>-56</td>
<td>41</td>
<td>14</td>
<td>20</td>
<td>04</td>
<td>68</td>
<td>None</td>
<td>M</td>
<td>Professor: History</td>
</tr>
<tr>
<td>4</td>
<td>-23</td>
<td>61</td>
<td>-18</td>
<td>44</td>
<td>39</td>
<td>48</td>
<td>Protestant</td>
<td>M</td>
<td>Funeral Director</td>
</tr>
<tr>
<td>5</td>
<td>-21</td>
<td>74</td>
<td>26</td>
<td>50</td>
<td>60</td>
<td>61</td>
<td>Catholic</td>
<td>F</td>
<td>Professor: Nursing</td>
</tr>
<tr>
<td>6</td>
<td>40</td>
<td>38</td>
<td>-33</td>
<td>-05</td>
<td>72</td>
<td>76</td>
<td>Protestant</td>
<td>F</td>
<td>Retired Nurse</td>
</tr>
<tr>
<td>7</td>
<td>13</td>
<td>33</td>
<td>73</td>
<td>63</td>
<td>50</td>
<td>55</td>
<td>None</td>
<td>F</td>
<td>Nurse</td>
</tr>
<tr>
<td>8</td>
<td>34</td>
<td>71</td>
<td>40</td>
<td>70</td>
<td>53</td>
<td>60</td>
<td>Protestant</td>
<td>F</td>
<td>Social Worker, Hospice Nurse</td>
</tr>
<tr>
<td>9</td>
<td>-07</td>
<td>69</td>
<td>21</td>
<td>52</td>
<td>68</td>
<td>31</td>
<td>Catholic</td>
<td>M</td>
<td>Physician</td>
</tr>
<tr>
<td>10</td>
<td>-29</td>
<td>39</td>
<td>58</td>
<td>53</td>
<td>39</td>
<td>70</td>
<td>Protestant</td>
<td>M</td>
<td>Physician</td>
</tr>
<tr>
<td>11</td>
<td>09</td>
<td>76</td>
<td>18</td>
<td>59</td>
<td>28</td>
<td>50</td>
<td>Jewish</td>
<td>F</td>
<td>Nurse Practitioner</td>
</tr>
<tr>
<td>12</td>
<td>-15</td>
<td>32</td>
<td>54</td>
<td>55</td>
<td>20</td>
<td>49</td>
<td>Catholic</td>
<td>F</td>
<td>Nurse</td>
</tr>
<tr>
<td>13</td>
<td>47</td>
<td>67</td>
<td>-02</td>
<td>49</td>
<td>54</td>
<td>45</td>
<td>Catholic</td>
<td>F</td>
<td>Nurse</td>
</tr>
<tr>
<td>14</td>
<td>-02</td>
<td>87</td>
<td>10</td>
<td>42</td>
<td>40</td>
<td>42</td>
<td>Catholic</td>
<td>F</td>
<td>Nurse</td>
</tr>
<tr>
<td>15</td>
<td>21</td>
<td>31</td>
<td>23</td>
<td>39</td>
<td>67</td>
<td>53</td>
<td>Protestant</td>
<td>M</td>
<td>Professor and Ethicist</td>
</tr>
<tr>
<td>16</td>
<td>-34</td>
<td>66</td>
<td>33</td>
<td>79</td>
<td>24</td>
<td>31</td>
<td>Jewish</td>
<td>F</td>
<td>Professor: Philosophy</td>
</tr>
<tr>
<td>17</td>
<td>-11</td>
<td>44</td>
<td>40</td>
<td>55</td>
<td>09</td>
<td>50</td>
<td>Protestant</td>
<td>M</td>
<td>Physician</td>
</tr>
<tr>
<td>18</td>
<td>67</td>
<td>01</td>
<td>-15</td>
<td></td>
<td></td>
<td>43</td>
<td>Catholic</td>
<td>M</td>
<td>Professor: Philosophy</td>
</tr>
<tr>
<td>19</td>
<td>21</td>
<td>61</td>
<td>03</td>
<td>77</td>
<td>33</td>
<td>44</td>
<td>Catholic</td>
<td>M</td>
<td>Hospital President</td>
</tr>
<tr>
<td>20</td>
<td>-13</td>
<td>61</td>
<td>21</td>
<td>63</td>
<td>13</td>
<td>51</td>
<td>None</td>
<td>M</td>
<td>Attorney</td>
</tr>
<tr>
<td>21</td>
<td>58</td>
<td>10</td>
<td>08</td>
<td>50</td>
<td>56</td>
<td>62</td>
<td>Catholic</td>
<td>F</td>
<td>Nurse</td>
</tr>
<tr>
<td>22</td>
<td>63</td>
<td>24</td>
<td>02</td>
<td>-01</td>
<td>57</td>
<td>60</td>
<td>Catholic</td>
<td>M</td>
<td>Physician</td>
</tr>
<tr>
<td>23</td>
<td>-19</td>
<td>75</td>
<td>21</td>
<td>85</td>
<td>-01</td>
<td>51</td>
<td>None</td>
<td>M</td>
<td>Physician</td>
</tr>
<tr>
<td>24</td>
<td>08</td>
<td>57</td>
<td>08</td>
<td>65</td>
<td>-07</td>
<td>58</td>
<td>Protestant</td>
<td>M</td>
<td>Clergy: Presbyterian Minister</td>
</tr>
<tr>
<td>25</td>
<td>65</td>
<td>34</td>
<td>-01</td>
<td>21</td>
<td>52</td>
<td>46</td>
<td>Protestant</td>
<td>F</td>
<td>Physician</td>
</tr>
<tr>
<td>26</td>
<td>-11</td>
<td>63</td>
<td>31</td>
<td>50</td>
<td>54</td>
<td>19</td>
<td>None</td>
<td>F</td>
<td>College Student</td>
</tr>
<tr>
<td>27</td>
<td>-19</td>
<td>85</td>
<td>04</td>
<td></td>
<td></td>
<td>58</td>
<td>Jewish</td>
<td>M</td>
<td>Clergy: Rabbi</td>
</tr>
<tr>
<td>28</td>
<td>-15</td>
<td>49</td>
<td>28</td>
<td>85</td>
<td>28</td>
<td>37</td>
<td>None</td>
<td>M</td>
<td>Librarian</td>
</tr>
<tr>
<td>29</td>
<td>-07</td>
<td>56</td>
<td>49</td>
<td>70</td>
<td>43</td>
<td>62</td>
<td>None</td>
<td>F</td>
<td>Elementary School Teacher and Psychological Counselor</td>
</tr>
<tr>
<td>30</td>
<td>-44</td>
<td>59</td>
<td>10</td>
<td>73</td>
<td>-21</td>
<td>60</td>
<td>Protestant</td>
<td>M</td>
<td>Clergy: Minister</td>
</tr>
<tr>
<td>31</td>
<td>-24</td>
<td>63</td>
<td>23</td>
<td></td>
<td></td>
<td>79</td>
<td>Quaker</td>
<td>M</td>
<td>Professor: Chemistry</td>
</tr>
</tbody>
</table>

*Note: Decimals to two places omitted; loadings in boldface significant (p<.01).*
Appendix B: Participants’ Factor Loadings and Demographic Data, n= 41 (cont’d).

<table>
<thead>
<tr>
<th>P</th>
<th>Q Factors</th>
<th>Policy Factors</th>
<th>Age</th>
<th>Religion</th>
<th>Sex</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>I</td>
<td>II</td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>34</td>
<td>37</td>
<td>32</td>
<td>30</td>
<td>58</td>
<td>43</td>
</tr>
<tr>
<td>33</td>
<td>-49</td>
<td>41</td>
<td>38</td>
<td>68</td>
<td>37</td>
<td>44</td>
</tr>
<tr>
<td>34</td>
<td>56</td>
<td>18</td>
<td>0</td>
<td>-11</td>
<td>63</td>
<td>25</td>
</tr>
<tr>
<td>35</td>
<td>-20</td>
<td>75</td>
<td>38</td>
<td>47</td>
<td>Soto Zen</td>
<td>M</td>
</tr>
<tr>
<td>36</td>
<td>60</td>
<td>26</td>
<td>06</td>
<td>45</td>
<td>35</td>
<td>53</td>
</tr>
<tr>
<td>37</td>
<td>43</td>
<td>19</td>
<td>01</td>
<td>-07</td>
<td>69</td>
<td>53</td>
</tr>
<tr>
<td>38</td>
<td>46</td>
<td>41</td>
<td>-03</td>
<td>66</td>
<td>14</td>
<td>53</td>
</tr>
<tr>
<td>39</td>
<td>14</td>
<td>67</td>
<td>26</td>
<td>47</td>
<td>Neopagan</td>
<td>F</td>
</tr>
<tr>
<td>40</td>
<td>-08</td>
<td>61</td>
<td>24</td>
<td>66</td>
<td>14</td>
<td>48</td>
</tr>
<tr>
<td>41</td>
<td>47</td>
<td>31</td>
<td>-07</td>
<td>50</td>
<td>Catholic</td>
<td>F</td>
</tr>
</tbody>
</table>

Note: Decimals to two places omitted; loadings in boldface significant (p<.01).
### Appendix C: Policy Factor Scores, N=35

<table>
<thead>
<tr>
<th>Policy Factor</th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Use the United States Drug Enforcement Agency to control physicians’ use of lethal drugs.</td>
<td>-.98</td>
<td>-1.17</td>
</tr>
<tr>
<td>(2) Institute a policy that patients seeking PAS must initiate contact with the physician themselves; i.e. prevent physicians from making the initial contact.</td>
<td>-.68</td>
<td>.97</td>
</tr>
<tr>
<td>(3) Limit the option of PAS to patients who are diagnosed with a terminal illness and who have no more than six months left to live.</td>
<td>-.79</td>
<td>.69</td>
</tr>
<tr>
<td>(4) Extend the option of PAS to chronically-ill patients and patients with mental illnesses as well as terminally-ill patients.</td>
<td>0</td>
<td>-2.24</td>
</tr>
<tr>
<td>(5) Collect information and statistics on all cases of PAS and make the data available to the public.</td>
<td>.65</td>
<td>.49</td>
</tr>
<tr>
<td>(6) Make every effort to keep the physician-patient relationship confidential.</td>
<td>1.18</td>
<td>.32</td>
</tr>
<tr>
<td>(7) Create a federal agency that is responsible for monitoring and collecting data on PAS.</td>
<td>-.65</td>
<td>-.63</td>
</tr>
<tr>
<td>(8) Impose a residency requirement for patients who seek PAS and require options for patients with no access to hospice care.</td>
<td>-.76</td>
<td>-.42</td>
</tr>
<tr>
<td>(9) Require physicians to indicate the purpose of the prescriptions that they write so that practitioners opposed to a PAS law can opt out of filling the prescription.</td>
<td>-1.39</td>
<td>-.38</td>
</tr>
<tr>
<td>(10) Keep PAS a “poorly kept secret,” i.e., do not regulate the practice.</td>
<td>-.14</td>
<td>-2.41</td>
</tr>
</tbody>
</table>
### Appendix C: Policy Factor Scores, N=35 (cont’d).

<table>
<thead>
<tr>
<th>Policy Statement</th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>(12) Create a law prohibiting the crossing of state lines in order to obtain a PAS, so as to prevent states like Oregon from becoming Meccas for people who want to end their lives with the help of a physician.</td>
<td>-1.60</td>
<td>-.64</td>
</tr>
<tr>
<td>(13) Institute a policy within the Department of Health and Human Services that insures that federal money is not used for PAS.</td>
<td>-1.99</td>
<td>1.00</td>
</tr>
<tr>
<td>(14) Remove restrictions requiring a dying patient to obtain a mental health evaluation prior to seeking a PAS.</td>
<td>-.77</td>
<td>-.61</td>
</tr>
<tr>
<td>(15) Require that patients seeking an assisted suicide be adults, i.e., 18 years of age or older.</td>
<td>-.22</td>
<td>.95</td>
</tr>
<tr>
<td>(16) Limit authorization for PAS to responsible physicians licensed to practice medicine in the state.</td>
<td>1.21</td>
<td>-.16</td>
</tr>
<tr>
<td>(17) Insure that a request for PAS is fully informed, reasoned, free of influence from others, and not the result of distorted judgment due to depression or other mental illness.</td>
<td>.70</td>
<td>1.23</td>
</tr>
<tr>
<td>(18) Insure that individuals be permitted a PAS if they suffer from a terminal illness that is intractable or a bodily illness that is unbearable.</td>
<td>1.79</td>
<td>-1.19</td>
</tr>
<tr>
<td>(19) Establish mechanisms and procedures for continuing oversight and regulation of physician-assisted dying.</td>
<td>-.10</td>
<td>.51</td>
</tr>
<tr>
<td>(20) Require that patients repeat their requests for PAS on at least two separate occasions without self-contradiction.</td>
<td>-.09</td>
<td>.93</td>
</tr>
<tr>
<td>(21) Make available to all patients any medical and hospice care that is consistent with accepted practice for the purpose of curing illness or alleviating painful symptoms.</td>
<td>.82</td>
<td>1.02</td>
</tr>
</tbody>
</table>
### Appendix C: Policy Factor Scores, N=35 (cont’d).

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Counsel patients to inform their families of their PAS request if they have not already done so.</td>
<td>.33</td>
</tr>
<tr>
<td>24</td>
<td>Discuss with patients <em>all</em> information that would be necessary for making a reasoned choice, including diagnosis, prognosis, treatment options, the medical means of suicide, and the benefits and burdens of all these.</td>
<td>1.10</td>
</tr>
<tr>
<td>25</td>
<td>Require the presence of at least two adults—one of whom should have no affiliation with the physician and could not benefit in any way from the patient’s death—to witness the discussion of options and medical information with each patient.</td>
<td>-.57</td>
</tr>
<tr>
<td>26</td>
<td>Document the discussion between physician and patient regarding PAS, and require that witnesses attest in writing to the accuracy of the documentation.</td>
<td>-.24</td>
</tr>
<tr>
<td>27</td>
<td>Before PAS is even considered, require the written opinion of a qualified physician that the patient is suffering from a terminal illness that is intractable and unbearable.</td>
<td>.36</td>
</tr>
<tr>
<td>28</td>
<td>Before PAS is considered, require the written opinion of a psychiatrist or clinical psychologist that the patients’ judgment is not being distorted by depression or other mental illness, and that the patient is free of undue influence by any other means.</td>
<td>-.03</td>
</tr>
<tr>
<td>29</td>
<td>Provide legal protection for those opposed to PAS from being required to assist physicians in administering the medical means of suicide.</td>
<td>.42</td>
</tr>
<tr>
<td>30</td>
<td>Permit health care facilities opposed to PAS as a matter of policy to prohibit their personnel from providing the medical means of suicide to patients who are within their facilities or under their care.</td>
<td>-.80</td>
</tr>
<tr>
<td>31</td>
<td>Prevent physicians, health care facilities, insurance companies, and any other agencies associated with health care from requiring individuals to request PAS as a condition of eligibility for services or benefits.</td>
<td>1.53</td>
</tr>
</tbody>
</table>
**Appendix C: Policy Factor Scores, N=35 (cont’d).**

<table>
<thead>
<tr>
<th>Policy Factor Score</th>
<th>I</th>
<th>II</th>
</tr>
</thead>
<tbody>
<tr>
<td>(32) Prevent physicians, health care facilities, insurance companies, and any other agencies associated with health care from refusing services or benefits to patients requesting PAS.</td>
<td>.89</td>
<td>-.63</td>
</tr>
<tr>
<td>(33) Prohibit insurance companies from voiding the policies of patients who have chosen PAS in compliance with laws which permit suicide.</td>
<td>2.02</td>
<td>-1.24</td>
</tr>
<tr>
<td>(34) Prevent PAS by instituting severe penalties (including fines, decertification, and imprisonment) that punish physicians for assisting a patient to commit suicide.</td>
<td>-1.69</td>
<td>-1.43</td>
</tr>
<tr>
<td>(35) Retain the status quo—that is, do not legalize PAS, but do not prosecute physicians who assist in dying either.</td>
<td>-.76</td>
<td>-.93</td>
</tr>
</tbody>
</table>
Appendix D: Consent Form

Consent for Participation in a Study about Physician Assisted Suicide, Aid in Dying and Public Policy

Physician assisted suicide is an important ethical and public policy issue. This study examines the relationship between ethical positions and public policy dealing with the regulation and practice of physician assisted suicide and euthanasia.

Were you to agree to participate, it would take about 45 minutes of your time, during which you will be asked to represent your thoughts on the matter by (1) writing a brief response to a short essay, (2) ranking a set of 36 statements according to the extent to which you agree with them, and (3) ranking a second set of 35 statements according to the extent to which you agree with them.

Some other questions would be asked of you, including age, gender, ethnicity, professional role, religion and political affiliation. This information is optional and will be kept confidential.

Participation is entirely voluntary and you are free to terminate your involvement at any time. To assure confidentiality, your name is optional and need not appear on any of the forms containing your responses. No one will be aware of your identity except the person who is conducting the research for this study; if your name appears on the score sheet, then your identity will also be known by a faculty advisor.

Your participation in this study may benefit you in terms of allowing to clarify your own views on the subject of this study. If you desire, I would be glad to provide you with a summary of the findings following the completion of the study.

If you would like to know more about this study, please feel free to contact me at (330) - 672-2060 (office) or (330) 297-7739 (home) or email: tnewman@kent.edu. This study has been approved by Kent State University. If you have any questions regarding Kent State University’s rules for research please contact Dr. M. Thomas Jones, phone (330) 672-2851.

Sincerely.

Timothy D. Newman
Doctoral Candidate

I agree to take part in this project. I know what I will have to do and that I can stop at any time:

Signature ___________________________ Date ___________________________

160
REFERENCES


*Quill v. Vacco*, 80 F. 3d 716 2nd Cir. (1996).


Tolbert, C. J., (2001). Public policy and direct democracy in the twentieth century: The more things change, the more they stay the same. In M. D. Waters (Ed.), *The battle over citizen lawmaking* (pp. 35-55). Durham, NC: Carolina Academic Press.


