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ANALYSIS OF SELECTED FACTORS AS PREDICTORS OF SURVIVING FAMILY MEMBERS' ATTITUDES TOWARD EUTHANASIA

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Jeffrey Lee Hoyer
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DEDICATION

This dissertation is dedicated to the memory of my father, Virgil Hoyer who died April 27, 1999. Although he did not live long enough to see me complete my doctoral program, through the process of dying he taught me the value of life.

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Abstract

The purpose of this cross-sectional study was to analyze factors which may relate to surviving family members' attitudes toward euthanasia and to determine their significance, if any. This research used data which were collected by telephone survey from a sampling frame comprised of adult surviving family members whose names were listed in the *Knoxville News Sentinel* between July 1997 and April 1998. One thousand, six hundred seventy eight adults were listed on the sampling frame. Three hundred forty nine persons were randomly selected from the population to ensure a 95% confidence level and a permissible error of ± .04. The response rate based on the number of persons completing the survey relative to the number in the sample was 38%. The response rate which took into consideration those in the sample who were noneligible and nonreachable was 85%.

The survey instrument was comprised of three scales: a euthanasia preference scale, a general self-efficacy scale, and an intrinsic religious orientation scale. Additionally, respondents were asked to complete a demographics section.

A pilot study was carried out using sixty persons randomly drawn from the sampling frame to assess the survey instrument. SPSS® was used to carry out an item analysis of the scales resulting in the following Cronbach Alpha values: euthanasia scale (.76); self-efficacy scale (.84); and , intrinsic religious orientation scale (.66).

Data were analyzed using regression analysis in SPSS®. Following the data analysis, it was concluded that the correlation (-0.44 at $p<0.001$) and regression model ($p<0.001$) show that there is a significant inverse relationship between the euthanasia and intrinsic

religious orientation scores in this study. However, relationships between other predictors did not exist or were not able to be tested in this study due to paucity of data in some data cells.

In conclusion, within the limitations of this study, intrinsic religious orientation is a predictor of euthanasia preference among surviving immediate family members.

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CHAPTER I

INTRODUCTION

The term "euthanasia" comes from the Greek "eu" which means "well" and "thantos" which means "death. (Hendin, 1973). Tordella (1977) defines euthanasia as "the act of allowing or inducing death for merciful reasons which may include the act of withdrawing or withholding treatment." This definition encompasses the two main elements found in most definitions of euthanasia--that the outcome is death and that the death induced either directly (active euthanasia--termination of life) or indirectly (passive euthanasia such as withholding or withdrawing treatment) was done for merciful reasons. Although the meaning of the term (well death) is simple, its interpretation has affected legal, medical, and social controversy as far back as Hippocrates who said, "I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect." This view is the philosophical basis for the Hippocratic Oath taken by doctors today which promises to relieve suffering and prolong and protect life (Doukas,Waterhouse, Gorenflow & Seid, 1995). However, with the advances in medical technology and availability of new drugs, physicians are forced to deal not only with medical decisions, but also with the controversy involving ethical considerations of interventions that end a person's life (Rushton & Terry, 1995).

Euthanasia as a movement in the U.S. can be traced back to 1938 when the Euthanasia Society of America was established (Wintersheimer, 1995). In recent years,

media attention in the U.S. has focused on the topic due in part to landmark cases such as *Cruzan v. Director, Missouri Department of Health* and the *Quinlan* court case where surrogate decisions were questioned and decisions made on withdrawal of support based on the patients informal comments before the patient entered the vegetative state and incompetency (King, 1991). Euthanasia has become especially salient in current social debate because in the contemporary arena of medical ethics and philosophy, "quality of life" has become almost as important as the biological definition of death (Koop, 1989; Schewe & Ritz, 1994). The decisions surrounding death especially through euthanasia have become complex "including the definitions of life and death, and of human personhood, the question of the meaning, value, and purpose of human life, and the dilemma posed by our various duties to ourselves, our families, patients, clients, and society at large" (Smolin, 1994).

Problem Statement

The problem in this study was to determine if general self-efficacy, intrinsic religious orientation, and selected demographic variables could serve as predictors of attitude toward euthanasia among surviving immediate family members.

Purpose of Study

The purpose of the study was to analyze factors which may relate to surviving immediate family members' attitude toward euthanasia and to determine their significance, if any. The study population consisted of adults (persons over 18) who were identified

as immediate family members of deceased persons whose death was reported in the obituaries printed in the *Knoxville News Sentinel* from July 1997 through April 1998. This study was delimited to: 1) family members (mother, father, husband, wife, daughter, son, brother, sister) of persons whose death was reported in obituaries which appeared in the Knoxville *News Sentinel* from July 1997 through April 1998 (Note: the sample was drawn in retrospect from the 1997-1998 time frame to ensure the participating family members would have a greiving time before being contacted) with the sample being drawn through systematic random sampling; 2) participants who were adults (minimum age 18); and 3) respondents who could be contacted by telephone.

The factors identified for analysis in this study were: general self-efficacy, intrinsic religious orientation, respondent's age, respondent's education level, age of the deceased, respondent's family income level, length of illness, race, gender, religious preference, and relationship to the deceased.

Research Question

The purpose of the study was specifically addressed by the assessment of the following research question:

> What relationship, if any, is there between a surviving immediate family member's attitude toward euthanasia and general self-efficacy, intrinsic relgious orientation, respondent's age, respondent's formal education level, age of the deceased, respondent's annual family income level, length of illness, race, gender, religious preference, and relationship to the deceased?

Need For the Study

Markson (1995) notes that the issue of how and when we die is important because the cost of health care is the most rapidly rising portion of the consumer index. Markson (1995) notes, "Medicare expenses are the highest in the last year of life and an estimated 37 million people remain uninsured making euthanasia increasingly salient." Studies also suggest that doctors and other health care providers are often hesitant to consider the family's and often the patient's wishes regarding advance directives because they are busy, afraid of upsetting the patients, may have a lack of experience regarding advance directives procedures, or may be concerned about legal ramifications (Bedell & Delbanco, 1984; Bedell, Pelle & Majer, 1986).

Most euthanasia research has focused on health care providers (Baume, O'Malley & Bauman , 1995; Christakis & Asch, 1995; Doukas *et al.*, 1995; Fins & Bacchetta, 1994; Pijnenborg, van Delden, Kardaun, Glerum, and van der Maas, 1994; Rushton & Terry, 1995). Many of these studies reveal that many health care providers do not communicate with their patient's families effectively, and because of their personal commitment to sustaining life, are not always interested in hearing or doing what the immediate family wants if it is contrary to opinions held by the health care providers.

Additionally, with advances in medicine, a patient can be kept "alive" longer, but may experience a severe reduction in the quality of life (Koop, 1989). With health care costs rising sharply and many persons uninsured, there is debate in the medical ethics

community questioning whether money should be spent on cases which appear to be hopeless since provision of healthcare is a limited resource (Markson, 1995)

Although uncommon in the United States, in Britain and the Netherlands, the practice of euthanasia is common (Seale & Hall, 1995). In recent years, the issue of euthanasia in the U.S. has become salient, due in part to media coverage of landmark legal cases such as *Cruzan v. Director, Missouri Department of Health* and the *Quinlan* court case where surrogate decisions were questioned and decisions made regarding withdrawal of support based on the patients informal comments before the patient entered the vegetative state and incompetency (King, 1991).

Medical costs are increasing. The health care industry, through advanced technology, is able to support life beyond limits even imaginable a few years ago. Legal issues surrounding both support and withdrawal of life support are becoming increasingly complex. Research on the attitudes held by family members of ill or deceased patients regarding euthanasia is limited (Rothchild, 1994; Seale and Hall, 1995a; Seale and Hall, 1995b). However, immediate family members are often asked to interpret and make life-support decisions (withholding or withdrawing treatment, assignment of durable power of attorney, and living wills). Therefore, the study proposed by this paper would: 1) add to the literature, 2) assist health care providers in better understanding the role of family members in making medical decisions, and 3) assist religious and other support professionals in helping family members during the difficult times of decision making by helping them understand the variables which may influence decision-making behavior.

Assumptions

The following assumptions were made regarding this study:

1. Family members have attitudes toward euthanasia and these attitudes could be evaluated through use of a self-report survey.
2. Family members participating in the study responded to the questionnaire truthfully.
3. The scales used in the study are reliable and valid instruments.

Delimitations of the Study

This study was delimited to:

1. family members (mother, father, husband, wife, daughter, son, brother, sister) of persons whose death was reported in obituaries which appeared in the Knoxville *News Sentinel* from July 1997 through April 1998 (Note: the sample was drawn in retrospect from the 1997-1998 timeframe to ensure the participating family members would have a greiving time before being contacted) with the sample being drawn through systematic random sampling;
2. participants who were adults (minimum age 18); and
3. respondents who could be contacted by telephone.

Limitations of the Study

The following limitations were made

1. The survey instrument (questionnaire) used in this study required self-report.

2. The participants responded while in varied settings.

3. Use of a homogeneous sample resulted in paucity in some data cells.

4. Generalizability is limited to the study population represented by the sampling frame.

Definitions of Terms

The following definition of "euthanasia," was selected to ensure internal consistency because it was the one used for development of the euthanasia scale used in this study (Tordella, 1977).

Euthanasia: the act of allowing or inducing death for merciful reasons which may include the act of withdrawing or withholding treatment (Tordella, 1977).

Other defined terms include:

General Self-Efficacy: a person's ability to cope with a large variety of stressors as measured by the self-efficacy scale used in the study (Schwarzer, 1994).

Intrinsic Religious Orientation: The direct application of one's religious beliefs to daily life and the response to it (Feagin, 1964).

Euthanasia Favorableness or Unfavorableness: The degree, as determined by the Tordella Scale, to which an individual favors or does not favor allowing or inducing death for merciful reasons including the act of withdrawing or withholding treatment (Tordella, 1977).

Chapter Summary

This chapter has provided a brief introduction to the study and described the study problem, study purpose, research question, need for the study, assumptions, study delimitations, limitations, and definitions of terms which may need to be operationally defined for the study.

The purpose of the study was to analyze factors which may relate to surviving immediate family members' attitude toward euthanasia and to determine their significance, if any. The need for this study is supported by a review of the literature which shows that studies surveying family attitudes regarding euthanasia are extremely limited. Additionally, the topic of euthanasia and families attitudes regarding it are more salient with increases in life expectancy, increases in the cost of health care, and the advances in technology supporting life since more and more families will face the economic realities of providing care to an aging family members and find themselves left with decisions which may include euthanasia. Koop (1989) notes with advances in medicine, a patient can be kept "alive" longer, but may have decreased quality of life. As laws are made and the legal, moral, and philosophical issues are debated, the attitudes of family members regarding euthanasia need to be considered. Decisions need to reflect not only the attitude of health care providers, but also family members.

CHAPTER II

LITERATURE REVIEW

Literature and Studies Related in Content

A review of literature and studies related in content to this study provide a foundation to understanding what work has been done in the area proposed by the study. It allows the researcher the opportunity to expand on earlier work and to compare similar elements done in this study with those previously investigated. It is through a review of content that the researcher establishes a framework upon which to add to the body of knowledge already established.

Persons other than the patients themselves often participate in decisions regarding euthanasia. Others involved include health care providers (physicians, nurses); family members, close friends, legal representatives, and when the person adheres to a religious faith, often a representative of the faith (clergy, rabbi, priest, etc.). Each of these groups has its own agenda when facing euthanasia and the perspectives represented by individuals within each group must consider situational, financial, legal, and the moral and ethical elements represented by the particular situation that affects the life or death dilemma. The following paragraphs describe studies which have been carried out specific to each category identified.

Withdrawing/Withholding Treatment (Passive Euthanasia)

Rothchild (1994) reviewed twenty five sources (books and journals) which were published between 1978 and 1992 to ascertain the family dynamics which are involved in end-of-life treatment decisions when life support was to be withheld or withdrawn. He

ascertained on the basis of the studies reviewed that variables affecting family decision making included:

1. Patient's Role in the Family: The part the family member plays relates to his/her perceived role in the family unit such as boss, scapegoat, caregiver, etc. Rothchild (1994) notes that families are more likely to feel inclined to prolong the life of a parent with young children than they are of an aging bachelor. Also, a person who has traditionally wielded control (boss) may also expect other family members to acquiesce to his/her decision.

2. Developmental Stage of the Patient and Family: Whether a person is young or old often affects family decision making. Rothchild (1994) suggests that we let go of the aged chronically ill more readily than we do the young. Also, he notes that elderly who have children are more inclined to avoid advanced directives expecting family members to know their wishes and act accordingly. Lansky, Cairns, & Hassanein (1978) note that young families who must deal with a child having a severe illness in which treatment or withdrawal of treatment decisions must be made have a higher incidence of marital breakup than do older families.

3. Family Cohesion: Decisions regarding withholding or withdrawing treatment can be complicated by polarization caused when old loyalties or conflicts are brought to the surface in situations where families are involved in divorce. For example, treatment decisions for children where there are also custody considerations can stir up conflicts. Similar situations arise where decisions must be made involving children and spouses of a former marriage regarding an aging parent.

4. Definitions of What Constitutes a "Family:" Increasingly with the advent of some persons involved in nontraditional lifestyles, the situation of what constitutes family becomes increasingly difficult. Rothchild (1994) cites a case (Steinbrook & Tirpack, 1985) where a lesbian housemate of a patient dying from esophageal cancer was asked by the medical staff to make end-of-life decisions for the patient who did not have an advance directive. The "housemate" was not comfortable making the decision and finally located a nephew and brother who had not seen the patient in years and the decision was made by them even though they had far less contact with the patient than did the housemate. Rothchild (1994) also cited a letter to the New England Journal of Medicine which acknowledged a situation where a patient did not believe his/her children had the same views he/she held and signed over power of attorney to a trusted friend rather that the children.

5. Family Structural Characteristics: Based on her review of the literature, Rothchild (1994) also notes that "families differ in their problem-solving style, openness, and assertiveness towards, or compliance with, the treatment teams recommendations." Based on these differences, decisions may be determined by age, gender, or in other families, there may be an equality shared by all family members. The style of how a family shares or refuses to share information therefore can influence end-of-life decision making. A dysfunctional or enmeshed family rather than focusing their anxiety or anger on the patient, may actually focus it on the treatment team.

6. Denial, Guilt, and Anger: If a family member harbors, any of these emotions, he/she may push for prolonging of dying rather than withdrawal or withholding treatment.

Rothchild refers to this as the "Daughter from California syndrome" and cites as a hypothetical example an unmarried devoted daughter who cares for her mother until an end-of-life decision eventually must be made. At that time, a second daughter from California who has not seen the mother for years arrives and accuses her sister of scheming to get the estate and demands that the decision to withdraw treatment be rescinded.

7. Communication of Treatment Wishes to Proxies: Neither families nor physicians are good predictors of patient's wishes without discussing the options with the patient. In summarizing studies she had reviewed, Rothchild noted that in general, families tended to choose more treatment, and physicians less treatment than the patients endorsed. Also, family members making decisions for incompetent persons sometimes knowingly chose contrary to the patient's wishes.

In addition to the previous inter- and intra-individual factors described, Rothchild noted an additional four cultural and external factors which influence family decision making with regard to end of life decisions. They include:

1. Sophistication. Some rural families, less familiar with the medical terminology and technology try to protect themselves and the ones they love by insisting that "everything" be done. In contrast, better educated families involve themselves in the ethics committee meetings and articulate their view.

2. Ethnicity and Religion. Minority status can heighten a families distrust of the medical team and their recommendations. Rothchild (1994) suggests Mexican-Americans are more accepting of death than Anglos. He also notes Catholics, as a group, are more

ready to accept do not rescesitate orders. Rothchild (1994) also suggests African-Americans who believe in divine intervention lean toward maintaining life.

3. Economic Pressures. The high cost of medical care can sway a family to choose to hasten death, especially in countries without universal health care.

4. Illness Variables. Smedira, Evans & Grais (1990), cited by Rothchild, noted that in intensive care units, families were more inclined to agree with the physicians in limiting care if the patients had metastatic cancer and severe head injuries than if they had respiratory or multiple organ failure. Also, certain illnesses with social stigmas such as AIDS can reinforce family members decisions to withhold or withdraw care.

A study done by Seale and Hall (1995) in England which surveyed relatives and others who knew people who had died revealed that spouses were more likely than others to say that a later death would have been better. The study was a summary of two surveys based on the death certificates of 3,696 persons who died in 1990 and an earlier sample of 639 drawn in 1987. The researchers did a random sample of death certificates from each of 20 district health authorities across England and followed up with interviews. The response rate was 69% with those being interviewed identified in the following categories: spouses (36%), other relatives (45%), friends/neighbors (9%) and 10% officials (wardens of sheltered housing, etc.). The authors used mutivariate analysis with logistic regression to analyze independent variables in the study. The authors conclude that the respondents

were influenced by considerations in their own lives rather than the condition of the deceased. According to the authors:

> Spouses were less likely than others to feel that it would have been better if the person died earlier. .. and spouses were more likely than others to say that a later death would have been better, though not in cases where the deceased was reported as having said they wanted to die soon. Spouses were influenced by the loss which the death of the person represented for them, being more likely than others to say they missed the person who died a great deal, and felt loneliness was a big problem. Non spouses (children and other relatives of the deceased, friends, neighbors, and a few officials) . . .were more likely than spouses to say an earlier death would have been better. They were more likely than spouses to say this when the deceased was not said to have wanted to die earlier. This was influenced by the fact that they experienced care as more burdensome than spouses, finding it restricted their lives.

The issue of withholding or withdrawing treatment is not only difficult for family members, such activities cross over into medical ethics, legal concerns, and also religious orientation.

Physicians and other health care providers often find themselves at the center of the medical and ethical dilemma. One example of the complexity of issues involved in withholding or withdrawing treatment is views regarding nutrition and hydration in the terminally ill. Craig (1994), a consultant Geriatrician, suggests that sedation without hydration or nourishment for the terminally ill may in fact lead to death from lack of hydration or nourishment rather than the disease, which is tantamount to murder. He notes, "to take a decision to sedate a person, without hydration, until he/she dies is a very dangerous policy medically, ethically, and legally." He notes that dehydration can result in circulatory collapse, renal failure, anuria, and death. A key issue he notes currently being

debated in English courts is whether artificial feeding counts as medical treatment--which can lawfully be discontinued if the patient is receiving no benefit--or simply the means of sustaining life, which if withdrawn could lay a doctor open to a charge of murder. He believes that in making decisions regarding sedation and nutrition and hydration, "the underlying reasons for sedation and the cause of the patient's inability to eat and drink are obviously of critical importance. He advocates communication between medical staff, the patient before the need arises, and the family to make sure that at the "end of the day there should not be the slightest grounds for suspicion that death was due to anything but the disease."

The honorable Donald C. Wintersheimer (1995), a justice of the Supreme Court of Kentucky addressed the role of courts in terminating nutrition and hydration for incompetent patients. As one of two justices who dissented in a case in Kentucky in which the court authorized the discontinuance of gastrostomy tubes used to provide nourishment and water to an incompetent patient, he felt that the opinion was in error because it viewed artificial feeding of the patient by tube as an extraordinary medical treatment. He felt the majority opinion of the court adopted the view that there were no significant differences between terminating food and water and withholding or withdrawing life-sustaining medical treatment. He notes that food and water are basic human needs and the process of feeding by tube is no more medical treatment than unassisted feeding is self-medication. The judge's concern focuses on the "slippery slope" concept where the termination of life moves from the realm of "voluntary" to

"involuntary." Additionally, he points out that the right to live precedes the right to choose because the right to live is the ultimate right, or the right to have rights.

The honorable Charles Leibson, (1995), a justice in the Supreme Court of Kentucky was the author of the majority opinion in the case described in the previous paragraph. He described why the Kentucky court allowed removal of the feeding tubes for Martha Sue DeGrella. He notes that as the case was discussed, it became obvious that the patient had expressed her choice informally while competent, although not in writing, to family members (husband, parents, brother) that she would not want to be kept alive by extraordinary means--either mechanical or other artificial means. The court cited cases supporting the opinion recognizing the right of a guardian of a person in a persistent vegetative state to terminate nutrition and hydration for "an incompetent individual who has made his or her medical desires known prior to becoming incompetent." Since Martha DeGrella had been in a nursing home for nine years with severe brain damage for which no medical treatment would benefit, the court ruled in favor of her mother who was acting as legal guardian and who desired termination of treatment. In summary, the decision to allow withdrawal of treatment was made because the court believed a person in a persistent vegetative state has a right to withdrawal of further medical treatment under the individuals common-law rights of self-determination and informed consent being carried out by an incompetent person through the process of surrogate decision making so long as the wishes of the patient are known. They further determined in this case that the declared question in terminating life-sustaining medical treatment was a factual, not legal consideration noting, "If the attending physician, the hospital or nursing home ethics

committee where the patient resides, and the legal guardian or next of kin, all agree and document the patient's wishes and the patient's condition, and if no one disputes their decision, no court order is required to proceed to carry out the patient's wishes."

In the DeGrella case, Leibson (1995) noted that medical testimony established that the patient reacted only at the reflexive level meaning she would withdraw from a painful stimulus, but did not experience pain by cognitive thought. This was as a result of the massive brain damage sustained in the injury causing her 9-year vegetative state. Increasing, discussion of euthanasia has centered on the definition of death. Schewe and Ritze (1994) discuss the term "brain death" and postulate that 'cortical death' or 'apallic syndrome' which involve 'irreversible loss of consciousness' be included under the term brain death. They contend that under such a definition it would be easier morally, ethically, and legally to make decisions regarding the removal of life-supporting devices. They note that "if determination of brain death meant the diagnosis of death, no room would remain for a moral conflict as to the cessation of treatment." Furthermore, the authors point out, "a clear cut distinction between life and death is a basic requirement for ensuring the rule of law. It should always be so because legal uncertainty can lead all to easily to the loss of moral standards.

Another area where withholding or withdrawing treatment are considerations is the area of ventilator support. This is an area of potential ethical controversy. Rushton and Terry (1995) describe a case study illustrating the ethical complications that can arise in such a situation. A 78-year old woman was admitted to the Medical ICU with severe viral pneumonia. After having been on a ventilator for 4 weeks she showed no improvement.

Her husband produced a durable power of attorney which designated him as her legal surrogate. Since she had moderate renal failure, upper gastrointestinal bleeding, and several other complications, the medical team and family decided that the goal was to allow her to die. However, disagreement arose between the nurse caring for the patient and the attending physician when the physician wrote an order for a neuromuscular blocking agent because he did not want the patient to gasp or show signs of struggle for the sake of the patient and family. Although it was within the legal and ethical considerations of the situation to withdraw the ventilator, the question of the use of the neuromuscular blocking agents raised additional ethical questions. The discussion focused on who's needs were being met, the patient's or those who were to attend the death. The author's contend that the use of the agents were not justified because the focus was not consideration for the patient but others involved. The authors conclude by noting that physicians and nurses must continue to critically examine the ethical justification for actions they undertake.

Although decision to have life support withdrawn and to die are best made by the patients, physicians take part in and sometimes make such decisions. Christakis and Asch (1995) have studied physician characteristics associated with decisions to withdraw life support. The authors surveyed 862 Pennsylvania internists and asked them to make decisions in response to hypothetical vignettes. The physicians were also asked to report their actual experience with the withdrawal of life support. The response rate was 56% (n=485) and the data were analyzed using regression models. The response may be considered good considering that the survey involved completion of a 20-page survey

booklet. With other factors controlled, the results showed that physicians were more willing to withdraw life support if they were young, practiced in a tertiary care setting, or spent more time in clinical practice. They were less willing if they were Catholic or Jewish. Physicians reported a higher frequency of actually withdrawing life support if they were young, had more contact with ICU patients, spent more time in clinical practice, or were specialists. Physicians with a greater willingness to withdraw were more likely to report having done so. The study suggests that patient preferences and clinical circumstances do not exclusively govern such ethical decisions as withdrawal of life support but physician attributes may also play a part.

Physician-Assisted Suicide and Voluntary Euthanasia (Active Euthanasia)

Fins and Bacchetta (1994) assembled an annotated bibliography of 24 articles focusing on the topic of physician assisted suicide and voluntary active euthanasia. The authors selected the articles based on "how frequently they were cited and how well they were argued." The authors were selected from a variety of fields and hold differing perspectives. The 24 articles were compiled originally as educational material for the ethics committee of the New York Hospital. Salient elements of many of the articles are given below and represent the euthanasia debate as it relates to physician-assisted suicide and voluntary active euthanasia and represents those points brought out by the authors cited by Fins and Bacchetta.

Battin (1991) compared the process of dying and attitudes toward euthanasia in the Netherlands, Germany, and the United States. The author found that in the United States most people die in healthcare institutions, and the vast majority of the patients die from

"electively withholding some form of life-sustaining treatment." She states that in the Netherlands, 3.2% of the deaths per year are the result of voluntary active euthanasia (voluntary active euthanasia is legal in the Netherlands). In Germany, there is little tolerance for physician's involvement with assisted suicide or voluntary active euthanasia even though "assisting suicide" is not a violation of the law there. The author notes that the burden of history--the Holocaust and Nazi-sanctioned involuntary active euthanasia may impact the people's attitudes. She suggests that the Netherlands's well-developed tradition of primary care makes it more amenable to voluntary active euthanasia than either Germany or the U.S. where the physician-patient relationship is less continuous. The author notes that the litigious climate in the US would make the Dutch model of accommodation unworkable. She also suggests that in the U.S., the lack of universal healthcare would make it easy to see that the poor and disenfranchised might feel pressure to seek active euthanasia even if they did not really want to make such as choice.

Brock (1992) presents the pros and cons in the debate regarding voluntary active euthanasia (VAE). He notes that the two basic values on which the argument "for" VAE rests are "individual self-determination or autonomy and individual well-being." However, he concludes that the patient's "right of self-determination does not entitle patients to force physicians to act against their own or professional values. In summarizing views "against" VAE, the author says that euthanasia is always unethical and a second argument is that according to some who suggest it "may not be ethically wrong" in certain cases, public and legal endorsement could lead to adverse consequences. He contributes three features associated with moral culpability (consent of the patient, physical intention, and

social and legal sanction). He concludes that letting die and killing are morally equal, and if we accept letting die as an acceptable practice, we should also acknowledge the reasonableness of euthanasia. Brock (1992) in looking at the question from the patient's point of view says that competent persons can waive their right to life (this is contested in Callahan[1992] in one of the following paragraphs). The author further argues that our pluralistic society should not ground policy in religious beliefs which many in our society reject and suggests that the slippery slope arguments are the last refuge of conservative defenders of the status quo. However, he does admit that legalization of VAE would lead to pressure to legalize some nonvoluntary euthanasia of incompetent patients unable to express their own wishes. Considering the various concerns and perspectives he feels that physicians are the most appropriate group to carry out VAE to ensure that there are procedural safeguards and regulation.

Brody (1992) views physician-assisted suicide and VAE under a clustered category of "assisted death" and sees no legal or moral difference between the two. His views are based on negotiation, compromise, and practical reasoning rather than abstract ethical theory. He sees "assisted death" as a compassionate response to medical failure where medical interventions fail to arrange a good death. Although the author recognizes the psychological reasons for preferring patient control over physician-administered lethal injection, he objects to what he calls "letting the patient do the dirty work because this can be an abrogation of responsibility rather than an exercise of professional integrity. The approach he recommends is a legal modification of the practice in the Netherlands (where the practice is legal) and an "intraprofessional review, in an especially rigorous version of

the mortality and morbidity conference." This process would compel the physicians who assist patients in death to defend their actions against their peers in an open forum. He suggests that regular hospital ethics committees are ill suited to such as process because they are generally nonadversarial.

According to Callahan (1992), euthanasia is a challenge to traditional Western views on the legitimate conditions under which one person can kill another, the limits of self-determination, and the types of claims that individuals can make on medicine. Proponents of euthanasia generally have arguments which fall into four categories according to the author including 1) the moral claim of self-determination and well-being; 2) the moral irrelevance of the difference between killing and allowing to die; 3) the supposed paucity of evidence to show likely harmful consequences of legalized euthanasia; and 4) the compatibility of euthanasia and medical practice. The author attacks each of these arguments. He says that since euthanasia requires two people to enter into an arrangement with social sanction, it trespasses the bounds of self-determination. He does not feel that a person can consent to be killed although they can consent to their death by requesting that life-sustaining therapy be withheld or withdrawn. The author cautions that legalization of euthanasia could lead to legal abuses because of the technical difficulty that comes with writing and enforcing procedural safeguards noting that many problems relate to the ambiguity of the language of the debate on euthanasia. He also says that questions of illness and mortality are both medical and philosophical or religious. He says, "It is not medicine's place to determine when lives are not worth living or when the burden of life is too great."

Unlike many other authors who are either pro or con relative to the physician-assisted suicide and VAE debate, Clouser (1991) sees a "dynamic tension" between the various arguments as a means to prevent the development of detrimental policy and a way to foster sound social and legal policy in a pluralistic society. He emphasizes a need for "empirical evidence" arguing that using particular cases makes for poor policy development and cautions the reader against institutionalizing a morally acceptable action into public policy. In a summarizing statement he emphasizes the "need to consolidate our position (on self-determination and the zone of privacy) as it exists in right-to-die legislation and to clarify, refine, and inform, while. ..carefully and empirically studying the effects of a policy that would allow suicide and assisted suicide."

Citing studies done by the World Health Organization, the American Medical Association, the American College of Physicians, and the American Pain Society, Foley (1991) reports that management of pain and symptoms of patients with cancer is inadequate. She notes that inadequate access to palliative care can pressure impoverished patients to consider death as their only option. She also reviews the psychological factors that influence suicidal ideation in cancer patients. She states, "the meaning of pain, is chronicity, and the lack of pain relief all contribute to the patient's psychological morbidity. This diminishes the patient's quality of life, and increases the likelihood of requests for assisted suicide." For this author, the debate that focuses on termination of life for patients with far-advanced disease should first focus on assessing the availability of continuing care for such patients."

From the perspective of political science, Jennings (1991) highlights a contradiction in libertarian bioethics which on the one hand affirms the right of self-determination, and at the same time prohibits the authority to short-circuit the natural process of dying. He notes that failing to develop a societal notion of the good death limits the individual's power over the circumstances of death. He says that with this concept, it will be difficult to affirm the patient's right to forgo life-sustaining treatment and at the same time proscribe VAE. He opposes public endorsement and legitimation of physician-assisted suicide and VAE because he does not believe the health care system could practice euthanasia humanely and without substantial abuse.

Kass's approach to the debate of physician-assisted suicide and VAE is to focus on the duties and responsibilities we have to each other rather than the language of rights (Kass, 1990). He sees a link between our dignity and the sanctity of life. He says, "death with dignity, rightly understood, has largely to do with exercising the humanity that makes life possible and very little to do with medical procedures or the causes of death." Furthermore, he notes that "the sanctity-and-dignity of life is entirely compatible with letting die, but not with deliberately killing." The authors sees several dangers in active euthanasia suggesting it subjects the aged and vulnerable to untenable social pressure, and, thus, threatens bad social consequences. He believes that euthanasia "violates the inner meaning of the art of healing."

Koop (1989) believes that euthanasia is an affront to our Judeo-Christian tradition which places a consistent and primary emphasis on the supreme value of life. He states that proponents of euthanasia challenge essential, "life-centered" values and undermine the

fact that each individual is personally responsible for being a life-centered member of the human community. He takes issue with making assessments of patient's quality of life, suggesting that it is impossible to judge another person's values concerning his or her quality of life.

Miller and Fletcher (1993) challenge seven arguments against euthanasia. They suggest that "killing another who requests to be relieved of suffering may be an act of compassion or caring" regardless of whether or not it is morally legitimate. They also do not feel there is a moral distinction between killing patients and allowing them to die when the burdens of treating a terminally ill patient outweigh the benefits. The authors also reject the slippery slope argument and suggest the key moral issue in legalizing VAE is whether a policy can be developed and implemented that maximizes the probable benefits and minimizes the risks of morally objectionable abuses. The authors argue that euthanasia does not attack the distinctiveness and limitations of being human noting that choice and control are distinctly human qualities. When confronting the argument that VAE is an assault on the human community, they point out that no reasonable persons would define killing as caring, though he or she might recognize cases in which killing at the request of the suffering person is the caring thing to do. They assert that VAE enables competent patients to request physicians to help them exercise their liberty. They also suggest that VAE does not undermine the integrity of medicine because it serves the beneficent end of relief of suffering. Although they are in favor of policy which legalizes VAE, they would limit their policy to patients who can make voluntary requests, are competent, and are terminally ill.

Miller *et al.* (1994) provide a comprehensive approach to physician-assisted death for a restricted group of patients. First they would limit physician-assisted death to "competent patients suffering from terminal illness or incurable, debilitating disease who voluntarily request to end their lives." They believe such policy would protect patients, preserve professional integrity of physicians, and assure the public that voluntary physician-assisted death occurs only as a last resort. They believe that voluntary physician-assisted death serves the moral goals of relief of suffering and self-determination. Unlike many other authors who support physician-assisted suicide or VAE, they feel that physician-assisted death is only a legitimate option after standard measures for comfort care have been found unsatisfactory by competent patients in the context of their own situation and values. They condemn Jack Kevorkian's approach and express concerns about "secret" physician-assisted death in the U.S. which is unregulated.

Miller (1992) looks at hospice care as an alternative to euthanasia. He asserts that hospice care responds compassionately to the "greatest needs and fears of the dying; fears of uncontrolled pain; loneliness and abandonment; and loss of control." He believes aggressive management of pain and attention to the patients and their families' physical and psychosocial needs obviate the call for euthanasia. As regards to policy, the author suggests proponents of hospice care must convince legislators to ensure that barriers to pain and symptom control are eliminated because most patients withdraw requests for suicide when they receive adequate pain control.

Miller's emphasis on pain as a primary consideration and the need for good palliative care is somewhat supported by the New York State Task Force on Life and Law (1994).

The members of this task force were appointed by Governor Cuomo and the monograph report explores the ethical, legal, and public policy implications of the decriminalization of physician-assisted suicide and VAE. Basically they found that the dangers of such a dramatic change in public policy would far outweigh any possible benefits. They found that, "changes in the law could place the elderly, poor, socially disadvantaged and those without access to good medical care at risk." The members found that "pain is often inadequately treated, and that the patients' depression is currently under-diagnosed and poorly managed" and that these omissions correlate highly with suicide requests by patients who are terminally ill.

Pellegrino (1992) takes the perspective that the two most powerful arguments against euthanasia are the Jewish and Christian belief that humans are stewards and not masters of the gift of life and the Christian belief that even human suffering may have meaning. However, even though he mentions faith in his essay, the main thrust of his arguments against euthanasia involve philosophy rather than religion. He believes that physicians should not kill directly or indirectly, but that it is permissible to withhold or withdraw care feeling that there is a difference between killing and letting die. He says than in euthanasia, "the physician is the immediate cause of a death that she fully intends" while it is the disease that overwhelms the patient when treatment is withheld or withdrawn. He further argues that socially or legally sanctioned euthanasia "devalues all life, but especially the lives of certain citizens--the chronically ill, the aged, and the handicapped."

In an essay cited in Fins and Bacchetta (1994), 13 Jewish and Christian theologians, philosophers, and legal scholars took a stand against euthanasia. Their basic arguments

were that euthanasia is contrary to faith, is based on grave moral error, does violence to our political tradition, and undermines the integrity of the medical profession. They noted that although it may sometimes appear to be an act of compassion, killing is never caring. The contributors contended that physician-assisted suicide and VAE were an evasion of moral duty. However, they did accept withholding or withdrawing medical treatments that are useless or excessively burdensome. Furthermore, they asserted, "we can and should allow the dying to die, but we must never intend the death of the living." They also attacked current proposals to legitimize euthanasia for the terminally ill because they felt it would lead beyond VAE and into involuntary euthanasia. They suggest we turn to religious, moral, political, and institutional sources of wisdom that teach us again always to care, never to kill.

Studies Related in Content and Methodology

A review of studies related in content and methodology assists the researcher in selection of appropriate methodology. The review can be used by the researcher to become aware of the strengths and weaknesses of various approaches used in the study area. Every study is unique; however, an awareness of techniques commonly used in the study area aids the researcher in selection of the approaches most appropriate for the study and provide support to defend use of the approaches selected.

Research focusing on formal development of scales to measure attitudes regarding euthanasia appears to be very limited in spite of the fact that several studies used non-validated scales within their surveys to query their samples regarding their "feelings" on

various aspects of the topic (exceptions to this include Tordella [1977] and Doukas *et al.* [1995] whose studies are described in detail in the paragraphs which follow) .

Tordella (1977) developed a Thurstone scale to measure college students "favorableness" and "unfavorableness" toward euthanasia. She established content validity through her use of college students in actual item development and followed Thurstone's use of judges to scale the items. She established the reliability of the scale using the test-retest method. The resulting Pearson Reliability Coefficient was .84 which exceeded the lower threshold requirement of .60 to .70. The author carefully followed Thurstone development protocols, and the scale appears to be a valid and reliable tool although it could not be determined within this literature review whether or not the scale had found use beyond the initial development. Considering the scale developer used a diverse student population (multiple majors and ages), and the fact that health care professionals (professors, authors, lecturers) served as judges, the scale may have potential for use beyond college students.

The review of euthanasia literature reveals that when studies are done regarding attitudes toward euthanasia, physicians appear to be the ones most commonly sampled (Cohen *et al.*,1994; Doukas, *et al.*, 1995; Pijnenborg, *et al.*,1994). However, Seale and Hall (1990) have done two studies in England that were national in scope and involved over 4000 participants (over 80% of the sample was comprised of family members, with the remaining sample consisting of friends and government officials) and which focused on families' attitudes regarding euthanasia.

Basically all of the studies identified in this literature review relating to attitude and euthanasia used a survey methodology and some form of self-report questionnaire. Additionally, data analysis in each of the studies was done using statistical analysis (multivariate analysis, factor analysis, analysis of variance, x^2 tests, regression analysis, etc.). One possible exception to this is the Cohen (1994) study which was cited in Fins & Bacchetta (1994) and was described in percent of respondents without data analysis discussed by the authors citing the study. Specifics for the various studies are given in the descriptions of the studies which follow.

Cohen *et al.* (1994) studied the attitudes of physicians in Washington State toward assisted suicide and euthanasia. The authors report that 48% of the physicians sampled thought"that euthanasia was never justified" and 42% felt it was an acceptable option in some cases. Although 54% surveyed thought euthanasia should be legal, only 33% said they would be willing to perform euthanasia. Thirty-nine percent of the sample felt that physician-assisted suicide is never ethically justified. Although 53% thought assisted suicide should be legal in some situations, only 40% said they would be willing to assist a patient in committing suicide. Of all the respondents, hematologists and oncologists were most likely to oppose physician-assisted suicide and voluntary assisted euthanasia. The authors summarizes the study by noting that VAE and physician-assisted suicide were divisive issues for physicians in Washington State and most were reluctant to participate despite a slim majority who approve their legalization.

The attitudes and behaviors on physician-assisted death was explored by Doukas *et al.* (1995) based on a survey of Michigan oncologists. The authors mailed surveys to all 250

practicing oncologists in the state of Michigan. The actual study was carried out between February and April of 1993. The authors used a Belief-Attitude-Intention Behavior model originated by Fishbein as a basis for the theoretical framework for the structure of the questionnaire. The 4-page self-administered questionnaire began with definitions of passive euthanasia, assisted suicide, and action euthanasia followed by 24 statements on these issue derived from statements on attitudes, intentions, and experiences from previous surveys. Respondents rated their level of agreement with each statement on a 5-point Likert scale. The first 22 of the 24 items formed the attitude scale, while the last two items asked whether most oncologists and most nonmedical people would favor legislation allowing a terminally ill patient to ask an attending physician to help end his or her life. In addition, respondents were also asked to tell whether they had any experience with passive euthanasia, assisted suicide, and active euthanasia. The draft survey instrument was reviewed for validity by representatives from both side of the debate and tested on 25 oncologists at the University of Michigan. Based on feedback, the survey was refined and the final survey was reviewed and endorsed by the Michigan State Medical Society. The questionnaire was mailed with self-addressed envelopes to the sample of 250 physicians with a reminder notice sent 10 days later. After 3 weeks, a second mailing was sent to nonrespondents followed with a final postcard reminder. A cover letter was used to tell the respondents the purpose of the study and provided assurances that responses were anonymous. The response rate was 61.6% (n=154). Analysis of the results involved frequency and summary statistics for each item followed by a principal component factor analysis of the 22 attitude items. Then t-tests were used to determine associations

between attitudes, demographics and experiences. Where appropriate, Mann-Whitney U tests, x^2 tests, and analysis of variance were employed. The results following analysis revealed: five distinct, meaningful factors regarding approval or disapproval of physician-assisted death. The factors reflected global attitudes toward physician-assisted death, passive euthanasia, philosophical prohibitions toward physician-assisted death, concerns of legal consequences with physician-assisted death, and attitudes that physician-assisted death could be avoided with better end-of-life care (alpha levels were noted at .94, .74, .76, .87, and .84 respectively). The survey discovered the level of therapy withdrawal at 81% with significant reservations toward assisted suicide and active euthanasia although the reported participation in such actions was noteworthy (18%and 4%). The scales reflecting global and philosophical attitudes correlated with several attitudes and behaviors toward physician-assisted death ($P<.001$). Physician-assisted death legislation was favored by 20.8% of the respondents.

Pijnenborg *et al.* (1994) carried out a nationwide survey of physicians in the Netherlands concerning end-of-life practice in that country. They carried out a stratified random sample of physicians in the Netherlands based on type of specialty and followed the sampling with interviews. Out of the 447 physicians sampled, 41 (9%) did not have time to be interviewed (the interview took 2 ½ hours). One interview, according to the authors yielded useless information so, therefore, the interview portion of the study yielded an n=405. The interview involved asking the doctors about their involvement in various end-of-life decisions including questions about the characteristics of the patient and the decision made. Phase II of this study involved taking a stratified sample of the

death certificates dated from August to November 1990. Stratification was based on the probability that an end-of-life decision was made. Forms detailing cause of death for all 41,587 deaths over this period were reviewed by two physicians and assigned to one of five groups. When the end of life decision was thought to be high, a questionnaire was sent. After selecting a stratified sample, 6,942 cases were drawn. A return response rate on the questionnaire was 76%. The results of the survey revealed 2/5 of all patients in the Netherlands die at home. General practitioners made fewer decisions about end of life than hospital doctors and doctors in nursing homes (34%, 40%, and 56% of all dying patients respectively). Euthanasia or assisted suicide was performed in 3.2% of all deaths in general practice compared with 1.4% in hospital practice. In more than half of the cases which involved pain relief or non-treatment, general practitioners did not discuss the decision with the patient mostly because of incapacity of the patient, but 20% of the cases cited paternalistic reasons. Older general practitioners discussed such decisions less often with their patients. Colleagues were consulted more often if the general practitioner worked in a group practice. The study noted that differences in work situations between general practitioners and hospital doctors and differences between the group of general practitioners contribute to differences in the number and type of decisions about the end of life and the decision making process.

Seale and Hall (1995) did two surveys in England which sampled relatives and others who knew people from samples drawn from death certificates. One of the surveys was based on a sample of 3,696 people who died in 1990 (20 health authorities) and the other was from a national sample of 637 people who died in 1987. Data were analyzed using

logistic regression, bivariate and multivariate analysis. Dependency and distress were found to be important factors compared to social class, strength, and type of religious faith and urban rather than rural location which in this study played little part. According to the authors, spouses were less likely than others to feel that it would have been better if the person had died earlier. Spouses were more likely than others to say that a later death would have been better except in cases where the deceased was reported as having said he/she wanted to die sooner. Non spouses, in contrast, were more likely than spouses to say an earlier death would have been better. The authors also noted that people who received hospice care were more likely to have respondents who felt it would have been better if they died earlier. Two important variables which influenced this appeared to be level of distress and dependency experienced by the dying person.

Theoretical Basis

The theoretical basis for the study is found in attitude measurement using Thurstone scales and Likert scales and in various elements of The Health Belief Model, and The Theory of Reasoned Action. Each of these and the two main independent variables for this study are explained in the following paragraphs followed by a section which provides rationale as to how they relate to the study.

Attitude Measurement

Since "Attitude" is an abstract concept, it is hard to define, and multiple researchers have defined it in a variety of ways. The following are examples of how attitude has been defined:

Crutchfield, Kretch, & Ballachey (1962) define attitude as an enduring organization of motivational, emotional, perceptual and cognitive processes with respect to some aspect of the individual's world. Green (1954) defines attitude as an implicit response that is both anticipatory and mediating in reference to patterns of overt responses, that is evoked by a variety of stimulus patterns. Fishbein (1967) defines it as a mental and neural state of readiness exerting a directive influence upon the individual's response to all objects and situations with which it is related and individual mental processes which determine both the actual and potential responses of each person in a social world. Remmers (1954) defines attitude as an affectively toned idea or group of ideas predisposing the organism to action with reference to specific attitude objects. Crutchfield, *et al.* (1962) have included in their definition the three necessary and inclusive components of an attitude which involve the cognitive, effective, and behavioral elements. They have defined attitude as a system of three components centering about an object involving the beliefs about the object (a cognitive component), the affect connected with the object (a feeling component) and the disposition to take action with respect to the object (an action tendency component) (Crutchfield *et. al*, 1962). The authors further define the "attitude object" as anything that exists for the individual. The concept of attitude and studies of the concept can be traced back to the 1800's and form the basis for much of the field of social psychology (Fishbein, 1967). Actions of individuals are governed to a large extent by attitudes. Since the concept of an attitude is abstract, measurement of an attitude or change of attitude is indirect. Fishbein (1967) notes that attitudes can be measured only on the basis of inferences drawn from the responses of the individual toward the object--his

overt actions and his verbal statements of belief, feeling, and disposition to act with respect to the object. The result of measurement of an attitude is an indication of direction and magnitude of the person's action toward the object (Ferguson, 1941; Tordella, 1977). Attitude measurement is most often done through the use of attitude scales. The basic assumption in using scales is that there are differences in the responses of individuals to attitudinal statements and that these differences reflect attitude direction (favorable or unfavorable) on a psychological continuum as well as the magnitude (degree of favorableness or unfavorableness). There are three major types of attitude scales including summated rating scales, equal-appearing interval scales, and cumulative scales. The advantages and disadvantages of each are summarized as follows: The Guttman scale (cumulative) consists of a small number of unidimensional items with an individual's response to the scale being reproducible. This type of scale measures one attitude and is considered reproducible if the score an individual receives indicates the items of the scale with which he agreed. Major disadvantages of this type of scale is that it is unidimensional and Guttman suggested that items had to have a coefficient of at least .90 for the items to possess scalability. According to Tordella (1977), researchers such as Festinger questioned the value of a homogeneous scale over a heterogeneous one in that favorableness or unfavorableness towards an object could be indicated in a variety of ways by different people and the favorability would have different sources. Therefore, heterogenous scales such as Likert or Thurstone scales would serve as better indicators of the strength and direction of a given attitude. Issues of dimensionality are not the only criticisms. Criticism of Guttman scaling has also focused on item selection. Guttman

emphasized intuition and experience in item selection while Edwards (1957) favored item analysis before testing for scalability.

Another scaling option is Thurstone's method of equal-appearing intervals which was first described in 1929 (Edwards, 1957). Use of this technique involves the printing of statements about an attitude-object on separate cards with judges asked to separate the statements into eleven categories representing degrees of favorableness, unfavorableness, and neutrality. The eleven categories are seen to represent equal intervals on a psychological continuum. The judgements are analyzed to find both a scale value (median of the distribution of the judgements for each statement) and a Q value (interquartile range of the judgements for each statement). The Q value measures the variation among the judges. Generally, a large Q value is seen by some researchers as an indication that the particular statement is ambiguous and should be discarded. The final scale constructed using this method consists of items with low Q values and which are relatively equally spaced along the psychological continuum (Edwards, 1957). Individuals who respond to the final scale indicate the statements to which he or she agree and the median value of those statements represent the individual's score.

The third scale type is summated ratings (Likert Scaling) which was developed by Likert in 1932. His goal was to develop a scale that was a reliable and valid as the equal-appearing interval scale, but less labor intensive in development. Likert eliminated use of judges and went directly to respondents with a collection of a group of attitude statements representing a spectrum of favorableness and unfavorableness to some attitude-object. The respondents were asked to respond to each statement by putting the statement into

one of five categories: strongly agree, agree, undecided, disagree, or strongly disagree. The sum of the responses were the individual's score. Selection of items for a final scale were based on whether numerical scales were properly assigned and the statements were differentiating. Item analysis (calculation of the correlation coefficient of each statement with the battery) was one method used to determine acceptability of a given statement (Fishbein, 1967). If a correlation coefficient was negative, the numeric values assigned to that item was reversed. If the coefficient was zero or very low, the statement failed to measure what it was intended to measure and, therefore, was undifferentiating and was discarded.

Although reliabilities for results of scales constructed using the Likert and Thurstone techniques have varied, Edwards (1957) concludes that the method of equal-appearing intervals (Thurstone Scaling) is comparable to summated ratings (Likert Scaling) with respect to time and labor involved and that it is possible to construct scales by both methods which would yield comparable results.

Literature and Studies Related in Theoretical Perspective

Good research is based on a foundation of theory. Theory provides the framework upon which to expand knowledge into uncharted areas. This study is constructed around behavioral constructs appearing in the Health Belief Model and the Theory of Reasoned Action as described in the following paragraphs.

Health Belief Model

The health belief model has demonstrated its applicability in health research in "at-risk" and "sick-role" situations over several decades (Janz,& Becker, 1984, Mullen, Hersey & Iverson, 1987). Janz *et al.* (1984) define sick role behavior as "actions taken after diagnosis of a medical problem in order to restore good health or prevent further disease progress." Glanz, Lewis & Rimer (1990) summarize the model based on health belief research dating from 1958 through 1984 noting that:

> individuals will take action to ward off, to screen for, or to control ill-health conditions if they regard themselves as susceptible to the condition, if they believe it to have potentially serious consequences, if they believe the course of action available to them would be beneficial in reducing either their susceptibility to or the severity of the condition, and if they believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits.

Mullen, Hersey and Iverson (1987) note that:

> The model affirms that readiness to take action for health stems from a perceived threat of disease, coming from an individual's perception of his or her *susceptibility* to the disease and its potential *severity.* The *cue for action* can be triggered by an individual's private perception or by reading about health matters. Behavior is evaluated from an estimate of the potential *benefits* of healthseeking action to reduce susceptibility or severity. The benefits are then weighed against perceptions of physical, psychologic, financial, and other costs or *barriers* inherit in the health-finding effort.

Authors have shown that the Health Belief Model dimensions exist and can be measured with a substantial amount of validity using Likert or multiple choice questionnaire items," (Cummings, Jette & Rosenstock, 1978; Maiman, Becker, Kirsch, Haefner & Drachman, 1977). Maiman *et al.* (1977) summarize some of the shortcomings

of the model pointing out that the constructs are operationalized differerently by researchers depending on what is being studied and that lack of standardization makes it difficult to compare various studies done by researchers. However, the model continues to be widely used. Glanz *et al.* (1990) describe it as "one of the most influential and widely used psychosocial approaches to explaining health-related behavior."

Theory of Reasoned Action

The Theory of Reasoned Action suggests that the immediate determinant of a person's behavior is his intention to perform or not perform a specific behavior and that the behavior is under volitional control of the individual (Ajzen & Fishbein, 1980). These authors note that behavioral intention is a function of 1) attitude toward the behavior, and 2) a subjective norm which is reflective of social influences. They describe the subjective norm as an interaction between the person's perception of how significant others in their social environment feel toward his/her performance of the behavior and the person's motivation to comply with these significant others. In contrast to the subjective norm which is reflective of social influence on the individual, attitude toward the behavior is a personal factor. Together, the person's "attitude toward the behavior," and the subjective norm influence the person's intention to perform the behavior. A more recent model of the Theory of Reasoned Action includes "past behavior" as a construct along with attitude toward the behavior and the subjective norm (Bentley & Speckart, 1979). Bentley & Speckart (1979) note that past behavior influences future behavior directly and indirectly. However, in this current study past behavior may be a minimal influence since the

decision-making with regard to initiating euthanasia is not normally one that would be frequently carried out by a respondent.

Self-Efficacy as an Independent Variable

Self-efficacy was introduced by Bandura as a core aspect of his social-cognitive theory (Bandura, 1977, 1997). The construct of self-efficacy refers to person's expectancy with regard to his ability to deal with a stressing situation. Although early theory suggested that self-efficacy was domain specific (relates specifically to a situation); recent research supports a view of generalized self-efficacy which is a global confidence in one's ability to cope across a wide range of stressful situations (Schwarzer, 1994). Glantz *et al.* (1990) note that the addition of self-efficacy to the Health Belief Model increases it's explanatory power.

Several studies have demonstrated the importance of self-efficacy in making successful adjustment to negative life events including such things as rheumatoid arthritis, myocardial infarction, and abortion (Bandura , 1977, 1991; Cutrona & Troutman, 1986; Schiaffino & Revenson, 1992; Smith & Coyne, 1988; Cozzarelli, 1993). Self-efficacy has also been examined in studies in the following areas: smoking, weight control, contraceptive behavior; alcohol abuse, and exercise (Strecher, DeVellis, Becker, and Rosenstock,1986)

Cozzarelli (1993) notes that self-efficacy affects human behavior through motivational, cognitive, and affective intervening processes and those with strong feelings of self-efficacy have been found to be less likely to abort coping efforts prematurely and to be willing to flexibly adopt new coping strategies when confronted with initial coping failure.

Religious Orientation as an Independent Variable:

Baume *et al.* (1995) conducted a survey of 1,238 doctors on the issues of active voluntary euthanasia and physician-assisted suicide and found that attitudes varied significantly based on religious affiliation with more doctors without formal religious affiliation (non-theists) being sympathetic toward euthanasia than doctors who professed religious affiliation. Baume, *et. al* (1995) also noted that of those reporting a religious affiliation, Protestants were intermediate in their attitudes between those who were agnostic/atheist and the Catholic groups. Catholics recorded attitudes most opposed to euthanasia (Baume, et. al, 1995). Doukas, et. al. (1995) found similar results among a survey of 250 Michigan oncologists noting those respondents professing no relgious affiliation had more favorable attitudes toward assisted suicide and active euthanasia than did Catholics, Jews or Protestants.

In an essay cited in Fins and Bacchetta (1994), 13 Jewish and Christian theologians, philosophers, and legal scholars took a stand against euthanasia. Their basic arguments were that euthanasia is contrary to faith, is based on grave moral error, does violence to our political tradition, and undermines the integrity of the medical profession. Pellegrino (1992) noted that the two most powerful arguments against euthanasia are the Jewish and Christian belief that humans are stewards and not the absolute masters of the gift of life and the Christian belief that even human suffering may have meaning. Christakis and Asch (1995) in a study of physican characteristics associated with decisions to withdraw life support noted that based on their study of 862 physicians, physicians are less willing to withdraw life support if they are older, or if they are Catholic or Jewish.

American Orthodox Jews strictly prohibit euthanasia based on their view that life is infinitely valuable (Rosner, 1986). The Roman Catholic position under the principle of double effect (the permissibleness of bad effect if the intent was good) is to allow physicians to alleviate the suffering of dying patients even if it shorten's life, but they do not sanction euthanasia (Pope Pius XII, 1980). Some Catholics refuse to tolerate termination of life under any circumstances (Doerflinger, 1989).

Several prominent psychologists such as Allport, Jung, and Erikson have placed great importance on religion as a "unifying philosophy of life" and an integral part of personality (Hergenhahn, 1980). According to Hergenhahn (1980), Allport believed that the person is by no means simply a passive reactor to the environment, but that a person's behavior generated from within by the personality structure.

Integration of the Theoretical Basis

Glantz *et al.* (1990) note that the addition of self-efficacy to the Health Belief Model increases it's explanatory power. The authors also note that self-efficacy is quite similar to the Health Belief Model concept of perceived benefits.

Although no research on self-efficacy has been done in the area of euthanasia (the closest studies would be those relating to abortion) the construct may provide insight into a modifying factor which may influence a person's decision to carry out the act. Strecher, *et al.* (1986) note that self-efficacy affects people's emotional reactions, such as anxiety and distress, and thought patterns. Thus, individuals with low self-efficacy about a particular task may ruminate about their personal deficiencies rather than thinking about accomplishing or attending to the task at hand; this, in turn, hinders successful

performance of the task. Efficacy expectations are learned from four major sources, 1) personal experience, 2) vicarious experience such as learning through observation from events and other people, 3) verbal persuasion, and 4) one's physiological state (e.g., high physiological arousal usually impairs performance) (Stretcher, *et. al*, 1986). The authors (Stretcher, *et al.*, 1986) also note that "where the health practice is believed to lead to desired consequences but the change is difficult to make, self-efficacy considerations are probably paramount."

The independent variable, intrinsic religious orientation, may be an important predictor variable. The previous studies cited in this chapter highlight that religion has frequently been included in studies relating to euthanasia and acknowledge that a person's belief structure may be an important element affecting a person's perception relative to euthanasia. However, most studies have not considered religious orientation but religious association. A few of the studies have used the term "religiosity," but have considered church attendance to be a measure of "religiosity." Church attendance is only one dimension of the construct of religiosity and as such using only one dimension would result in a poor measure. The same might be said of group or denominational association. The intrinsic religious orientation scale used in this study measures "one's application of the one's belief system to his or her daily environment." Measurement of one's perception of the importance of application of one's personal creedal system may be an important predictor variable in euthanasia studies that may have been overlooked.

Both The Health Belief Model and the Theory of Reasoned action are rooted in the tradition of value expectancy theories which provide a method for defining and assessing

the elements of decisions (Glanz, *et al.*, 1990). Glanz (1990) notes that "attitudes play a stronger role in the Theory of Reasoned Action than in the Health Belief Model, but both place a strong emphasis on the role of beliefs in understanding health behavior."

Mullen, *et al.* (1987) are critical of The Theory of Reasoned Action noting that its emphasis is almost entirely rational and does not recognize emotional fear-arousal elements such as perceived susceptibility to illnesses. Glanz (1990) suggests that to explain behavior better, The Theory of Reasoned Action might need to be supplemented by the Health Belief Model. The independent variables of self-efficacy and intrinsic religious orientation can fit well as predictor variables in both the theory and the model. These variables can be seen as modifying factors which influence decision making. Self-efficacy may be an integral part of personality and as such affect the attitude component in the Theory of Reasoned Action. Intrinsic religious orientation could be both internal and attitudinal as well as normative in that the person may make decisions based on how he or she feels the group feels regarding euthanasia and additionally may have internalized the dogma intrinsically so that attitude is a personal one with reinforcement from the normative influence. Within the Health Belief Model, self-efficacy and intrinsic religious orientation may be seen as modifying factors influencing perceived threat based on the elaboration of the model by Dignan and Carr (1992).

Chapter Summary

Review of the related literature and studies reveal that measurement of attitudes regarding euthanasia can be done in a defensible manner. However, most published euthanasia research does not provide rationale regarding the theoretical framework upon which the research is based. Additionally, research which has been done has focused almost extensively on the healthcare providers with limited investigation done on family members as decision-makers regarding euthanasia.

The health belief model has been used in many "at risk" and "sick-role" health research studies (Glanz *et al.*, 1990) and may provide assistance in understanding decision-making by family members with regard to euthanasia. In addition, the Theory of Reasoned Action appears to provide a theoretical framework for the study because the theory demonstrates how both attitudes and subjective norms influence intention to perform an action. The two main independent variables in this study, self-efficacy (attitude) and intrinsic religious orientation (subjective norm) are constructs which will fit well within the Theory of Reasoned Action and also are consistent with constructs contained in the Health Belief Model. However, there appears to be no literature which specifically relates self-efficacy or intrinsic religious orientation to euthanasia decision making.

A better understanding of factors relating to how families make decisions with regard to euthanasia might help healthcare professionals and religious representatives to better assist family members who must make difficult and complex choices for family members who are in the process of dying.

CHAPTER III

METHODOLOGY

Introduction

This chapter describes the study subjects and instruments used in the study, and summarizes the methods and protocols used to collect, tabulate, and analyze the data.

Study Population Description and Selection

The study population for this study consisted of adults (persons over 18) who were identified as immediate family members of deceased persons whose death was reported in the obituaries printed in the *Knoxville News Sentinel* in July 1997, October 1997, January 1998, and April 1998. Systematic random sampling was used to determine the months used in sampling. Twelve numbers representing each month of the year were placed in a box and a single number drawn to represent the beginning month for the interval sample. The number 7 was drawn so the first month to be selected was July. The researcher set the sampling interval at a three-month interval to ensure coverage over one year resulting in the selection of the remaining months which were October 1997, January 1998, and April 1998. This approach was intended to ensure that all members of the population had an equal opportunity to be selected over a year timeframe and to negate any seasonal intervening variables which may have influenced death rates (e.g., it is common knowledge that older persons do not tolerate heat as well as younger persons so a hot summer could

potentially result in an increase in the death rate of this age group if they did not have access to air conditioned facilities). The sampling frame was constructed by reviewing the obituary listing in the *Knoxville News Sentinel* for each month sampled and selecting family members who met the following sampling criteria: 1) name and city of habitation were listed in the obituary; and, 2) the name and address in the obituary listing identified them as being within the local calling area based on the listing of cities identified as in the local calling area in the front of the Knoxville phone directory. Names and addresses of potential respondents were then compared to listings of names and addressses in a computer disk phone directory in an attempt to match phone numbers. This process resulted in 1,678 persons being identified as potential participants in the study. Three hundred and forty nine persons were then randomly selected from this sampling frame to meet sample size determination protocols described by Wang, Fitzhugh, and Westerfield (1995) for a 95% confidence level and permissible error of ±.04 based on a selection table included in the publication. SAS® was used to generate the random numbers which were matched with the corresponding listing numbers in the sampling frame to identify the 349 persons who would be selected.

Instrumentation

The following paragraphs describe the instrumentation used in the study including instrument construction, pilot study testing, data collection, and data recording and analysis.

Instrument Construction

The telephone survey instrument constructed for this study contained an introduction, three scales, and a demographic question section (See Appendix A). The three scales in the instrument were selected to help address the study research question which was:

> What relationship, if any, is there between a surviving immediate family member's attitude toward euthanasia and general self-efficacy, intrinsic relgious orientation, respondent's age, respondent's formal education level, age of the deceased, respondent's annual family income level, length of illness, race, gender, religious preference, and relationship to the deceased?

Part I of the instrument contains a Thurstone scale to determine favorableness for or against euthanasia (Tordella, 1977). The author of the scale reports a Pearson Reliability Coefficient of .84 for the scale (Tordella, 1977). The dependent variable in this study, euthanasia score, was derived through use of the euthanasia scale developed by Tordella.

Part II of the survey instrument was a General Self-Efficacy scale. The general self-efficacy scale used in this study was originally developed in Germany, has been translated

into 21 languages and has been modified from a 20-question Lickert scale to a 10-question Licket scale (Jerusalem & Schwarzer, 1992). Schwarzer (1998) notes:

> It has been used in numerous research projects, where it typically yielded internal consistencies between alpha=.75 and .91. The scale is not only parsimonious and reliable, it has also proven valid in terms of convergent and discriminant validity. For example, it correlates positively with self-esteem and optimism, and negatively with anxiety, depression and physical symptoms

The English version of the scale has an internal consistency alpha of .90. General self-efficacy is one of the independent variables identified in the research questions and use of the general self-efficacy scale allowed for the testing of this attribute.

The third scale contained in the survey instrument was the Intrinsic Religious Orientation Scale (Allport & Ross, 1967). Robinson and Shaver (1975) note, "in studies done by Feagin (1964) and by Allport and Ross (1967), as well as in unpublished research available to us, the Intrinsic-Extrinsic Scale appears to consistently demonstrate its construct validity." The Intrinsic Religious Orientation Scale was first provided for researcher use in 1969 in *Measures of Social Psychological Attitudes* and has been retained for researcher use in the subsequent 1973 and 1975 editions.

Instrinsic religious orientation was one of the independent variables identified in the research questions for this study. The intrinsic orientation scale which was incorporated into the instrument for this study made it possible to use the instrument to measure the intrinsic religious orientation of each family member participating in the study.

Part III of the instrument was followed by a demographic query section (See Appendix A). The demographic questions did not require scaling so data generated by the demographic questions themselves were used directly in the study analysis.

Pilot Study Testing

The survey instrument described in the previous paragraphs was tested in a pilot study. Members of the author's doctoral committee were asked to evaluate the instrument. Feedback from them regarding wording, display and format were incorporated into a refined instrument. Then, the refined instrument was tested on 60 persons selected randomly from the study population. Feedback from the 60 pilot study participants was used to further refine the survey instrument and also to test data recording and transfer protocols. During the pilot study, SPSS® was used to carry out an item-analysis of the scales resulting in the following Cronbach Alpha values: euthanasia scale, .76; self-efficacy scale, .84; and , intrinsic religious orientation scale, .66.

Validity of the instrument was supported by: 1) use of random sampling; 2) use of scales that have already been used by researchers and described in published literature and; 3) use of a pilot study to test and refine the instrument.

Data Collection

SAS® was used to generate 349 random numbers. These random numbers were matched to the corresponding numbers on the sampling frame with each selection highlighted to represent which potential survey participants were to be called from the 1,678 person sampling frame. Then, each potential survey participant was called. Wrong numbers and disconnected lines were identified as such on the sampling frame. A

maximum of five callbacks were made for each phone number listed. If contact was not made by the fifth call, the number was identified on the sampling frame as a nonreachable number. One hundred fifty five people met sampling criteria of being able to be contacted by telephone out of the 349 persons randomly selected to be called. One hundred and thirty one persons consented to participate in the survey out of the 155 persons eligible to participate.

Two response rates were calculated based on formulae available from the Subcommittee on The Role of Telephone, Mail and Personal Interviews in Federal Statistics Methodology (1984). The two formulae are as follows:

(1) Response Rate= (# completed/# in sample) x 100. and;

(2) Response rate= # completed/ (# in sample - (noneligible + nonreachable)) x 100

Based on the above formulae, the response rate based on the number of persons completing the survey relative to the number in the sample was 38%. The response rate which took into consideration those in the sample who are noneligible and nonreachable was 85%.

Calling was most frequently done from 6:30 to 9:30 pm during the week and from 9am to noon on Saturdays. Calling was done from 7 pm to 9 pm on Sundays. The average number of surveys completed in each calling session was three.

The purpose and importance of the survey was explained to each contact. Additionally, he or she was provided assurances of confidentiality and was asked to respond to the survey instrument items (See Appendix A). The dialogue was scripted to ensure that each contact was made in a similar fashion.

Data Recording and Analysis

Upon completion of the data collection and recording of data on the survey sheets (See Appendix A), the instrument scales and demographic data were summed and transferred to Microsoft Excel under unique headings appropriate for each variable. The euthanasia raw scale score for each observation was rounded to the nearest tenth and multiplied by 10 so that each score would be a whole number which would reduce the possiblilty of data transfer errors that might occur when transferring decimal numbers (although the scores were left in the study based on the previously described conversion, each euthansia score can be converted to a raw scale score by dividing by 10). Each record was given a chronological identification for compilation for data analysis to ensure proper configuration control for data manipulation. Data was exported from Excel into SPSS (SPSS reads Excel data files) for analysis.

Descriptive statistics (mean, range, standard deviation, frequencies) were reviewed and variables screened for analysis based on availability of data in the various data cells. Wimmer and Dominick (2000) suggest data cells with less than 30 observations may produce results that are unstable. Therefore, in this study, based on the descriptive analysis, variables showing a paucity of data were eliminated from further analysis.

The Forward Stepwise regression protocol was used to introduce the selected independent variables into the regression model. This process ensures that the computer analysis would result in the most parsimonious equation to account for the greatest variance in the model using a subset of the explanatory variables (Reed, personal communication, 1999).

Study Design

This study was carried out using a cross-sectional study design. Such studies are common in health research and met the needs required for the purpose of the study.

Study Variables

The dependent variable included in this study was the respondent's attitude toward euthanasia as determined by the respondent's score on the euthanasia scale (See Part I, Appendix A).

There were initially 11 independent variables included in this study. They were: general self-efficacy (See Part II, Appendix A), intrinsic religious orientation (See Part III, Appendix A), respondent's age, respondent's education level, age of the deceased, respondent's family income level, length of illness, race, gender, religious preference, and relationship to the deceased.

Based on a review of the descriptive statistics only five variables were included in the regression analysis because the others showed paucity of data which would produce results that would not have been stable. The independent variables retained for analysis were: general self-efficacy, intrinsic religious orientation, age of the deceased, length of illness, and gender (included as a dummy variable).

Chapter Summary

This chapter describes the study methodology. Major topics discussed include study population description and selection; instrumentation including instrument construction, pilot study testing, data collection, data recording and analysis; and study design including a description of the study variables.

Each procedure was tested during the pilot study to ensure its appropriateness and usability. Feedback from pilot study participants and committee members was used to enhance the design and approach to ensure successful completion of the study. Additionally, a professional statistician reviewed the protocols and monitered the analysis process to ensure adherence to established statistical procedures including appropriate interpretation of analysis results.

CHAPTER IV

ANALYSIS OF THE DATA

Introduction

This chapter provides the results of the analysis of the survey data collected in this study. Data were analyzed from 131 family members who responded to the survey. The purpose of the study was to analyze factors which may relate to surviving immediate family members' attitudes toward euthanasia and to determine their significance, if any.

The factors initially identified for analysis in this study were: general self-efficacy, intrinsic religious orientation, respondent's age, respondent's education level, age of the deceased, respondent's family income level, length of illness, race, gender, religious preference, and relationship to the deceased. However, due to paucity of data (See Demographic Analysis), only general self-efficacy, intrinsic religious orientation, age of the deceased, length of illness and gender were retained for regression analysis.

The study population consisted of adults (persons over 18) who were identified as immediate family members of deceased persons whose death was reported in the obituaries printed in the *Knoxville News Sentinel* from July 1997 through April 1998.

This study was delimited to: 1) family members (mother, father, husband, wife, daughter, son, brother, sister) of persons whose death was reported in obituaries which appeared in the Knoxville *News Sentinel* from July 1997 through April 1998 (Note: the sample was drawn in retrospect from the 1997-1998 timeframe to ensure the participating family members would have a greiving time before being contacted) with the sample being

drawn through systematic random sampling; 2) participants who were adults (minimum age 18); and 3) respondents who could be contacted by telephone.

The purpose of the study was specifically addressed by the assessment of the following research question:

> What relationship, if any, is there between a surviving immediate family member's attitude toward euthanasia and general self-efficacy, intrinsic relgious orientation, respondent's age, respondent's formal education level, age of the deceased, respondent's annual family income level, length of illness, race, gender, religious preference, and relationship to the deceased? deceased, relative to a family member's attitude toward euthanasia

Demographic Analyses

The demographic characteristics of the study population are described in the paragraphs which follow and are presented in Table 1. The family member characteristics examined included: gender, race, age category of the respondent, number of years of formal education, respondent's annual family income, relationship to the deceased, illness prior to death, and religious preference.

The study population had a fairly equal gender distribution with 55% males and 45% females. Ethnicity in the sample was skewed with 97% of the respondents being Anglo-American and the remaining 3% being African-American. No other races were represented. The age, formal education, annual family income, relationship to the

Table 1: Demographic Profile

Category	Respondents % (N)	Category	Respondents % (N)
Gender		Relationship to Deceased	
Male	55.0 (72)	Father	00.0 (00)
Female	45.0 (59)	Mother	04.6 (6)
Ethnicity		Husband	05.3 (7)
Anglo-American	97.0 (127)	Wife	13.0 (17)
African-American	03.0 (4)	Daughter	26.0 (34)
Age (Years)		Son	34.4 (45)
18-29	00.8 (1)	Brother	09.2 (12)
30-39	09.9 (13)	Sister	07.6 (10)
40-49	22.1 (29)	Illness Before Death	
50-59	27.5 (36)	Ill	80.0 (105)
60-69	15.3 (20)	Not Ill	19.0 (25)
70+	24.4 (32)	No Response	01.0 (1)
Formal Education (Years)		Religious Preference	
1-6	03.0 (4)	Protestant	85.5 (112)
7-8	04.6 (6)	Catholic	03.8 (5)
9-12	40.4 (53)	Jew	00.8 (1)
13-14	21.4 (28)	Other	08.4 (11)
15-16	20.6 (27)	None	01.5 (2)
17-18	06.1 (8)		
19+	03.8 (5)		
Annual Family Income (Thousands)			
<12	10.3 (13)		
12-15	12.0 (15)		
16-20	06.3 (8)		
21-25	05.6 (7)		
26-30	10.3 (13)		
31-35	05.6 (7)		
36-40	02.4 (3)		
41-45	04.8 (6)		
46-50	06.3 (8)		
51-55	08.7 (11)		
56-60	01.6 (2)		
60+	26.2 (33)		

deceased, and religious preference categories all showed paucity of data in several of the data cells (see Table 1). Eighty percent of the respondents reported that the deceased family member was ill before death. Nineteen percent reported that the deceased family member was not ill, and one person did not respond.

Assessment of Euthansia Scale Scores

The dependent variable in this study was the respondent's average score on the euthanasia scale. The euthanasia score reflects the respondent's degree of favorableness for or against euthanasia. A higher score indicates more favorableness while a lower score indicates lower favorableness toward euthanasia. The comparison of scores on the euthasia scale by race (ethnicity), gender, age of respondent, category of formal education, religious preference, relationship to the deceased, and family income level is presented in the Table 2 which follows and discussed in the subsequent paragraphs.

There were only two races represented in the sample; Anglo-American and African-American. There was also paucity of data in comparing the mean euthanasia scores of Anglo-Americans and African-Americans (See Table 2). There were only four respondents who were African-American and the rest of the respondents were Anglo-Americans.

Gender was more equally represented in the study population than race with 72 repondents reporting they were males and 59 reporting they were females. Males and females had similar mean euthanasia scores (See Table 2).

Table 2: Euthanasia Scores by Independent Variable

Variable	N*	M (SD)**	Variable	N*	M (SD)**
Gender			Relationship to Deceased		
Male	72	29.39 (5.60)	Father	0	00.00 (-)
Female	59	28.71 (5.28)	Mother	6	27.00 (5.66)
Ethnicity			Husband	7	31.71 (5.02)
Anglo-American	127	29.06 (5.49)	Wife	17	28.65 (3.87)
African-American	4	29.75 (4.34)	Daughter	34	29.41 (5.65)
Age (Years)			Son	45	29.40 (5.75)
18-29	1	29.00 (-)	Brother	12	28.58 (5.70)
30-39	13	30.08 (6.32)	Sister	10	27.30 (5.89)
40-49	29	29.34 (5.79)			
50-59	36	30.14 (5.49)			
60-69	20	29.00 (4.53)	Religious Preference		
70+	32	27.31 (5.18)	Protestant	112	28.90 (5.32)
Formal Education (Years)			Catholic	5	25.00 (6.60)
1-6	4	24.75 (4.43)	Jew	1	33.00 (-)
7-8	6	28.83 (3.92)	Other	11	30.91 (4.95)
9-12	53	28.57 (5.35)	None	2	37.50 (4.54)
13-14	28	29.86 (5.02)			
15-16	27	28.74 (6.00)			
17-18	8	34.25 (4.03)			
19+	5	27.60 (6.43)			
Annual Family Income (Thousands)					
<12	13	28.54 (4.50)			
12-15	15	29.60 (3.14)			
16-20	8	26.50 (4.04)			
21-25	7	27.86 (3.89)			
26-30	13	28.08 (4.91)			
31-35	7	26.00 (5.16)			
36-40	3	26.33 (6.11)			
41-45	6	28.17 (4.96)			
46-50	8	30.38 (6.44)			
51-55	11	31.09 (7.44)			
56-60	2	35.50 (2.12)			
60+	33	30.52 (6.01)			

N*= Number of Respondents
M (SD)**= Mean/ Standard Deviation

Note: Mean euthanasia score for the study population (N=131) was 29.17 with a standard deviation of 5.38

All age categories were fairly well represented with the exception of the 18-29 age category which contained only one respondent. The 50-59 age category contained the largest number of respondents. A generally accepted rule is that a data cell should contain at least 30 respondents to ensure stability of data in data analysis (Wimmer & Dominick, 2000). The 70+ age category meets this as does the 50-59 age category. The 40-49 age category is very close to this research standard with 29 respondents. The 60-69 age category, the 30-39 age category, and the 18-29 age category all fall below the minimum N so data stability cannot be ensured during data analysis.

The description of euthanasia scores based on years of formal education is shown in Table 2. As the table shows, there was some paucity of data in the 1-6, 7-8, 17-18 and 19+ categories with the three remaining categories (9-12, 13-14, and 15-16) being well represented. The 1-6 years of formal education had the lowest euthanasia score mean and the highest mean was in the 17-18 years of formal education category.

The study population was heavily skewed toward the Protestant category of religious preference (See Table 2). The remaining categories showed paucity of data. The None category of religious preference was represented by two respondents; however, it showed the highest mean euthanasia score of any of the religious preference categories.

The Relationship to the Deceased category which was most represented in the study population was the Son category with 45 respondents. The next largest was the Daughter category with 45 respondents. There were no fathers represented by the study population. Although the Son and Daughter categories contained sufficient data for

analysis, the remaining categories all showed paucity of data lower than the threshold required for analysis (See Table 2).

Table 2 also presents the comparison of euthanasia mean scores by annual family income. Almost all of the data cells showed paucity of data except the $60+ category which was represented by 33 respondents. Although there is a limited amount of data, the higher euthanasia mean scores appear at the upper portion of the income categories with the means of over 30 beginning at $46,000 through $60,000. Scores below $46,000 ranged from 26.00 to 29.60.

Forward Stepwise Regression Analysis of Study Data

Forward Stepwise regression was used to carry out the statistical analysis in this study to determine if there were any independent variables which would be significant predictors of euthanasia preference. The subsequent paragraphs describe in the detail the Forward Stepwise regression model testing.

Forward Stepwise Regression Analysis

A stepwise procedure using forward selection based on controlled entry of independent variables was used to obtain a regression model. The Forward Stepwise procedure analyzes each variable to see if it meets a tolerance criterion (0.05) to be entered into the regression equation. The selection process stops when the established criterion for the F statistic is no longer met. One benefit of using Forward Stepwise is that as insignificant variables are removed there may be less masking of the influence of the

remaining variables and contributing variables and their contributions are more clearly identified.

Study variables used for the analysis were: general self-efficacy, intrinsic religious orientation, age of the deceased, length of illness, and gender. Other independent variables initially identified in this study were omitted from analysis because of paucity of data in some of the data cells. Wimmer and Dominick (2000) suggest that analysis of data with cells containing less than 30 respondents produce results that are unstable.

Although general self-efficacy, intrinsic religious orientation, age of the deceased, length of illness, and gender were introduced into the model, the Forward Stepwise procedure only retained intrinsic religious orientation.

Table 3 presents the regression coefficient and t-test on the individual parameter estimate. Intrinsic religious orientation is the only independent variable in the model with a regression coefficient significantly different from 0 ($p < 0.001$) and appears to be the only significant predictor of euthanasia preference based on Forward Stepwise regression. The model reveals the euthanasia score decreases by .657 for every unit that intrinsic religious orientation rises. The relationship is inverse with a Pearson's Correlation Coefficient of -0.44 and a $p < 0.001$ (See Table 4).

The model explains slightly over 18% of the variation in score (See Table 5).The ANOVA for the Forward Stepwise Regression Model is shown in Table 6. The table shows an F value of 29.489 and a significance level of $p < 0.001$.

Table 3. Forward Stepwise Regression Model Coefficient[a]

Forward Stepwise Regression Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	48.631	3.609		13.474	0.000
Intrinsic Rel. Orientation Score	-0.657	0.121	-0.442	-5.509	0.000

[a] Dependent Variable: Euthanasia Score

Table 4. Correlations

Independent Variable	Correlation	Significance
General Self-Efficacy	-0.020	0.819
Intrinsic Religious Orientation	-0.439*	<0.001
Age of Deceased	-0.064	0.469
Length of Illness	-0.114	0.198
Gender	-0.062	0.481

* significant variable

Table 5. Forward Stepwise Regression Model Summary

Model	R	R Square	Adjusted R^2	Standard Error of the Estimate
Forward Stepwise	.433[a]	.187	.181	4.87

[a] predictor: Intrinsic religious orientation score

Table 6. Forward Stepwise Model ANOVA[b]

Initial Regression Model Source	Sum of Squares	df	Mean Square	F	Significance
Regression	698.093	1	698.093	29.489	0.000[a]
Residual	3030.184	128	23.673		
Total	3728.277	129			

a. Predictors: Intrinsic religious orientation
b. Dependent Variable: Euthanasia Score

Chapter Summary

The correlations and regression model show that there is a significant (p <0.001) inverse relationship (-0.44) between the euthanasia and intrinsic religious orientation scores in this study. The model reveals that the euthanasia score decreases by 0.657 for every unit rise in the intrinsic religious orientation score. However, significant (0.05) relationships between other predictors in this study do not exist, or were not able to be tested in cases where variables showed a paucity of data in some data cells.

CHAPTER V

STUDY SUMMARY, FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

Study Summary

The purpose of the study was to analyze factors which may relate to immediate surviving family members' attitudes toward euthanasia and to determine their significance, if any. The factors identified for analysis in this study were: general self-efficacy, intrinsic religious orientation, respondent's age, respondent's education level, age of the deceased, respondent's family income level, length of illness, race, gender, religious preference, and relationship to the deceased. Each of these was identified as an independent variable which may relate to the participating immediate family member's attitude toward euthanasia, which was the dependent variable measured in this study using the euthanasia scale.

The purpose of the study was specifically addressed by the assessment of the following research question:

> What relationship, if any, is there between a surviving immediate family member's attitude toward euthanasia and general self-efficacy, intrinsic relgious orientation, respondent's age, respondent's formal education level, age of the deceased, respondent's annual family income level, length of illness, race, gender, religious preference, and relationship to the deceased?

Findings

Forward Stepwise regression analysis was used to answer the research question. The following findings are based on the analysis of data using Forward Stepwise regression analysis as presented in Chapter 4:

Research Question

What relationship, if any, is there between a surviving immediate family member's attitude toward euthanasia and general self-efficacy, intrinsic religious orientation, respondent's age, respondent's formal education level, age of the deceased, respondent's annual family income level, length of illness, race, gender, religious preference, and relationship to the deceased?

Research Question Findings

1. General self-efficacy did not appear to be a significant predictor ($p<.05$) of euthanasia scores in the regression model tested in this study.
2. Intrinsic religious orientation appeared to be a significant predictor ($p<0.001$) of euthanasia scores in this study.
3. Respondent's age was not analyzed in this study because of paucity of data in several data cells.
4. Respondent's formal education level was not able to be analyzed in this study because of paucity of data in several of the education level categories.
5. Age of the deceased did not appear to be a significant predictor ($p<.05$) of euthanasia scores in the regression model tested in this study.

6. Respondent's family income level was not able to be tested in this study because several of the income level categories showed paucity of data.
7. Length of illness did not appear to be a significant predictor ($p<.05$) of euthanasia scores in the model tested in this study.
8. Race was not able to be tested in this study since the sample was fairly homogeneous with only two races represented and with one of two races only represented by 4 individuals.
9. Gender in this study in this study does not appear to be a signficant predictor of euthanasia scores.
10. Relgious preference was not able to be tested in this study because of paucity of data in some of the data cells.
11. Relationship to the deceased was not tested in this study because of paucity of data in some of the relationship categories.

Conclusions

Within the limitations of this study, intrinsic religious orientation is a predictor of euthanasia preference. Other factors analyzed in the study do not appear to be predictors of euthanasia preference.

Recommendations

The following recommendations for further study are based on the findings and conclusions presented in this chapter:

1. Due to the paucity of data in some categories of the race, education, income, respondent's age, religious preference, and relationship to the deceased variables, a study similar to this study should be conducted with a larger more diverse sample to determine if there are significant differences in attitudes regarding euthanasia with regard to each of these variables. If the study is replicated using a study population similar to the one used in this study, stratified sampling may be a sampling methodology which may yield a higher cell count for analysis.
2. Because this study revealed that a trait such as intrinsic religious orientation can be identified as a strong highly significant predictor of euthanasia scores even in a regional homogenous sample, perhaps researchers should identify and study other traits which may relate to euthanasia preference in addition to the demographic variables which are more frequently studied.
3. Although general self-efficacy was not a significant predictor of euthanasia preference in this study, persons may want to replicate this part of the study using a self-efficacy scale which is domain specific to euthanasia to determine if self-efficacy which is specific to euthanasia is a predictor of euthanasia preference.
4. Additionally, because this study has shown that immediate family members will respond to survey questions, additional studies should be made of this group to determine their degree of involvement in health care decision making and attitudes they may have in making such decisions.

CHAPTER VI

THE STUDY IN RETROSPECT

This concluding chapter covers elements of the study not necessarily supported by the data, but which may add to the understanding of the study and which may benefit others who carry out additional research in the area.

This study demonstrates that research can be carried out on sensitive topics such as euthanasia if the researcher is consistent in his approach and demonstrates sensitivity to the respondent while making the contact and throughout the survey process. However the difficulty of getting to the intended audience may make the effort arduous and time consuming. The researcher must be prepared to spend the time it takes to solicit the responses in a manner which will encourage the respondents' participation. Also, the researcher should be prepared to use a sampling replacement methodology to ensure that participation is maximized to ensure adequate data for analysis. The actual time to complete the survey questionnaire contained in the appendix of this study was approximately 12 minutes. However, in addition to the time actually answering the questions, this researcher estimated that additional time would be required based on other influences such as callbacks, disconnected phones, interruptions during the survey, etc. Considering these variables the researcher estimated that it would be possible to complete five surveys in a three-hour calling period. The actual average number completed during a three-hour calling period during this study was three surveys. Sunday evenings and Saturday mornings appeared to be the best time to reach potential respondents.

Upon initial contact, respondents in general appeared slightly apprehensive and asked questions regarding the study even though an introductory script provided an overview. Once the respondents received additional assurances of the importance of the study and assurances of confidentiality they appeared willing to participate and as the survey progressed even appeared grateful to participate in many instances. Often following completion of the survey questionnaire, the respondents wanted to talk personally about their experiences and some even expressed feelings of "guilt" and "aloneness" in having had to make or participate in euthanasia decisions. After the respondents had an opportunity to talk about their feelings, many expressed appreciation for the call and noted that the interchange had provided a sense of closure. This researcher notes that although it is not part of this research, the responses suggest there may often be influences, possibly cultural or role related, which inhibit family members from having psychological closure on euthanasia decisions once they are made.

Only two persons who were potential respondents and who refused to participate expressed strong feelings against the survey. One individual thought the phone call was an attempt to sell burial insurance or a grave plot even though the researcher attempted to explain before the respondent hung up on the interview. Another respondent was in the middle of litigation with the tobacco industry over the allegedly tobacco-induced death of a family member and was told by her lawyer not to take any phone calls regarding the family member's death. She believed the researcher was probably a representative of the tobacco industry trying to influence the case.

Although this study did identify that intrinsic religious orientation is a significant predictor of attitude toward euthanasia, many of the variables included in the study were not able to be adequately tested due to paucity of information in some of the study cells. This was due in part to the sample size, but also may have been influenced by the homogeneity of a regional sample. For example, the study only had two races represented; Anglo-American and African-American. However, only 4 African-Americans responded to the survey. A similar observation can be made about religious preference where most of the respondents were Protestant (N=112). Other respondents reporting religious preference included Catholic (N=5), Jew (N=4), Other (N=11) and None (N=2). The "None" category had the highest euthanasia scores of any group but was only represented by two individuals. Although the sample was representative, with limited data in some cells the study may not have been sensitive enough to pick up some influences which may appear significant in a study from a less homogenous population and larger sample. This does not suggest that research should not be done on a regional sample, but it does suggest that a researcher may want to use data collection methodologies which ensure adequate data cell counts and exercise caution in selecting variables to be studied depending on whether it is a regional or national study taking into consideration that some effects may not be as readily detected in a homogenous regional sample. The researcher may also want to exercise caution in establishing categories which are so restrictive they reduce data cell counts to critical levels. For example, if a researcher created an income category on increments of $10,000 rather than $5,000 more data would be clustered in each cell and the danger of minimal data representation in a cell would be reduced.

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APPENDIX

APPENDIX A

Analysis of Selected Factors as Predictors of Surviving Family Members' Attitudes Toward Euthanasia.

InterviewerVoice Track

Hello, this is Jeff Hoyer from the University of Tennessee College of Health, Leisure and Safety Sciences. Are you the (family member) of (deceased) who passed away (Month, Year)? We are conducting a survey about family attitudes regarding euthanasia which is the act of allowing or inducing death for merciful reasons. This survey is important because although health care givers have been surveyed regarding their attitudes, no one has asked family members how they feel. Participation in the survey is limited to persons 18 years of age and older. Your participation in the 10 to 15 minute survey is voluntary and all responses are confidential. If during the survey you wish to discontinue you may do so. Also, your name will not appear anywhere on the survey. Your telephone number was selected randomly from listings of those persons in the area who have lost a loved one in the past two years. May I interview you?

(If "YES" continue with survey, if "NO," say "thank you," and hang up and select the next potential respondent).

INTRODUCTION (Part I):

Part one deals with general questions on euthanasia.There are no right or wrong responses and your responses are entirely confidential and will be mixed in with other persons' comments.

Part I (5 Minutes)

I am going to read you a series of questions. Please take a second and either "agree" or "disagree" with the statement.

[Note to Coder: if person agrees, write the "value" in the "agree" column for later tabulation]

	Value	Agree
1. A person with a terminal illness has the right to decide to die.	4.15	_____
2. God gave us life and he should be the only one to end it.	1.81	_____
3. Euthanasia is acceptable if the person is old.	3.41	_____
4. Inducing death for merciful reasons is wrong	1.65	_____
5. Euthanasia should be accepted in today's society	4.45	_____
6. There are never cases when euthanasia is appropriate.	1.09	_____
7. Euthanasia should be allowed only if the family consents	3.25	_____

8. Death should be allowed but not induced in cases of terminal illness.	3.76	_____
9. Euthanasia is helpful at the right time and place (under the right circumstances).	4.03	_____
10. Euthanasia is a humane act.	4.50	_____
11. Euthanasia should be against the law.	1.23	_____
12. The question of euthanasia should be left up to the entire family and not the individual.	2.83	_____
13. There are very few cases when euthanasia is acceptable.	2.07	_____
14. A person should NOT be kept alive by machines.	2.44	_____
15. Euthanasia should be used ONLY when the person has a terminal illness.	3.63	_____
16. Natural death is a cure for suffering.	2.71	_____
17. The taking of human life is wrong no matter what the circumstances.	1.36	_____
18. Euthanasia is acceptable in cases when all hope of recovery is gone.	3.90	_____
19. Euthanasia gives a person a chance to die with dignity.	4.29	_____
20. Euthanasia should be practiced only to eliminate physical pain and not emotional pain.	3.00	_____
21. Man's job is to sustain and preserve life, not end it.	2.22	_____

TOTAL Respondent "Agree" Value _____ Average ____

INTRODUCTION (Part II):

Part two deals with 10 general questions on self-efficacy which some authors say is a person's ability to make decisions in stressful situations. Again, it is emphasized there are no right or wrong responses. Your responses are entirely confidential and will be mixed in with other persons' comments.

Part II (4 Minutes)

Please respond in one of four categories. "Not true (1);" "Hardly true (2);" "Moderately True (3);" or "Exactly True (4)."

	Numeric Value
1. I can always manage to solve difficult problems if I try hard enough.	_____
2. If someone opposes me, I can find means and ways to get what I want.	_____
3. It is easy for me to stick to my aims and accomplish my goals.	_____
4. I am confident that I could deal efficiently with unexpected events.	_____
5. Thanks to my resourcefulness, I know how to handle unforeseen situations	_____
6. I can solve most problems if I invest the necessary effort.	_____
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	_____
8. When I am confronted with a problem, I can usually find several solutions.	_____
9. If I am in trouble, I can usually think of something to do.	_____
10. No matter what comes my way, I am usually able to handle it.	_____
SUM	_____

INTRODUCTION (Part III):

Part three deals with 9 general questions on intrinsic religious orientation which looks at how a person applies his or her belief system to daily life. Again, there are no right or wrong responses. Your responses are entirely confidential and will be mixed in with other persons' comments.

Part III (3 Minutes)

Please respond in one of five categories given for each question:

1.I try hard to carry my religion over into all my other dealings in life.

Definitely disagree	Disagree	Agree	Definitely Agree	
1	2	3	4	_____

2. Quite often I have been keenly aware of the presence of God or the divine being.

Definitely not true	Tends not to be True	Tends to be True	Definitely True	
1	2	3	4	_____

3. My religious beliefs are what really lie behind my whole approach to life.

Definitely not so	Probably not so	Probably so	Definitely so	
1	2	3	4	_____

4. The prayers I say when I am alone carry as much meaning and personal emotion as those said by me during services.

Almost never	Sometimes	Usually	Almost always	
1	2	3	4	_____

5.If not prevented by unavoidable circumstances, I attend Church:

< once a month	Two or three times a month	About once a week	> once a week	
1	2	3	4	_____

6. Religion is especially important to me because it answers many questions about the meaning of life.

Definitely disagree	Tend to disagree	Tend to agree	Definitely agree	
1	2	3	4	_____

7. I read literature about my faith (or church).

Never	Rarely	Occasionally	Frequently	
1	2	3	4	_____

8. If I were to join a church group, I would prefer to join (A.) a social fellowship, or (B.) a bible study group.

Would prefer bible study	Probably prefer bible study	
1	2	
Probably prefer social fellowship	Would prefer social fellowship	
3	4	-------

9. It is important to me to spend periods of time in private religious thought and meditation.

Never true	Rarely true	Occasionally true	Frequently true	
1	2	3	4	_____
			SUM	_____

Thank you for participating in this survey. Before closing I'd like to get some general information that may also be valuable in the study.

Demographic Information

Category which best describes your age? (Circle one): 18-29, 30-39, 40-49, 50-59, 60-69, 70+
Years of formal education) Circle one: 1-6, 7-8, 9-12, 13-14, 15-16, 17-18, 19+
Gender?Male___ Female___; Race? White____Black____Hispanic____Asian____ Native American___ Other____
Age of deceased loved one _____
Relationship to the deceased (circle one)? mother/father/husband/wife/daughter/son/brother/sister

Approximate level of annual family income (Circle One)?

Less Than $12000
$12,000 to $15,000
$16,000 to $20,000
$21,000 to $25,000
$26,000 to $30,000
$31,000 to $35,000
$36,000 to $40,000
$41,000 to $45,000
$46,000 to $50,000
$51,000 to $55,000
$56,000 to $60,000
Over $60,000

Was the deceased ill prior to death? Yes___NO___. If "Yes," estimated length of time under the care of a care giver prior to death_____(days).
Religious preference: Protestant ___, Catholic ____, Jewish ____, Other ____ None ___

Scale Source Citations

Part I: Euthanasia Scale

Tordella, M. An instrument to appraise attitude of college students toward euthanasia, Thesis, Department of Health Sciences, Western Illinois University, 1977.

Part II: Self Efficacy Scale

Schwarzer, R. Measurement of perceived self-efficacy. Psychometric scales for cross-cultural research. Berlin, Germany: Freie Universitat Berlin, 1993.

Part III: Intrinsic Religious Orientation

Robinson, J. & Shaver, P. Measures of Social Psychological Attitudes. Appendix B to measures of political attitudes. Survey Research Center Institute for Social Research. Revised Edition,1975.

VITA

Jeffrey Lee Hoyer was born in Fargo, North Dakota on June 14, 1949. He graduated from Wessington Springs Academy, Wessington Springs, South Dakota in 1967.

He has an A.A. degree (1969) from Central College, McPherson, Kansas; a B.A. degree (biology/psychology, 1972) from Tabor College, Hillsboro, Kansas; a M.S. degree (biology, 1976) from Middle Tennessee State University; a M.S. degree (communications, 1986) from the University of Tennessee, Knoxville; and a Ph.D degree (community health, 2000) from the University of Tennessee, Knoxville.

He has several years of high school teaching experience having taught general science, biology, earth science and coached high school soccer in Virginia and Tennessee. He has also taught biology, botany, and zoology at Middle Tennessee State University as a graduate teaching assistant. Additionally, he taught business and technical writing for three years as an adjunct instructor for Tennessee Wesleyan College.

For five years he worked as a curriculum editor for the Free Methodist Headquarters and Aldersgate Publications Association--a 10-denomination curriculum development and publishing cooperative. During this time he developed New Horizons Bible Studies which is a book by book study series of the Old and New Testaments.

He has also worked as a writing and publications consultant writing, editing publications, and doing grants and proposals for Indiana Vocational Technical College, the University of Tennessee, The EC Corporation, Beacon Hill Press, Light and Life Communications, and Wesley Press.

He worked six years for the EC Corporation, an engineering and contracting firm, serving both as the company's proposal team manager and as the corporate spokesperson involved in media relations.

He left the EC Corporation to work for Bechtel National Inc. where he served as a document coordinator and senior technical writer. He wrote and edited documents for the $5 million remedial investigation feasibility study project and had oversight responsibility for all documents processed through the project including subcontracts placed where the company was the prime contractor.

Following two years at Bechtel, he worked for eight years for Martin Marietta Energy Systems where he was the environmental management and enrichment facilities command media manager. He was responsible for 2,700 documents and supervision of up to 15 employees who developed procedures for handling and disposal of hazardous waste. Additionally, he also carried out liaison roles between the company and the Department of Energy in the planning and development of work protocols.

He is currently (since August 1999) working for the University of Tennessee at Martin where he is an assistant professor in the Department of Communications. He is teaching a variety of communications courses and is the faculty advisor for the public relations student society.

He has received numerous corporate achievement awards and is a recipient of the Award of Excellence from the Society for Technical Communication for newsletter preparation and the Bronze Quill Award from the International Association of Business Communicators for annual report preparation.