



Theses, Dissertations, and Projects

2008

Physician assisted suicide: a survey of North Caroline end of life care workers

Ollie Dooling Walker Smith College

Follow this and additional works at: https://scholarworks.smith.edu/theses



Part of the Social and Behavioral Sciences Commons

Recommended Citation

Walker, Ollie Dooling, "Physician assisted suicide: a survey of North Caroline end of life care workers" (2008). Masters Thesis, Smith College, Northampton, MA. https://scholarworks.smith.edu/theses/435

This Masters Thesis has been accepted for inclusion in Theses, Dissertations, and Projects by an authorized administrator of Smith ScholarWorks. For more information, please contact scholarworks@smith.edu.

Ollie Dooling Walker Physician Assisted Suicide: A Survey of North Carolina End of Life Care Workers

ABSTRACT

The quantitative study reported here surveyed North Carolina clinicians who perform end of care about their attitudes toward physician assisted suicide (PAS). Twenty-four clinicians, representing varying disciplines from within the field of end of life care, shared their opinions via a 12-item survey. Clinicians were asked to think about PAS in terms of their stance as to when it may or may not be an appropriate practice, and how their own personal, religious, professional, and ethical beliefs influence their views on PAS. Participating clinicians were also surveyed about the recently enacted North Carolina Right to a Natural Death Act. Findings indicated that knowledge about the Right to a Natural Death Act is rare in the participation group. Less than one-third of respondents were aware of the North Carolina Right to a Natural Death Act. Findings showed clinicians' attitudes towards patients' rights to autonomy and self-determination when making end of life decisions are positive ones, consistent with findings from public opinion polls for the U.S. population as a whole over many recent years. The most surprising finding was that, within this sample, clinicians considered the views held by physicians on PAS to be as important to take into account as those of the patient and that patient's family.

PHYSICIAN ASSISTED SUICIDE: A SURVEY OF NORTH CAROLINA END OF LIFE CARE WORKERS

A project based upon an independent investigation submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

Ollie Dooling Walker

Smith College School for Social Work Northampton, Massachusetts 01063

2008

ACKNOWLEDGEMENTS

I want to acknowledge my class, the A08's. What luck to have entered Smith the year that I did and to get to work beside you all.

Thank you to Bill Meyer and Diane Meglin. Two incredible supervisors who have been so generous with their time and knowledge.

To my advisor, Gael McCarthy. For all your thought and all your hours.

Paige and Jeff, I love you both. Your support has been unending.

Amy Beth. The waves, the walks, the talks. Thank you, always.

LV. What can I say? You're the best. Absolutely. (PVIM)

To the Wicked Witch of the West: I adore you. I always have. Thank you.

Joseph, you will always be more than my best friend. And I will always be more than honored to know you. I thank you, every day.

To my mother, Gay Haley Walker: I am so grateful for you. I love you so much and am proud of every moment and every memory of you. I can never thank you enough.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	ii
TABLE OF CONTENTS	iii
LIST OF TABLES	iv
CHAPTER	
I INTRODUCTION	1
II LITERATURE REVIEW	5
III METHODOLOGY	16
IV FINDINGS	19
V DISCUSSION	37
REFERENCES	46
APPENDICES	
Appendix A: HSR Approval Letter	48 49 50 52 54
Appendix 2. 1001010110110 Dimini	5 1

CHAPTER I

INTRODUCTION

Physician assisted suicide (PAS), otherwise known as physician assisted death (PAD), is a topic that has been researched, scrutinized, fought for and against, and taken a profound emotional toll on many people. As death is the one experience that we all must endure, and terminal illness something that does not discriminate against race, ethnicity, sex, socio-economic status, gender identity, or sexual orientation, the topic of how to handle such illness and how to negotiate one's inevitable end is a much-heated debate. The PAS debate is a debate that must be taken seriously, a debate that must take all things into consideration. This debate must also demand that in the effort to ensure just practices are offered to all, serious ethical thinking must look closely at what is beneath the request for a physician assisted suicide when illness, suffering, and death are near.

Many public opinion polls have been conducted in order to gauge where this country's citizens stand on this contentious issue. A public opinion poll ranging from 1936 to 1998 showed that while the vast majority of Americans were in opposition to the legalization of PAS, the number of proponents has been steadily increasing since 1973 (Allen, Chavez, DeSimone, Howard, Johnson, LaPierre, Montero, & Sanders, 2006). Physician assisted suicide is particularly relevant to clinicians working in end of life (EOL) care. Discovering views held by this most intensely involved professional group may be helpful not only to fellow clinicians in the end of life care field, but also to the

general public who may or may not be faced with a situation where physician assisted suicide is highly relevant.

There are medical professionals, for example, social workers, registered nurses, licensed practical nurses, licensed counselors, and medical doctors in every state of this country who work in end of life care. PAS is illegal in all states in the U.S. but Oregon, where it became legal in 1997. In January of 2008, North Carolina passed the Right to a Natural Death Act which details a patient's right to refuse life sustaining measures given that the patient meets certain criteria laid out by the law and to be determined by the attending physician. This Act does not include the practice of PAS; however, it is a step towards furthering a patient's right to autonomy and self-determination, and the debate over whether or not PAS should be legalized has a lot to do with a patient's autonomy and self-determination. As medical professionals are working directly with people who are dying, this is a topic that affects micro level medical professionals as well as the profession as a whole. If this option were ever to be provided for patients at the end of their lives, clinicians within the medical field have the responsibility to be informed on this topic, on the concerns that are held by patients and their families, and on any issues that may arise for them if they were to be in a situation where PAS were an option. This study looks at views about PAS that are held by clinicians who perform end of life care in the state of North Carolina.

Research has been gathered that looks at the beliefs and views held by patients, families, clinicians, and the American public as a whole on the issue of PAS. There is a wealth of research on the subject of PAS but, to date, no research has been located that looks specifically at the views held by practicing end of life clinicians in North Carolina,

and certainly no research has been located looking at this after the addition of North Carolina's Right to a Natural Death Act in January of 2008.

The initial aim of the study was to collect surveys from a minimum of 50 clinicians who perform some sort of end of life care in the state of North Carolina. Participants had to have access to a computer, be fluent in English and hold the title of social worker (SW), registered nurse (RN), licensed practical nurse (LPN), medical doctor (MD), or some sort of licensure in counseling or therapy. Participants were recruited by word of mouth and/or email, and were clinicians known to me or known to my colleagues, and found through a snowball sampling method. The intended audience for this study is clinicians who perform end of life care. These end of life clinicians will no doubt have to confront the topic of PAS, either directly or indirectly, and will need to be knowledgeable and comfortable with it so as to make this difficult time less difficult for the population they are devoted to working with. The goal is for these clinicians in the health care field to be informed by their colleagues and to create a dialogue for themselves that will address this pressing and salient issue.

Terms used in this study that are common to end of life work are identified as follows. "Physician assisted suicide" is defined as a physician's providing a competent patient with a medication or other intervention that, when self administered, will bring an end to his or her life (Allen, Chavez, DeSimon, Howard, Johnson, LaPierre, Montero, & Sanders, 2006). "Physician assisted dying" carries the same definition as PAS, in that it entails a physician's prescribing a lethal dose of medication that a competent patient can administer to bring an end to life (Sears & Stanton, 2001). The difference between PAS and PAD falls in the use of the word dying as opposed to suicide. "Voluntary refusal of

food and fluids" (VRFF) entails a patient's volunteering to decline taking in food and liquid in order to bring an end to her or his life (Harvath, Miller, Smith, Clark, Jackson, & Ganzini, 2006).

"Euthanasia" can be broken down into three different terms: "passive euthanasia," "active voluntary euthanasia," and 'involuntary euthanasia." "Passive euthanasia" involves artificial life support being withdrawn or withheld, allowing the patient to die. "Active voluntary euthanasia" involves a physician's actually administering a lethal dose of medication to a patient who has requested this while of sound mind. This differs from "physician assisted suicide" wherein the physician merely supplies the patient with the lethal dose but does not administer it. "Involuntary euthanasia" involves a medication or other form of intervention that will bring an end to life being administered to a patient without the patient's requesting this and/or without her or his informed consent (Allen et al., 2006).

CHAPTER II

LITERATURE REVIEW

This chapter will discuss the debate over the legalization of physician assisted suicide (PAS) in relation to American public opinion, religious and spiritual beliefs related to PAS, beliefs about PAS held by clinicians, and finally in terms of PAS- related beliefs of patients and families. Each of these categories will be examined in order to showcase a broad understanding of the heated debate and varied compelling arguments made for and against the legalization of PAS in America.

Public Opinion and Physician Assisted Suicide

End of life decisions have been a major point of contention in North America for a significant amount of time. There have always been people suffering from terminal illness and there have always been issues over how to adequately treat these conditions and the patients who are suffering. It is not surprising that the issue of hastening death has been debated for many years. Public opinion polls ranging from 1936-2002 were used in order to get an informed look at what Americans' views towards euthanasia and physician assisted suicide (PAS) are and how they have changed (Allen et al., 2006). *Voluntary Euthanasia*

From 1936 to 1950, the majority of Americans did not support voluntary euthanasia. However, since 1950, the number of Americans in support of voluntary euthanasia has been rising steadily. This rise has continued as Allen and co-authors show that, from 1973 to 1991, support of foregoing life-sustaining treatment rose from 62% in

opinion polls stating foregoing life-sustaining treatment was appropriate to 85% in favor of it (Allen et al., 2006). Voluntary euthanasia, however, refers to a patient's taking of his or her own life. Ending one's life with the help of a physician (PAS) has been viewed differently by respondents to the large-scale public opinion polls.

Physician Assisted Suicide/Death

Physician assisted suicide is the most aggressive of all the approaches to hastening death that were discussed in these polls, and it is also the approach that has the least amount of support by Americans (Allen et al., 2006). Many believe that this intimate decision of whether or not to end their own lives is theirs to make, but only as long as their means to hasten death fit into certain parameters that may or may not be consistent with the individual's wishes.

Opinion polls show that fairly consistently, from 1990 to 1998, the practice of PAS has not been deemed an appropriate option for patients in the end of life. One of the biggest arguments held against PAS is that it is believed to be in direct violation of the Hippocratic oath (Allen et al., 2006). In this oath, which all physicians take on being licensed, doctors swear "primum, non nocere" -- first of all, to do no harm. The issue currently seems to turn on whether the failure to relieve suffering, even if this relief might constitute ending a life, is in fact to do harm; or whether, no matter what the suffering involved, a physician must preserve life as part of doing no harm. Clearly, this is a difficult issue involving obvious value judgments and interpretations.

Burdette, Hill, and Moulton (2005) found that within society as a whole, there are certain demographic factors that are associated with an individual's being an opponent of PAS. These demographics are: older age, female gender, identifying as Black, having

fewer years of education, holding politically conservative views, and living in a Southern or rural region (Burdette et al, 2005).

The "Slippery Slope of Abuse" Argument Against PAS

One of the most compelling arguments that opponents of PAS hold is the "slippery slope of abuse" that some see as inevitable if PAS were to become a legal practice. What is meant by this "slippery slope" is a sort of snowballing of abuses that would steadily increase were PAS to be legal. Opponents say this might begin with PAS being practiced by terminally ill patients who chose the option while of sound mind, but eventually could become a practice that patients feel forced or pressured into pursuing for reasons such as old age, severe cognitive impairment, or extreme physical disabilities. The pressures could go on to apply to any disenfranchised group that might be seen as a "burden" upon their families and a financial liability to insurance companies.

Morrison and Meier (1994) have examined this societal topic and the large amount of attention it receives in medical literature and the media. While there is much information on PAS, on the debate to legalize PAS, and on many different aspects of PAS ranging from family and friend involvement to forming guidelines for clinicians who may have to participate in PAS, Morrison and Meier (1994) are proposing that there is a gross lack of sufficient data about the practice of PAS and a surplus of speculation and theorizing. It is suggested that this lack of sufficient data leaves an ill formed foundation upon which to fashion public policy (Morrison & Meier, 1994). However, much information has been presented on the effects that this hypothesized "slippery slope" would have on society if PAS were legal. Notably, none of the available data supported any current abuses taking place in the system (Morrison & Meier, 1994).

When PAS was first brought to the American Courts in the early 1900's, documentation of early debates over the legalization of PAS showed that the "slippery slope" argument began as one of the most compelling arguments opposing legalization (Appel, 2004). Currently, the "slippery slope" argument still carries a large amount of force and reason behind it, but two other very compelling arguments have also made their way to the forefront of the legalization debate. These are patient autonomy or self-determination and religion (Appel, 2004).

Patient Autonomy and Self-Determination

In the past one hundred-plus years since this debate began among Americans in the courts, the main arguments by the opponents and proponents of PAS have shifted. Originally, opponents would use the potential for future abuse as their main argument against PAS, while proponents spoke about how PAS would act for the greater good of society (Appel, 2004). The lack of mention of patient autonomy as a significant argument used by the original supporters of PAS may be explained by the changes in society as a whole in the past century and most notably in the past few decades. Rothman (2001) documents how patient autonomy and rights to self-determination were almost nonexistent topics in the mid twentieth century. Patients are now taking more ownership over their treatment and expecting and demanding more agency when it comes to making their own medical decisions (Rothman, 2001).

While it is widely held that prolonging suffering is not appropriate, as stated in the public opinion polls above, many continue to hold the view that PAS is not appropriate, regardless of the circumstances (Allen et al., 2006). Here the issue over patients losing their autonomy is acknowledged by those opposed to PAS, but this

opposition is often met with the argument that with better palliative care, pain management, and hospice services, the need for PAS would greatly diminish. It is professed that the role of medicine is to support lives, not end them (Radtke, 2005). This argument does speak to quality of life in terms of the implied value that the medical profession should be making the end of life more comfortable for patients (Sears & Stanton, 2001).

The history of the legal battle to have PAS and euthanasia legalized in this country in a sense showcases patients' and citizens' increasing tendency to fight for autonomy and self-determination, but under the guise of promoting the greater social good. Rothman (2001) suggests that patient autonomy has led to the debate over PAS becoming such as contentious issue in this country. However, history shows that before patient autonomy was a key issue, this fight for PAS had already begun (Appel, 2004).

Religious and Spiritual Views and Physician Assisted Suicide

Considering today's most compelling arguments for and against the legalization of PAS, religion is a main factor in the argument against legalization. Differing denominations hold differing degrees of tolerance or intolerance for the practice of PAS. Individuals' religious affiliations and their faith's practices are factors associated with whether or not they will support the practice of PAS. This research shows two main factors that spread across many denominations that seem to make positioning oneself against the legalization of PAS more likely. The two factors shown to contribute to the opposition of PAS are church attendance and the strength of one's religious affiliation. This research suggests that participation in one's religious community, such as church attendance and contribution to one's church events members is linked with opposition to

PAS. Also, biblical literalism and fear of a vindictive god is shown to positively correlate with opposition to PAS (Burdette et al, 2005).

Traina (1998) documents that the major religious traditions have historically been opponents to PAS. Buddhist and Hindu faiths are alike in holding that intentionally shortening one's own life, while it may ease pain and suffering in the present, may make for amplified future suffering. The Roman Catholic and Easter Orthodoxy faiths argue that hastening death may ultimately interfere with God's plan for one's soul.

It is evident that much research has been compiled on faith and its effect on one's views about the practice and legalization of PAS. A group that has been neglected in this research is the atheist group (Smith-Stoner, 2007). End-of-life (EOL) preferences for this group should, presumably, be taken into consideration and should be given the same respect as those of the group who are religiously affiliated. However, atheists as a whole are understudied with regard to their views on PAS and palliative care. Smith-Stoner's (2007) study showed that 95% of atheist participants were in favor of PAS. The atheist participants felt that since death is something we must all face on our own, the decision to die is one we must have the right to make on our own. Also, as against some groups who think of PAS as murder or suicide, these participants reported that it was instead "a dignified way for someone with a terminal illness to minimize suffering for self and others" (Smith-Stoner, 2007).

Historical evidence shows that the original and most compelling arguments for and against the legalization of PAS and euthanasia do not hold religion and morality as the most significant reasoning in society's determination to decide on this poignant issue (Appel, 2004). However, today religion, faith, and belief systems play a significant role

in one's views on death and dying. In support of this argument, it has been shown that the stronger the ties one has to an organized religion, the stronger the chance one will be in opposition to the practice and legalization of PAS. This is significant, as religion seems to inform the personal and political views of individuals; however, should these personal views based on a personal religion inform a nation-wide debate that is held in our courts, not our churches?

Clinicians' Views and Concerns Regarding PAS

Oftentimes a patient may wish to choose PAS, but the patient's family does not support this decision. While the ill patient is technically the client of the nurse or social worker, there is still a dilemma when there are such conflicting beliefs being held and the care and well being of all involved, including the patient and his/her family, are of great importance to the hospice workers (Harvath et al., 2006).

As the word "suicide" carries much weight and negative connotations in this society, another term for PAS has been created, "physician assisted dying" (PAD). The American Psychological Association (APA) has a goal for psychology to become more visible in the area of PAD. The APA notes four areas where there visibility should be increased; these roles would be as educators, advocates, practitioners, and researchers (Sears & Stanton, 2001). DiPasquale and Gluck (2001) look into the personal beliefs and values of mental health professionals in New Mexico, as well as their willingness to participate in PAS. The participating psychiatrists and psychologists were asked if PAS should be legal in certain types of cases; three fourths of them responded with an affirmative answer. A slight majority (55%) of participants reported that they would be willing to participate in PAS. A patient's autonomy was noted as the most compelling

reason to legalize PAS (DiPasquale & Gluck, 2001). This recent research lends great insight into the views currently held by mental health professionals about PAS.

Research has shown that clinicians from different disciplines and health care professionals have expressed concern over patients wanting to participate in PAS because their pain is not under control. A number of patients diagnosed with a terminal illness support this concern, as they reported that when their pain was unmanageable they say they would have requested PAS had it been an option. These patients have since gotten their pain under control, however, and reported that on the day of the interview they would not request PAS (Wilson, McPherson, Allard, Gagnon, Le Luca, Kuhl, Chochinov, Skirko, Chary, Macmillan, O'Shea, Fainsinger, Karam, & Clinch, 2007). This is certainly a significant finding, as the presence of appropriate pain management and palliative care is often cited as one of the most compelling reasons for opposing the legalization of PAS.

Manetta and Wells (2001) conducted an exploratory study looking into the views held by 66 South Carolinian social workers and their views on PAS. In their research, Manetta and Wells speak to the lack of concrete guidelines available to social workers working in end of life (EOL) care. However, in South Carolina, it is mandated that when social workers are assisting a patient at the end of his/her life and the workers are not sufficiently trained in this discipline, they must refer the patient to a clinician who does hold this sufficient training. Nevertheless, when the study was conducted, there were also no specific guidelines reflecting what sufficient training in EOL care constituted (Manetta & Wells, 2001).

The state of Oregon enacted the Death With Dignity Act in 1997. In this one single U.S. state where PAS has been legalized, interviews and surveys completed by hospice nurses and social workers reveal some of the dilemmas they face when working with terminally ill patients in a state where PAS is accessible. Hospice workers reported on experiences with both voluntary refusal of food and fluids (VRFF) as well as PAS. The nurses and social workers noted many dilemmas. There is a feeling of increased responsibility felt by these workers when they have patients considering PAS. Clinicians noted less feeling of increased responsibility for patients who were considering VRFF. This may be because health care professionals play a more active, or seemingly aggressive, role in PAS, than they do in VRFF (Harvath et al., 2006). Hospice nurses and social workers normally support a patient's autonomy, but a portion of the nurses did state that they had tried to convince patients not to choose PAS, and that if better palliative care were offered, PAS would not be needed. On the other hand, one nurse reported coming to the realization that honoring a patient's right to self-determination may in fact be more ethical then withholding or refusing PAS. Furthermore, while PAS in Oregon is legal, there are still many legal and professional concerns to take into account, and many places where the boundaries as to what is legal or ethical may be blurred. Again, this speaks to the increased responsibility that must be held by the nurses and social workers in this area Harvath et al., 2006).

The profession of social work is guided by the National Association of Social Workers' (NASW) Code of Ethics. Self-determination is noted in this code to be an entity that social workers must seek, promote, and honor on behalf of their clients (NASW, 2006). More information on the specific trainings given to social workers

performing end of life care may prove to show that regardless of whether PAS is a legal practice in Oregon, social workers may be -- and sometimes may not be -- fulfilling their ethical duty to promote self-determination in their clients.

Concerns and Beliefs As Disclosed by Patients and Their Families

In Oregon, where PAS is legal, ninety-eight patients with advanced cancer and their respective families were surveyed to gather their views on PAS. For the patients who were considering PAS, about half of these patients' families were in support of this decision, 30% opposed their decision, and about 19% were unable to come to a decision as to whether or not to support their family member. For the most part, it appears that patients and family members are aware of the beliefs held by the other (Ganzini, Beer, & Brouns, 2006).

As noted above, as a concern held by clinicians about the practice of PAS is research highlighting the clinician's concern that patients may opt for PAS if their pain is not under control. This research also speaks to the concerns that patients' family members may have about PAS being used in the absence of proper pain management. Patients diagnosed with a terminal illness were interviewed in Canada. A portion of the participants reported that if PAS had been legal, they would have already chosen to request this service and end their lives. As previously mentioned, the interesting finding was that at the time of the interview, these individuals stated that while they would have requested PAS at one point in time, they now say that they would not request this service today. The main reason for these patients changing their minds was that their pain at one point was unmanageable and that has since changed (Wilson et al., 2007). This change in opinion or preference could lead to much confusion and hesitation on behalf of not only

patients but their families as well. On the other hand, one person's story may prove to inform what rights another person with a different circumstance may or may not be granted. Again, this does speak to the argument that with better pain management, there would be less need or desire for PAS. Despite these participants' changing their minds about their desire for PAS, the majority of those interviewed did support the legalization of PAS, noting a patient's autonomy and compassion to be driving reasons for this support of legalization (Wilson et al., 2007). An important consideration, also, is depression in terminally ill patients; depression needs to be taken into account when one is considering PAS, as depression is a treatable condition. Connecting with the recently noted research on unmanageable pain influencing patients' desire to end their lives, it is noted that uncontrollable pain is most often associated with depression in a patient with terminal illness (Farberman, 1997).

Summary

Physician assisted suicide (PAS) is something that affects patients, families, clinicians, and society as a whole. There are many compelling arguments for and against the use of PAS including personal experience, religion, ethical dilemmas, and patients' rights. All of these are important considerations that health care professionals need to take into account as they do end of life work, and may encounter patients and families who wish to have PAS as an option. Also, the research should clinicians strengthen their views and opinions of PAS, as they need to be aware of this important end of life issue while working in the field.

CHAPTER III

METHODOLOGY

Formulation

This study examined clinician attitudes to physician assisted suicide (PAS) – in particular, the views held on the topic by clinicians performing end of life work in the state of North Carolina. Physician assisted suicide has been a widely debated and controversial issue for over one hundred years. Workers involved in end of life care in North Carolina have recently been presented with new ethical and procedural challenges with the debate and passage of the January 2008 "Right to a Natural Death" legislation. The project proposed here used purposive snowball sampling (Anastas, 1999), aiming to survey at least 50 clinicians working in end of life care to assess their current attitudes and reactions to the various ethical issues raised by "right to die" and PAS issues.

Sample

The sample included 24 clinicians who perform some sort of end of life care in the state of North Carolina. These clinicians ranged across disciplines from nurses to medical doctors to social workers. From within these disciplines, many types of end of life care were represented in the sample. (See demographics in Chapter IV for more information.) To be eligible for participation, clinicians had to be in practice performing some form of end of life care in the state of North Carolina, be fluent in English, and hold the professional title of either registered nurse, licensed practical nurse, social worker, medical doctor, or licensed therapist or counselor.

Data Collection

The participants' confidentiality was protected and each participant remained completely anonymous. This was possible using an online survey via www.surveymonkey.com. Participants were found by word of mouth and/or email, and were clinicians known to me or known to my colleagues or found through a snowball sampling method. Clinicians from various area agencies such as Duke University Medical Center, the University of North Carolina Hospital and North Carolina Hospice agencies were contacted, as they employed clinicians eligible for this study.

The participants completed the surveys from their home or work computers at their convenience. The survey could be completed online via a link provided to the instrument located at SurveyMonkey.com. The survey consisted of twelve concise questions. Estimated time needed to complete the survey varied with each participant, but could be completed in as quickly as ten to fifteen minutes.

Participants were asked at the beginning of the on-line survey to acknowledge consent or refusal to participate in the survey by clicking on a "button" at the end of an informed consent document contained within the online survey itself. Upon beginning the twelve-question survey, participants were asked to provide some basic demographic information including their age, ethnicity, religion, gender, and professional title.

Data Analysis

Descriptive statistics were used to summarize demographic characteristics of the participants included in the sample. Given that the sample size was only 24, descriptive statistics were also used to look at each of the twelve items included in the study's

survey. Results of the analysis of the survey data are contained in the Findings chapter to follow.

CHAPTER IV

FINDINGS

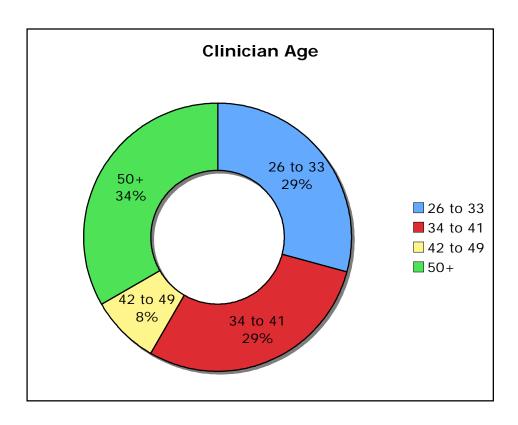
As indicated in the Methodology chapter above, this study consisted of a twelve-question survey to be completed online via www.surveymonkey.com. Before beginning the twelve-question survey, participants read the informed consent letter and clicked an option to continue on with the survey, indicating their consent to participation; then participants were asked to answer four demographic questions about her/his professional discipline, title, specific area of work, age, and gender.

Clinicians' Demographics

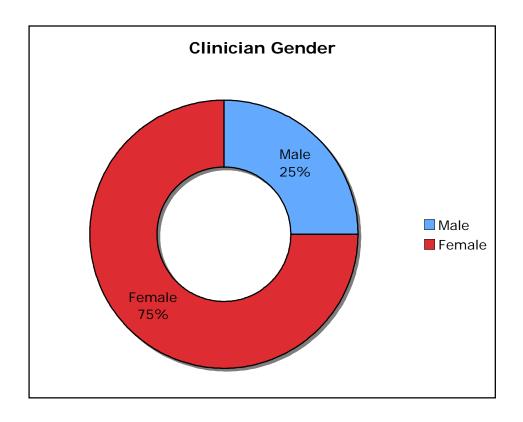
The participants in this sample were clinicians who practice some form of end of life care in the state of North Carolina. The disciplines recruited for this survey were social workers, nurses, medical doctors, and licensed therapists or counselors. Of the 28 clinicians who responded to the survey, 24 responded to the four demographic questions at the beginning of the survey. Information reporting participants' ages, gender, professional titles, and specific fields of work was requested in this brief demographic section.

Clinician Age and Gender

Clinician age differences. The ages of participants ranged from 26 to 61. The average age of participating clinicians was 42, with a median age of 41; the modal age of participants was 56. This wide range from 26 to 61 suggests that a varied amount of life and professional work experience is represented in this study.

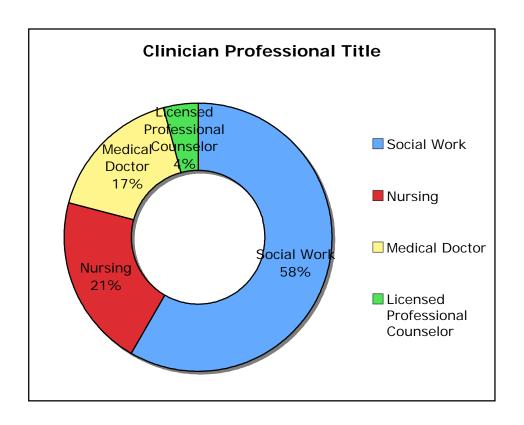


Clinician gender. Of the 24 clinicians who completed the question on gender, 18 responded as female and only 6 as male. This gender distribution was not unexpected, as typically females make up a larger section of the helping professions that these participating clinicians work in.



Clinician Professional Title and Specific Field of Work

Clinician professional title. The responses for participants' professional titles included clinicians from varying disciplines involved in providing health or mental health services. From the social work discipline, 14 clinicians participated, with three social workers, five licensed master's degree level social workers, and six licensed clinical social workers involved. Participants included five from the nursing field including four registered nurses, one of whom also works as a clinical research nurse coordinator, and one end of life care nurse. Physicians or medical doctors made up four of the 24 participating clinicians, including one professor of medicine. One licensed professional counselor participated in the study as well.



Clinician specific field of work. Of the various disciplines from the health and mental health fields listed, the participating clinicians also performed varying types of work within the spectrum of end of life care. The specific fields of work participants listed were: mental health therapy, hospital social work, recovery room nursing, gastrointestinal oncology, palliative care, neurology intensive care, three hospice workers, clinical research, thoracic oncology, gynecological oncology, neurosurgery, surgical oncology, mental health in an HIV clinic, social work, pediatric brain tumor, inhome family therapist, solid organ transplant, oncology, radiation oncology, multi-system trauma surgery; surgical intensive care unit, traumatic brain injury, and pediatric bone marrow transplant.

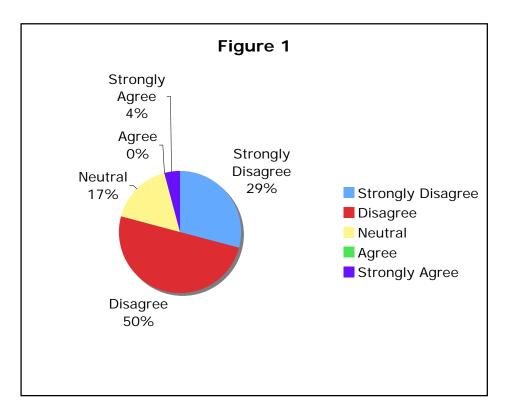
Survey for Clinicians Performing End of Life Care Work in North Carolina

Participants were asked to answer a twelve-item survey via

www.surveymonkey.com. Each of the twelve items had a scale of options for answering ranging from strongly disagree to strongly agree with there being a option to choose neutral as the middle of the five options. Clinicians were informed that they need not complete each one, if they did not wish to do so, and not all items got responses.

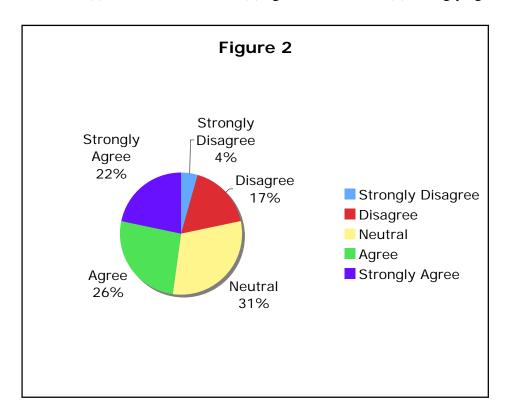
Survey Item 1: Taking one's own life is acceptable in any circumstance. Of the 24 participating clinicians, the responses indicated were 29.2% (7) strongly disagree, 50.0% (12) disagree, 16.7% (4) are neutral, 0% (0)agree, and 4.2% (1) strongly agree.

Clinicians' Survey Results



With 79.0% falling into the disagree or strongly disagree categories, it is evident that the majority of participants do not hold the belief that it is acceptable to take one's own life in any circumstance. There is some showing (16.7%) of neutral beliefs held on this question and a small percentage of 4.2%, or 1 participant, strongly agreed that it is acceptable to take one's own life in any circumstance.

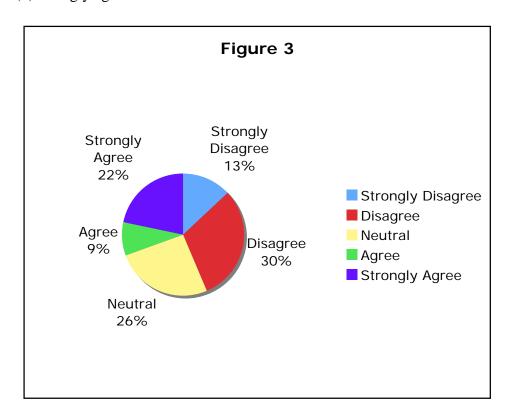
Survey Item 2: Taking one's own life is acceptable if one is terminally ill. Of the 23 participating clinicians, 4.3% (1) reported they strongly disagreed, 17.4% (4) disagreed, 30.4% (7) were neutral, 26.1% (6) agreed, and 21.7% (5) strongly agreed.



Participants' views have now shifted; as before, 79.0% of participating clinicians answered strongly disagree or disagree when the issue of taking one's own life in any circumstance arose. However, when the issue concerns the case where one is terminally ill, only 21.7% of participants fall into the strongly disagree or disagree category. More

participating clinicians are neutral over this issue, as that percentage rose from 16.7% to 30.4%. The majority of clinicians fell into the agree or strongly agree categories with a total of 47.8%; this is a quite significant jump from the 4.2% who answered in the first survey item.

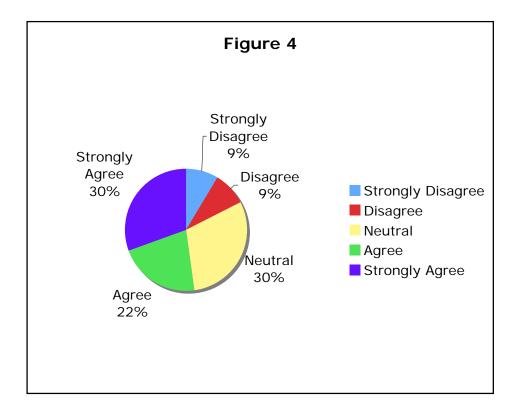
Survey Item 3: Physician assisted suicide should be an available practice for all patients who wish to use it. Of the 23 participating clinicians, 13.0% (3) reported they strongly disagreed, 30.4% (7) disagreed, 26.1% (6) were neutral, 8.7% (2) agreed, and 21.7% (5) strongly agreed.



This third item does not demonstrate the same evident majority that was seen in items one and two. Now we see 43.4% who either strongly disagree or disagree, 26.1% who remain neutral, and 30.4% who either agree or strongly agree with the statement that physician-assisted suicide should be an available practice for those who wish to use it.

The strongly disagree and disagree categories contain the largest percentage of participating clinicians' responses, but these numbers are closer in terms of the disagreeing and agreeing categories then we have seen in previous items.

Survey Item 4: Physician assisted suicide should be an available practice for those patients with a terminal illness. Of the 23 participating clinicians, 8.7% (2) reported they strongly disagreed, 8.7% (2) disagreed, 30.4% (7) are neutral, 21.7% (5) agreed, and 30.4% (7) strongly agreed.

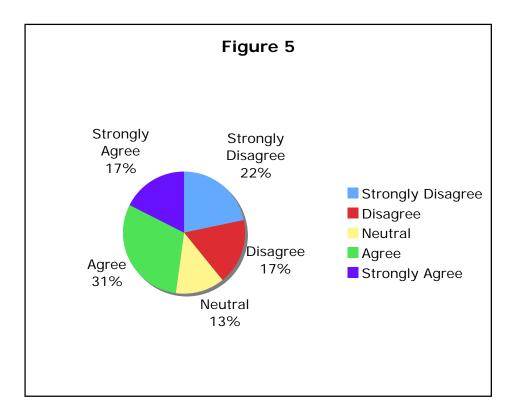


Item 4 is showing a noticeable shift from the responses in item 3. In item 3, when it was proposed that physician assisted suicide should be available to all patients wishing to use it, there was not as evident as a split between those who were either in the strongly disagree and disagree categories, and those in the agree and strongly agree categories.

When considering whether physician assisted suicide should be an available practice for

patients with a terminal illness only 17.4% of participants rated themselves in the disagree category and 52.1% were included in the agree category. There is not much change in the amount of neutral responses as they went from 26.1% in the previous item to 30.4% in this present item.

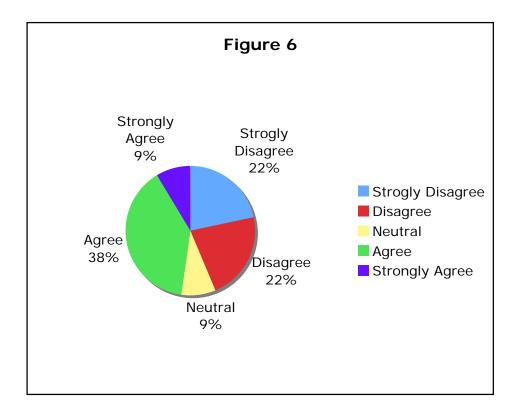
Survey Item 5: The religious and spiritual beliefs of the medical practitioners should be taken into account when deciding if physician assisted suicide is an option. Of the 23 participating clinicians, 21.7% (5) reported they strongly disagreed, 17.4% (4) disagreed, 13.0% (3) were neutral, 30.4% (7) agreed, and 17.4% (4) strongly agreed.



Item 5 shows a similar response to item 3 in that when considering whether the religious and spiritual beliefs of the medical practitioners should be taken into account when deciding whether or not physician assisted suicide should be an option, 39.1% fell into the strongly disagree or disagree categories and a not too much higher percentage of

48.1% participants fell into the agree or strongly agree categories. Fewer participants were reporting they felt neutral on this item, with only 13.0% giving neutral for their selection option.

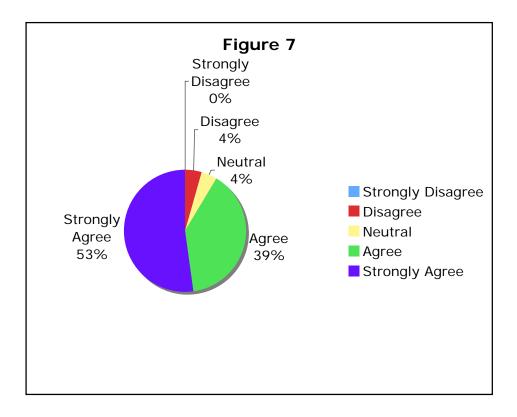
Survey Item 6: The religious and spiritual beliefs of the patient's family should be taken into account when deciding if physician suicide is an option. Of the 23 participating clinicians, 21.7% (5) reported they strongly disagreed, 21.7% (5) disagreed, 8.7% (2) were neutral, 39.1% (9) agreed, and 8.7% (2) strongly agreed.



Item 6 was also delving into the topic of religious and spiritual beliefs and what effect they should or should not have when considering physician assisted suicide as an option; however, in this item, instead of whether it is appropriate to take the medical practitioner's beliefs into account, the item now asks if the patient's family's beliefs should be taken into account. Results from this item were not terribly different than for

number 5 with 43.4% of participating clinicians answering in the strongly disagree and disagree categories and 47.8% of clinicians answering in the agree and strongly agree categories. Similarly, 8.7% of participating clinicians remained neutral on this topic.

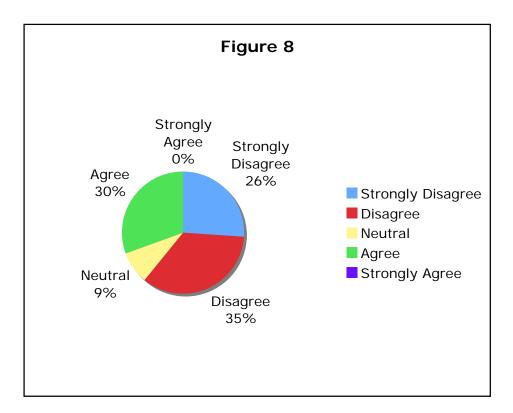
Survey Item 7: A patient's right to autonomy and self-determination should be taken into account when deciding if physician assisted suicide is an option. Of the 23 participating clinicians, 0.0% (0) reported they strongly disagreed, 4.3% (1) disagreed, 4.3% (1) were neutral, 39.1% (9) agreed, and 52.2% (12) strongly agreed.



Results from item 7 are showing the largest majority yet, in response to a patient's right to autonomy and self-determination being taken into account when deciding if physician assisted suicide should be an option. Only 4.3% of participating clinicians answered in the strongly disagree or disagree categories, opposing a patient's autonomy and self-determination being taken into account. Fewer neutral responses were given as

well, with only 4/3% answering with this option. The agree and strongly agree categories were significantly larger with a full 91.4% of participating clinicians answering within these two options.

Survey Item 8: If physician assisted suicide were legal and a patient wished to discuss this option with me, I would have a difficult time staying objective and keeping my own beliefs out of the discussion. Of the 23 participating clinicians, 26.1% (6) reported they strongly disagreed, 34.8% (8) disagreed, 8.7% (2) were neutral, 30.4% (7) agreed, and 0.0% (0) strongly agreed.

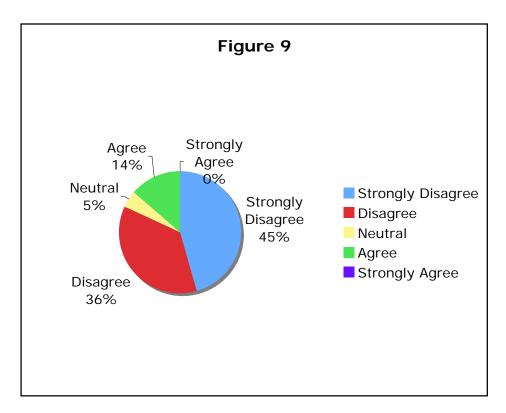


Participating clinicians showed a strong response when considering whether they would have a difficult time staying objective and keeping their own beliefs out of the discussion of whether or not a patient should choose physician assisted suicide.

Demonstrating that they would not have a hard time staying objective, 60.9% of

participating clinicians answered in the strongly disagree and disagree categories. A small percentage of clinicians were neutral on this topic with only 8.7% of the responses being answered this way; 30.4% of participating clinicians answered that they agreed that it would be a difficult task to remain objective with 0.0% falling into the strongly agree category.

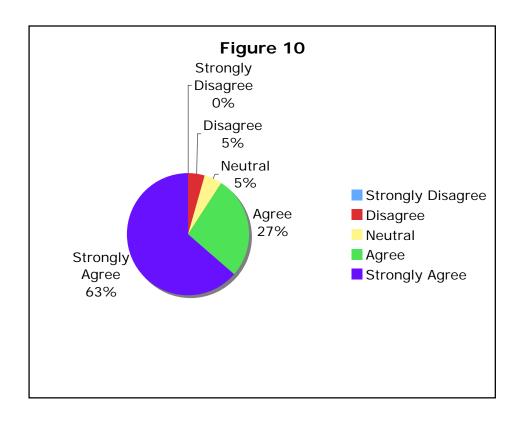
Survey Item 9: If physician assisted suicide were legal and my faith and/or belief system found this practice to be wrong, I would discourage patients from using this option. Of the 22 participating clinicians, 45.5% (10) reported they strongly disagreed, 36.4% (8) disagreed, 4.5% (1) were neutral, 13.6% (3) agreed, and 0.0% (0) strongly agreed.



Item 9 is similar to number 8 as it also shows a strong majority response from the participating clinicians. Clinicians were asked to consider whether, if the practice of

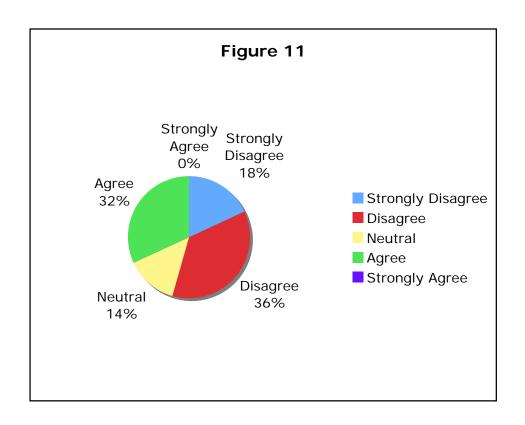
physician-assisted suicide were legal, would their own spiritual or religious beliefs or practices lead them to discourage the patient from using this option. A large 71.9% of participating clinicians reported in the strongly disagree and disagree categories, stating that their own beliefs would not in fact interfere with the patient's right to choose. Again, as with number 8, a small response was given in the neutral category with only 4.5% of responses falling here. The agree and strongly agree categories were also smaller with 13.6% of participating clinicians answering this way and 0.0% answering with strongly agree.

Survey Item 10: As a health care worker, it is my ethical and professional duty to ensure that all patients have access to information on all available treatments and procedures regardless of my opinion of these treatments and procedures. Of the 22 participating clinicians, 0.0% (0) reported they strongly disagreed, 4.5% (1) disagreed, 4.5% (1) were neutral, 27.3% (6) agreed, and 63.6% (14) strongly agreed.



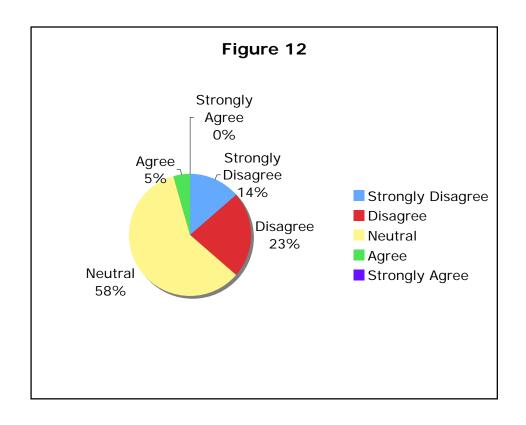
With item 10, we see a very strong response to whether or not it is the clinician's ethical duty to ensure that patients have access to information on all available treatments and procedures regardless of their own opinion of these treatments and procedures. Not one clinician fell into the strongly disagree category and only 4.5% of clinicians disagreed that this was their ethical duty. Few clinicians felt neutral on this topic, with a small 4.5% answering this way. The largest response was in the agree and strongly agree categories together totaling 91.0%. This is the largest majority represented in this study.

Survey Item 11: I am aware of recent changes in North Carolina's Right to a Natural Death Act. Of the 22 participating clinicians, 18.2% (4) reported they strongly disagreed, 36.4% (8) disagreed, 13.6% (3) were neutral, 31.8% (7) agreed, 0.0% (0) strongly agreed.



In response to the item about awareness of the recent changes in North Carolina's Right to a Natural Death Act, 54.6% of respondents answered in the strongly disagree and disagree categories showing that they were not aware of this change, 13.6% remained neutral and 31.8% answered in the agree and strongly agree categories, with 0.0% of these answers coming from those who strongly agreed.

Survey Item 12: The Right to a Natural Death Act has changed my views on end of life care. Of the 22 participating clinicians, 13.6% (3) reported they strongly disagreed, 22.7% (5) disagreed, 59.1% (13) were neutral, 4.5% (1) agreed, and 0.0% (0) strongly agreed.



Number 12 is similar to number 11, as clinicians were again surveyed about the Right to a Natural Death Act; however, this time the item concerns whether the change in the law had altered their own views on end of life care. This item elicted the largest neutral response in this study, with 59.1% of participating clinicians answering this way. Furthermore, 26.3% of clinicians answered that they strongly disagreed or disagreed showing that this change in the law has not altered their views, and only 4.5% of participating clinicians fell into the agree and strongly agree categories, with 0.0% of those answering "strongly agree."

Results for the survey items were provided by from 22 to all 24 of the participants, as not all 24 answered every item. These participants represented the disciplines of social work, nursing, doctors or physicians, and licensed professional counseling. From within these disciplines, the participating clinicians held a wide variety

of job spanning widely across the field of end of life are. Furthermore, the large age range (26 to 61) indicates responses were given from clinicians who may have just entered the field, to well seasoned clinicians, to clinicians who may be close to retirement. This large display of age, discipline, and specific field of work represents an impressively diverse sample from end of life care. However, while representing a diverse sample, the sample of participants in this study is too small to be representative of the larger group of end of life care workers.

CHAPTER V

DISCUSSION

The research reported here involved a quantitative study using an online survey via www.surveymonkey.com. The intention was to gather responses from a minimum of 50 eligible participants. Eligibility criteria specified that participants must have access to a computer, be fluent in English and must hold the title of social worker (SW), registered nurse (RN), licensed practical nurse (LPN), medical doctor (MD), or hold some sort of licensure in counseling or therapy, and that participants' must be practicing some form of end of life care in the state of North Carolina. Unfortunately, it was not possible to gather data from the desired sample of at least 50 clinicians; only 24 clinicians responded to the survey and with respect to the 12 questions included on the survey, the number of participating clinicians who responded ranged from 22 to 24.

This study was intended to get a sense of the views held by clinicians practicing some sort of end of life care in the state of North Carolina. Despite the fact that physician assisted suicide (PAS) is not a legal practice in North Carolina, it is remains a heated topic of great relevance to clinicians in this state. As stated in Chapter II, research and public opinion polls have shown increasing support for PAS, for a patient's right to autonomy, and ultimately for a patient's right to decide whether to live or die. The major point of contention in all of this is the degree to which a patient may exercise rights to choice: whether to refuse treatment, to refuse food and fluids, or even to choose to die using some means to terminate life (Allen et al., 2006).

January of 2008 was significant in the state of North Carolina, as citizens of the state are now covered under the Right to a Natural Death Act. A patient is now legally protected in choosing not to use life-prolonging procedures if an attending physician has found that these following criteria are met:

- a. The declarant has an incurable or irreversible condition that will result in the declarant's death within a relatively short period of time: or
- b. The declarant becomes unconscious and, to a high degree of medical certainty, will never regain consciousness; or
- c. The declarant suffers from advanced dementia or any other condition resulting in the substantial loss of cognitive ability and that loss, to a high degree of medical certainty, is not reversible.

(North Carolina General Assembly, 2008)

While this legislation does not permit PAS, it seems logical to conclude that this Act is evidence of the primacy of life care decisions in North Carolina today, and of a patient's autonomy being highly valued. One may postulate that this is a stepping-stone on the way to legalized PAS in the state of North Carolina, as is currently the reality in the state of Oregon and some European countries.

Although the passage of the Right to a Natural Death Act is significant, however, it is not yet clear if this change has had much of an impact on North Carolina clinicians practicing end of life care. Results from this study may suggest how little this change in the law has impacted the clinicians' practices or attitudes, but because of the small sample size (22 clinicians responded to this question), the results may not be representative of the end of life care group as a whole. When asked about their personal

awareness of the change in North Carolina's Natural Death Act, only 31.8% of participants reported being aware of this change. Furthermore, when asked if this Act has led to any changes in their views on end of life care, only 4.5% of participants reported noticing a change. These numbers lead one to conclude that the changes offered by the Right to a Natural Death Act have not yet been publicized long and widely enough to have had significant impact, so that clinicians are not sufficiently aware of this change in the law, which leads to their lack of positive response to the item.

Following in the vein of patients' autonomy and self-determination, when asked if patients' rights to autonomy and self-determination should be taken into account when deciding if PAS should be an option, a clear majority reported that yes, these factors should be taken into account when considering PAS, with 39.1% saying they agree that autonomy and self-determination should be a factor and 52.2% saying they strongly agree. With this total of 91.4% agreeing and more than half (52.2%) strongly agreeing, there is a finding of clear support for a patient's right to autonomy and self-determination in the responses of participants of this study. It is an expected finding that such support would today be a major consideration, given the trends evident in the literature reviewed in Chapter II above.

However, as also noted in Chapter II, this trend towards patient autonomy and self-determination is fairly recent as these phases and practices were almost nonexistent in the mid twentieth century (Rothman, 2001). Historically, major religious traditions have been opponents to PAS (Traina, 2000). Nevertheless, when the legal battle was waged in attempt to legalize the practice of PAS, religion was not noted to be one of the most compelling arguments in opposition to PAS (Appel, 2004). Just as patient autonomy

has become a significant factor in patient care and a profound argument in favor of PAS, attitudes on religion have shifted over the years, as well. Research shows that two factors have shown a positive likelihood that respondents will oppose the legalization of PAS and these factors are not constrained to a single religion or denomination, but across the board. These two factors are one's church attendance and the strength of one's religious affiliation (Burdette et al., 2005). Moreover, these factors are not constrained to a single religion or denomination, but apply to the entire spectrum of religious faiths. Research concludes that individuals' spiritual and religious beliefs and practices do seem to be components of their views on whether to legalize PAS, and findings from this study are consistent with this research.

Chapter IV findings indicate that when asked whether the religious or spiritual beliefs of the medical practitioner should be taken into account with deciding if PAS is an option, 39.1% of participants disagreed with this and 48.1% of participants did agree that these religious or spiritual beliefs should be taken into account. Respect and tolerance for one's patient's spiritual or religious practice is one thing, but denying a patient a treatment option based upon someone else's beliefs is another, and the reality tat a full 48% of respondents answered this way is striking. These results do not indicate that taking the medical practitioner's religious and spiritual beliefs into account would necessarily lead to a patient's being denied a treatment, but they do lend credence to that concern.

A second item concerning one's spiritual and religious beliefs was included in the survey with similar results to the one mentioned above. When asked if the religious and spiritual beliefs of the patient's family should be taken into account when deciding if

PAS is an option, 43.4% of participating clinicians disagreed that the family's beliefs should be taken into account and 47.8% reported that they did agree these religious and spiritual beliefs should be taken into account. What seems most interesting in this response is that a larger percentage of participants reported that the medical practitioner's spiritual and religious beliefs should be taken into account than said the beliefs of the patient's family should be considered. This actual difference is very minimal, with 48.1% in favor of considering the medical practitioner's beliefs and 47.8% in favor of considering the beliefs of the family member. Because of its size, this percentage is not significant; however, it is interesting to see how the personal beliefs of clinicians are valued as highly as those of the patient's family. This speaks to not only to the value that is given to one's own spiritual and religious beliefs by the participants, but also to the value they place on the physician's beliefs in the doctor-patient relationship. Perhaps the idealizing of physicians that has been a dominant theme in our culture is another factor in producing such a strong deference to physician beliefs and values.

A third item about spirituality and religion showed some different results from the two mentioned. Item 9 concerned whether a clinician would discourage a patient from using PAS if it were a legal practice but their own faiths or belief systems found it to be a wrongful practice. A large majority of the participating clinicians reported they disagreed with discouraging a patient based upon their own beliefs, with 45.5% (10) stating they strongly disagreed and 36.4% (8) participating clinicians stating they disagreed. One participant (4.5%) remained neutral on this issue and 13.6% (3) of participating clinicians agreed that they would discourage a patient from choosing PAS if it were legal but went against their personal beliefs or faiths. These results are interesting, as they link religion

and patient autonomy. In the prior two survey items, there was strong support for patients not having PAS as an option, based on the beliefs and practices of the medical practitioner and those of the patient's families. The strong response for clinicians disagreeing with the rightness of discouraging a patient shows support for fostering patient autonomy and self-determination. However, based upon the previous two responses discussed, it may not seem consistent that now patient autonomy seems to be more greatly honored. This researcher believes this may be explained by one of these two things: first, instead of the words religion and spirituality, the words faith and belief system were used. Perhaps these last two words were not automatically associated with religion, which perhaps did not make the issue as compelling as when religion and spirituality were directly referenced. Furthermore, perhaps because the question was worded so as to direct clinicians to think of themselves and not the medical practitioner or the patient's family, it seemed less ethical to bring one's own beliefs into the professional realm. However, when a physician's religious beliefs are considered a deciding factor, this does constitute bringing an individual's personal beliefs into the professional realm. Did participants give this response because they interpreted "medical practitioner" to mean "physician" and because they hold physicians' views in higher esteem? This is not clear and cannot be decided by the findings of this study. Further research using similar questions with different wording may assist in explaining these particular results.

Responses given for Item 10 do not appear consistent with the responses about the Right to a Natural Death Act given for number 11. Item 10 concerned whether a health care worker considered it their his/her and professional duty to ensure that all patients

have access to information on all available treatments and procedures regardless of their own opinions of these treatments and procedures. The percentage of those who agreed that it was their ethical duty to ensure that patients have access to all treatments and procedures was very significant with 27.3% (6) reporting they agreed it was their duty and 63.6% (14) strongly agreeing it was their duty.

Item 11 asks about a clinician's awareness of the changes in North Carolina's Right to a Natural Death Act, 18.2% (4) reported they strongly disagreed, and 36.4% (8) reported they disagreed in regards to being aware of the change. Furthermore, 13.6% (3) gave a neutral response to this item, indicating that they may or may not have been aware of the change, or may have been unsure they had heard about it. Those responding with "agree" stating that they were aware of this change were 31.8% (7), and 0.0% responded with "strongly agree." This is not consistent with the overwhelming majority of a total of 91.0% (20) who reported they either agreed or strongly agreed that it was their ethical duty to ensure patients had access to all information regarding treatments and procedures.

Limitations of Study

As mentioned previously, the intention was to have a minimum of 50 participants take part in this study. Due to difficulty in recruiting participants, there are responses from only 24 clinicians. Part of the difficulty with recruitment stemmed from the study's being limited to clinicians who live in North Carolina. This criterion was set with the presumption that because of the change in North Carolina law in January of 2008 with the Right to a Natural Death Act, the new legislation might affect clinicians in their views and practices. However, as the two questions related to this new law drew the lowest number of responses and showed that the majority of clinicians were not aware of the

law, it is evident that this presumption was incorrect. A strength of the study is that many disciplines from the spectrum of end of life care represented; however, because of the small sample size, there are not adequate data for the findings to be representative of end of life care workers in North Carolina.

Because the study was conducted using an online, closed question survey, there was no opportunity to collect more in-depth input from participants. Had face-to-face interviews been conducted, there would have been opportunities for participants to expand upon their views. An example of when this may have been beneficial was referenced above, where it appears that responses to Items 10 and 11 are not consistent with each other.

Applications of This Study to the Field of Social Work

This study included not only social workers but also nurses, physicians, and a licensed counselor. Representation from different disciplines is important to the field of social work, as social workers performing end of life care work side by side with doctors, nurses, and counselors. Each is an important part of the clinical team that treats and works with the patient and family; asking these questions of the disciplines that make up this team leads to the conclusion that a better idea of the views and beliefs held by a comprehensive set of a patient's providers is being given. It is important for social workers to be informed about the population they are dedicated to working with as well as the other professionals with whom they perform this work.

End of life care is performed in every state of this nation. Social workers provide much of the support to patients and their families as part of their role in end of life care. Having access to the views held by others within their profession and others within the

medical helping field is vital to a social worker, just as is being urged to think personally about the issue of PAS. To determine one's own stance on such issues is vital; it would be desirable to conduct future surveys of this kind with larger samples, perhaps including face to face interviews, and to conduct the studies following more extensive education of the populace about changing laws.

Concluding Thought

A decision of whether or not to hasten death when faced with a life threatening illness is a significantly profound and personal one to make. In the state of North Carolina, no one is safe from terminal illness; no one is exempt from the possibility of being ill in such a way that neither treatment nor procedure can ease the pain of illness, nor return the independence and quality of life that has been taken away by sickness. None of us today can legally make the decision, along with our family and medical team, to hasten the inevitable, to hasten death so that our suffering and the suffering of our loved ones may cease.

The decision of whether or not to choose PAS, while ultimately may be one that should rest with the patient, is one that if made a legal option would affect the patient's family, the patient's medical team, and one that would result from a long battle in our courts. The fight to legalize PAS began over one hundred years ago in this country; it continues to be fought today. It is important that the general public as well as health care professionals are aware of this practice, of the debate over its legalization, and of the views held by those who may or may not be in the position to grant or deny someone this right to hasten their own death in a safe and legal fashion.

REFRENCES

- Allen, J., Chavez, S., DeSimone, S., Howard, D., Johnson, K., LaPierre, L., Montero, D., & Sanders, J. (2006). Americans' attitudes toward euthanasia and physician-assisted suicide, 1936-2002. *Journal of Sociology & Social Welfare, XXXIII*.
- Anastas, J. W. (1999). *Research design for social work and the human services* (2nd ed). New York: Columbia University Press.
- Appel, J. M. (2004). A duty to kill? A duty to die? Rethinking the euthanasia. Controversy of 1906. *Bulletin of the History of Medicine*, 70, 610-634.
- Burdette, A. M., Hill, T. D., & Moulton, B. E. (2005). Religion and attitudes toward physician-assisted suicide and terminal palliative care. *Journal for the Scientific Study of Religion*, 44(1), 79-93.
- DiPasquale, T., & Gluck, J. Pl (2001). Psychologist, psychiatrists, and physician-assisted suicide: The relationship between underlying beliefs and professional behavior. *Professional Psychology: Research and Practice*, 32 501-506.
- Farberman, R. K. (1997). Terminal illness and hastened death requests: the important role of the mental health professional. *Professional Psychology: Research and Practice*, 28, 544-547.
- Ganzini, L., Beer, T. M., & Brouns, M. C. (2006). Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management*, 32, 230-236.
- Harvath, T. A., Miller, L. L., Smith, K. A., Clark, L. D., Jackson, A., & Ganzini, L. (2006). Dilemmas encountered by hospice workers when patients wish to hasten death. *Journal of Hospice and Palliative Nursing*, 8, 200-209.
- Manetta, A. A., Wells, J. G. (2001). Ethical issues in the social worker's role in physician-assisted suicide. *Health & Social Work*, 26(3), 160-166.
- Morrison, S. R., Meier, D. E. (1994). Physician-assisted dying: Fashioning public policy with an absence of data. *Generations*, 18(4), 48-54.
- NASW, (2006). NASW Code of ethics. Washington DC: NASW.
- North Carolina General Assembly. (2008, January). Article 23. Right to natural death:
 Brain death. Retrieved May 20, 2008, from North Carolina General Assembly
 Online via:
 http://www.ncga.state.nc.us/EnactedLegislation/Statutes/HTML/ByArticle/Chapte
 r 90/Article 23.html

- Radtke, R. (2005). A case against physician-assisted suicide. *Journal of Disability Policy Studies*, 16, 58-60.
- Rothman, D. J. (2001). The origins and consequences of patient autonomy: A 25-year retrospective. *Health Care Anaylsis*, *9*(*3*), 255-264.
- Sears, S. R., & Stanton, A. L. (2001). Physician-assisted dying: Review of issues and roles for health psychologists. *Health Psychology*, 20, 302-310.
- Smith-Stoner, M. (2007). End-of-life preferences for atheists. *Journal of Palliative Medicine*, 10(4), 923-928.
- Traina, C. L. H., (1998). Religious perspective on assisted suicide. *The Journal of Criminal Law & Criminology*, 88(3), 1147-1154.
- Wilson, K. G., McPherson, C. J., Allard, P., Gagnon, P. R., De Luca, M., Kuhl, D., Chochinov, H. m., Skirko, M. G., Chary, S., Macmillan, K., O'Shea, F., Fainsinger, R. L., Karam, A. M., & Clinch, J. J. (2007). Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology*, 26, 314-323.

APPENDIX A

HSR APPROVAL LETTER

April 2, 2008

Ollie Dooling Walker

Dear Ollie,

Your revised materials have been reviewed and we find that all is now in order. We are happy to give final approval to your interesting study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman, D.S.W. Chair, Human Subjects Review Committee

CC: Gael McCarthy, Research Advisor

APPENDIX B

DEMOGRAPHIC QUESTIONAIRE

- 1. Age
- 2. Gender
- 3. Professional title
- 4. Specific field of work

APPENDIX C

SURVEY

rongly gree
-

of my opinion of these treatments			
and procedures.			
I am aware of recent changes in			
North Carolina's Right to a Natural			
Death Act.			
The Right to a Natural Death Act			
has changed my views on end of life			
care.			

APPENDIX D

LETTER OF INFORMED CONSENT

March 3, 2008

Dear Research Participant:

My name is Ollie Walker and I am a current Master's of Social Work Student at Smith College School for Social Work in Massachusetts. I am conducting a study of clinicians who work in end of life care and their views on physician assisted suicide. The purpose of this study is to provide new and valuable information to those who work in end of life care as well as to the general public as end of life care and the option of physician assisted suicide are topics that may touch every citizen. **Obtained data will be used to**formulate a thesis, which will be presented at Smith College as part of a dissemination process and for possible publication and presentation.

Qualification for participation in this study is based on two factors: you must work in the field of end of life care in the state of North Carolina as a Social Worker, Registered Nurse, Licensed Practical Nurse, Medical Doctor, or be a licensed counselor or therapist; and you must be fluent in English. The study will be asking for your views of physician assisted suicide, not for any past experience with the topic. This indicates that the emotional risks of participation will be minimal. A possible benefit of participating is the opportunity for participants to give voice to their own views on a topic that has been heatedly debated in the courts of the United States for over one hundred years.

If you choose to participate, the survey itself should take no longer 10 to 15 minutes to complete. As this survey is being conducted completely online, your participation is completely anonymous and no specific answer can be traced back to any particular respondent. The link to the survey does not retain email addresses or ask that you give your name. The software program collects and initially compiles the data for further research and the researcher is given these complied data in aggregate form with no names, addresses, locations, or other identifying information about the participants except the data included in the demographic questions. Only my research advisor, the Smith College School of Social Work statistical analyst and this researcher will have access to these materials. All research data will be kept secure in a

locked location for three years, as mandated by federal law. After three years, I will continue to keep the materials secure or destroy them if they are no longer needed.

Your participation in this study is voluntary and you may decline to be involved in this study without repercussion. I welcome your questions and comments. I can be reached by email at (removed). If you have any concerns about your rights or any aspect of this study, please contact me at the above email or contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) **585**-7974. I hope you will decide to participate in this study.

You must read and electronically sign this informed consent form by clicking on the "yes" option below before being able to proceed with the survey. If you choose to consent, please print off this page and keep it in your records. If you click on the "no" option below, you will immediately be exited from the survey. During the survey, you may decline to answer any questions you do not feel comfortable answering. You have the right to exit this study at anytime prior to pressing the "DONE" option at the end of the survey. Once you have submitted your completed questionnaire, you will not be able to withdraw from this study since there is no identifying information on the surveys that would connect a particular survey to your responses and permit the information to be selectively deleted.

YOUR CLICKING THE "YES" BUTTON INDICATES THAT YOU HAVE READ
AND UNDERSTOOD THE ABOVE INFORMATION; THAT YOU HAVE HAD THE
OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR
PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO
PARTICIPATE IN THE STUDY.

APPENDIX E

RECRUITMENT EMAIL

Dear Health Care Professional,

My name is Ollie Walker. I am writing to you as a second year student at the Smith College School for Social Work to request your participation in a brief online survey regarding the views held by health care professionals performing end of life care on physician assisted suicide. Physician assisted suicide is defined as when a patient takes his or her own life with the aid of a physician. This aid is normally provided by the physician supplying the patient with a prescription for a lethal dose of a drug that the patient will then administer. The survey questions ask about your personal views on the topic of physician assisted suicide and how these views may or may not affect your clinical work in the field of end of life care.

In order to participate in this study, you must be a Social Worker, Registered Nurse, Licensed Practical Nurse, Medical Doctor, or a licensed counselor. You also must work providing end of life care to individuals in the state of North Carolina.

Access to your individual submissions will be limited to this researcher, my research advisor, and the Smith College School of Social Work statistical analyst. I hope to incorporate your anonymous contributions, in aggregate, into my master's thesis and in future research and presentations. The survey is brief and should not take more than 10-15 minutes of your time. You may skip any question you prefer not to answer. You can access the survey via the link below.

http://www.surveymonkey.com/-----

Your responses will help give voice to the views held by end of life clinicians on

a much debated topic. I hope you decide to take part in the survey. Thank you in advance

for your input. Please feel free to contact me with questions or concerns you may have at

the email listed below.

Thank you,

Ollie Dooling Walker

55