7-2011

Terminal Sedation

Karen L Smith
kehlebra@utk.edu

To the Graduate Council:

I am submitting herewith a dissertation written by Karen L Smith entitled "Terminal Sedation." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Philosophy.

John Hardwig, Major Professor

We have read this dissertation and recommend its acceptance:

David Reidy, Glenn Grabor, Nan Gaylord

Accepted for the Council:
Dixie L. Thompson

Vice Provost and Dean of the Graduate School

(Original signatures are on file with official student records.)

TERMINAL SEDATION

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

Karen L. Smith
August 2011

ACKNOWLEDGEMENTS

There are many people whom I ought to thank for their invaluable assistance to me in completing this dissertation. My family, Channing and Bailey, did without in numerous ways to allow me the time and mental space to accomplish my work. Dr. John Hardwig, remained supportive of my intense desire to work as a clinical ethicist and provided practical assistance throughout my education at the University of Tennessee and guidance in the art of philosophy. His direction, prodding and insightful questioning has always been directed at my improvement. I am grateful to the members of my committee, Dr. Reidy, Dr. Graber, and Dr. Gaylord, who somehow didn't give up on me throughout my long hiatuses. I also would be most remiss if I did not acknowledge the efforts my good friend, Susan Williams provided in her constant encouragement and helping to keep my ducks in a row during this process. But, mostly this work is dedicated to my mother, a nurse, who died too soon to realize what an inspiration she provided.

ABSTRACT

This dissertation will support full ethical endorsement of terminal sedation for those most urgently in crisis and need of beneficence, those who are dying and in the final hours or days and suffering. To clarify the practice I first detail ethical differences between euthanasia, physician assisted suicide and terminal sedation. Moreover, I identify new areas where harms and benefits need to be evaluated as affecting not only patients, but also families and caregivers. I evaluate the current practice to allow the development of ethical guidelines and greater consensus on deciding the hard cases. This work may also serve to assist those looking to enlarge the practice in the future with ETS for those with debilitating diseases or disability, but they are not my primary goal.

Below is the standard I propose for moral allowability for the use of terminal sedation. I will refer to it often in the pages that follow simply as *my standard*.

> **Terminal sedation** is the appropriate and intentional use of medications (benzodiazepines and/or narcotics) to produce ongoing, deep unconsciousness upon 1) *a terminal patient's (or surrogates) request* due to 2) *suffering intractable pain or other distressing clinical symptoms intolerable to the patient* when 3) *death is expected within hours or days (less than two weeks)* due to the terminal illness, injury, or disease.

I offer two versions of initial guidelines for development of hospital policy. The first version outlines minimal guidelines that ought to be utilized to allow TS for patients who fit my standard. The minimal guideline is based upon the recommendations of the American Medical Association with some modifications. The guideline is admittedly restrictive in hopes of gaining wider societal support for a currently controversial practice. Secondly, I offer more moderate guidelines for policy that could become a standard in the future. It maintains the restrictive focus of the minimal guidelines and offers additional education and support to others which has yet to be broadly provided. The moderate guidelines would mark an important step forward for allowing more choices in dying and offering additional supports to those involved with dying patients.

TABLE OF CONTENTS

Chapter Page

Table of Contents

CHAPTER 1 1
WHAT IS TERMINAL SEDATION? 1
Introduction 1
Background and History 5
The Problem of Definition 11
Drugs and Dosages 20
An Evolving Consensus or More Conflict? 22
Is TS a type of Death? 25
Operational Definition 27
CHAPTER 2 30
DISTINGUISHING TERMINAL SEDATION FROM 30
PHYSICIAN-ASSISTED SUICIDE OR EUTHANASIA AND THE DOCTRINE OF DOUBLE EFFECT 30
Euthanasia 31
Physician-Assisted Suicide (PAS) 36
Terminal Sedation 42
The Doctrine of Double Effect 48
Additional Criticism against Terminal Sedation 53
Alternate Evaluations 57
CHAPTER 3 62
BENEFITS AND HARMS FOR THE PATIENT 62
Introduction 62
Relief from Suffering 64
Sedation like Sleep 66
Slippery Slope Concerns 67
Autonomy and Control 71
Nutrition and Hydration 72
Consent 75
Surrogate Consent 78
Unproven Effectiveness 83
Existential Concerns 87
Suffering & Religion 91
Special Concern for the Demented 93
Responsibility in Dying & Death Roles 97
Teaching Compassion for the Dying 99
Unburdening Others 100

Conclusion 102
CHAPTER 4 104
ETHICAL BENEFITS AND HARMS FOR THE FAMILY 104
Introduction 104
Why Families? 106
Research on the Burdens of Surrogate Decision Makers 111
Benefits of TS for Families 116
Indirect and Direct Family Benefits 117
Harms to Families from TS 118
Harms similar to suicide in the family & guilt 119
Confusions 122
Fears of mercy killings 124
Complicated Bereavement 125
Moral objections 126
Conclusion 135
CHAPTER 5 139
ETHICAL BENEFITS AND HARMS TO HEALTHCARE PROFESSIONALS 139
Introduction 139
Problem Number One….Lack of Training in Care of the Dying 141
Health Care Professionals Attitudes and Beliefs about End-of-Life Care 146
Cognitive Dissonance in Withdrawal of Care 149
Attitudes towards TS Specifically and Emotional Burdens of Healthcare Workers 153
Fear of Litigation 158
Systems-Based Practice 162
Palliative Sedation as a Practice against Personal Conscience 173
Conclusion 175
CHAPTER 6 178
POLICY GUIDELINES AND FUTURE NEEDS 178
Introduction 178
Why Clear Policy? 180
Minimal Policy Guidelines 182
Moderate Policy Guidelines 193
Future TS policy 201
Future Needs & Conclusions 203
BIBLIOGRAPHY 206
APPENDIX 213
Appendix 1 Critical-Care Pain Observation Tool 214
Appendix 2 AMA Policy on Palliative Sedation 215
Appendix 3 Recommendations for Conducting a Family Meeting When the Patient Is Unable to Participate Prepare for the Meeting 216
Vita 217

LIST OF TABLES

Table Page

Table 1. Definitions of Terminal Sedation……...13-17

LIST OF FIGURES

Figure Page

Figure 1 : The Dutch Guideline for Sedation 45
Figure 2. AMA-CEJA Policy..... 185

CHAPTER 1

WHAT IS TERMINAL SEDATION?

Introduction

This dissertation will be evaluating the benefits and harms of terminal sedation and will focus on bringing light to potential harm yet to be thoroughly evaluated. Improving our moral inventory about the types of harms and benefits involved in the practice of terminal sedation will assist us in making decisions on the tough cases within the current scope of practice.[1] Issues related to dying have been in the forefront of medical ethics since its inception, yet appropriate methods for treating the dying are still debated and clearly no consensus has been reached. The practice of terminal sedation has been hailed as a legal practice of choice to relieve intractable suffering for those dying. It is utilized to address intractable pain or other distressing clinical symptoms in those who are known to be in the final phase of terminal illness.

It will be important to clarify several related terms for use in clearly understanding this issue. First, let us define a terminal disease as a disease process that will advance to produce death in a patient. Patients may live with a terminal disease for many months or years due to our current advanced medical treatments. Sometimes persons with terminal diseases look and feel perfectly normal and can work or carryout normal activities. Those who have a terminal disease will eventually reach a state of terminal illness with their disease and this is commonly understood to be when it is expected that they have less than six months of life expectancy. This is an inexact

[1] A thorough evaluation will also assist in evaluating the options of expanding this practice but this will not

amount of time but is often used to allow those persons with a terminal disease to qualify for other benefits such as hospice insurance benefits. Usually by this point in their disease process patients are looking and feeling ill and may require assistance completing normal daily activities. When those who have been living with terminal disease progress to terminal illness and come to the final phase of the disease (sometimes also called the terminal phase), body processes are slowing down (such as urine output, intestine motility, heart rate), and breathing becomes shallow and ragged, they are said to be 'actively dying'. When someone is actively dying, death is expected in hours to days, perhaps a week or two as the outside marker.

Terminal sedation (TS) is the provision of medications to sedate to unconsciousness, usually in patients who have stopped eating and drinking with the intent to maintain this sedation until the death of the patient. Although terminal sedation is legally allowable in the United States and elsewhere, there remain significant ethical concerns that prevent this practice from being wholeheartedly endorsed by many. The practice of terminal sedation has yet to obtain any widely accepted normative guidelines and this has hampered the philosophical acceptance of the practice as well. Since, at root, most of these concerns are based upon the notion that palliative sedation may prematurely end the life of a person, these are grave moral concerns and therefore deserve careful philosophical evaluation.

Terminal sedation is currently a practice that is justified and established as a legal option for end-of-life care but sorely lacking in any wide spread normative consistency in application. Evaluation of any harm or benefit will suffer from the incumbent perspective of the philosophical framework utilized and therefore what is clearly

beneficial from one perspective may be harmful in another. It is not my goal to render conclusions on what counts as a benefit or harm in cases where terminal sedation may be utilized as these must be evaluated on an individualized basis. Rather, I will attempt to identify additional potentially relevant concerns deserving careful ethical evaluation. This work will serve to assist in making decisions to allow or deny terminal sedation in particularly hard cases and in making relevant normative guidelines.

I focus my evaluation primarily in terms of benefits and burdens. This is not done due to a Utilitarian intent, but because this is the most common method utilized in medical ethics to evaluate complex situations. Principlism[2] utilizes four mid-level principles; autonomy, beneficence, nonmaleficence and justice, to evaluate ethical situations. These principles are then weighed and balanced within each situation as is appropriate. This method has been utilized extensively in medical ethics and although additional methods may also be used, Principlism remains a primary starting point for evaluations. When utilizing a Principlism framework, TS may be ethically appropriate for some and not for others given the personal evaluations of the patients and physicians involved. This evaluation is more than a simple Utilitarian consequentialism looking at the benefits verses burdens, as it gives substantial weight to the preference of the patient and her autonomous choice, and her evaluation of the benefits and burdens involved to herself and others.

The principles and their respective benefits and burdens may be evaluated differently given differing individual's situations and perspectives and this is to be

[2] Beauchamp, T., L. , & Childress, J., F. . (1994). *Principles of Biomedical Ethics* (Fifth ed.). New York, Oxford: Oxford University Press.

expected. At times, the principles may also highlight conflicts apparent in the medical situation. I endorse this variation as strength of Principlism in allowing each case to weigh and balance differently to allow a moral decision to be reached in each situation. These decisions should be based upon the unique factors and values of the case despite the fact that many, if not most, cases will involve similar components. Many Deontological concerns will be addressed in Chapter 2 where I focus on the intentions and actions involved in differing end-of-life options.

Since terminal sedation is as yet a relatively obscure and rarely utilized treatment, the current literature and case studies have focused almost exclusively on either the clear benefit for the suffering patient as an overwhelming benefit or perceived harms of the practice being too closely related to physician-assisted suicide (PAS), or euthanasia. This focus has limited serious consideration of other potential effects related to this manner of medically managing a death by elimination of consciousness.

While the practice of terminal sedation has had many critics, their opposition is mostly due to concerns that terminal sedation is too close to either physician-assisted suicide, or euthanasia. **I will argue the restricted focus of ethical evaluation concerning TS thus far has eliminated investigation into *other* potential harms and benefits related to TS and these factors are deserving of careful philosophical evaluation. These concerns affect not only the patient but many others who are involved with the process of enduring a modern death with TS. My dissertation will focus on broadening the scope of evaluation of the potential harms and benefits of TS to allow better evaluation of the difficult cases to establish a baseline for ethical guidelines for consideration of utilizing TS.**

Does accepting TS mean giving up other important goods, perhaps those that make for a good death? Could perhaps surviving family members be harmed in important ways? They are the ones who must live on with the legacy of how the death occurred. There may also be unintended harm to professional caregivers, both MD's and RN's, who provide and monitor the provision of medications. Do they carry additional emotional burdens which stem from their participation in TS? Might even the trust our society has in the physician-patient relationship and the healthcare system be harmed if TS can be seen as an expedient way to reduce costs involved in caring for the dying? By altering the traditional dying process and the roles assigned to those involved in that process, are we harming our sense of connectedness and relationships in ways which ought not to be altered? Or are we perhaps restoring an ancient rite of passage? I will explain why I believe some of these fears are well-founded and deserving more intense ethical analysis. Further where harms are substantiated, I will show how we might institute new policies to reduce the potential for these harms to occur or to limit their effects.

Background and History

Terminal sedation is a way of arranging one's death with assistance from health care professionals. The health care professionals provide medications to eliminate consciousness until death. Currently, it is the only legal method available to many of those in the final stages of incurable illness who are suffering intolerably. This is an option not available until relatively recently, at least not available openly or not called by this name. In times past, humans simply awaited death and endured as best they could.

Nowadays, most deaths occur following lengthy illness and many, at least in part, come about as a result of withholding or withdrawal of medical interventions. This withholding or withdrawal of medical intervention usually comes only after some process of negotiations with patients, families and medical staff. Thus, one may now, in part, negotiate when their death occurs. How did we get to this point?

Death in the Middle Ages was much simpler, there was little medicine could do to prevent death and those who were dying often advised others of the fact that they would soon die. Phillipe Ariès quotes Jean Guitton in his epic book *The Hour of Our Death*.

> We see how the [people] in those bygone days passed from this world into the next simply and straightforwardly *observing the signs*, and above all, *observing themselves*. They were in no hurry to die, but when they saw the time approaching, then not too soon and not too late, but just when they were supposed to, they died like Christians. [3]

Most persons died at home or where they fell due to illness, accidents or injury, and they were expected to be the ones directing how their death would go. Medicine had little to offer in the way of preventing the progression of disease or easing death. "In those days death was rarely sudden, even in the case of accident or war, and sudden death was much feared, not only because there was not time for repentance, but because it deprived a man of the experience of death."[4] There was great ritual over dying and "As soon as someone was helplessly sick in bed, His room filled with people- parents, children, friends, neighbors, fellow guide members……The approach of death transformed the room of a dying man into sort of a public place."[5] Not only did others know they were expected to arrive and speak to the dying, "The leading role went to the

[3] Aries, P. (1981). *The Hour of Our Death* (H. Weaver, Trans.). New York: Alfred A. Knopf. Pg. 10.
[4] Aries, P., translated by Valerie M. Stannard. (1974). The Reversal of Death: Changes in Attitudes toward Death in Western Societies. *American Quarterly, 26*(5 Special Issue: Death in America), 536-560.pg 538.
[5] Ibid. pg. 539.

dying man himself. He presided over the affair with hardly a misstep, for he knew how to conduct himself, having previously witnessed so many similar scenes."[6] Ariès reports that in the 18th and 19th centuries, the dying person gave the orders, even when this person was very young, or almost a child.[7] He further notes the dramatic changes today,

> Today nothing remains either of the sense that everyone has or should have of their impending death, or of the public solemnity surrounding the moment of death. What used to be appreciated is now hidden; what used to be solemn is now avoided. [8]

Medical science was advancing dramatically throughout the late 1800's and early 1900's. The advancement was uniformly heralded as a societal good. It allowed improved health, prolonged life, and the eradication of prevalent diseases, such as polio as well as cures for many illnesses that were previously untreatable. This advancing medical science altered daily life in many ways including moving both birth and death out from family homes. Both being born and dying shifted to occur routinely in hospitals, aided by doctors and nurses even when no problems were anticipated. In the 1800's and early 1900's the family had a primary role when a member was dying. Family members were tasked to stand bedside and wipe a brow, be a comforting presence, or listen for final words. Medicine had a rather small role, mostly for rudimentary pain relief. Following the 1920's discovery of antibiotics, medical science was booming and seemed always to have something new to offer in attempts to keep death at bay. Families were ushered away from the hospital bedside and out into sterilized waiting rooms only to be told later if the patient had survived or died from the doctors intensive efforts.

[6] Ibid. pg. 540.
[7] Ibid., pg. 540.
[8] Ibid., pg. 540.

By the 1980's many people began to fear a death that was artificially prolonged due to the use of medical technology and intensive medical care. There was a growing mistrust in physicians making all of the decisions regarding what treatments and medical care one would receive. Moreover, the costs of all this technology was starting to add up. Signs of public unrest with the fast advancing medical technology were starting to surface. The landmark cases of Karen Quinlin (1985) and Nancy Cruzan (1990) led the way for progress in one's right to refuse medical interventions. The 1990 OBRA[9] amendment mandated that all patients must be asked if they have an advance directive and offered the opportunity to complete one upon hospital admission through the Patient Self-Determination Act. The import of allowing patients the right and opportunity to have written directions regarding healthcare that they would *not* want to receive was further enforced by Health Care Financing Association (HCFA) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) mandates controlling Medicare and Medicaid payments to healthcare institutions. Facilities failure to comply could result in losing certification and thereby state and federal dollars.

Medical institutions during the first half of the 19th Century made great advances in the ability to cure disease and prolong life, but did little to ease the final agony of death. The hospice movement started in the United States in the early 1970's and grew into a distinct discipline about the time of the AIDS epidemic. Hospice allowed those dying new options for focusing on comfort and quality of life while dying versus ongoing curative efforts and aggressive medical treatment. Part of this included the greater use of

[9] The Omnibus Budget Reconciliation Act of 1990, (OBRA-90) was enacted November 5, 1990 in efforts to reduce the United States federal budget deficit. The Patient Self-Determination Act was a portion of this act directed at healthcare institutions. The act also included other efforts to affect Medicare and Medicaid recipients related to prescription drugs.

narcotics for pain and symptom relief. This effort was increased following the landmark SUPPORT study[10] which began a period of greater interest in palliative care that continues today.

Today, almost 70% of persons die in hospitals or other medical institutions.[11] Further, most now die from chronic diseases following a lengthy period of disability. Most deaths are now, at least in part, negotiated or, as Stefan Timmermans states, brokered.[12] This is often due to the reliance on therapeutic interventions to postpone death for as long as possible. Then many patients become stuck, late in the game, dependent upon lifesaving technology and merely prolonging an inevitable death. One must then decide when to withdraw or withhold medical interventions in order to *allow* death to occur.

The ability to accurately predict when someone is likely to die is now significantly more difficult than in the days before our technological advancements. In fact, many persons dying with congestive heart failure are routinely given a 50% chance of living six months three days before death.[13] Further, one may remain unconscious and dependent on medical interventions for all bodily processes or in a Persistent Vegetative State (PVS) for years without the ability to improve or return to any active form of life. These cases have pushed our ethical sensibilities and forced us to evaluate the concern

[10]The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients". JAMA Vol. 274, No. 20. (1995).
[11] Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., et al. (2004). Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA: The Journal of the American Medical Association, 291*(1), 88-93.
[12] Timmermans, S. (2005). Death brokering: constructing culturally appropriate deaths. *Sociology of Health & Illness*, 993-1013.
[13] JW.Levenson, Carthy, E. M., Lynn, J., Davis, R., & Phillips, R. (2000). The Last Six Months of Life for Patients with Congestive Heart Failure. *J Am Geriatr Soc, May, 48*(5 Supp), 101-109.

that 'even though we *can* continue extensive medical support for biological existence, is continued medical treatment what *ought* to be done?'

Medical ethics developed in the late 1960's and continued to grow into a distinct profession in the 1980's and 1990's as society struggled with the questions of how we ought to utilize the technology available and where limits were needed. Questions of how we ought to best allow death were also inevitably caught up in this discussion. In the United States, this discussion included movements for the support of Physician Assisted Suicide (PAS) and the Hemlock Society. [14] The legal options for physicians to provide assistance to the dying vary according to location, culture and political landscape and remain open to further changes. Although the legal options may change, the ethical responsibility to provide relief for end-of-life suffering remains unchanged since the origin of the practice of medicine.

Opiates were used even in Hippocrates' time for pain relief and insomnia.[15] He was one of the first to dispute the "magic" and promote the juice of the poppy as a narcotic to treat internal diseases and diseases of women.[16] Following the invention of the hypodermic needle in 1853, morphine became a primary and effective form of narcotic pain reliever for both surgical intervention and end-of-life care. The provision of medications to relieve extreme end-of-life pain, or to provide relief from air hunger and the feeling of suffocation for someone being removed from a ventilator, has been a well-

[14] The Hemlock Society (originated by Derek Humphrey in 1980) changed its name to End-of-life Choices (2003) and merged with Compassion in Dying in 2004 to become currently Compassion and Choices.
[15] The Poppie Shop, The Discovery of the opium poppy. http://www.poppiesshop.com/poppies-information/opium-poppy.html (accessed on July 19, 2010).
[16] Opioids: Past, present and future. http://www.opioids.com/opium/hippocrates.html (accessed on July 19, 2010).

used and routine medical practice.[17] Originally, this part of medical care was done by the physician, upon his order alone, without much oversight or examination, and was considered as part of good care for the dying patient when nothing more could be done. Narcotics were commonly and quietly used to provide a peaceful death without much comment until the practice came under ethical review and new terminology sprang up.[18] This scrutiny began with an article focused on concerns that cancer patients were dying in pain.

The Problem of Definition

Dr. Robert E. Enck is the physician most often cited for coining the term 'terminal sedation'. This occurred in September, 1991 in the article, "Drug-induced terminal sedation for symptom control", in *The American Journal of Hospice & Palliative Care*. Enck's initial article provided a needed review of recent studies of the time[19] showing that up to 50% of patients dying of cancer reported the pain and suffering was "unendurable". Enck did not specifically define 'terminal sedation' but presented studies showing that some patients dying with cancer had unrelieved suffering in their final days and that providing medication to relieve this suffering could only be accomplished by reducing their consciousness as well. Enck questioned the apparent confusion in that while some studies showed no increase in end-of-life cancer pain other studies showed "unendurable pain" for some. He opined, "One answer may be that

[17] Way, J., Back, A. L., & Curtis, J. R. (2002). Withdrawing life support and resolution of conflict with families. *BMJ, 325*(7376), 1342-1345.
[18] Ibid.
[19] Green, W. R., Davis, W.H. . (1991). Titrated intravenous barbituates in the control of symptoms in patient with terminal cancer. *Southern Medicine Journal, 84*, 332-337. And also, Ventrafridda, V., Ripamonti, C., & DeConno, F. e. a. (1990). Symptom prevalence and control during cancer patients' last days of life. *Journal of Palliative Care, 6*, 7-11.

results of scientific inquiry do not always reflect the realities of hospice care. Another answer may be confusion regarding terminology such as pain, symptom definition, suffering and the like."[20] Unfortunately, this confusion has continued and may be considered as a paramount issue in understanding the conflicts involved in determining the ethical permissibility of terminal sedation

Terminal sedation (TS) is one of many terms used to identify the practice whereby persons purposely undergo a medically induced sedation to an unconscious, or near unconscious state to relieve otherwise intractable distress at the end of their life. It has been called palliative sedation (PS), by those favoring its use in aggressive palliative care[21] or alternatively slow euthanasia[22] by those who view it as simply a cloak of nomenclature for an unethical and illegal practice. Various other names have also been used to describe the practice, such as: Sedation for Intractable Distress in Dying, (SIDD); Sedation *for* or *in* the Imminently Dying patient (SFTID, SITID); Palliative Sedation to Unconsciousness (PSU) or Palliative Sedation Therapy (PST).[23] (See Table 1, Definitions of Terminal Sedation, next page.)

[20] Enck, R. E. (1991). Drug-induced terminal sedation for symptom control. *American Journal of Hospice and Palliative Medicine, 8*(5), 3-5.
[21] John F. Peppin, "Intractable Symptoms and Palliative Sedation at the End-of-life " *Christian Bioethics*, Vol. 9, No. 2-3, (2003), pp. 343-355. Also, C. Peruselli, e. a. (1999). Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliat Med, 13*, 233-241.
[22] David Orentlicher, "The Supreme Court and physician-assisted suicide – rejecting assisted suicide but embracing euthanasia". *N.Engl J Med* Vol. 337, No. 17 (1997), pp. 1236-1239. Also, Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. *Journal of Palliative Care, 12*(4), 21-30.
[23] See Table 1. Definitions of Terminal Sedation table is a listing of terms used for practice of sedation for those suffering at end-of-life compiled by date seen in research literature. I will use the terms terminal sedation or palliative sedation interchangeably, although I have a slight preference for terminal sedation as I am using it exclusively to discuss the use of the practice for those in the terminal phase of illness rather than as an intermittent palliative therapy that may be utilized at any point in a serious or life threatening illness.

Table 1. Definitions of Terminal Sedation

Group Defining	Definition TS – Terminal Sedation PS – Palliative Sedation Others as listed	Terminal Px Required?	Expected survival	Only for Intractable symptoms?	Year Developed or endorsed
Robert E. Enck, MD[24] (TS)	Drug-induced terminal sedation for symptom control	Yes	Not stated	Yes	1991
Ventafridda [25] et al (Sedation-induced sleep)	* No definition provided by authors, however mentioned made of sedation-induced sleep for physically unendurable symptoms. Article cited by Enck.	Yes	"last days of life"	Seemingly so – not specifically addressed	1990
Billings & Block[26] (Slow Euthanasia)	*The clinical practice of treating a terminally ill patient in a fashion that will assuredly lead to a comfortable death, but not too quickly.	Yes	"last few days of life"	No	1996
Fondras (Sedation from Latin sedare, to calm)	*Sedation may be defined as the prescription of psychotropic agents, in the main benzodiazepines and neuroleptics, with a view to controlling physical symptom (pain, dysponoea), psychological symptoms (insomnia, anxiety crises, agitation), or to make a patient unconsciusin certain dramatic situations (eg. sudden haemorrhage).	No	Not stated	No	1996
Morita et all (Sedation)	*A medical procedure to palliate patients' symptoms by intentionally making their consciousness unclear. It includes an increase in morphine dose resulting in secondary somnolence, and the use of sedative drugs.	No	Not stated	No	1996
Quill[27] et al (TS)	Suffering patient is sedated to unconsciousness, usually through ongoing administration of barbiturates or benzodiazepines.	Yes	Days to weeks	Yes	1997

[24] Enck, R. E. (1991). Drug-induced terminal sedation for symptom control. *American Journal of Hospice and Palliative Medicine*, *8*(5), 3-5.
[25] Ventrafridda, V., Ripamonti, C., & DeConno, F. e. a. (1990). Symptom prevalence and control during cancer patients' last days of life. *Journal of Palliative Care*, *6*, 7-11.
[26] Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. Ibid., *12*(4), 21-30.
[27] Quill, T. E., Lo, B., & Brock, D. W. (1997). Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *Jama*, *278*(23), 2099-2104.

Table 1. Continued

Group Defining	Definition TS – Terminal Sedation PS – Palliative Sedation Others as listed	Terminal Px Required?	Expected survival	Only for Intractable symptoms?	Year Developed or endorsed
Chater[28] et al (TS)	The intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances. These are: -for the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death, or – for the relief of profound anguish (possibly spirtiual, psychological,or other interventions, and the patient is perceived to be clsoe to death.	Yes	Close to death	Yes	1998
Fainsinger [29] (TS)	*[30]The prescription of psychotropic agents to control physical and psychological symptoms by makin gthe patint unconscious	Yes			1998
Fleischman (TS)	*Sedation at the end-of-life to alleviate severe and unremitting pain.	Yes	"end-of-life "	Yes	1998
Hallenbeck (TS)	* The induction and maintence of a sedated state with the intent of relieveing otherwise intractable distress, both physical and mental, in a patient close to death.	Yes	"close to death"	Yes	1999
Morita [31]et al (Sedation)	A medical procedure to palliate patients'symptoms refractory to standard treatment by intentionally diminishing their consciousness . Levels of sedation defined as primary, secondary, intermittent,and continuous. Mild and deep sedation also defined.	Yes	Not defined	Yes	1999, 2000
Peruselli et al (Total pharmacological sedation)	*The administration of drugs to obtain total loss of consciousness.	No	Not defined	No	1999

[28] Chater, S., Viola, R., Paterson, J., & Jarvis, V. (1998). Sedation for intractable distress in the dying- a survey of experts. *Palliat Med, 12*, 255-269.

[29] Fainsinger, R. L., Landman, W., Hoskings, M., & Bruera, E. (1998). Sedation for uncontrolled symptoms in a South African hospice. *J Pain Symptom Manage, 16*(3), 145-152.

[30] Beel, A., McClement, S. E., & Harlos, M. (2002). Palliative sedation therapy: a review of definitions and usage. *International Journal of Palliative Nursing, 8*(4), 190-199. * Definitions denoted by * are from Beel, et al. 2002 a good source for review of terms, definitions and research study done in the first ten years of the accepted use of palliative sedation therapy.

[31] Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Do hospice clinicians sedate patients intending to hasten death? *J Palliat Care, 15*(3), 20-23, Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (2000). Terminal sedation for existential distress. *Am J Hosp Palliat Care, 17*(3), 189-195.

Table 1. Continued

Group Defining	Definition TS – Terminal Sedation PS – Palliative Sedation Others as listed	Terminal Px Required?	Expected survival	Only for Intractable symptoms?	Year Developed or endorsed
Quill [32]et al (TS)	*Heavy sedation to escape pain, shortness of breath, other severe symptoms. The patient is sedated to unconsciousness to relieve severe physical suffering and is then allowed to die of dehydration or some other intervening complication.	Yes		Yes	2000
Krakauer et al Sedation for Intractable Distress of a Dying Patient (SIDD Pat)	* Use of sedating medications to relieve severe symptoms that cannot be controlled adequately despite aggressive efforts without sedation.	Yes	"dying"	Yes	2000
Wein (TS, and sedation in the imminently dying patient)	*Uses Chater et al (1998) definition of TS, however, emphasizes that the term 'terminal sedation' should be avoided because it could be interpreted as meaning sedation intended for terminally ill patients or sedation for the purpose of terminating the patient's life. Wein suggests using the term 'sedation in the imminently dying'.	Yes	Near end-of-life , or imminently dying	Yes	2000
American College of Physicians-American Society of Internal Medicine Consensus Panel[33] (PSU)	The purpose of the medications is to render the patient unconscious to relieve suffering, not to intentionally end his or her life. However, in the context of far-advanced disease and expected death, artificial nutrition, hydration. antibiotics, mechanical ventilation, and other life-prolonging interventions are not instituted and are usually withdrawn if they are already in place.	Yes	"End-of-life "	Yes	March 2000

[32] Quill, T. E., Lee, B. C., & Nunn, S. (2000). Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med*, *132*(6), 488-493.

[33] Quill, T. E., Byock, I. R., & For the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus, P. (2000). Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal. *Annals of Internal Medicine*, *132*(5), 408-414.

Table 1. Continued

Group Defining	Definition TS – Terminal Sedation PS – Palliative Sedation Others as listed	Terminal Px Required?	Expected survival	Only for Intractable symptoms?	Year Developed or endorsed
Calgary Regional Hospice[34] (PS)	Palliative sedation defined as "the intention of deliberately inducing and maintaining deep sleep, but not deliberately causing death in very specific circumstances: (1) for the relief of one or more intractable symptoms when all other possible interventions have failed and the patient is perceived to be close to death or (2) for the relief of profound anguish (such as spiritual anguish) that is not amenable to spiritual, psychological, or other interventions, and the patient is perceived to be close to death.	Yes	Days	Yes	2003
Council on Ethical and Judicial Affairs, American Medical Association[35] (PSU)	Palliative sedation to unconsciousness is the administration of sedative medication to the point of unconsciousness in a terminally ill patient. It is an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond to aggressive symptom-specific palliation.	Yes	"Final stages of terminal illness" *not supported for existential distress only	Yes	June 2008
International Consensus Panel[36] (PST)	PST is defined as the use of specific sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness, using appropriate drugs carefully titrated to the cessation of symptoms.	Yes	Hours to days	Yes	2007
Royal Dutch Medical Association[37]	The deliberate lowering of a patient's level of consciousness in the last stages of life.	Yes	One to two weeks	Yes	Jan 2009

[34] Braun, T. C., & Hagen, N. A. (2003). Development of a Clinical Practice Guideline for Palliative Sedation. *Journal of Palliative Medicine*, *6*(3), 345.
[35] http://www.ama-assn.org/ama1/pub/upload/mm/code-medical-ethics/2201a.pdf. Accessed June 9, 2010.
[36] Graeff, A. D., & Dean, M. (2007). Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards. *Journal of Palliative Medicine, 10*(1), 67-85.
[37] *knmg.artsennet.nl/web/file?uuid=e9a9c569-39de-4dd7. Accessed on June 10, 2010*

Table 1. Continued

Group Defining	Definition TS – Terminal Sedation PS – Palliative Sedation Others as listed	Terminal Px Required?	Expected survival	Only for Intractable symptoms?	Year Developed or endorsed
Cowan and Walsh Palliative Care of E. TN, and Cleveland Clinic[38] (PS)	We consider it involves the following: (1) the patients are terminally ill with advanced and incurable illness; (2)they are actively dying i.e. death is expected in hours or days as judged from blood pressure, pulse, respiration, urine output, and level of consciousness; (3) acute or refractory symptoms such as pain, nausea, myoclonus, restlessness, or respiratory distress are present; (4) these symptoms have not responded to conventional management, or the severity of the symptoms and trajectory of the illness require prompt intervention to relieve distress;(5) sedation is chemically induced using a nonopioid drug to control the symptom; (6) causing death is not the intent, although it is implicit that it may not be possible to achieve adequate symptom control except at the risk of shortening life.	Yes	Hours to days	Yes	May 2001
American Academy of Neurology (AAN) (SFTID)	Sedation for the imminently dying (SFTID). Allows for the administration of titrated sedation to patients who are imminently dying and whose suffering remains refractory to other interventions.	YES	Imminently dying	Yes	2004
American Academy of Hospice and Palliative Medicine[39] (PS, but def. seems more like PSU)	Palliative sedation (PS) to unconsciousness The administration of sedatives to the point of unconsciousness, when less extreme sedation has not achieved sufficient relief of distressing symptoms. This practice is used only for the most severe, intractable suffering at the very end-of-life .	Yes	"Very end-of-life "	Yes	September 15, 2006

Those who practice in the specialty of Palliative Care often use differing types of sedation as treatments for addressing distressing symptoms during the course of treating incurable illness prior to the final days of life. They are more likely to cite the differing levels of sedation and intent more clearly, and to endorse more precise terminology to be used for justification of sedation. Palliative Care specialists may order sedation, with

[38] Cowan, J. D. a. D. W. (2001). Terminal sedation in palliative medicine –definition and review of the literature
Support Care Cancer 9, 403-407.
[39] http://www.aahpm.org/positions/sedation.html Accessed June 9, 2010.

distinctions made between level of sedation, such as light or moderate sedation where the patient may still be able to converse or to be aroused if needed, and deep sedation to unconsciousness. Other distinctions physicians may make are between lengths of sedation desired, such as episodic or intermittent, to allow patient a respite from symptoms or assistance to sleep at night versus continuous sedation until death occurs. Intractable distress or refractory symptoms are the common terms as defined by Cherny and Portenoy[40] utilized for extreme suffering experienced. 'Intractable' or 'refractory' are used to describe pain (or other coexisting noxious symptoms such as dyspnea, vomiting, nausea, delirium, agitation, myoclonus, or others, including some forms of existential suffering) that has proven to be resistant to multiple attempts at traditional treatment. "It is when a patient's symptoms become refractory that sedative medications can be considered a therapeutic option."[41]

Another of the confusing factors in evaluating the practice of terminal sedation is that there is a not universally accepted criterion of what *exactly* is considered to be terminal or palliative sedation versus what is considered to be routine symptom control or routine palliative care at the end-of-life. Sedation to the point of unconsciousness in palliative care has been used for three related, but distinct, purposes: (1) to relieve physical pain and produce amnesia of uncomfortable medical interventions; (2) to produce an unconscious state before the withdrawal of artificial life support; (3) to relieve

[40] Cherny, N. I., & Portenoy, R. K. (1994). Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. *J Palliat Care, 10*(2), 31-38.
[41] Kathryn Lanuke, et al., "Two Remarkable Dyspneic Men: When Should Terminal Sedation be Administered?", *J of Palliative Medicine,* Vol. 6 No. 2,(2003), pp. 277-281. pg. 279.

non-physical suffering.[42] The use of large doses of narcotics in providing palliative care to achieve the first objective has been relatively uncontroversial. This large dosage of narcotics has been questioned at times in achieving the second objective but remains in those cases still markedly less controversial than when used to achieve the third objective. It now appears that a fourth category, one that merges parts of those above and serves to eliminate one's participation in the final act of dying has developed. In the newest cases, terminal sedation is used to achieve a peaceful dying process for patients and for those caring for them upon explicit request for this type of death. It is important to note that the first two purposes have traditionally been initiated by physicians and are commonly accepted as ethically allowable. The third is exclusively and controversially requested by patients and has yet to gain widespread ethical support. The fourth (the primary focus of this dissertation) is usually part of a negotiated death including patients, families, and physicians and also remains ethically controversial.

The word sedation is itself a very slippery term at times. Consider the following: Do we want to talk about a patient who is sedated to the point of feeling no pain but is arousable or one who is completely unconscious? Do we intend for sedation due to narcotics for pain relief only (so we may rouse the patient intermittently to converse, evaluate pain control or relief) or continued unremitting sedation due to benzodiazepines with the expressed effect of permanent analgesia through unconsciousness (perhaps in a patient with existential suffering who does not want to be awakened again)? In all the

[42] Rob McStay, "Terminal Sedation: Palliative Care for Intractable Pain, Post Glucksberg and Quill" *Am. J of Law & Medicine*, Vol. 29 (2003) pp. 45-76. pg. 46.

above cases medical staff would state, "The patient was sedated" and that is how it would likely look in a hospital record.

Drugs and Dosages

A further inconsistency related to the use of terminal sedation is the great variety of drugs and dosages used to obtain sedation as well as the route administered. Most current studies in America and Europe show a preference for the benzodiazepine drug Midazolam. Although Midazolam is favored, Haloperidol and Morphine are also not infrequently used and occasionally Levomepromazine, Hyoscine or barbiturates such as Phenobarbital are utilized.[43] A much newer drug, Propofol is also considered by some to be a 'good drug' to use for palliative sedation but is restrictive in that it is expensive, must be given in the hospital, and requires intravenous (IV) for route of drug delivery.[44] Midazolam offers quick and effective sedation, is cheap, and may be given IV or subcutaneously (SC), it also has an antidote (Flumazenil) available if reversal of sedation is required.[45] Midazolam is historically known and utilized in medicine for its amnesic effects and is often given to patients in intensive care on ventilators to reduce the stress of being on the breathing machine, or given prior to and during surgery in order to allow patients to forget the experience. A well known side effect of Midazolam, and other similar drugs, is the potential to slow heart rate and breathing and thus its use requires close supervision. This known and usually unwanted side effect is what produces the

[43] Porta Sales, J. (2002). Palliative sedation : Clinical Aspects. In C. Gastmans (Ed.), *Between Technology and Humanity: The Impact of Technology on Health Care Ethics* (pp. 219-238): Leuven University press. Pg. 230.
[44] Ibid. pg. 234.
[45] National Institute on Health, MedlinePlus on line. http://www.nlm.nih.gov/medlineplus/druginfo/meds/a609003.html (accessed on July 12, 2010).

'double effect' often attached to the ethical controversy regarding palliative sedation. Narcotics, such as morphine, also have the side effect of respiratory depression and respiratory depression is greatly exacerbated when benzodiazepine and narcotics are combined.

The mean dosage of drugs used has been evaluated in a review study by Josep Porta Sales and showed daily rates of Midazolam used in patients for palliative sedation in published studies between 1996 and 2001 varied from a 24mg/day to as high as 88mg/day.[46] While benzodiazepines are most often used for sedation, opioids may also be used for pain control in patients who are sedated. Mean Morphine dosage varied from a low of 12 mg/day to as much as 100mg/day.[47] Such great variations in the amounts of medications used clearly show that a universal practice has yet to be defined. It also may allow the ethical intentions of the practice to be questioned. Usually in cases of palliative sedation as currently practiced, the intention is for *both* relief of physical symptoms and sedation to unconsciousness and therefore includes the use of both opioids and benzodiazepines. In some cases, such as those with severe dyspnea or delirium it may be possible to utilize only the sedation to offer relief, but those with great pain such as cancer pain will require narcotics to relieve symptoms as well. They may also increase pain medications if breakthrough pain becomes apparent. In this aspect, the term palliative sedation to unconsciousness (PSU) does provide greater clarity and transparency. The concern regarding physician intentions and double effect will be

[46] Ibid. (Sales 2002). pg. 232.
[47] Ibid.

addressed in greater detail in the following chapter as this is a separate concern in the ethical debate on terminal sedation.

An Evolving Consensus or More Conflict?

Despite these significant obstacles, it does now appear that some consensus is starting to emerge at least on a few primary points. Terminal sedation is most often considered a medical treatment for a patient when three components combine in a patient situation. This is when patients are diagnosed with a *terminal disease* and experiencing *intractable symptoms* of pain or suffering and are in the *last days or weeks*[48] of life. Terminal sedation is frequently,[49]although not always, accompanied by the withdrawal of any other life sustaining interventions such as nutrition and hydration, ventilator support or intravenous medications which maintain cardiac function. The National Hospice and Palliative Care Organization[50] has compiled a resource guide and encourages hospitals and palliative care providers to develop formal practice guidelines for the use of TS but they have yet to gain wide application. Furthermore, there is currently debate on widening the use of TS and changing guidelines to include allowing more existential suffering and for death to perhaps come from the expected TS dehydration rather than exclusively from the underlying disease process.[51] That TS is practiced as a treatment for those exclusively facing the end of their lives has prompted the intense ethical debate to

[48] Admittedly, this is an inexact determination but can usually be assessed by decrease in urine output, respirations, and other bodily functions combined with physician practice knowledge.
[49] Sedation may be unaccompanied by withdrawal of other medical technology or nutrition and hydration due to expected closeness of death or never having started these treatments.
[50]*Total Sedation: A Hospital and Palliative Care Resource Guide*. Alexandria, VA: National Hospice and Palliative Care Organization; November 2000. Accessed at www. Nhpco.org/files/public/NHPCOTotalSedationSHORT.pdf on May 25,2010.
[51] Berger, J. T. (2010). Rethinking Guidelines for the Use of Palliative Sedation. *Hastings Center Report, 40*(3), 17-21.

focus on comparisons to the practices of physician assisted suicide (PAS), and euthanasia, both of which are illegal in most jurisdictions in the United States.[52] This is an important ethical concern but it may not be the *only* important concern related to the practice of TS. With the majority of interest focused on the above concerns, ethicists have mostly ignored other potential harms and hence those potential other harms are the focus of this dissertation.

Despite some emerging consensus, there continues to be controversy concerning terminal sedation, with a great deal of published discussion occurring following the Supreme Court's tacit endorsement of the practice in 1997.[53] The fact that the goal of TS is continuous medication which renders patients permanently unconscious, coupled with the withdrawal of nutrition and hydration, pricks the ears of those ethically uncomfortable or unconvinced of the moral nature of this practice. The ethical concept of autonomy has been clearly shown and legally established to support allowing patients to refuse any medical treatment, including the provision of nutrition and hydration, and this principle also supports the patient when this refusal is combined with the request for TS. Autonomy is strongly supported when TS is requested by the patient herself and it is increasingly addressed by palliative care physicians prior to the final stage of an illness when discussing advance directives. Yet the fear exists that the medications and methods used in TS are used to *hasten* death rather than merely eliminate intolerable symptoms by those without a clear understanding of the practice. This would make the practice of TS closer to euthanasia and therein unacceptable to many. Many studies state terminal

[52] This topic will be explored in Chapter 2 in detail.
[53] Washington v. Glucksberg, 521, U.S. 702 (1997) and Vacco v. Quill, 521, U.S. 793 (1997).

sedation is most commonly utilized only in the last hours or week of life.[54] Peppin and others[55] have suggested that, "from the current studies there is no difference in survival between those who receive PS (palliative sedation) and those who do not."[56] This is easily believable assuming that palliative sedation is in fact only utilized in those who have already been diagnosed with an imminently terminal stage of illness or disease and who have mostly stopped eating and drinking. However, even with these assumptions, questions can be raised in how these statistics were gathered and how terms (such as 'intractable', 'sedation', and 'end-of-life ') were defined. In fact, Peppin admits that although further research is needed to more accurately evaluate changes in survival rates between those who undergo TS and those who do not, the only way to "prove" these claims would be to do randomized, placebo controlled, double blind studies which would neither pass Institutional Review Boards (IRB's) nor be ethical to attempt. Thus, he argues, the only approach feasible to evaluate when TS is medically appropriate is the judgment of the palliative care and pain medicine specialist.[57] Even then, in a summary of international guidelines for the practice of PSU,[58] although there was agreement on TS used with 1) only those with terminal illness and, 2) only if symptoms are intolerable and

[54] Peruselli, et al., found 25% totally pharmacologically sedated during last 12 hours of life. Peppin, J., F. (2003). Intractable Symptoms and Palliative Sedation at the End of Life. *Christian Bioethics: Non-ecumenical Studies in Medical Morality, 9*(2/3), 13.Peppin, cites multiple studies, Italian and Canadian study which found average time from palliative sedation until death was 1.3 days, Japanese study 3.9 days, South Africa 2.5 days. It may be important to note that none of these studies were conducted in the United States and cultural differences may be important to consider when relating to the use of palliative sedation practices. This is an area where concurrent American research results would yield valuable contributions to the discourse.

[55] Ibid. Also, Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Do hospice clinicians sedate patients intending to hasten death? *J Palliat Care, 15*(3), 20-23, Muller-Busch, H. C. C., Andres, I., & Jehser, T. (2003). Sedation in palliative care- a critical analysis of 7 years experience. *BMC Palliative Care, 2*(2).

[56] Peppin, pg. 347.

[57] Ibid. pg.349-350.

[58] Jeffrey T. Berger, "Rethinking Guidelines for the Use of Palliative Sedation", *Hastings Center Report*. Vol 40. May-June (2010), pp. 32-38.

refractory, there was variance in its use for 3) existential suffering in addition to physical pain, and 4) in expected survival until death from hours up to one to two weeks or vague terminology such as "end-of-life". There remain concerns that TS will be used on those who may survive for several weeks or longer and some fears that it will be overused. Prevalence of the practice of TS varies from lows of 2% up to 52% of deaths in patients with terminal illness.[59] In part, the wide divergence in percentages shown for the practice must come from the differences already mentioned concerning how one defines the practice of palliative sedation as distinct from general good end-of-life palliative care.[60] I believe it also shows that much more information on the entire field of TS needs to be gathered and evaluated.

Is TS a type of Death?

There has been a renewed interest in reevaluation of the Uniform Determination of Death Act and discussion of the whole brain versus higher brain definition of death. Critical in the higher brain definition is the total loss of consciousness and inability to communicate or perceive. Higher brain death is not currently a definition of death in any jurisdiction in the United States. But I bring up this issue because the practice of terminal sedation, while providing aggressive symptom control, forces patients to accept a total loss of consciousness and inability to communicate as a trade off for no longer perceiving their intolerable symptoms. Further, this medically induced state is intended to persist until biological death occurs. Is terminal sedation therefore, in effect, producing a type of

[59] Angela Barreth, et al., "The Challenge of Communicating Intent of Sedation in Advanced Illness", *J of Palliat Care*, Vol 19. No. 3,(2003). pp. 217-219. pg. 218.
[60] It may also in part come from methods of either including or not including TS to those who are incompetent and may have had surrogate or lack of surrogate consent. Surrogate consent will be addressed more fully in both Chapter 2 and Chapter 3.

death by eliminating personal consciousness of one's dying? Clearly, once enacted, the patient who has entered a final medically induced coma and ceased all consciousness, communication or perception has ended her social and biographical participation in her life. But, does this equal death? I think not.

Although terminal sedation, as a treatment at the end-of-life, does affect how one will die, once chosen, one will no longer be able to converse with family or hear their voices saying loving words of farewell or have any perceptions due to a deeply unconscious state. This state is medically induced and at least potentially reversible.[61] In TS the perception of sensation has been altered by medications and the organic functioning of the brain remains unaltered. In those who have suffered higher brain death, the lack of perception and consciousness is due to organ damage (in the brain) and is rarely, if ever, chosen by those who lose consciousness in this manner. The election of terminal sedation in a competent patient allows one's reason and autonomy to reign in choosing to forego consciousness in order to eliminate suffering. This occurs when the patient has been informed and accepts both the benefit (relief from intolerable suffering) and harms (loss of consciousness, perception, and ability to communicate) involved in requesting terminal sedation. In cases of underlying dementia, delirium, or other illness, the decision to utilize terminal sedation must meet the requirements of surrogate request based upon overriding beneficent concern or prior requests of the patient.

[61] Unless one accepts the Higher Brain definition of death, there are those whose deaths may come many, many months or years after becoming unconscious due to irreversible severe brain injury.

Operational Definition

For the purpose of clarity in this dissertation I will utilize a standard to allow terminal or palliative sedation when the following conditions apply. Terminal sedation is the appropriate and intentional use of medications (benzodiazepines and/or narcotics) to produce ongoing, deep unconsciousness upon 1) *a terminal patient's (or surrogates) request* due to 2) *suffering intractable pain or other distressing clinical symptoms intolerable to the patient* when 3) *death is expected within hours or days*[62] *(less than two weeks)* due to the terminal illness, injury, or disease. This may be done with or without the concurrent withdrawal of artificial nutrition and or hydration, but would exclude the starting of such support in all but the most extraordinary of circumstances. This definition seeks to exclude the sort of coma or unconsciousness that many experience naturally at the end-of-life due to advancing disease, or that which may come from purposeful cessation of eating or drinking or from accidental overdose or buildup of medications in those with advanced disease. Further, I include not only patient requests, via current or previous discussions with physicians but also the requests of those close family members, loved ones or other surrogates who are often called upon to make end-of-life decisions.[63] I also include the requirement that the pain or other clinical symptom causing the patient's suffering be evaluated as intractable or refractory. This serves to eliminate those who may be able to be effectively treated in other ways, and does signify TS as a practice of last resort.

[62] The prediction of an anticipated death is always inexact but ought to be anticipated to occur within two weeks to meet my understanding of actively dying.
[63] The additional concerns that allowing proxy decision makers involves are addressed further in Chapter 2 and Chapter 3.

I do not explicitly exclude existential suffering, as it may also become unbearable and intractable, this is less often the case, and existential suffering is often inseparably connected to other physical forms of unendurable suffering at the end-of-life. I do mean to deny TS for those who do not have any physical suffering and cases of exclusively existential suffering in those who do not also have a terminal diagnosis and are not in the active phase of dying. Attempts to relieve these sorts of existential crises are not without philosophical merit, but they do not fall under the classical medical purview and inpatient hospital care that I have focused this dissertation to address.

Lastly, although I acknowledge that the practice of TS may also rightly serve those suffering intractable symptoms from illness or disease or those who are not able to be categorized as imminently terminal or those who justly and autonomously desire relief from ongoing chronic suffering due to grave disability, I have purposely excluded them. Some suffering (such as those undergoing burdensome but curative cancer or burn treatments) may be better treated with intermittent, light or moderate episodic sedation. This is not to say that I am indifferent to those suffering chronic grave disability or ongoing non-terminal suffering. Rather, I exclude them in an attempt to clarify the current debate and delimit a practice that has many vague and variable factors.

For those who are suffering with diseases of a progressive disabling nature such as Alzheimer's disease, amyotrophic lateral sclerosis (ALS), and other non-imminently fatal diseases or not imminently fatal at the point in time TS is requested, the use of TS to allow death, has significantly different moral evaluations. The refusal of nutrition and hydration prior to the state of actively dying (although well within their autonomy rights) significantly hastens death and then may alter the moral evaluation of the physician's role

in providing sedation for symptom control to be closer to providing assistance for suicide. The practice of allowing those with debilitating illness to use TS has been recently termed Early Terminal Sedation (ETS) by Victor Cellarius[64] because without the TS the patient may survive for additional months prior to dying from their underlying disease. Although I anticipate important progress into this area of inquiry, it is beyond the scope of this work.

This dissertation will support full ethical endorsement of terminal sedation for those most urgently in crisis and need of beneficence, those who are dying and in the final hours or days and suffering. Moreover, I will attempt to identify new areas where harms and benefits may need to be evaluated as affecting patients, families and caregivers. I will evaluate the current practice to allow the development of ethical guidelines and greater consensus on deciding the hard cases. This work may also serve to assist those looking to enlarge the practice in the future with ETS for those with debilitating diseases or disability, but they are not my primary goal.

To review, below is the standard I propose for moral allowability for the use of terminal sedation. I will refer to it often in the pages that follow simply as *my standard*.

> **Terminal sedation** is the appropriate and intentional use of medications (benzodiazepines and/or narcotics) to produce ongoing, deep unconsciousness upon 1) *a terminal patient's (or surrogates) request* due to 2) *suffering intractable pain or other distressing clinical symptoms intolerable to the patient* when 3) *death is expected within hours or days*[65] *(less than two weeks)* due to the terminal illness, injury, or disease.

[64]Cellarius, V. (2011). 'Early Terminal Sedation' Is A Distinct Enity. *Bioethics, 25*(1), 46-54.
[65] The prediction of an anticipated death is always inexact but ought to be anticipated to occur within two weeks to meet my understanding of actively dying.

CHAPTER 2

DISTINGUISHING TERMINAL SEDATION FROM PHYSICIAN-ASSISTED SUICIDE OR EUTHANASIA AND THE DOCTRINE OF DOUBLE EFFECT

Introduction

A moral concern exists in that the appropriate use of the practice of terminal sedation may be viewed by some as equivalent to euthanasia or physician-assisted suicide (PAS). This position has been held by many, including ethicists,[66] physicians and families. It is important to have a clear understanding of the differences among the three types of death currently requested by those wanting more control in arranging their manner of death. Each option gives the dying person, to a greater or lesser extent, more control over when and how death will occur. One ought to also consider that these three forms are all choices that one would usually make only under extreme situations, when suffering was felt to be unendurable during the dying process.[67] Many persons, perhaps even most, are able to tolerate their dying process and able to utilize the conventional medical and social supports to allow a death to happen more naturally, that is without additional medical interventions.

This chapter will first provide a brief examination of the practices of euthanasia and physician-assisted suicide with a focus on the moral intent, specific actions, and the methods utilized. I will then do the same for the practice of terminal sedation to allow

[66] See Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. *Journal of Palliative Care, 12*(4), 21-30.

[67] This chapter will provide only a brief discussion on euthanasia and physician-assisted suicide. My efforts are directed towards a more complete discussion on the benefits and burdens of terminal sedation as it is the only option currently available in most of the United States.

evaluation of the critical similarities and differences amongst the three methods. This will allow us then to concentrate more fully on terminal sedation.

Next, I will illustrate where the ethical debate on terminal sedation has mostly been focused since its inception in1991 and the major positions held by the proponents and those opposed to utilizing TS. Included in this debate is whether or not TS can be morally justified by utilizing the Doctrine of Double Effect. There are many varied and complex interpretations of how the Doctrine of Double Effect applies or does not apply to TS. There is also great debate as to whether TS is one act or two. My intent is not to resolve these issues here, but merely to advise the reader of the current positions and my evaluation of them at this date. Then we will be able to move forward to looking at other potential harms and benefits of TS that have thus far escaped close ethical evaluation. Let us begin by clarifying the differences between euthanasia (EU), physician-assisted suicide (PAS) and terminal sedation (TS).

Euthanasia

In active euthanasia,[68] the physician intent is to alleviate intractable suffering by the death of the patient. Death is obtained by application of specific medicines (usually through injection) and dosages which will, in themselves, produce death. The physician is responsible for administering the final dosage of medications and usually remains present until breathing and respirations have stopped and the patient is pronounced dead. When speaking of euthanasia one is usually, more accurately, speaking of voluntary active euthanasia, wherein a patient has voluntarily made the explicit request for

[68] When I use the term euthanasia in this document I am intending the form of voluntary active euthanasia at all times and will not address any other form of euthanasia.

physician administration (*active process*) of drugs to assist in dying. There are also, however, many reports of cases of what might be called *presumed* voluntary euthanasia in which the patient is not competent and her wishes are not known but it is believed that a reasonable person in her situation would have wanted relief from the suffering her situation involves. A variety of mediations may be utilized to achieve this goal. These include potassium chloride, to stop heart function; a combination of sodium thiopental to sedate and pancuronium bromide to paralyze heart/lung function; or a large dose of a single barbiturate such as Phenobarbital or opioids such as morphine to stop respiratory functions. In most cases death occurs in minutes following the injection of lethal medication. Physicians may, where legal, provide additional medications if needed when the original dosage does not quickly provide cessation of heart and lung function.

Voluntary euthanasia is not legal in the United States. It is legal in the countries of The Netherlands (since 1984), Belgium (since 2002), and Luxembourg (since 2009).[69] Euthanasia was briefly legal in Australia (1996-1997), then rescinded.[70] It is technically legal in Japan but does not meet our usual American understanding of the term.[71] Involuntary euthanasia, without patient request for death, would be murder and is not legal (except in cases of ordered execution) in any country.

The Netherlands is the country with the most experience with physicians' provision of active voluntary euthanasia upon patient request. Frances Norwood is an

[69] Norwood, F. (2009). *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care- Lessons from The Netherlands*. Duram, North Carolina: Carolina Academic Press.pg. 78.
[70] Ibid. Euthanasia was only legalized in the Northern Territory of Australia prior to the law being rescinded.
[71] In Japan, it is considered euthanasia (passive) when medical intervention is withheld or withdrawn. This does not meet our usual understanding of euthanasia which is the voluntary active type of euthanasia. Norwood. 2009.

anthropologist who lived in The Netherlands and completed an ethnographic evaluation on the practice of euthanasia for over 15 months. She worked directly with the medical practitioners, called *huisarts*, who provide euthanasia to their patients who request it. In her recent book, *The Maintence of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care- Lessons from The Netherlands*, [72] Norwood sheds a remarkable light upon what has been, at least to American eyes, a shadowy practice. The *huisartsen* follow a well developed protocol that requires multiple steps and involves both the patient's extended family members and other physicians prior to the request for euthanasia being granted. This protocol follows The Netherlands national policy, *Termination of Life on Request and Assisted Suicide Act of 2002.*

> *The Termination of Life on Request and Assisted Suicide (Review Procedures) Act (The Act 2002)* According to the Act, euthanasia and assisted suicide must always be provided by a physician who:
> a. holds the conviction that the request by the patient was voluntarily and well-considered
> b. holds the conviction that the patient's suffering was lasting and unbearable
> c. has informed the patient about the situation he was in and about his prospects
> d. be provided by a physician who holds, as does the patient, the conviction that there was no other reasonable solution for the situation he was in,
> e. has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a-d and
> f. has terminated a life or assisted in a suicide with due care (Requirements for Due Care, Article 2 The Act 2002) [73]

In addition to the above legal requirements, Norwood has elucidated the informal and unspoken rules that shape the practice of euthanasia in The Netherlands. Importantly, Norwood identifies the practice of 'euthanasia talk', as requiring multiple conversations

[72]Norwood. 2009.
[73] Norwood, F. (2009). *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care- Lessons from The Netherlands*. Duram, North Carolina: Carolina Academic Press.pg. 47.

between patient and family; patient and doctor; doctor and family; and patient, family, and doctor; and lastly, patient and consulting doctor. Euthanasia talk is significant in playing an essential part in acknowledging the dying patient as an important person in the lives of others. Euthanasia talk also serves in reducing the social death and isolation the dying often feel, and feelings of being marginalized because they now must take the lead in requesting and justifying their request for euthanasia. Therefore, euthanasia talk often begins months prior to the time that it would be required.

There are five stages of euthanasia talk required. The first is an initial verbal request and then a written declaration of intention. These two stages may occur anywhere from years to days before death. According to Norwood, "Initial request and written declarations and subsequent repeated requests are typically as far as most people go in the stages of a euthanasia discussion."[74] This fact is verified by the national statistics showing that in 2005, of 28,600 initial requests for euthanasia or PAS, only 8.6% continued on in the process to eventual euthanasia death.[75] The third stage occurs only if the *huisartsen* concur with the request and all conversations with family have occurred (the *huisartsen*, may agree or may not agree that euthanasia is the best option) then the *huisartsen* will schedule a consulting doctor to evaluate the patient for a second opinion. If a second physician's opinion agrees to the appropriateness of euthanasia and the patient is still requesting it, then a date will be set when death is getting near. Finally at the agreed upon time of the patient choosing, if all remain in agreement, death by injection will proceed. The death by injection is hastening with clear intention as

[74] Ibid. pg. 46.
[75] Ibid.

compared to the dying process that would have occurred from the disease progression alone. But, as is apparent, there are many points, even up to the day set for death, that the patient, family or physician may decline this option, delay the time or choose to try other efforts. Also, patients may die from the disease process or other complications prior to reaching a date for euthanasia to occur.

The act of choosing euthanasia also provides the patient and all others involved a clear role related to the upcoming death with duties involved. This clearly demarked and socially endorsed role delineation for the dying process has benefits for both the dying and the surviving in terms of providing norms and social role identification throughout the process. Even when euthanasia is not ultimately the manner of death, the evaluation of this possibility requires both patients and families to have direct conversations with each other and the physician that proclaim death as immanent and that elicit patient preferences for how it ought to occur. It also validates the dying process as a 'special event' of sorts in one's life and one that ought to be prepared for and marked by unique preparations. This is in opposition to dying in American society where death is often denied right up until the final moments.

To use the Dutch process as a well established example of medically endorsed euthanasia we can see unmistakably that the physician intends his action (providing an injection of medication(s)) to have the effect of the death of his patient. The dosage and type of medication used are those that will directly cause death. There is a requirement for 'the conviction that the patient's suffering was lasting and unbearable' but this requirement does not specify that the suffering be physical or that the patient have a terminal diagnosis. That euthanasia is autonomously the patient's desire and relieves her

of extreme suffering are important ethical considerations. But, it is the physician intent and actions that are most clearly at issue regarding the topic of how terminal sedation is similar or different from euthanasia. Euthanasia is the physician act of providing lethal medications in lethal dosage with the intent to provide a hastened (usually to only minutes) death for the patient.

Physician-Assisted Suicide (PAS)

In PAS the physician intent is to allow *the patient* the choice to take her own life in order to relieve intractable pain or other distressing clinical symptoms by giving the patient medications (or a prescription for medication) which will provide a dosage to allow suicide.[76] The physician is responsible for writing a prescription for medications which when taken in sufficient amounts would be lethal and for educating the patient on the amounts and route of administration which will likely produce death. The medications ordered are usually in pill form (which may be crushed and put in liquid or soft food) or liquid form and this requires the patient to be able to swallow the drugs and to maintain their ingestion without vomiting. The drugs utilized are usually barbiturates, such as Secobarbital or Pentobarbital to induce sleep or in combination with opiates like morphine or Fentanyl for pain relief.

Currently PAS is legal in the states of Oregon (since 1997), Washington (since 2008), and Montana (since 2009). PAS is also available in the countries of Switzerland (since 1937), The Netherlands (since 1984), Belgium (since 2002), and Luxembourg

[76] With the notable exception of Dr. Kevorkian who usually brought medications himself, most cases of PAS involve the giving of a prescription to the patient which she may elect (or not) to fill.

(since 2009).[77] PAS is technically legal in Germany but lacks acceptance of routinely established and open procedures.[78] Physicians or others may or may not be present when the patient takes the lethal dosage of medication. That the final act is intended to be autonomously done by the patient is what holds ethical import. This 'final act' of ingesting the lethal dosage of medication has been interpreted in various ways. Some interpret it to hold the patient as acting *entirely* independently in *obtaining and ingesting* the drugs while others hold that assistance in obtaining and preparation of the drugs is fine as long as the *final ingestion* is a voluntary act of the patient.

In Switzerland, the organization, *Dignitas*, is a group that offers assistance in PAS that has attracted international visitors for the explicit purpose of obtaining PAS. They have a well established protocol for offering assistance with the final act of suicide. This is only done after a physician evaluation of the patient to determine that they are suffering intolerably and facing certain, if not imminent, death from their disease or disability. American professor, Craig Ewert was living in Britain and allowed his PAS to be filmed for a Public Broadcasting System (PBS) television documentary. He narrates for viewers, with his wife assisting, the process of obtaining and undergoing PAS authorization and his death.[79] As shown on video, once the physician has evaluated and written the prescription, the *Dignitas* assistant will prepare the medication and even assist

[77] Norwood, F. (2009). *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care- Lessons from The Netherlands*. Duram, North Carolina: Carolina Academic Press. Pg. 78.

[78] Ibid. The German method of PAS is usually done with non-physician helpers as due to the Nazi experience they have kept all physicians clear of PAS. Battin, M., P. (2005). Euthanasia: The Way We Do It, the Way They Do It. In M. P. Battin (Ed.), *Ending Life: Ethics and the Way We Die* (pp. 47-68). Oxford, New York: University Press

[79] For a clear discussion and example of the process see the Public Broadcasting System (PBS) Frontline special on *The Suicide Tourist* aired on March 2, 2010. Available at http://www.pbs.org/wgbh/pages/frontline/suicidetourist/view/ (Accessed on July 28, 2010).

in holding a cup with a straw for the patient requesting death.[80] This process is videotaped for the authorities and the patient is clearly asked if they understand that drinking the liquid will produce death and if that is in fact their intention. If the patient confirms that they understand and consent, the process proceeds and the patient's death follows the ingestion of the lethal medications. This usually occurs within minutes. It is the patient who must initiate and voluntarily ingest the lethal medications with the knowledge that doing so will bring about their death.

Many of the processes and benefits of PAS are either the same as or close to that of euthanasia. First, as in requests for euthanasia, the physician must evaluate and agree that the patient is both suffering and has few, if any, other options for elimination of continued suffering until death in order for the authorization of the practice to proceed. Second, similar to euthanasia, the act of requesting PAS may in itself offer the patient solace that options exist for the quick elimination of extreme suffering should it ever become too much. This may then be the end of the process if the patient is reassured. Moreover, the request for PAS offers an opportunity for the clear acknowledgement that death is approaching and a frank discussion of how it may occur, fears related to dying, and options available for orchestration of the dying process to meet the goals and desires of the patient. Finally, PAS also requires a considered process which takes time for approval and allows the patient time to reflect upon her decision. Differing from euthanasia, this option, once the medication is procured, is entirely in the patient's control as long as they can prepare and swallow the drugs. This knowledge also may in itself allow the patient to continue living with her illness until a natural death occurs. Knowing

[80] Ibid.

that an escape is possible and can be had based upon the patient's determined time and desire allows strong autonomy needs to be fulfilled.

In The Netherlands the process for PAS is combined with the request for euthanasia in *The Termination of Life on Request and Assisted Suicide Act (The Act 2002)*, cited above and includes a concurring second physician opinion. *The Oregon Death with Dignity Act* was the first statute in the United States to legalize PAS in 1997 and also has a detailed protocol requiring:

> an adult who is capable, is a resident of Oregon, and has been determined by the attending physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request [to physician] for medication for the purpose of ending his or her life." (ORS 127.800 to 127.897 1997)[81]

The physician, if agreeing to provide PAS, must then fulfill the following additional steps.

Attending Physician Responsibilities.

> (1) The attending physician shall:
> (a) Make the initial determination of whether a patient has a terminal disease, is capable, and has made the request voluntarily;
> (b) Request that the patient demonstrate Oregon residency pursuant to ORS 127.860;
> (c) To ensure that the patient is making an informed decision, inform the patient of:
>
> > (A) His or her medical diagnosis;
> > (B) His or her prognosis;
> > C) The potential risks associated with taking the medication to be prescribed;
> > (D) The probable result of taking the medication to be prescribed; and
> > (E) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control;
>
> (d) Refer the patient to a consulting physician for medical confirmation of the diagnosis, and for a determination that the patient is capable and acting voluntarily;
> (e) Refer the patient for counseling if appropriate pursuant to ORS 127.825;
> (f) Recommend that the patient notify next of kin;
> (g) Counsel the patient about the importance of having another person present when the patient takes the medication prescribed pursuant to ORS 127.800 to 127.897 and of not taking the medication in a public place;
> (h) Inform the patient that he or she has an opportunity to rescind the request at any time and in

[81] Taken from the Oregon.gov website Health and Human Services page on the Death with Dignity Act. http://www.oregon.gov/DHS/ph/pas/ors.shtml (Accessed on July 27, 2010).

any manner, and offer the patient an opportunity to rescind at the end of the 15 day waiting period pursuant to ORS 127.840;

(i) Verify, immediately prior to writing the prescription for medication under ORS 127.800 to 127.897, that the patient is making an informed decision;

(j) Fulfill the medical record documentation requirements of ORS 127.855;
(k) Ensure that all appropriate steps are carried out in accordance with ORS 127.800 to 127.897 prior to writing a prescription for medication to enable a qualified patient to end his or her life in a humane and dignified manner; and
(l) (A) Dispense medications directly, including ancillary medications intended to facilitate the desired effect to minimize the patient's discomfort, provided the attending physician is registered as a dispensing physician with the Board of Medical Examiners, has a current Drug Enforcement Administration certificate and complies with any applicable administrative rule; or
(B) With the patient's written consent:
(i) Contact a pharmacist and inform the pharmacist of the prescription; and

(ii) Deliver the written prescription personally or by mail to the pharmacist, who will dispense the medications to either the patient, the attending physician or an expressly identified agent of the patient.
(2) Notwithstanding any other provision of law, the attending physician may sign the patient's death certificate. [1995 c.3 s.3.01; 1999 c.423 s.3][82]

The Oregon Department of Health and Human Services has maintained rigorous statistics on the utilization of the Death with Dignity Act (DWDA) since its inception.

> In 2009, 95 prescriptions for lethal medications were written under the provisions of the DWDA compared to 88 during 2008 (Figure). Of these, 53 patients took the medications, 30 died of their underlying disease, and 12 were alive at the end of 2009. In addition, six patients with earlier prescriptions died from taking the medications, resulting in a total of 59 DWDA deaths during 2009. [83]

As you can see, the number of persons actually going through with PAS is much lower than those who requested a prescription and completed all the required additional steps in order to obtain it. The reasons for requesting PAS are those that you might expect to see: "As in previous years, the most frequently mentioned end-of-life concerns were: loss of autonomy (96.6%), loss of dignity (91.5%), and decreasing ability to participate

[82] Ibid. ORS 127.815 s.3.01.
[83] Ibid. from DWDA Annual Reports.

in activities that made life enjoyable (86.4%)."[84] Each of these reasons has a primary locus of evaluation from the patient's viewpoint. Many persons and groups opposed to allowing legalized PAS in the United States have voiced concerns that it would be overused or lead to physician misuse. Yet in 2009 only one case was referred to the Oregon Medical Board for review for a physician who failed to submit a witnessed written consent form. [85]

The Oregon statute serves as a clear example of legalized PAS. We can see the physician act of providing a prescription for lethal medication(s) and education on drug use, with the intent of allowing the patient the option of independently taking the medicine to bring about her death at a time of her choosing. The physician intent is to support patient autonomy by providing the means to allow the patient the choice of ending her suffering and her life by suicide. It is by the patient's hand, or direct action that the medication is taken and the patient has much greater autonomy in deciding the time for her death to occur. PAS cannot occur here without direct patient intent to end her life. Again, as in the euthanasia guidelines, there is not explicit requirement that there is extreme physical pain. However, the Oregon statute does require the patient to have a terminal diagnosis. The ethical support is still focused upon the patient's autonomy. Many may find the comfort they need in the knowledge that they may use the medication if needed and do not ever actually take the drugs.

I have detailed how I think the process of legalized PAS ought to commonly occur. I would be remiss if I did not also note that many persons, with or without the

[84] Ibid. It is interesting that pain and suffering are not explicitly on this list.
[85] Ibid.

knowledge and/or assistance of their physician, may stockpile prescription drugs or request prescriptions for barbiturates to aid in sleeping with the intent to secretly take their own life.[86] There are also numerous published stories of physicians or family members aiding their dying loved ones.[87] This underground practice undoubtedly occurs in every state where open PAS is not allowed and may also occur where PAS is allowed.

Terminal Sedation

In terminal sedation (TS) the physician intent is to relieve the patient's suffering and both the medicines and dosages used are aimed at producing relief of intolerable symptoms. TS has moral grounding in the principles of beneficence, mercy and compassion towards relieving the suffering of the dying. Medications are ordered by physicians and may be administered by physicians or nurses with the intent to alleviate the patient's pain and provide deep sedation until death occurs from the underlying disease process. This is usually combined with the withdrawal of nutrition and hydration. This practice is not specifically prohibited in any country and it is done in the United States. It has been evaluated by some as merely the end point of the provision of good palliative care.[88] As stated in Chapter 1, there are no universal guidelines as yet for the practice of terminal sedation. In 2009 the Royal Dutch Medical Association (KNMG) Committee on National Guideline for Palliative Sedation compiled a 75-page guideline

[86] Lay groups such as the Hemlock Society and Compassion and Choices in Dying also offer assistance to those looking for assistance with suicide. I have not included details on these groups as my focus is on authorized medical assistance in dying.
[87] Quill, T. E. (1993). Doctor, I want to die. Will you help me? *JAMA, 270*(7), 870-873.
[88] Carr, M. F., & Mohr, G. J. (2008). Palliative Sedation as Part of a Continuum of Palliative Care. *Journal of Palliative Medicine, 11*(1), 76-81.

booklet to provide descriptive and detailed assistance to their practitioners.[89] This has not been done in the United States or other countries, although the American Medical Association did make a recommendation report to the Council on Judicial and Ethical Affairs in 2008 which gave a guideline for TS.[90] TS is to be utilized only with those diagnosed with a terminal condition and in the active phase of dying. Most patients have also already decided on a Do Not Resuscitate (DNR) status order in case of pulmonary or respiratory arrest. While closeness to death is an imprecise requirement, those who have been working with the dying are able to identify some markers. The following Dutch guideline gives a good approximation of how to make that determination.

> It is not always easy to estimate how long a patient is likely to live. But once a number of characteristics of the phase of dying have been observed, it can be assumed that the patient is approaching the point at which death is inevitable. The most characteristic feature is that patients virtually cease to eat and drink. In addition, they are frequently cachectic, tired and debilitated, and bedridden. They may also be drowsy and disoriented. It is up to the physician to factor these matters into the decision-making, along with the worsening symptoms of disease, without the expectation that the moment of death can be predicted precisely.[91]

When the distressing and intolerable symptoms cannot be eliminated, sedation is used to reduce the patient's conscious awareness of the distress through sedation. The medications used (detailed in Chapter 1) vary but are generally benzodiazepines, such as Midazolam, that produce both sedation and amnesia, and opioids, such as morphine, for pain relief. The physician orders medications and monitors the effects, but the actual drugs may be administered by nursing staff. It is common for the physician to be present at the initiation of TS and it is recommended in several of the guidelines that currently

[89] Committee, o. N. G. f. P. S. (2009). *KNMG Guideline for Palliative Sedation 2009*: KNMG.
[90] Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care* (No. CEJA Report 5-A-08): American Medical Association
[91] Committee, o. N. G. f. P. S. (2009). *KNMG Guideline for Palliative Sedation 2009*: KNMG.

exist.[92] The administration of medications by the physician is directed at relieving the primarily physical symptoms that have been unable to be controlled by other methods. The primary ethical motivation is from beneficence to eliminate the unbearable suffering. The goal is to allow the patient relief from intolerable symptoms therefore the dosage of medications required for this to occur will vary according to the patient's past tolerance of the medication and the severity of the symptom(s) experienced. Once again, the Dutch have developed a clear protocol for medicating patients to produce sedation to unconsciousness (see next page).

The patient is monitored to assure that there is deep sedation and that it does not appear that she is experiencing distress or pain (done by monitoring of blood pressure, facial grimacing, moaning, or twitching). Unlike in euthanasia or PAS, death with TS may take hours, days, or up to two weeks to occur as it is not intended to be due to the sedating medications. Death is intended to come from the advancement of the terminal disease process.[93] Usually, but not always the patient (or surrogate) has made the decision to forgo artificial nutrition and hydration. TS may be done while continuing to provide artificial nutrition and hydration but these measures are often evaluated as non-beneficial since they will not assist the patient to return to good health (the usual goal of medical treatment). Moreover, they may serve to delay inevitable death or cause additional problems if the patient has abdominal motility problems or fluid overload.

---

[92] Ibid.

[93] It may be, but is not always, the case that death is slightly hastened by the lack of nutrition and hydration. Removing nutrition and hydration is not done with the primary intent to hasten death; rather it is removed by patient choice as it is not beneficial to prolong patient dying. I do not support Early Terminal Sedation (ETS) for those with chronic diseases, as in these cases death is undoubtedly caused by the lack of nutrition and hydration since they could otherwise live many weeks or months with their diseases. It is the intention not to artificially delay death by the provision of nutrition and hydration. This aspect of TS is more fully covered in Chapter 3.

	Drug	Bolus	Continuous administration
Phase 1	Midazolam	10mg s.c. at the initiation of sedation, 5 mg s.c. every 2 hrs if necessary	Initially 1.5-2.5 mg/hr s.c./i.v., increase dose by 50% after a minimum of 4 hrs I f effect is insufficient, always combined with a bolus of 5 mg s.c. If risk factors are present (age >60, weight<60kg, severe kidney or liver function disorder, very low serum albumin and /or co-medication that could exacerbate the effect of sedation): -lower initial dose (0.5-1.5 mg/hr), and -longer interval (6-8hrs) before increasing maintenance dose. In the case of doses > 20mg/hr, see phase 2.
Phase 2	Levomepro-mazine	25 mg s.c./i.v., Followed by 50 mg 2 hours later if desired	0.5-8 mg/hr s.c./i.v. in combination with midazolam. After 3 days halve the dose to prevent accumulation. If the desired effect is not achieved, stop administering midazolam and levomeproma-zine; see phase 3.
Phase 3	Propofol	20-50 mg i.v.	20 mg/hr i.v., increased by 10 mg/hr every 15 minutes. Administration under supervision of an anesthetist advisable. In hospital setting, may also be considered for phase 2.

The initial doses are based upon the average patient. The physician should base his decision on the effect of the medication. In the presence of extreem risk factors, such as patient with a high (e.g. 100kg) or low (40kg) weight, the intial and subsequent doses may be adjusted upward or downward correspondingly. In the case of doubt concerning the dose to be administered, the opinion of a palliative care consultant should be sought.

Figure 1 : The Dutch Guideline for Sedation [94]

At times death may come from the resulting dehydration due to lack of artificial hydration. Again, this is not the intention of the treatment, merely a potential side effect. In these cases death is anticipated to arrive within hours, days or a couple of weeks and if it is shortened at all for a particular patient, it is not greatly shortened. Nutrition and hydration – whether given or forgone – for the group of patients I have included in my TS standard, will not greatly affect their life expectancy for they will die soon (hours to two weeks), regardless, due to their underlying disease.

[94] Ibid. pg. 9.

TS in the above patients differs greatly from the cases of those patients facing a future death with known advancing debilitation due to disease but, who are not yet actively dying. If patients, who are facing death (in perhaps many weeks to months or years) due to chronic and progressive diseases, such as ALS, have requested TS, then I would classify them as *not* meeting my proposal for standard TS. Rather, if allowed TS, they would meet Cellarius' standard for early terminal sedation (ETS), in which case they would in fact die as they would intend due to malnutrition or dehydration *rather than* their underlying disease.

Respiratory depression is also a known side effect of both benzodiazepines and narcotics. This causes both a lowering of the hypoxic drive to take in oxygen (lowering partial pressure oxygenation, pO_2 intake) and also a buildup of the waste gas (carbon dioxide, CO_2) due to lack of complete expiration.[95] This respiratory depression may also cause the resulting death. These possibilities should be explained to the patient and family in advance of initiating TS. In my experience, during 25 years of working in hospitals, often in ICU situations with dying patients and families, this detail of what respiratory depression actually means is rarely, if ever, adequately explained.

Optimally, the patient herself has had prior conversations with the physician to discuss the fact that extreme distress in dying may occur and that it is possible that the benefit of symptom relief may come only at the expense of losing consciousness. It is only when symptoms become intolerable to the patient that such measures for relief will be utilized. As with euthanasia and PAS, for many patients, simply knowing that an

[95] This information came from a detailed personal conversation on July 30, 2010 with a Board Certified and practicing anestheologist, Dr. John McNutt, who has experience in surgery and ICU care.

option exists to end their intolerable suffering may be the reassurance they need to allow them to continue living until a more natural death occurs. If the patient has not been alert or oriented prior to the onset of such extreme, intolerable symptoms, due to illness or dementia, TS may be requested by the surrogate or family member.[96] A benefit of TS in end-of-life care is that although clear communication between physician and patient and family remains a requirement, it does not necessarily need to occur days or weeks before the provision of TS. Unlike in euthanasia or PAS, there is no prior written documentation requesting sedation required. The intent of TS is not to produce death, but to allow death to occur while ensuring the patient remains free from the intractable pain or other distressing clinical symptoms as it ensues. The patient may, in fact, desire a hastened death, and the physician may concur that a death sooner rather than later would in most evaluations be 'best', all things considered, but the medications given and the dosages administered in TS ought not to produce that effect.

To review the primary ethical points involved in TS: The physician intent in TS is to eliminate the patient's ability to experience intolerable symptoms producing distress by the provision of medications to ensure unconsciousness. The medications are given, based upon physician order or by the physician, in an initial and then ongoing dosage to ensure deep sedation. The sedating medications are not, in themselves, lethal medications nor are they intended to be given in lethal dosage. TS is initiated when it becomes apparent that the patient's symptoms are both unbearable and refractory. This is a marked difference between euthanasia and PAS, where the patient's desired timeframe

[96] The fact that TS may be elected by a surrogate makes it not as clearly voluntary as other end-of-life options such as PAS and, therein, may allow for abuse. This point comes from an earlier draft of this document and comments of John Hardwig.

is the primary determinant in timing due to a primary focus on autonomy. Death may not occur for hours to days or even up to two weeks following the initiation of sedation. Thus, the intent is to relieve intolerable symptoms, not to hasten death.[97]

Narcotic medications are given to relieve intolerable pain. In some cases, the ongoing provision of narcotic medication in the dosage required to relieve the pain may affect respirations and therein shorten life. But that may happen even without TS and the provision of pain medications at the risk of shortening life has been an ethically accepted practice since the beginnings of modern medicine. The risk of shortening life due to respiratory depression from the combination of sedating medications and pain medications is surely a significant risk and may also be a burdensome side effect. But it is one that, when there exist no other options, may be morally allowable. Many other medical treatments also come with significant risks involved (such as open heart surgery), even when the intent is to prolong life. This moral permissibility in the case of TS is usually based upon beneficence and the good intention to provide relief from intense pain and/or suffering and is granted by utilizing the Principle or Doctrine of Double Effect (DDE).

The Doctrine of Double Effect

The Doctrine of Double Effect (DDE) was originally developed by St. Aquinas to support the religious and moral permissibility of actions which have two or more effects, a primary good or intended effect and a secondary less good or bad effect. The concept

[97] In patients close to death who have slowed metabolism due to actively dying it is debated whether or not their deaths are actually hastened by the concurrent refusal of nutrition and hydration. In some patients their death may be considered not artificially prolonged by the use of artificial nutrition and hydration rather than as hastened by the lack thereof. Regardless, hastening death is not the primary intent of TS.

has been used often in both medicine and law since many human actions have more than one effect. The DDE has several necessary conditions that must be met in order to assure the moral permissibility of a proposed action. First, the intended final end (good effect) must be good in itself. Second, the intended means to that end must be morally acceptable. Third, the foreseen bad effect must not be intended or the means to obtain the good effect. Lastly, the good effect must be of proportionally greater import to justify the foreseen bad effect.[98]

As related to palliative care in general, the aim of narcotic medication is for pain relief and quite often patients must make decisions concerning the undesired side effects of sedation or loss of lucidity. At times one may choose to simply be free of pain. One may be unconcerned that they may be unable to maintain alertness or lucidity or have prominent confusion that impairs conversations with family members or others. Other times, patients decide that they will tolerate even considerable amounts of pain in order to maintain alertness. They choose to prioritize having full competence when conversing with loved ones or others over having all pain eliminated. When the former (pain relief with less lucidity) is chosen by the patient, the DDE supports the pain relief (good effect) even when the loss of lucidity (bad effect) is foreseen. In this situation the mental impairment (bad effect) is judged allowable since the need for pain relief (good effect) is greater than the harm of being less alert or confused.

This concept has also been used for those experiencing extreme and intolerable suffering at the end-of-life. In order to obtain relief from intolerable symptoms (good

[98] Beauchamp, T., L. , & Childress, J., F. . (1994). *Principles of Biomedical Ethics* (Fifth ed.). New York, Oxford: Oxford University Press. pg. 129.

effect) patients may request medications that will also eliminate all consciousness and have potential to depress respirations (bad effect). The medication (Midazolam) and the amounts used are, in themselves, morally allowable since medications are routinely used to eliminate the consciousness and memory of events which are known to be extremely painful (as is routinely done in surgery or when patients must be maintained on ventilators). The good effect (relief from suffering) is seen as a proportionally greater good to the bad effect (loss of consciousness and respiratory depression).

For those who are experiencing extreme pain at the end-of-life, the use of large doses of opioids to relieve pain (good effect) even when acknowledging the foreseeable reduction in respiratory function and therein a shorten life (bad effect) has also been evaluated as morally allowable. The large dose of medication (morphine) is given with the intention of providing pain relief. It is not immoral to administer morphine to achieve pain relief. The patient's death is not the means for achieving pain relief and the good of providing relief from extreme pain at the end of a life is proportional to the bad effect of a potential shortening of that life. That life is, in fact, shortened by the use of TS has also been debated as some studies have shown that TS does not hasten the occurrence of death.[99]

Stated in this way, TS can appear to be relatively uncontroversial. However, much of the moral permissibility rests in the evaluation of the "intentions" and how they are interpreted. One of the basic tenets on almost any moral framework is the overwhelming imperative to never intentionally cause the death of an innocent person. This is the

[99] Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Do hospice clinicians sedate patients intending to hasten death? *J Palliat Care, 15*(3), 20-23.

moral reasoning many use to unequivocally disallow the practices of both euthanasia and PAS. Although both have the same goal as TS, the relief of intolerable suffering at the end-of-life, they do so *by causing with intent* the hastened death of the patient, or stated another way, death is the means of obtaining relief from suffering.

Many of those who oppose TS argue that using the DDE merely obfuscates the intentional hastening of the death for a terminally-ill patient.[100] Further, some argue that in medicine, as in many parts of life, intentions are often multiple and complex and are thereby too difficult to clearly delineate in actions that have more than one outcome.[101] Others, opposed to TS, declare DDE acts merely as a "psychological defense" to physicians.[102] Admittedly, part of the issue is that the combination of benzodiazepines and narcotics is known to have a greatly exaggerated yet imprecisely (in any one patient) identifiable effect of respiratory depression which may, in fact, hasten death, especially if this is combined with the refusal of artificial nutrition and hydration. The medications may be a significant risk to those who have also made decisions not to undergo ventilator support for breathing. This decision though seems a reasonable one to someone who is dying of a terminal disease. Being put in ICU on a ventilator to die is seen for many as one of the worst sort of deaths imaginable. Yet, if given a certain death with uncontrollable and intolerable suffering and or pain, versus calm death with even a foreseeable hastening, hastening may be allowable if one believes the bad effects are not

[100] Rady, M. Y., & Verheijde, J. L. (2010). Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death? *American Journal of Hospice and Palliative Medicine, 27*(3), 205-214.
[101] Quill, T. E., Dresser, R., & Brock, D. W. (1997). The rule of double effect--a critique of its role in end-of-life decision making. *N Engl J Med, 337*(24), 1768-1771.
[102] Wein, S. (2000). Sedation in the imminently dying patient. *Oncology (Williston Park), 14*(4), 585-592; discussion 592, 597-588, 601.

what is intended. But not everyone believes you can only have good intentions related to TS, and the DDE will, therefore, not hold moral sway.

There are those who argue that TS, when it is accompanied by withholding or withdrawal of nutrition and hydration, must be done with the intention of hastening death.[103] Some, such as David Orentlicher, dispute that one can *not intend* to cause death when *intentionally* withholding or withdrawing nutrition and hydration from a comatose person. He states the clear intention to make the patient comatose and clear intention not to provide nutrition and hydration to someone unable to eat or drink (due to being comatose) couple to produce an intention to hasten death. This is because it is known that anyone not given nutrition or hydration will die and that in those weakened by advanced disease, this is especially so. Thus, these bioethicists find fault with the previous argument that the overriding good intention is solely to provide relief from suffering and dispute DDE as holding moral sway.

Their argument, I believe, is misguided. Although the intent to undergo TS will understandably bring up the issue of nutrition and hydration, it does not mandate that it be stopped. In the imminently dying patient, the provision of nutrients and hydration cannot be evaluated in the same rubric as when they are evaluated in a patient who, although comatose and ill, may be expected to recover. The issue of providing artificial nutrition and hydration always must be evaluated on its own merits for the patient and family involved. Patients or families may not believe that there is sufficient benefit to either maintain or initiate artificial treatments which could have the effect of prolonging

[103]Orentlicher, D. (1997). The Supreme Court and Physician-Assisted Suicide- Rejecting Assisted Suicide but Embracing Euthanasia *N Engl J Med, 337*(17), 1236-1239. Craig, G. M. (1994). On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? *Journal of Medical Ethics, 20*(3), 139-145.

the dying process. This evaluation of the burdens and benefits ought to be done from each patient's specific value set. The principle of autonomy allows them the moral authority to make decisions related to any treatment or refusal of treatment. Moreover, the right to forgo medical treatment, including nutrition and hydration, has been a well established legal right based on autonomy for the patient.[104] Further, TS *may* be provided along with the continuation or initiation of artificial nutrition and hydration. The fact that this is rarely done is not based upon any prohibition incumbent in the practice. Rather, it is likely due to the null or limited benefits that such treatment would offer the patient.[105]

Additional Criticism against Terminal Sedation

There are other criticisms of terminal sedation. The combination of bad effects involved in TS, the respiratory depression due to medications and the common withholding of nutrition and hydration, has led some to declare that TS is merely "slow euthanasia."[106] In a widely cited article, "Slow Euthanasia",[107] Billings and Block unveil the practice of "turning up the morphine drip"[108] for patients at the end-of-life. Although, they are widely cited as being against TS, what they described in their article and the physician quotations cited regarding pushing or ordering increasing administration of morphine, regardless of patient response, is not equivalent to TS. Orders to turn up a narcotic drip past the point of obtaining patient relief from symptoms and knowing it will

[104]Quill, T. E., Byock, I. R., & For the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus, P. (2000). Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal. *Annals of Internal Medicine, 132*(5), 408-414.
[105] The mere extension of life may not be considered as a benefit to all or not enough of a benefit to justify starting or continuation of artificial nutrition and hydration.
[106] Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. *Journal of Palliative Care, 12*(4), 21-30.
[107] Ibid.
[108] Ibid.

hasten death could be malpractice, negligence, or euthanasia. Billings and Block correctly state this practice, when done with attempts to use DDE to justify the actions, as an "unconvincing rationalization." They also emphasize the slowness of the effects as a sort of psychological defense. "The slowness of the process - the series of small steps that gradually lead to death - softens the sense of the physician's agency in this instance of mercy killing. ….Moreover, many physicians may have written orders on the patient and many nurses may have been involved in care, thus diffusing responsibility."[109] This practice may indeed occur in many hospitals surreptitiously, but the provision of narcotics beyond the amount required for adequate symptom relief is not TS and ought not to be evaluated as such.

How ought one to then evaluate or attempt to determine the differences between what may be euthanasia and what is appropriate TS of a patient suffering intolerably at the end-of-life? I will argue that there are identifiable differences including stated intent, and close evaluation of actions and prescribing practices.

A physician who states, "Let's get this over today" and who writes orders to increase morphine by 2mg/hr continuously will ensure both that the patient will not suffer and that she will not survive the level of narcotics provided for long. A physician who states, "This suffering must stop" and who writes for Midazolam 5mg to start and then to be administered until the patient appears to be resting comfortably and to continue current dosage of Morphine or increase only until patient shows no signs of discomfort has a different agenda. Those attempting to evaluate the differences in these situations admittedly must gain new skills, not merely asking the hard questions of intent, but also

[109] Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. *Journal of Palliative Care, 12*(4), 21-30.

evaluating prescribing methods. This will require also learning the particular patient's past narcotic usage and tolerance. The drugs and dosage become part of the morally important facts that need to be evaluated. This need for closer evaluation does not in any way indicate that a standard dosage for either narcotics or sedatives could or ought to be established.

The unique patient differences remain important and each person's past narcotic use and length of time using narcotics establish differing levels of tolerance, as does the type of pain that they are experiencing. At times, what appears to be a huge dose of narcotics may still allow some individuals to remain alert and conversant. This is admittedly a complex situation even to attempt to evaluate. A dosage that could be easily used to euthanize one patient with little or no narcotic tolerance could be routinely prescribed to another patient who has been taking it for many months and allow her to be up and walking about. The important point to evaluate is not merely the dosage but the history of drug prescription dosage in specific patients. What was "normal" for them? What extra dosage was routinely used for breakthrough pain in addition to the usual narcotics ordered? How long had increasing doses been required to obtain the same results? How long had even increasing dosage been ineffective? These issues also highlight the need for the practice of TS to be directed by well educated physicians.

Given that it has only been in recent years that physicians have begun to aggressively treat pain[110] and that many still fear litigation or federal investigation due to

[110] This trend began following the SUPPORT study showing many patients dying with uncontrolled pain.

prescribing practices for pain medications,[111] it is little wonder that this remains an area of high emotions and conservative treatment at times. The effort to differentiate between what may be high dosages required to eliminate suffering, versus excessive dosage meant to hasten death, will be a complicated call to make at times. Yet, I do not believe that it will always, or even usually, be an impossible distinction to make. Orders that specify titration only to patient comfort and that require ongoing patient monitoring for signs and symptoms of both apparent comfort (an indication to hold levels of medication) or distress (an indication to continue to titrate up medication) thereby allow an objective indication of physician intent. Physicians need to remain available to monitor that the patient is not getting over- or under-medicated and because adjustments to dosage may be expected during any individual's treatment.

In TS the goal is to alleviate the patient's perception of her suffering by provision of unconsciousness, not to eliminate suffering by intentionally hastening the death of the patient. Grey areas will remain and the evaluation will likely always be difficult. Admittedly, there may not always be a clear cut and precise method to identify the differences in 'real life' practice between intent for TS versus euthanasia. Still, this sort of evaluation (looking at medication history and dosage), when included in protocols, will assist in clarification and be an applicable method in many situations. Having set practice protocols for TS would contribute to the establishment of routine guidelines and physician norms for enacting a treatment that, although rarely considered necessary, provides additional options for compassionate care at the end-of-life.

[111] Cohen, L., Ganzini,L., Mitchell, C.,Arons, S., Goy, E.,Cleary, J. (2005). Accusations of Murder and Euthanasia in End-of-Life Care. *Journal of Palliative Medicine, 8*(6), 1096-1104.

Alternate Evaluations

The use of the DDE is the most referenced tool or guideline for the moral allowability of providing TS, but it is not the only evaluative framework available. Roger S. Magnusson, from the United Kingdom, added a perspective to the debate utilizing what he calls "the devil's choice". Magnusson cites the torment depicted in the film *Sophie's Choice.*[112] He relates Sophie's forced choice, to decide which of her two children to send to the Auschwitz ovens, to "the devil's choice".

> A choice coerced by circumstances beyond one's control, and made all the more terrible by the conviction that tragedy will follow, whichever option is taken. In so far as morality and ethics are useful when facing the devil's choice, it cannot be to point out the "right choice", because circumstantial constraints mean that all the options are perverse. …..The benefit of applying the devil's choice to palliative care is that it permits empathy with the dilemmas physicians' face, while still acknowledging the extraordinary power that physicians have over the lives of patients at what is perhaps the most vulnerable time of their lives. [113]

This evaluation does seem to hold in many cases where the physician is faced with either providing medications to relieve intractable pain or other distressing clinical symptoms that will also eliminate any consciousness and has at least a slight risk of hasten death or allowing the patient to continue to suffer intolerably until death occurs. The physician, by sanction of position, is forced to choose between alternatives that are not of the chooser's making and are both perverse. Further, it is not possible not to choose since the physician is morally and legally charged with the care of the patient. The beneficence of providing adequate relief from suffering with the foresight of possibly hastening death, versus the concerns of non-maleficence in allowing one's patient to continue to suffer in unremitting torture, traps the physician in the devil's choice. Both choices are *prima*

[112] Magnusson, R., S. . (2006). The Devil's Choice: Re-Thinking Law, Ethics, and Symptom Relief in Palliative Care. *Race & Ethcnicity, Fall*, 559-569.
[113] Ibid.

facie binding and may only be overridden for compelling moral reasons. Magnusson states admitting to a noxious choice among poor options is a more transparent and honest position than reliance on the DDE. He states, "Whatever else it achieves, the foresight/intention distinction can be manipulated at will in a way that permits euthanasia to blend, seamlessly, into the spectrum of conventional palliative practices."[114] Magnusson promotes new legislation be adopted to allow a defense of "necessity" when patient situations force a physician into the circumstances of a devil's choice. Whether these circumstances apply or not, Magnusson argues, could then be evaluated by the doctor's choice in sedatives and analgesics (those routinely used in TS, versus potassium chloride) and that their administration appears to be proportional to the degree of suffering the patient was enduring.

While most religious moral views do not encourage the hastening of death, many also do not support the prolongation of dying. One moral framework that is often used in evaluation of ethical decision making in medicine is Principlism. Recall that the traditional concepts of Principlism[115] uses four primary values (beneficence, nonmaleficence, autonomy and justice) weighed and balanced against each other to provide moral guidance. This view would promote ethical decisions to be reached by competent patients (or their surrogates) and physicians by effectively evaluating the benefits and burdens involved in accepting TS and making an autonomous decision in light of personal values. The values of beneficence versus nonmaleficence are evaluated

[114] Ibid. pg. 564.
[115] Beauchamp, T., L. , & Childress, J., F. . (1994). *Principles of Biomedical Ethics* (Fifth ed.). New York, Oxford: Oxford University Press.

from the particular patient's perspective and value system with a strong preference placed upon the patient's autonomy in weighing the former two principles.

The fact that we all live our lives intertwined with families and others that we care about is inescapable. Quite often we make decisions in our lives based upon not only our own concerns but on how our decisions will affect others. This fact promotes the closer evaluation of the potential effects of TS on not only the patient but others involved with patient care and provision of TS services. Those who favor Care Ethics will also evaluate the effects of TS on those family members and others who are in close relationships with the patient. In all moral frameworks there will be difficult decisions to make and those which involve the death of one we love will always be the hardest. There are many other situations in medical treatment in which patients must make personal evaluations concerning their quality of life verses a potential hastening of death. These decisions are routinely involved in acceptance of cancer treatments, undergoing risky (or potentially any major) surgery or choosing non-treatment in many situations.

If one were merely concerned with the legal allowability of the practice of TS, the Supreme Court ruled in 1997 on two decisions[116] which clearly showed support for allowing terminal sedation with withdrawal of nutrition and hydration as two separate and allowable actions. The Supreme Court decision supports the provision of sedation and pain medication as allowable by the physician's responsibility to optimize palliative care in symptom relief to the dying, supported by the involvement of Doctrine of Double Effect (DDE), and the withdrawal of unwanted treatment and refusal of food and water as

[116] *Washington v. Glucksberg*, 521, U.S. 702 (1997) and *Vacco v. Quill*, 521, U.S. 793 (1997).

related to an individual's liberty interest. [117] This has not halted the opposition against TS and has led some to claim that the Supreme Court has acted in, "approving terminal sedation despite the fact that it amounts to euthanasia at times".[118]

It should now be apparent that since 1991 when the words 'terminal sedation' first appeared in the literature, they have engendered a great deal of moral controversy on many fronts. The ethical battle to declare TS as either synonymous to euthanasia or PAS or as distinct from or possibly superior to either continues to dominate the moral evaluation of the practice. My goal is not to settle this ongoing debate. As a secular ethicist, I see great value in the determination of each case based upon its individual merits and the benefits and burdens as evaluated in each specific case. Evaluation of the patient/family involved combined with close listening to patient/family and staff (physician/nursing/ancillary care) and evaluation of the methods (the types and amounts of medications) used will provide an evaluation that will vary from case to case. At times this will allow ethical endorsement of TS and at times not. Where TS cannot be ethically endorsed as appropriate, the case will need to be investigated further for other options in light of the legally allowable options available in the State and moral framework of those involved.

By endorsing TS, in some cases, one must accept that death *may* be hastened.[119] This is an important harm to be considered but there may be other overriding harms, *all*

[117] See, McStay 2003, for a detailed examination of the legal proceedings leading up to the Supreme Court decision. Also see, Sjef Gevers, "Terminal Sedation: A Legal Approach" *European Journal of Health Law*, Vol. 10, (2003) pp. 359-367, for a detailed and clear understanding of the role of DDE and how TS differs from euthanasia.

[118] Orentlicher, D. (1997). The Supreme Court and Physician-Assisted Suicide- Rejecting Assisted Suicide but Embracing Euthanasia *N Engl J Med, 337*(17), 1236-1239.

things considered. Clinical medical ethics often entails individual case evaluation. TS just may be one of the indicators for close ethical evaluation each and every time it is considered. My greater concern is that this intense focus on distinguishing TS from what are illegal, and considered by some to be immoral, practices in most of the United States has allowed significant evaluation of any *other* potential harms or benefits to go relatively unexamined.

The purpose of the following chapters will be a detailed examination of other potential effects related to TS. This includes how TS may affect those who choose TS, their family members, and those who participate in providing the treatment. We will begin this examination of other potential benefits and burdens associated with terminal sedation with a close focus upon the one most affected, the patient.

[119] Again, it is important to remember that hastening death is not the intention of TS, yet in a few cases due to the complexity of respiratory status, frailty of an individual, and narcotic uptake in the dying this may be the case. This has always been the case with narcotic administration to relieve great pain.

CHAPTER 3

BENEFITS AND HARMS FOR THE PATIENT

Introduction

Perhaps the most glaring ethical concern relates to the irreversible nature of terminal sedation upon the patient. Like the death penalty, one does not want to enact it in error. It is for this reason that when considering terminal sedation (TS), proper palliative care includes multiple attempts to address intractable symptoms with multiple methods, recurrent and clear discussion with patients and family members regarding the benefits and burdens of this or any treatment, and inclusion of the multidisciplinary team in assessing a patient's appropriateness to receive TS. This chapter will look at the benefits of terminal sedation for the patient as well as several potential harms to the patient when this method of ending life is utilized.

The primary and overriding benefit of TS is clearly the relief of intractable pain or other distressing clinical symptoms, causing intolerable suffering for the patient. Another major benefit is allowing the patient control in choosing how to face her death. These benefits cannot be undervalued when making moral evaluations but may not always be overriding, even when considering only the patient's concerns. Might there be other harms to consider given that relinquishing consciousness until death is the price? I will evaluate potential harms concerning the withholding of nutrition and hydration, the potential for questionable informed consent, surrogate consent (especially as it relates to the demented), and concerns about the effectiveness of TS. Next, I will briefly address a group of concerns related to existential issues that TS may affect. This includes concerns

related to religious beliefs concerning the potential for growth and self-actualization when dying and how TS may prevent one from achieving these opportunities. Lastly, I will look at how some traditional dying roles may be met or may require alteration when TS is utilized. I end with some recommendations for evaluation prior to allowing TS.

Case Example:

The patient is 52years old, married, and has 2 young adult children. Pt. has advanced throat cancer with an inoperable tumor that is fast growing and partially blocking the esophagus. In the prior 18 months the patient has undergone two surgeries and radiation therapy to remove tumor in back of throat/base of jaw that has also removed most of the tongue and a large portion of jaw that has failed to heal and now requires a packed wound dressing. This makes speaking all but impossible. The last surgery was one week ago. The patient is now grossly disfigured from the surgery with radiation burns to the face and neck. Patient is hospitalized for IV pain control and anxiety, as swallowing is extremely difficult due to advancing tumor size. The patient is on nasal canula oxygen support at this time and aware that nothing further can be done to treat the advancing cancer and tumor growth. Patient has been advised that tube feeding will allow nutrition directly into stomach and forego the need for oral intake and it has been refused. Only ice chips have been taken orally for about the last 4 days with a few sips of a supplement shake on day 3 following surgery. Patient has also made an advance directive to refuse intubation should the tumor grow to impair ability to breathe. The patient wishes to remain comfortable. Pain continues to be an issue and anxiety about suffocation due to tumor growth has increased. Nausea has become a new prime issue as routine medications have failed to reduce the feeling of extreme nausea from tumor secretions flowing into the stomach and patient is fearful of choking or aspiration during vomiting due to tumor blockage. Communication is difficult due to inability to enunciate following surgery and oral wound/dressing. The patient has written "please end this" and the patient and spouse have been approached about the option of terminal sedation.

In the above case, when evaluated by the standard I have proposed, terminal sedation could be granted. I have stated a standard to allow TS for those patients who request and have 1) a terminal illness in the final stages; 2) unrelieved, intractable pain or other distressing clinical symptoms; and 3) appear to be actively dying (in the last days or weeks of life) to be morally allowable to competent patients or by the request of their surrogates. Not everyone agrees with this standard. There are those who believe that the provision of narcotics and benzodiazepines to a patient in this situation, already so weakened by disease and lack of nutrition and hydration, would be hastening their death.

Further, they believe that this hastening is morally wrong in all cases. For patients who steadfastly believe this, TS would not be an option. Of course, not requesting TS and continuing on until death occurs is a morally allowable option and is not part of this current discussion. For patients who would want to choose TS, what are the potential benefits and harms that they may face? That is the focus of the present chapter.

To a patient like the one in the case example, the option of allowing sedation until death occurs would seem a compassionate action in order to promote a more peaceful death. In many cases, this could also extend to compassion for the family as well as the patient. That death might be hastened, due to medication effects for pain and symptom relief which cause respiratory depression, would be, if not a good thing then, at least, not a bad thing as evaluated by many.[120] In fact, a large section of society would rate a death in their sleep as one of the most desired. When polling my undergraduate students in medical ethics courses, this was always their number one choice.

Relief from Suffering

For those of us who have witnessed anyone in extreme pain it is easy to accept that ending pain often becomes the *only thing* that matters. In fact, freedom from pain was the most highly rated factor in a study done in 1999 looking at factors considered important at the end-of-life.[121] Freedom from pain was the number one concern not only with terminal patients, but also with family members, physicians, and other care

[120] It remains that TS is not intended to hasten death and this occurrence is unlikely, but remains a possibility for a few.

[121] Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA, 284*(19), 2476-2482.

providers.[122] Witnessing someone in pain often extends suffering to all those who must stand idly by watching, unable to offer solace or to reduce the intensity or duration. Those who are suffering with great physical pain while they are dying may also be experiencing various other forms of suffering. In our above case, these concerns are likely to be fears of choking, not being able to breathe due to tumor growth, and a gruesome final experience of dying by suffocation and/or aspiration. This may be coupled with more existential concerns and common fears of dying alone or facing the unknown upon death.[123] Allowing a patient, who meets the standard I have proposed, to undergo TS at the end-of-life could be evaluated as treating the suffering of both the dying patient and the family who suffers by watching a loved one's suffering go on without relief.

Often terminal and uncontrollable symptoms arise during the last 24-48 hours of life and even those patients who had been receiving hospice homecare are readmitted to hospitals for symptom control.[124] Hospitalization, when required in the final hours of life, is not uniformly seen as a less good option than dying at home. In the Steinhauser study, being able to die at home was considered important by fewer than half of the participants and of those who felt it was important it was the last rated of the 9 factors

[122] Ibid pg. 2481.
[123] I have not included existential suffering specifically in my general standard. I am endorsing a view that such suffering often coexists with the physical suffering of dying patients. I have stated that, at this point, due to the much more difficult nature of identification and treatment of existential suffering, I do not endorse TS as a treatment for this sort of suffering alone.
[124] Uncontrollable symptoms may also occur much earlier in the course of terminal illness and is not an uncommon reason for hospital admission with the expectation that the patient will be discharged upon stabilization of noxious symptoms. Although it is not always possible, physicians can usually perceive when the patient is likely to be unable to return home.

considered important by them.[125] Steinhauser cites a similar study by Fried et al[126] where they reported,

> The notion of dying at home may be romantic among health professionals who want to provide a good death. However, as symptoms accelerate in the last 24 to 48 hours, some patients and families may feel overwhelmed by concerns about symptom control or a dead body in the home and therefore, prefer a skilled care environment.[127]

To allow the patient to enter a medically induced sedation and to relieve patient and family suffering addresses multiple factors considered most important at the end-of-life. The provision of terminal sedation in this sort of situation would be evaluated as beneficent on most moral frameworks.

Sedation like Sleep

The idea of a death that comes during a deep sedation, 'like sleep' has many good connotations. This concept is often used for patients undergoing surgery that are medically sedated and told, "You'll be put to sleep and will never feel a thing." And then, "When you wake up it will be all over." Most of us, by adulthood, have had prior experiences of being 'put to sleep' and therefore the idea of being 'put to sleep' is a lot less scary than facing our own death. Yes, in surgery we may KNOW (as required by the strict intellectual knowledge that demands our informed consent for the procedure) that doctors are going to cut our heart out and repair it, then put it back in our bodies, but WE (the conscious persons that we hold our most true selves to be) are removed from having to have any sort of conscious participation in that process. Similarly, I could imagine,

---

[125]Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA, 284*(19), 2476-2482.

[126] Fried, T., van Doorn, C., O'Leary, J. Tinettti, M., Drickamer, M. "Older Persons' Preference for site of Terminal Care", Ann Intern Med. 1999; 131; 109-112.

[127] Steinhauser, et al.,2000.

although I may KNOW that I will die and not wake up, I can feel comforted in the thought that *I* will be removed from that conscious experience of my death.[128] Further, it is a sort of calmness in passing that one can easily wish to allow others.

If, in fact, terminal sedation can offer such a death, it could easily be imagined as a good death by many. Other good deaths exist and are wished for such as those without pain and surrounded by loved ones, but these deaths cannot be assured for everyone. Many who have less extreme pain may be satisfied with the provision of pain medication which allows, not clear consciousness, but a kind of cloudy or drowsy awareness. This may allow awareness of family presence at the bedside with the edge taken off their pain. But, for some whose symptoms become uncontrollable with lesser efforts, total sedation can be an option of last resort. The control currently possible in prescribing a variety of medications to relieve pain and produce deep sedation can allow most of us to know that, if needed, we can be made unaware of our intolerable pain, anxiety, dyspnea, tremors, vomiting or other noxious symptoms until our death occurs. It may not be the 'best death' for us to hope for, but it would be for many a 'good death' when compared to suffering until the end.

Slippery Slope Concerns

If TS did provide such a 'good death' then it would also be easy to imagine many persons who would want to claim that sort of death. The ethical concepts supporting patient autonomy and beneficence would endorse the moral allowability of TS for

[128] At least I will hope to be free from the conscious experiencing the pain or other noxious symptoms. We cannot know (yet) for certain what sorts of thoughts or fears may continue to exist in the unconscious minds of the dying.

terminal patients who were suffering intolerably at the end-of-life and requested this option.[129] TS is beneficent in serving to relieve the patients' experience of suffering. Those who favor strong patient autonomy and those of a libertarian bent can support TS. Terminal sedation fosters self-direction in allowing one to face death as they choose without harming others. TS ought to only be initiated by the consent of a patient or her surrogate, and this policy will help to prevent abusive TS in cases of those who may be frail and incompetent.[130] Further, TS may aid others by reducing unnecessary resource use from a lengthy hospitalization at the end-of-life. With concerns regarding the high cost of medical care and overuse of intensive care units for terminal patients, this could be seen as a responsible choice. This supports the principle of justice in not taking more than what is needed in care.

Although the option of TS is comforting to many, it also fuels the slippery slope concerns of those who fear that doctors would become caught up in orchestrating deaths rather than attempting to prevent them. Or worse, that the elderly, frail, and incompetent would receive TS without consent. Patient or surrogate consent is clearly required and failure to obtain such ought to be grounds for legal action as well as professional sanction. A strong vigilance towards ensuring that TS is appropriate for patients (by meeting the standard I have proposed) and that appropriate consent is obtained will work towards preventing many of the slippery slope concerns.

[129] The same principles would endorse TS when requested by an appropriate surrogate for the best interests of the patient.

[130] I could foresee the use of surrogate decision assistance teams, or ethics committees as appropriate venues for making evaluations on allowing TS for individual patients who are incompetent and lack an appropriate surrogate decision maker.

Another slippery slope concern may be that patient self-determination could easily run amok.[131] Imagine if, rather than being limited to the standards I have outlined,[132] upon my initial diagnosis of Alzheimer's disease at age 55, I could voluntarily stop eating and request TS so as not to suffer the indignity of slowly losing my identity and forcing my spouse to care for me when I no longer remember him.[133] I would simply arrange my affairs while competent and say my goodbyes. Knowing that I faced a future slow death that I would find unbearable, I could select a point of my choosing to quietly slip into a final slumber with the support and assistance of a medical team. If autonomy was the overriding value to be considered when allowing TS then I ought not be forced to wait until there are only days left of my natural existence. It ought to be available whenever I autonomously choose to enact that end-of-life treatment. The same options would exist for those newly diagnosed with ALS, debilitating strokes, or who simply tire of living after many years of slow decline due to multiple co-existing illnesses.

These numbers could be great given our current ability to live much longer lives with numerous chronic diseases and the burgeoning expansion of the elderly baby boomer population. That immensely increasing numbers of ailing elders will be a fact of our future may explain in part why some are fearful to allow TS even following the restricted limitations that I have endorsed. Victor Cellarius has termed the practice of TS

[131] Callahan, D. (1992). When Self-Determination Runs Amok. *The Hastings Center Report, 22*(2), 52-55.
[132] My limitations are 1) patient request with terminal diagnosis, 2) intolerable pain and suffering, and 3) in last few days or weeks of dying.
[133] The case example of my requesting TS due to an Alzheimer's disease diagnosis at age 55 upon diagnosis would fail to meet my standards because one would not be in the final days or weeks of illness. Alzheimer's or other dementia related illnesses could qualify for TS only if meeting all three requirements as determined by evaluation at a time when the illness was in a terminal stage.

in these sorts of situations as early terminal sedation (ETS) because these patients are not actively dying.[134] Without the sedation, coupled with their refusal of nutrition and hydration (and sedation preventing oral intake that would otherwise be possible given the medical condition), these persons could live many more months or longer. Physicians could then be evaluated as practicing a new form of assisted suicide[135] for those who could have otherwise lived many months or years with a disabling condition. I believe that some restrictions are appropriate and following the standard I have proposed those who breech the standard could be identified for sanction.

There will always be those who argue that it will be impossible to contain a practice once allowed and that innocent victims may be harmed. These fears are a mere potential whereas the actual persons who are currently suffering intolerably could be benefitted by allowing TS. I believe that the actual beneficence to eliminate suffering in those dying persons overrides the fears of potential maleficence to future unknown persons when there exists ways (policy guidelines, sanctions to those who do not follow practice/policy, legal sanctions) to limit the potential for such maleficence.

A more complete evaluation of whether or not this expansion of patient self-ending determination would be a help or hindrance to society would be a valuable contribution, but is not the primary mission of this work.[136] Let us continue to evaluate what potential benefits or harms allowing TS in the imminently dying might provide for the terminal individual and persons connected to a single individual. This will allow a

[134] Cellarius, V. (2011). 'Early Terminal Sedation' Is A Distinct Enity. *Bioethics, 25*(1), 46-54.
[135] This "new form" of physician-assisted suicide would be an arguably worse form of PAS since physicians would be administering the drugs rather than writing a prescription for patients to self-administer. Thank you to John Hardwig for pointing out this distinction.
[136] Additional reflections on how society may be affected by TS are offered in Chapter 6.

better determination of when TS is currently a moral treatment in those cases where moral quandary still exists.

Autonomy and Control

The principle of autonomy is often held paramount in medical ethics. Efforts to obtain some control over what happens when we are dying are a large part of what goes into the development of our individual advance directives. Supporting a patient's autonomous choice and allowing her to choose TS as the manner of dying if she is experiencing intense suffering, offers a measure of control that may offer comfort to many. This comfort may extend to many who do not end up requiring TS, but have comfort in knowing that TS is available if they come to need it. Similar comfort has been expressed by those in Oregon who have prescriptions for drugs for PAS yet never utilize them. Being able to control what happens to one's body is a central factor of being an autonomous human being. Fears of being out of control are one of the things some people fear most about dying. Oddly enough, in the Steinhauser study, "Respondents displayed broad variation in their desire to control time and place of their death. Those with less religiosity were most likely to want control."[137]

In ancient times we had little control over either time or place of our dying; now, with the expansion of the hospice movement, at least the place is generally within our control given a terminal diagnosis. The time of death remains largely out of our control unless we are removing life-saving technology and then we have begun "arranging for

[137] Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA, 284*(19), 2476-2482. pg. 2481.

discontinuation of treatments", which largely does allow us to approximate a time for dying. Following this trend, TS is a step to allowing us control over the manner of our death, the timing of our death will still be unknown and caused by the underlying disease process. For many persons, control over what happens when they are dying is an important factor affirming their autonomy. By allowing TS, we are supporting the autonomy of those patients who maintain capacity or who have stated their desires in an advance directive. TS can also support those who have previously selected surrogates act on their behalf.

Nutrition and Hydration

By the time one can be considered as suffering from an end-stage terminal illness the person has often already quit the regular consumption of meals. This may be due to physical problems related to the illness, medication side-effects, fatigue or a myriad of other reasons. Commonly, this voluntary stopping of eating and drinking is in itself a sign of the patient having reached the point of what is called 'actively dying.' Active dying is the final stages of illness when the body begins the slowing and shutting down of bodily systems such as stomach motility, the pooling of blood to the lower areas, slowing of heartbeat and respirations and other such ending of biological functions. Whether these patients continue to get nutrition or not, they are going to die soon due to underlying disease. The refusal of nutrition and especially hydration may in fact shorten their lifespan, but not significantly, and often will have no effect. Regardless, since the advent of medical science's ability to provide artificial nutrition and hydration the stopping of voluntary oral intake has become an 'issue' that must always be addressed.

There are many persons who believe that it is never morally allowable to withhold nutrition and hydration from the ill and even dying persons. The provision of artificial nutrition and hydration are considered to be ordinary and non-burdensome treatments and a minimal requirement for the continuation and support of life. These beliefs are often, but not only, held by those with strong religious (example, Catholic) value systems. Despite the Court's endorsement of terminal sedation as supported without legal jeopardy based on two allowable actions - first, the voluntarily refusal of artificial nutrition and hydration and second, the provision of complete sedation to alleviate distressful symptoms - there are ethical arguments to oppose both actions.

I do not support the concept that one is "harmed" by a competent and informed decision to forgo nutrition and hydration at the end-of-life. Not eating or drinking seems like part of the natural process of dying (especially if one is already diagnosed with a terminal illness) and it is only "artificial" feeding and hydration that might delay death. Even if it did constitute harm it may be overridden by the right to so choose or may clearly be a lesser harm to one than extended and untreatable pain. I will address this concern though because for some it is always unethical to withhold the provision of nutrition and hydration. Vitalists who believe that life should be supported at all costs would reject even an individual's right to refuse artificial nutrition and hydration or to withhold them from those in a persistent vegetative state. Additionally, theists who believe that it is a sin to attempt to assume control over the manner of one's death could not endorse refusal of nutrition and hydration. If one considers any reduction in possible life to be harm, then the moral allowability of not having nutrition and hydration apart from or in combination with TS will not be a moral option.

Moreover, reduction or stopping eating and drinking has always been a harbinger of death. Those who have voluntarily stopped taking adequate nutrition and hydration further emphasize that their death is approaching and the supplementation of artificial food and fluids may not offer any extension to many. Hospice research has indicated that the feeling of hunger does not exist for most of those close to death and that the fears many family members have concerning 'starving to death' or feelings of uncomfortable hunger simply do not manifest in those close to death.[138] There have long been studies to show the converse, that in those who have stopped eating and drinking there may be slight dehydration educed euphoria.[139] In fact, the provision of artificial nutrition and hydration may increase patient suffering from edema, mal-absorption or intestinal bloating.[140] Daniel Callahan has stated our belief that we are killing patients by discontinuing medical care including artificial nutrition and hydration is based on what he calls an artefactual fallacy.[141] He argues that death which has been artificially delayed by medical interventions and then allowed to occur when these technologies are removed is not equivalent to killing, and that the killing/letting die distinction maintains a moral allowability in these cases. This seems correct, however many in health care still fail to endorse this ethical distinction and this will be addressed further under physician harms in Chapter 5.

---

[138] Ganzini, L., M.D., M.P.H., Goy, E., R., Ph.D., R.N., Harvath, T., A., R.N., Ph.D., Jackson, A., M.B.A., & Delorit, M., A., B.A. (2003). Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death. *New England Journal of Medicine, 349*(4), 359-365.

[139] Sullivan, R. (1993). Accepting death without artificial nutrition or hydration. *Journal of General Internal Medicine, 8*(4), 220-224.

[140] Ibid.

[141] Daniel Callahan, "Terminal Sedation and the Artefactual Fallacy" pp. 93-102. Terminal Sedation: Euthanasia in Disguise?. Ed. Tannsjo, Torbjorn, (2004) Kluwer Academic Publishers,Dordrecht/Boston/London

When considering those health care professionals who are involved in the provision of TS, one may believe that there is harm in the provision of nutrition and hydration if it serves to extend another's suffering, or in refusing to honor a competent request to forgo such treatments. The fact that refusing such treatments is supported legally by the Court's acceptance of one's liberty interest and supported ethically with the endorsement of the principle of autonomy allowing an individual's right to refuse *any* medical treatment makes the withdrawal of nutrition and hydration ethically less controversial for many. Moral justification can be found to allow or disallow both TS and artificial nutrition and hydration using a variety of moral frameworks. The important issue to discern is 'What is the moral framework of the patient, family, and medical staff that are involved in *this* case?' Medical ethics has always had primary focus on the patient before us that is being considered. Each patient and family and physician will bring their own set of values in which the important concepts concerning autonomy and control, beneficence and determinations of what is good, nonmaleficence and what is considered harm and the ordering of these principles will need to be determined to elicit the moral allowability of terminal sedation in a specific case.

Consent

In medical care today one must generally give consent prior to any treatment or testing being performed. This is especially true when the procedure has inherent risks or side effects that need to be considered such as in surgery or chemotherapy. Informed consent supports the values of both patient autonomy and beneficence in allowing shared decision making between patient and physician. The physician provides the medical

information regarding various options and the patient applies them to her life in light of personal values. In bioethics we generally hold that informed consent means that the patient has been given all pertinent information regarding the medical treatment or test *and* has evaluated both the possible benefits and harms or side-effects *and* has had the opportunity for her questions to be answered and clarification given *prior* to indicating a desire to proceed. Certainly, given the significant stakes involved in terminal sedation it should only be done with the clearly informed consent of the patient or her surrogate.[142]

Shared decision making with a fully informed patient is an optimal goal in end-of-life decision making. Yet, many believe that it is an illusion and that physicians actually remain the primary decision makers.[143] Sadly, in a study in which elderly patients expressed their resuscitation preferences for several hypothetical scenarios and then the patients' physicians tried to predict the patients' preferences they were incorrect in a quarter to almost half the time.[144] Even when wrong, physicians believed that they were in fact correct over 75% of the time.[145] Other studies show that physicians tend to predict better for patients that are more like themselves in education and social status.[146] This makes sense as they may be more likely to share value sets and preferences.

---

[142]Surrogate consent is addressed later in this chapter. I allow appropriate surrogate consent for TS, as I believe it is similar to other important medical decisions such as open heart surgery, removal from the ventilator, or acceptance or refusal of other life altering procedures that surrogates may consent to for others. I am taking as a given that the surrogate consenting is one that has been appointed by the patient during capacity or an appropriate other assigned by physician in accordance with state laws. The allowability of surrogate consent for TS and other medical procedures is admittedly arguable but is not the focus in this paper.

[143] Orentlicher, D. (1992). The Illusion of Patient Choice in End-of-Life Decisions. *JAMA: The Journal of the American Medical Association, 267*(15), 2101-2104.

[144] Ibid. pg. 2104.

[145] Ibid.

[146] Ibid.

Nevertheless, a potentially legitimate concern exists regarding the validity of patient consent for TS. Illness, medication, and fatigue can all diminish one's ability to evaluate important information. Since the option for utilization of TS is not available until close to death when one's ability to process complex evaluations may be compromised and medications may muddle thinking, it is possible that true informed consent, at that time, is impossible. This concern is supported by research into the withholding of forms of life support like ventilators or dialysis in those nearing death. "Fewer than half of patients are able to participate in decisions to withhold life-support treatments. Even fewer patients (<10%) are able to participate in decisions to withdraw life-support treatments because these decisions generally occur within a few days of death."[147]

In most cases of informed consent for medical care, the patient has the responsibility of indicating that she not only understands the hoped-for benefit of treatment but also the potential harms and side effects that are likely. In a case like the one provided at the beginning of this chapter, given the extreme pain and anxiety, is it likely or even realistic to expect the patient to fully comprehend a discussion of the benefits and burdens of TS at the time she asks for help? We know the patient is experiencing extreme fatigue, has been unable to sleep and is suffering from ongoing, unendurable pain and inability to communicate effectively. Most would agree that this is not a good situation to be in when be making important decisions, let alone the last decision of one's conscious life. Might one make a hasty and permanent decision to end

[147] Jeanne M. Tschann, et al., "Family Involvement in End-of-Life Hospital Care", *JAGS*, Vol. 51,No. 6, (2003) pp.835-840.

their conscious life just to get some much needed rest? A giant error, similar to the one those who use suicide to address a temporary problem, could then be inappropriately endorsed if we uncritically accept *all* patients' requests in these situations. Yet, we would also shudder at ignoring their pleas for help and solace especially if we have no other means to address horrible pain and suffering.

To allow patients to reflect upon such an important decision with a clear mind, these decisions might be made earlier. This would allow a patient to have her desires reflected for end-of-life care and we might trust that her thinking was not unduly altered by pain or medications. In fact, this is exactly what we ask patients to do when completing advance directives. But there are problems with this solution, as well, for it requires the patient to accurately predict what they believe that they would want in a situation (actively dying) where they can have no legitimate knowledge on which to base the decision. They may then make unrealistic choices or ones that do not, in the end, serve their interests. However, we may assume patient predictions on what they believe to be the best course of action based upon their personal values ought to supersede others' evaluations. Only when patients are incapacitated and have not left advance directives do we turn to surrogates.

Surrogate Consent

In a perfect world, one could expect that the patient and primary physician had discussions earlier, perhaps on diagnosis of terminal illness, about what sorts of end-of-

life care the patient would want, allow and disallow.[148] This is rarely the case, but does seem to be increasing with the greater number of palliative care consult teams in acute hospitals today. Alternatively, if no advance directive exists, perhaps the expectation of informed consent ought to be disregarded in favor of paternalism or substituted judgment from the spouse or significant other. In cases where one might question a patient's ability to give informed consent yet where it would be compassionate to allow TS if requested, physicians must encourage more discussions with the available family member. This is needed to assure that they understand fully the TS process and the treatment plan to relieve the patient from experiencing suffering by the elimination of their consciousness with the use of medications.

Ought one to allow surrogate consent for treatment which eliminates one's consciousness and therein the ability to be in the world? This could be an appropriate solution for some, especially those who had both assigned a Power of Attorney for Health Care (POA) and discussed in detail what they would and would not want to happen to them at the end-of-life with their loved ones.[149] Unfortunately, the legal assignment of a POA is an option not completed by many whom it could usefully serve. Moreover, even when a clear surrogate has been assigned and preferences have been discussed, there is evidence that many surrogates, even when they are close relatives, remain uncertain that they are doing what their loved one would want or are able to understand the information

[148] This claim accepts that the patient is able to imagine her state of mind when dying and accept her coming death. Many persons will consciously or unconsciously remain in denial of their impending death and therein deny themselves the opportunity to have input into decisions regarding end-of-life care.
[149] There are many issues which complicate medical decision making even when there is a POA/surrogate assigned *and* when patients have discussed their wishes. For example, there are disagreements within the family concerning either who was assigned as surrogate or, that they are/are not "really" doing what patient would have wanted. This is admittedly a difficult issue for families to muddle through but not the focus of this project.

or options given to them by medical staff. Often those making medical decisions are elderly spouses or elderly adult children making decisions for very old parents.[150]

In 2002, the journal, *Health, Risk, & Society* reported a study done with older persons regarding their assessments of the risks and benefits of morphine and terminal sedation in end-of-life care. This study was done at a time when none of the participants were experiencing any significant health risk and when ample time for questioning and discussion was allowed in focus groups. The study found that most "understood an idealized death to be one in which morphine administration and terminal sedation serve to provide dying people with an easy, comfortable and quiet death."[151] Yet they also found that "the role of medicine in procuring an idealized death is linked to profound concerns about new risks that flow from the intermarriage of medical science with the basic human obligation of providing compassionate care to those who are dying."[152] This concern about exactly what is being said and done to family members and their role to make decisions for ill relatives can at times leave lasting guilt and doubt for the surrogate-survivors.[153]

> For example, Fay, who told the story of her mother's death….remembered that a doctor tried to raise with her the issue of terminal sedation for her mother, but she remains unclear about his meaning in so doing and what response was expected from her. For Fay, this left a profound uncertainty about whether she had represented her mother adequately and whether the doctor was proposing the best symptom relief available or something that was 'unnatural' and outside of accepted medical practice. She stated, "I think my doctor tried to broach the subject but because he did it in such a non-committal way I couldn't grasp what he was trying to say. I thought is he saying he's for euthanasia or he's not, or is he saying he wouldn't do anything, or is he trying to

[150] This knowledge comes from personal experience of over 20 years as a hospital social worker who has met innumerable times with family members in attempts to make treatment, discharge, or withdrawal-of-treatment decisions. It has also been confirmed by my colleagues in hospital services including physicians, nurses and administrators.

[151] Seymour, J. E., Bellamy, G., Gott, M., Ahmedzai, S. H., & Clark, D. (2002). Good deaths, bad deaths: older people's assessments of the risks and benefits of morphine and terminal sedation in end-of-life care. *Health, Risk & Society 4*(3), 288-302.

[152] Ibid.

[153] I discuss harms to family members in the next chapter.

> leave it open for me to broach him. He was very strange and then I just thought, well, let nature takes its course in the end- but I know he tried to- he brought the subject up." [154]

Although medical professionals at times feel compelled to question a patient's ability to give informed consent or their capacity to make medical decisions they rarely make a stand to question the decisions made by a patient selected surrogate. This is especially true when the surrogate is making the decision that the physician believes to be the most appropriate. There are few avenues to pursue questioning even when medical staff believes that legal surrogates are incapable of making appropriate decisions for their assigned patient. Thus, at times, an advance directive, if it lists your son to be POA and he is now demented himself, may not be the solution to assure that what you wanted done, or not done, is followed. Admittedly, as shown by Fay's story above, even when you have discussed situations in advance with a loved one, at the moment a decision needs to be made about terminal sedation, family surrogates may feel unprepared to offer any real assistance.[155]

Advance Directives done prior to the active phase of dying would eliminate some of these concerns, but most Americans still do not complete advance treatment forms in writing elucidating their wishes for end-of-life care. Physicians caring for those who are dying, even actively dying, do not always address with patients what limits to aggressive care they would desire or where the patients' personal marker would be between comfort and lucidity. Even those of us working in the medical field who loudly proclaim our right to mandate our end-of-life treatment in advance directives and who inform our

[154] Ibid. pg. 298.
[155] Additionally, there are issues of interpretation, "Is this the sort of situation mom meant?", "Is she actively dying NOW?" and other problems with determining the intentions of others.

family at every opportunity of what we would not want done often end up resuscitated and dependent on extreme forms of life support. Sometimes this is because family members give the go ahead in emergency situations and sometimes it is because we never thought that what seemed like a simple procedure with high chances of success could slide down through technological brinkmanship so swiftly. Studies show that there are variances in family members' concurrence with patient choices for end-of-life decision making, yet most patients would still choose to have family members make decisions if they are unable to participate.[156] Family members who have had prior conversations with patients about what they would like to have done and what they would like to forgo in end-of-life care state a greater confidence that they believe that they have "done the right thing."[157]

When patients are unable to make their own decisions, even important end-of-life care, it remains appropriate and important for physicians and other medical staff to involve the POA, surrogate or whatever family[158] is available to discuss issues such as TS and how such treatment may accord to patient values and advance directives (if available) prior to any initiation of treatment. There are patients who do not have family available and who have not assigned any proxy decision makers. Many states (including Tennessee), have then allowed physicians to assign a surrogate to make decisions for

[156] Tschann, J. M., Kaufman, S. R., & Micco, G. P. (2003). Family Involvement in End-of- Life Hospital Care. *Journal of American Geriatric Society, 51*(835), 835-840. Also see, Layde, P., Beam, C., & Broste, S. (1995). Surrogates' predictions of seriously ill patients' resuscitation preferences. *Arch Fam Med, 4*(518), 518-523.

[157] Tilden, V. P., Tolle, S. W., Nelson, C. A., & Eggman, S. C. (1999`). Family Decision Making in Forgoing Life-Extending Treatments. *Journal of Family Nursing, 5*(4), 426-442.

[158] By "family" I am including close friends and family of choice as well as blood relatives. TN state law indicates that the physician may assign as surrogate one who is willing, able, and available to serve as surrogate to patient who has knowledge of the patient's values and has shown special care and concern for the patient. TN State Code, Chap.862, HB 2582.2.

hospitalized patients. Often this may be a friend or neighbor who agrees to accept this responsibility. In cases where there are no options for even physician assigned surrogates, I would recommend evaluation by the hospital ethics committee.

There are real problems at times with surrogates determining the true intentions of patients in advance directive documents and in assuring that one has obtained valid informed consent. However, these problems do not have sufficient weight to override the intent to follow patient wishes for end-of-life care (as best as we can determine what their wishes would be), nor the intended beneficence in ending intractable pain or other distressing clinical symptoms causing the intolerable suffering of the dying.

Unproven Effectiveness

It is a common goal to "die in my sleep" and TS serves to approximate this goal through medications, but we do not know for certain that it succeeds. A potential harm to patients is that we do not know for certain whether or not TS actually treats a patient's suffering or merely makes the patient incapable of further complaints. Admittedly, this is an extremely difficult, if not impossible, issue to evaluate, and it is equally difficult to confirm and validate any findings. Fortunately, medical science has been expanding rapidly in understanding brain waves and the complex workings of intricate parts of the human brain. Recent studies have looked at trying to understand what sedated patients perceive. Many of them have focused on anesthetized patients in surgery who have had perceptions during sedation. Having perceptions during a surgery when one is expected to be deeply sedated is often called awareness during anesthesia.

Research into awareness during anesthesia has provided information about what patients who have received narcotics and sedatives are able to feel and perceive.[159] One Swedish study looked at ICU patients who were sedated while critically ill but were expected to recover.[160] This study is relevant to TS because the type of deep sedation used to keep patients from recognizing the distress of being on a mechanical ventilator or experiencing extensive post surgical pain from treatments, such as surgical debridement or trauma surgery, are meant to prevent the patient from suffering as well. One of the common medications that is used to sedate patients for surgery or ICU care, as well as for TS, is midazolam. It serves to offer a deep sedation, has multiple routes of administration and is relatively inexpensive. Yet, there are concerns about its use, as one physician using it stated, "We do not know much about how midazolam works even though it is widely used, at least it is a useful tool to induce what we think is a kind of sleep. But we do not know if it is a good kind of sleep."[161] There are reports from those patients who have been intentionally medically sedated and then recovered of having hallucinations, nightmares, and discomfort.[162] The study concludes, "On the whole, the epistemic situation is not satisfactory. We lack large systematic studies of how patients feel during sedation, even though we do know that many experience nightmares as a problem."[163] Surely, sending one to one's death and doing so knowing they were going to experience drug-induced nightmares would not be encouraged. But it is impossible to design a study

[159] Domino, K. B., Posner, K. L., Caplan, R. A., & Cheney, F. W. (1999). Awareness during Anesthesia: A Closed Claims Analysis. *Anesthesiology*, *90*(4), 1053-1061.
[160] Nortvedt, Gunnvald Kvarstein and Ingvild Jonland, "Sedation of Patients in Intensive Care Medicine and Nursing: Ethical Issues", *Nursing Ethics*, Vol. 12, No. 5, (2005).
[161] Ibid.
[162] Ibid.
[163] Ibid.

with those who have utilized TS to then provide us with data on their perceptions of the final sedation for feedback. As a next best option, we need more studies on anesthetized patients to further our knowledge in this area in attempts to assure that their sedation is a peaceful one.

There have also been recent studies looking at the possible perceptions or ability to suffer in those who are permanently unconscious by persistent vegetative states (PVS) which suggest that they may still be able to suffer.[164] This may be relevant information due to the concerns that we do not clearly understand what is going on in the brains of those who cannot communicate with us to share their experiences. These studies suggest that the ability to experience pain is in the more primitive parts of the brain and thus, "after extensive neocortical damage but preservation of brain stem structures, pain is more likely to persist than consciousness."[165]

If those with even grave brain injury may still be able to experience pain and suffering, then it would call into question whether or not those whom we intentionally sedate (but who retain normal brain functioning) may be only losing the outward expression of their pain. Thus, it is not an unreasonable concern to fear that those who have been medically rendered unconscious by TS and are, therefore, unable to communicate may also still retain the ability to experience pain and, therefore, suffer while being unable to express this experience to anyone. This would be a harm that would be ethically troubling if it were found to be the case. As things stand, when terminal sedation and narcotic pain relief is used for those suffering at the end-of-life, it

[164] J. Andrew Billings, et al., "Severe Brain Injury and the Subjective Life", *Hastings Center Report,* Vol. 40., No. 3. (2010). pp. 17-21.
[165] Ibid. pg. 19.

appears that their suffering is relieved and patients are more calmly able to slip beyond the realm of human experience. Again, notably, this perception is gathered from the experiences of those who have witnessed a death with TS and has been supplemented by signs of reduced blood pressures, heart rates, and facial grimacing. Data is not able to be gathered and empirically validated by those undergoing TS.[166] I have little hope that confirmation from the beyond will be available any time soon. Yet, it remains beneficent to reduce suffering when it is apparent to us and possible to do so and endorsed by patient or surrogate consent.

Limiting End-of-Life Potential and Role Fulfillment

A completely different harm may exist for patients involving what opportunities they may be forgoing by choosing TS as the manner of their death. It is a limiting factor of Western secular thought that it views a person's death focusing upon the end of the physical and biological existence only. Western medicine is also focused on the scientific technology we have to avert death and promote cure and thus, is especially narrowed to the physical. Yet, it would be a philosophical error not to investigate what possible harms may exist in prematurely ending one's consciousness as their death approaches. Potential psychic or existential harms must also be evaluated. There are many who believe that human suffering at the end-of-life holds great meaning and potential for growth and actualization.[167] Are we limiting this potential by allowing or even

[166] See appendix 1 for the Critical Care Pain Observation Tool that has been endorsed for use in those undergoing TS by the European Association for Palliative Care in their recommended framework for the use of sedation in palliative care. Cherny 2009 23:581.

[167] Lynn A. Jansen and Daniel P. Sulmasy, "Proportionality, Terminal Sedation and the Restorative Goals of Medicine", *Theoretical Medicine*, Vol. 23, (2002) pp. 321-337. See also, Byock, I. R. (1996). The Nature of Suffering and the Nature of Opportunity at the End of Life. *Clinics in Geriatric Medicine, 12*(2), 237-252.

encouraging elimination of the conscious awareness of one's death with TS?[168] Even if shortened by only a few hours or days, could those hours hold important meaning that it would be an error to eliminate? Research into this area would be especially important if an expanded practice of TS allowing persons with chronic disease such as ALS to request TS prior to the final days is being considered. I mention those with slower progressive disease here, as they may be experiencing more of the existential suffering and have less acute pain as they approach their death. These sorts of dying experiences – as opposed to those in the throes of final cancer pain – may lend to better evaluation of the potential for benefits of growth in those facing death.

Existential Concerns

Buddhism is one practice that teaches there is always meaning in our suffering. Suffering[169] is related to the dignity and aesthetics of a unified life with death as the final chapter. Fears of dependency and loss of control that are focused on during life may need to be adjusted to allow dignity in dying through the acceptance of these losses. For many in contemporary society, this is a new role to consider for suffering. But if sedation becomes the treatment of choice for those facing the end of their life, we may be

[168] It may be that the sort of actualization or growth that is able to be obtained during the dying process must be done much earlier in the dying process, or that for some this sort of growth is made impossible by the overwhelming pain and suffering that they experience.

[169] Suffering in this sense is the agony coming from the emotional component of the event distinct from pain. Ex. While an amputated leg may be painful, suffering comes from considering that I will never walk on my own leg again. Pain may be adequately treated but my suffering of the loss may continue despite adequate pain control. It has long been acknowledged that pain and suffering often accompany each other. Eric Cassel has remarked that suffering is increased when there is no acceptable reason for the pain (pain from child labor does not always cause suffering but often joy, where as cancer pain in dying may cause extreme suffering to those who see no reason to have gotten the disease.)

eliminating the opportunity for growth or meaning for those dying or forcing that work to be done much earlier.

Facing the end of our existence allows one the opportunity to reflect on what we have been able to achieve and the legacies we will leave behind. There exists, for all but true nihilists, the idea that our lives can have meaning, and for some, that our deaths also can have meaning and help shape our communal human existence. The idea that the 'work of dying' is in part to come to accept what you have accomplished and what you have left undone and to prepare others to continue on has a long history.

This requires admitting that our death is in fact coming! This is the part that has become so hard to do. Perhaps it is due to the progress in life-prolonging technology that we have lost the ability to admit that we are dying even when we have been living with terminal illness for many years. Acceptance of death was the completion of the Kubler-Ross[170] levels for working through the dying process. This work, done with the knowledge that one is dying, has been shown to have benefits for both the patient and family. A recent study, *Perceived Benefits and Psychosocial Outcomes of a Brief Existential Family Intervention for Cancer Patients/Survivors*, has shown an improved sense of well-being and quality of life for those involved in completing a video-taped interview and life legacy that was designed to address some of these existential issues.[171] Admittedly, if you are suffering intolerably, having any conversation, let alone one concerning your final existential concerns, may not be a priority or even a possibility for some. Yet, if these types of conversations occur they reduce some of the suffering that

[170] Kubler-Ross, E. (1969). *On Death and Dying* (Touchstone 1997 ed.). New York: Simon and Schuster
[171] Garlan, R. W. B., Lisa D.; Rosenbaum, Ernest; Seigel, Alison;Spiegel, David. (2011). Perceived Benefits and Psychosocial Benefits of a Brief Existential Family Intervention for Cancer Patients/Survivors. *Omega, Journal of Death and Dying, 62*(3), 243-268.

occurs at the end-of-life such as death anxiety, fears of being a burden and concerns about knowing that your life mattered.

Existential concerns are considered to be the source of psychosocial suffering for many who are facing their death. Extreme fears related to the process of dying and facing the beyond produce great anxiety in many. The concept of being sedated 'like sleep' may allow those with great death anxiety to then escape facing this particular fear. However, there are those who endorse TS only for physical pain and will disallow TS for psychosocial or existential suffering. This may be an appropriate denial for some patients, based upon concerns that those suffering from some forms of mental illness will then not receive appropriate treatment.

Refusal to allow TS for existential suffering would perhaps be appropriate for some patients with mental illness. But this refusal also risks not allowing it for the patient at the start of this chapter who has grave, realistic fears of suffocation and choking to death. Often, as in the case I presented, pain and existential fears coexist in the dying. But if TS is disallowed for psychological suffering, one is then faced with attempting to develop a method to discern what *exactly* would differentiate physical suffering from the psychological. Eric Cassel[172] has written extensively on suffering and is convinced that they are deeply intertwined and may not be properly separated. Further, many others who investigated suffering have found that with the advent of scientific medicine and the separation of mind and body, medicine has become less capable of adequately meeting

[172] Cassell, E. (1991). *The Nature of Suffering and the Goals of Medicine* New York, Oxford: Oxford University Press.

the joint needs of a *person* (made up of both psychological and physical elements) as one who is *suffering* with a medical illness.[173]

The debate among those who endorse TS on whether or not it ought to be allowed for those who suffer with only or primarily psychosocial or existential suffering is a worthy area of study but regrettably not the primary work of this paper. I have endorsed an initial standard which does not allow TS for *only* existential suffering when it can be reliably determined that this is the only suffering that a patient is experiencing. I accept that this may force many with amyotrophic lateral sclerosis (ALS) and other horribly debilitating diseases to suffer the existential pain of considering how their disease will slowly progress for many months prior to reaching the phase of "actively dying" which I state to be the period when it is accepted that death will occur within a few hours to a couple of weeks. I believe that those patients may still benefit from other forms of treatment (including assistance in counseling or intermittent sedation) to work on some level of acceptance in their dependence and reduction in fears as well as the ability to advise others on their wishes in advance directives, including the desire for TS.

Further, I could imagine my standard to be amended in the future once TS has become a more accepted medical practice for end-of-life care. I would not categorically rule out TS for primarily psychological/existential suffering in the future but would encourage caution and propose trials of intermittent sedation to allow respite from existential suffering with hope to then face the existential concerns anew. Additional safeguards, including qualified psychological evaluation, would also need to be added to

[173] Starck, P. L., & Mc Govern, J. P. (Eds.). (1992). *The Hidden Dimension of Illness: Human Suffering*. New York: National League fro Nursing Press, Young-Eisendrath, P. D., Polly (1996). *The Gifts of Suffering: Finding Insight, Compassion and Renewal*. Reading, Massachusetts; Menlo Park, California, New York: Addison-Wesley Publishing.

any protocol that could allow TS for primarily existential suffering. I will closely follow this area of research in the future.

Suffering & Religion

Religions disagree about what occurs upon our death and also about the role and value of suffering in human life. This concern may be relevant to those who believe that suffering at the end-of-life is meaningful or ought to be meaningful. Since TS may disallow this meaningful human experience, it ought to be evaluated in this light as a possible harm. If suffering is the primary concern and the goal is its elimination, then TS would not be evaluated as harm and TS ought to be endorsed. But, what if what is important to the patient in the dying process is what is to be shared and learned through suffering? In that case, TS and elimination of one's conscious ability to process her own suffering would be a grave harm.[174] The religious views of the patient concerning death and suffering are factors that ought to be evaluated prior to the initiation of TS whenever possible.

Are we perhaps responsible for our own suffering? Is one required to suffer? Certainly suffering is one factor which unites us and some (though varying) meaning is attached to one's suffering in all religions. The suffering of one who is dying has special significance in some but not all religions. If in TS we are eliminating one's ability to suffer *and* that suffering has value, then we are harming one's ability to gain what is to be valued there. "The value of suffering in our own development is a component of all major

[174] This concern is apart from those concerns that TS is similar to suicide or hastens your death. TS is not intended to hasten your death, merely to sedate you from the experience as death occurs due to the underlying causes.

religions, but its significance seems to have faded in the late twentieth century."[175] This is apparent in many Western societies but neither in all of that society nor all religions.

The Buddhist religion has strong emphasis on the meaning in suffering. Buddhist beliefs include that Karma is a defense against suffering because suffering is seen to result from behaviors of the individual in a previous incarnation. For Buddhists, suffering is, in part, "the discontent, the negativity or dissatisfaction that we often feel, sometimes in relation to pain or loss but also in response to ordinary hassles in life."[176] Judaism also values suffering and the belief that, "Acting virtuously necessarily entails suffering."[177] Christian beliefs often hold that suffering may bring the sufferer closer to Christ.[178] Suffering may have important purpose and value even in secular society in moving us to a higher level of emotional and intellectual transcendence without religious meaning. In *The Gifts of Suffering*, Polly Young-Eisendrath reports,

> Suffering is useful, and not merely a waste of time, when it awakens us to our responsibility for our own attitudes and thoughts and actions. Within suffering are the gifts of self-awareness and compassion.[179]

Transcendence is possible in many, if not all, religions and this locates the person in a far larger landscape. This may allow one who is suffering to see their suffering as only part of something bigger than their current experience. If through suffering one is able to finally accept her own death and the emergent need to beg forgiveness (from a person or God), it would be important to allow this to occur. If this is true, then physicians could

---

[175] Young-Eisendrath, P. D., Polly (1996). *The Gifts of Suffering: Finding Insight, Compassion and Renewal*. Reading, Massachusetts; Menlo Park, California, New York: Addison-Wesley Publishing. pg. 25. Moreover, there are some who would question what possible gains could be obtained from "development" or "growth" in the final days or hours prior to death.
[176] Ibid. pg. 27.
[177] Ibid. pg. 45.
[178] This may be coming closer to Christ through suffering in dying and in value for one's eternal life with Christ following death.
[179] Ibid. pg. 33

be harming or eliminating our opportunities for transcendence by masking or eliminating our ability to suffer at the end-of-life. I would argue that even if this was the case, this could be a lesser harm than ignoring pain or other distressing clinical symptoms causing intolerable suffering especially when relief from suffering is requested by a patient or surrogate. Patient autonomy in choosing TS could even override concerns about transcendence or karma, given a person's value and belief system.[180]

The question of whether or not there is value in suffering at the end-of-life is valid but I believe it cannot be decided by philosophers, medical ethicists or physicians. Rather, this question is to be answered by those individuals who believe it holds value as they come to face their death. As has been the tradition in medical ethics, I propose that the question of the meaning of suffering at the end-of-life is just one of the important questions that ought to be addressed in an evaluation of utilizing TS with each individual patient prior to the initiation of TS treatment. For each person who suffers must determine if their experience of it is valuable or not.

Special Concern for the Demented

Up to this point, I have been primarily discussing TS for competent, autonomous adults. Additional consideration is needed to evaluate how or if TS ought to be a treatment for the increasing numbers of persons facing the end-of-life with significant dementia. How we are most appropriately to assess the suffering of those with severe dementia, those who have lost the ability to express many, if not most, of their own

[180] Conversely, in some cultures patients (especially women) do not make their own medical decisions, and autonomy is not seen as a value to be endorsed, or at least not as greatly endorsed as it is in our medical system.

needs? Although some needs can be intuited or guessed, such as the need to avoid intense pain, we know that both understanding and expressive abilities are destroyed over time due to dementing illnesses. We can assume that those with severe dementia or Alzheimer's disease are no longer capable of growth or experiencing significant meaning in their deaths. But what of their ability to suffer?

If they do not overtly appear to be suffering, ought TS to be disallowed? I believe that this is the case. My standard allows TS for those who are suffering intolerably at the end-of-life. If one does not appear to be suffering, then they do not meet the requirements for appropriate TS. If a severely demented patient who is not able to express verbally their distress does appear to be suffering greatly, however, then the decision for TS should be permitted with surrogate consent.

If demented patients are denied TS, are we unduly requiring them to suffer just because they have left no prior directive? No, I do not believe that this will be the case. They will be denied because there is no evidence of their suffering (from facial expressions, sounds of distress, or grievous disease or injury known to produce great or excessive pain) or they have expressed prior value sentiments to those close to them that would not endorse such an action.

The more pressing concerns relate to assuring that appropriate decisions are made for the demented by the appropriate others in their lives. Are the demented likely to be disproportionally harmed by overuse of TS as elected by their families and surrogates? Who is most benefited by their sedation? Is it actually the demented patient or is it the family who is worn down and financially overburdened who gain the benefit? This issue is difficult on both sides. Both sedation and suffering are options appropriate for selection

by the competent patient, but they ought to be closely evaluated when chosen for one by another. The ramifications affecting families when TS is utilized in the demented require additional ethical evaluation for potential harm.

Within this concern of potential harm is the possibility that "because the final actors are clinicians, terminal sedation could be "carried out without explicit discussions."[181] This is not an unfounded concern, as a recent study, *Physician Reports of Terminal Sedation without Hydration or Nutrition for Patients Nearing Death in the Netherlands*, reports the use of deep sedation was not discussed with all patients (over 40%) for numerous reasons such as incompetence, dementia, 'discussion would have done more harm than good', or other reasons.[182] TS may have been discussed with other relatives, nurses, physicians or palliative care specialists according to the study:

> The major reasons for using terminal sedation were to alleviate severe pain, agitation, dyspnea and anxiety. [But,] in a review of 17 studies that addressed the use of sedatives in the care of patients with cancer who were in the final stages of life, a syndrome of delirium and agitation was the most frequently mentioned indication for sedative use; pain was a much less common reason for sedation.[183]

Thus, it appears that the patient's explicit consent for the use of TS is not always obtained in The Netherlands and this may allow some of the ethical concerns to remain unresolved.[184] This report also highlights one of the major issues contained within the scope of 'intolerable suffering,' the suffering which accompanies a final delirium. This

---

[181] McStay, pg. 63.
[182] Judith A.C.Rietjens, et al., "Physician Reports of Terminal Sedation without Hydration or Nutrition for Patients Nearing Death in the Netherlands", *Ann Intern Med*. Vol. 141 (2004) pp. 178-185.
[183] Ibid. pg. 183. However, most of these studies did not take into account the use of opioids (for pain relief). In addition, patients in some of these studies were only moderately sedated and cancer was the only diagnosis used.
[184] One must note that this is merely the results of one study and the results may not be able to be generalized to a US population. Further, in many cases TS was discussed with involved family members. I would endorse that prior to any TS, one would obtain surrogate consent for the demented patient. Provision of TS may remain ethically appropriate towards beneficence for the patient but could open one to potential litigation without consent. See more on this in chapter 5.

sort of agitated delirium leaves one distraught, confused, and unable to be calmed, or to understand the predicament that one is in. It is especially difficult to treat in those with an underlying dementia. As our population of the elderly and therein the demented elderly continues to expand, all of these problems and more, such as authorized surrogates also being demented will increase.

In cases of dementia (a long standing mental disorder, which may or may not be distressing to the patient) or delirium (an acute onset event of mental distress often causing intense distress, confusion, mistrust, paranoia and agitation) it is imperative that specialist care, often from palliative care specialists, be sought to ensure that there is not a reversible cause for the patient's dementia or delirium. Then, if no realistic hope is available for the return of competence to the patient, discussion with appropriate surrogates and family members may proceed. Since often these patients are nonverbal or unable to maintain conversation, close evaluation will be required to assess appropriateness of TS as an end-of-life treatment. There should be indications that the patient appears to be suffering from an intolerable symptom. These symptoms may be anything that would require restraints, produce wailing or crying out, wincing in pain, elevated blood pressure, quickened breathing, or clearly deviated behaviors from her norm that are unable to be resolved by other medical or behavioral methods. Clear documentation in the medical record of consults and attempts at alleviation of distressing symptoms is always required, but is more essential when there is no documentation of prior patient wishes, no clearly assigned prior POA or surrogate, a questionable family dynamic, or dissension within the family.

TS ought not to be disallowed for demented patients for greater harms could easily befall them if forced to endure intolerable suffering merely because they cannot autonomously request assistance. Demented patients who are appropriate for TS do require a close ethical evaluation and the involvement of a surrogate who can provide consent.

Responsibility in Dying & Death Roles

Since antiquity, physicians have had a responsibility to treat suffering. I started this chapter with a focus on a patient's suffering, mostly physical but, in part, existential or psychological suffering from anxiety due to fears of dying by air hunger due to tumor growth. Terminal sedation is now available to treat a patient's suffering. I have stated that it ought to be provided when a terminal patient's suffering is intolerable at the end-of-life and requests such treatment. We soundly value respecting a patient's autonomy and right to make decisions for herself. Could this dedication to following patients' autonomous request for TS inadvertently allow a greater harm to befall them or others even when it follows the standards I have proposed?

Although autonomy reigns supreme as a value directing ethical actions in medical care, other values such as beneficence, nonmaleficence, justice, responsibility, fidelity and care remain important. Does responsibility perhaps become more or less important as we face death? As persons, we fulfill many roles in our lives, each with incumbent responsibilities. As a spouse, we are responsible to love and support our spouse, to be faithful and present in their lives. As parents we are responsible for teaching our children values and skills to enable their eventual independence in the

world. Even as patients we have responsibilities to follow treatment orders, and honestly confer to our caretakers our symptoms, pains, and improvements. Each role has varied expectations attached, both for our own internal measure of fulfilling the role and for societal or external evaluation of our role performance. One may have earlier and additional responsibilities to their families if they would want to choose TS for end-of-life care. Although I address family issues more fully in the next chapter, I want to briefly look at what some of the potential issues a patient may have to address related to his family if TS is selected.

In many bygone eras, the dying were responsible for alerting others of their approaching death and then for imparting forgiveness to those who requested it and to request forgiveness from those whom they had harmed. The concerns and responsibility of the dying person was to right all earthly affairs before passing on. What are the new responsibilities of the dying, and what duties are to be performed? The following are some responsibilities I can imagine as pertaining to the dying which may then be affected if TS becomes a more routine method of death. If one has decided that they would choose TS if needed for end-of-life care, then it may be that they should also address much earlier their responsibilities associated with dying. This means that they must accept sooner and in a real way that they are going to die. They also must accept that TS, if utilized, will not permit any final words to accompany their last breaths and they should have all needed conversations well before their final few days or weeks. The accomplishment of this process, or death work, may become yet another benefit for those patients who undergo TS.

Teaching Compassion for the Dying

If we judge by how little the dying today actually admit or verbalize the fact that they are dying, we may assume one social role for the dying is to hide, deny, or reduce the acknowledgement and suffering they experience as it is seen by others. Admittedly, it makes everyone horrendously uncomfortable to hear someone wailing out in pain or to see someone tearfully suffering or crying out for help. But, is the most moral response merely to silence the one hurting? Perhaps our society needs to increase in our ability to show compassion to those suffering and allow their expression of suffering to be better shared. In essence, compassion is to suffer *with* another and eliminate their isolation.

Obviously, an increasing compassion for the dying is a good that ought to be increased in our society. But, putting the responsibility for teaching this compassion on the dying seems too great a charge upon them. This is true regardless of the use of TS in reducing intractable pain or other distressing clinical symptoms causing intolerable suffering. I view compassion for the dying as, in large part, accepting that there are many different versions of a 'good death' that may occur and helping each dying person to articulate and achieve a version of a good death that is acceptable to them. TS may allow a good death for many with terminal illness and great suffering.

Dignity

One often-stated goal in the role of the dying is to maintain their dignity. What this means varies among persons. Whether it means not having their suffering exposed, eliminating their experience of suffering, not requiring advanced personal or technological support, or retaining their mental faculties varies with each person. In considering TS, one must question if we must trade in consciousness in order to have the

perception of dignity. If so, what prompts us to make this trade off? Perhaps we need to work more diligently to alter our perception of dignity so as to allow even great amounts of personal assistance from others or to permit sharing our concerns of loss of both our personhood and our abilities when we are dying. This sharing by the dying is often made more difficult due to the discomfort of those to whom they would speak. Often, it remains that the dying are brushed off or their words discounted. In Tolstoy's story of Ivan Illich, Ivan was tormented by being told he would soon be on the mend when he knew he was dying. Palliative care teams offering interdisciplinary services with chaplains and social workers are now helping patients and families have meaningful conversations when someone is facing death.

Offering an example of facing death with dignity has long been a role for the dying. If dying and having one's choices respected allows one dignity in dying, then TS can be evaluated as approaching a dignified death. Many would evaluate being seen as crying out in pain as an undignified way to die. These patients would see dignity as being maintained by TS, since one would appear to be sleeping or resting and suffering would be either eliminated or not apparent. This is admittedly somewhat paradoxical because dignity also commonly includes not being dependent on others and by undergoing TS one becomes completely dependent upon others for all care. Yet, your final decision to be rendered permanently unconscious will have been respected.

Unburdening Others

Another often sought after goal, which may then confer a responsibility or role for the dying is to not be a burden. "Previous surveys of physicians who have received

requests for euthanasia or physician assisted suicide indicate that patients' fear of being a burden is a primary motivation for such inquires."[185] It is not unreasonable to assume that similar fears would also lead to requests for TS. These fears of being a burden may extend to family, society or the medical system. Interestingly, in a study looking at the economic and other burdens of terminal illness, Emanuel and Fairclough found that burdens of caregivers were significantly lessened when they reported having physicians who listened to their needs.[186] The amount of time spent listening to patient and family concerns is only one of many losses in medical care overtaken by HMOs and evidence based medicine.[187] TS could reduce the financial burden to family and society caring for someone who is dying.[188] The time required for death to occur would be under a month at most without nutrition and hydration, but it is usually only a matter of a few days. Patients will require total care as they are sedated, but these care needs will be minimal and include the usual comfort care (turning, mouth care, medication monitoring, bathing) and not extensive staffing. Often, family is able to assist in this basic comfort care for patients in the hospital.

This is merely a partial listing of what some of the role responsibilities for those who are dying and is not meant to be inclusive. The focus of this paper prevents a fuller

[185] Emmanuel, E. J., & Fairclough, D. L. (2000). Understanding economic and other burdens of terminal illnesses: The experience of patients and. *Annals of Internal Medicine, 132*(6), 451-459.
[186] Ibid.
[187] This subject will be addressed more fully in Chapter 5.
[188] Even though in the United States Medicare costs continue to rise, the constant media focus on the high cost of healthcare has made some impact on the ways many of the elderly view their entitlements. My 85 year old mother-in-law repeatedly remarks that she doesn't need this or that test or treatment because, "I'm old and had my time and care, I just need to be kept comfortable now until I go." She voices a concern that she not "over use" the system to allow care for those others in society who "still have things to do".

exposition of possible future roles for the dying and how these roles may be impacted by a greater incidence of TS utilization.[189]

Conclusion

I will conclude this chapter with some thoughts on the safeguards for the patient that need to be in place for TS to be utilized. In every case, frequent, clear and consistent communication between physicians, caregivers, patient (or surrogate) and family (if available) is to be encouraged. In optimal situations a thorough and open ended conversation with the patient prior to the final weeks of life should take place with the physician, patient and involved family members. The content of this discussion should address clearly and directly potential death scenarios that this particular patient may face. Also, they must inform the patient of the options available for treatments, placements and level of professional care during dying. They must specifically ask what the patient's preferences are for some specific end-of-life procedures such as CPR, ventilator support, dialysis, and TS in the face of intractable pain or other distressing clinical symptoms.

Discussion of the patient's advance directive (if any) ought to be addressed and the document amended if necessary to make it correspond to the current discussion with physician and family. The physician needs to document the content of discussion in the patient's record. If possible, this record should be co-signed by patient and family to note concurrence and understanding between all parties of the patient's desires for end-of-life care. In best case scenarios, the patient would make attempts during this period to address

[189] This will remain an area for continued research in my future.

her end-of-life concerns, make amends, allow forgiveness, and direct others on final wishes.

For physicians, when facing a patient who is dying and is enduring intractable pain or other distressing symptoms causing intolerable suffering that has been refractive to prior efforts for alleviation of that distress, and when TS appears to be a possible treatment, the following factors ought to be evaluated or reevaluated:

- Is the patient able to understand and consent to TS at this time?
- Has the patient made a prior request for TS if such a situation arose?
- Is distress truly refractory? Has any specialty care been consulted for additional input on treatments other than TS, such as pain service or palliative care?
- Is patient close to death with a terminal illness, death expected in hours or days?

CHAPTER 4

ETHICAL BENEFITS AND HARMS FOR THE FAMILY

Introduction

The family carries the legacy of the way a person dies. They are the ones who must carry the memories of the death with them and pass down the story in family history. Does promoting death with TS increase or reduce the burdens of a death in the family for the families? Concerns have developed which lead some to believe that while it may in some cases be "morally justifiable and psychologically rational (for suffering patients to decide to end their lives by TS), it does not automatically follow that such decisions are good for their children and family…"[190] These are concerns which have been falling through the cracks in the ethics literature and which I address in this chapter.

Increasingly, in our society family members are forced by physicians into making final decisions on the time and manner of loved ones deaths. These decisions place heavy moral burdens on families that never previously existed. Prior to the demise of rampant paternalism, families were not faced with deciding how long to keep gravely ill loved ones balanced someplace indefinable between mere existence and death, and dependent upon advanced medical technology. With medical progress, there are now many types of intensive care that allow patients to linger, too sick to participate in their own decision making and with little chance of improvement. Decisions to continue possibly futile treatment, to terminate care, or to initiate TS and end the possibility of

[190] Elliott J. Rosen, "A Case of 'Terminal Sedation' in the Family", *J of Pain and Symptom Management*, Vol. 16, No. 6 (1998), pp. 406-407.

consciousness are then thrust upon the family. There is little with empirical validity published in the United States on the burdens on families when TS is a final treatment. In fact, a PubMed search completed on June 17, 2011, provided only 134 total listings related to "family reactions + hospitalization + death" and many of these were from earlier than 1995. I will speculate on several potential harms, such as decision maker burden, guilt and complicated bereavement, which I believe ought to be evaluated prior to wholehearted endorsement of TS.

It is morally important to be concerned with the impressions and possible harms that are left to the surviving families of those who die under our care and in our hospitals. Although tradition may state that physicians are only responsible to those who become their patients, when families are forced into the medical/ethical arena (especially when forced to make crucial patient decisions) we are obligated to consider how those families will be affected. This is often, if not always, in difficult balance with the considerations of what is in the best interests of the patient.

Families have been a focus of treatment in other areas of healthcare such as cancer treatment and hospice where support groups, counseling and respite are now routinely offered to the families. Families are the ones who most often provide the patient with care for months or years when dealing with terminal illness. Often families bear immense burdens and subject themselves to great harms in efforts to support the patient's autonomy and interests. Terminal sedation is a final treatment and while it may serve the values of autonomy and beneficence for the patient, we must now also consider the family. In this chapter I will investigate the potential harms and benefits that may be incurred by families when the death of their loved one is accompanied by terminal

sedation. Although every death affects the remaining family members, we must look more closely at deaths with TS. This is because even though death is due to underlying terminal disease, terminal sedation alters the final perceptions and ability to interact with a loved one prior to their death.

Case example:

> ***Betty****- is an 88 year old widow, who now lives in her son's home with his family to assist in her care. Betty attends dialysis 3 times/week, she has advanced Alzheimer's type dementia, diabetes, and resulting decubitus on her buttocks. Betty has been declining recently and eating less (she must be hand fed by family) and sometimes simply refuses to eat. She had previously refused a feeding tube when it was suggested by physician to improve intake. Her poor nutrition has increased the problems with skin breakdown on her bottom and now has open bedsores/decubitus that are very painful and require dressings. Her family reports that she has become less alert and verbal and now screams in pain when moved. She does not have an advance directive and has been brought to the hospital by family for a fever. The fever is likely due to sepsis, UTI or pneumonia for which ER physician has ordered IVAB. The family requests that Betty be made DNR, dialysis be stopped and TS be employed.*

Why Families?

In stark divergence from the initial ethical directives of Beauchamp and Childress,[191] where benefits and burdens were evaluated strictly from the patient's perspective, those in palliative care have realized that the entire family must be considered. The reality is that families bear both benefits and burdens of decisions made by and for patients. Nowhere is this more apparent and complicated than in decisions relating to end-of-life care. These families have come up against what is possible to attempt with our advanced technology versus what ethically ought to be done. Increasingly, families must make excruciatingly difficult decisions when the patient is unable to speak for herself. Sharon Kaufman, in evaluating the SUPPORT study, states

[191] Beauchamp, T., L. , & Childress, J., F. . (1994). *Principles of Biomedical Ethics* (Fifth ed.). New York, Oxford: Oxford University Press.

that the study could not reveal some important facts. The first is "that patients and families, when faced with health crises and the surrounding plethora of medical options, *do not know what to want*, other than recovery or an end to suffering in a general sense."[192]

Families are often given massive doses of medical information concerning their loved one in language that is barely intelligible to them. Then they are burdened with trying to make sense of it all and directing the more aggressive, continued treatment or discontinuation of treatment for the one they love. For many, this comes after months or years of living with a loved one who "is terminal" and having potentially faced other "this is it" situations where the patient has ultimately returned home. Others may have had no or little contact with their family member in the years prior to being required to make important medical decisions. Overwhelming, tiring, confusing and simply frustrating are only a few of the reactions that are often expressed by these families.

Tschann et al found that, "Fewer than half of patients are able to participate in decisions to withhold life-support treatments. Even fewer (<10%) are able to participate in decisions to withdraw life support treatments, because these decisions generally occur within a few days of death."[193] Under a quarter of these patients had discussed their life sustaining preferences with physicians and half or less had discussions with family members prior to hospital admissions.[194] Given that most deaths (50-70%) are from such

[192] Kaufman, S. R. (2005). ...*And A Time to Die: How American Hospitals Shape the End of Life*. New York: Lisa Drew Book/Scribner. 34.
[193] Tschann, J. M., Kaufman, S. R., & Micco, G. P. (2003). Family Involvement in End-of- Life Hospital Care. *Journal of American Geriatric Society, 51*(835), 835-840.
[194] Ibid.

conditions as cancer, heart disease or lung disease and have a lengthy prodrome,[195] one would question how such conversations could have failed to occur. Difficulties in making end-of-life decisions occur due to a multiplicity of causes including clinical ambiguity about medical goals, difficulty in prognosis, and confusion about patient preferences. Since it is families that end up making these important end-of-life decisions, I believe it is imperative that we improve the communication of medical professionals with families. This improvement will require many other changes, including training, time for extensive discussions, and potential changes in reimbursements.

What about Confidentiality?

At this point some may be wondering what happened to patient confidentiality? Physicians and other health care professionals have made many adjustments in how they provide patient care in recent years. An important change came related to maintaining patient privacy. The Health Insurance Portability and Accountability Act (HIPPA) was developed due to concerns about electronic transfer of medical records. It also made important changes to how health care information is allowed to be shared and incidental disclosure of health related conditions. It mandates that health care information must be held confidential unless certain conditions apply.

> The Department recognizes that there may be times when individuals are legally or otherwise incapable of exercising their rights, or simply choose to designate another to act on their behalf with respect to these rights. Under the Rule, a person authorized (under State or other applicable law, e.g., tribal or military law) to act on behalf of the individual in making health care related decisions is the individual's "personal representative." Section 164.502(g) [196]

---

[195] Tilden, V. P., Tolle, S. W., Nelson, C. A., & Eggman, S. C. (1999`). Family Decision Making in Forgoing Life-Extending Treatments. *Journal of Family Nursing*, *5*(4), 426-442.

[196] U.S. Department of Health and Human Services, Understanding HIPPA Privacy http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalreps.html (accessed June 17, 2011.)

This prompted many to have concerns whether health care professionals could share medical information to multiple family members or only the "designated other." Dr. Michael W. Rabow, et al., addressed this issue in *The Journal of American Medical Association* and reported,

> The Health Insurance Portability and Accountability Act (HIPPA) has generated significant concern among physicians with regard to privacy regulations, but the impact of HIPPA on physician-family communication is not yet known…..The Office of Civil Rights Privacy Rule, as well as interpretation from the Web site of the Department of Health and Human Services, suggests that unless individuals have indicated that they do not want information shared with family members, HIPPA regulations allow it.[197]

Rabow et al. further suggest that physicians and health care professionals should discuss, with patients who are able, their willingness to have their care discussed with family members. Equally important to discuss with patients is who, if anyone in their family, the patient would *not* like to have their care information.

Problems with Family Decision Making

Health care professionals often request patients or families designate one decision maker to assist in communication with the health care institution. This gives doctors and nurses one authoritative decision maker to go to, but it endlessly complicates the dynamics within the patient's family. Perhaps as a consequence of considering the ramifications of designating just one family member as their surrogate, patients routinely identify "my family" to make decisions rather than any one individual. This factor has many cultural components that health care professionals must adapt to when providing end-of-life care.

> Patients develop treatment preferences, consider truth-telling and undertake decision making within a cultural and ethnic heritage. In a study of 200 elderly people from 4 ethnic groups, 57%

[197] Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting Family Caregivers at the End of Life. *JAMA: The Journal of the American Medical Association, 291*(4), 483-491.

> of Korean Americans and 45% of Mexican Americans believed that the family should be the primary decision maker, compared with 24% of African Americans and 20% of European Americans.[198]

To make things more complex, families have changed to include many variations in addition to the nuclear family unit composed of husband, wife, and their children. In 1998, already over a quarter of families were non-traditional families.[199] "Almost on third of the families in the United States are composed of members who are not biologically or legally related."[200]

Families also have many different ways of reacting to stress which will affect their abilities to make decisions. The psychodynamics of families are affected by factors in addition to the patient's health crisis, including their history of working together, the emotional and physical status of members, socioeconomic status, individual and family resources, and other simultaneously occurring events.[201] Families will vary in how they adjust to the burdens of decision making and coping with the death of a member. Not all of their reactions will be favorable.

"Even in cases where the patient has advance directives, family members may have conflicts of interest or disagree with one another."[202] Conflicts can develop over attempts to interpret patient wishes or bring up deeper religious or value conflicts between patients and their families. Often, the final hospitalization of a family member will bring together relatives who have had little contact for many years. These situations

---

[198] Ibid. pg. 486.
[199] Leske, J. S. (1998). Treatment for Family Members in Crisis After Critical Injury. *Americn Association of Critical Care Nurses*, *9*(1), 129-139.
[200] Ibid.
[201] Ibid.
[202] Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting Family Caregivers at the End of Life. *JAMA: The Journal of the American Medical Association, 291*(4), 483-491.

may offer comfort or bring up past disagreements. The issue for health care professionals then becomes attempting to obtain family consensus in making medical decisions.

> Strategies for achieving consensus among disagreeing family members include focusing on the known medical facts of the patient's conditions and continually refocusing on what is known about the patient's values and preferences. Directing the family through the precept of substituted judgment, physicians can encourage each family member (both appointed surrogates and others) to imagine and discuss what the patient would want done for himself or herself, which is not always equivalent to what the family member would want done for the patient.[203]

In situations where TS is an appropriate treatment this would require health care professionals to assist family members in understanding and accepting the patient's death in the near future (less than two weeks in all cases and maybe in mere hours or days). Health care professionals must also clearly convey the failure of other methods to successfully relieve the patient's pain or other distressing clinical symptoms, in addition to providing clear information on the practice of TS. It is important to return the focus to what the patient would want in this situation and the goal of working together to accomplish that goal. Understandably, accepting death and the methods involved in TS could be overwhelming for families to absorb. Empathetic responses can go far to offer support and respect for the difficult situation that faces families making end-of-life decisions for loved ones.

Research on the Burdens of Surrogate Decision Makers

Some research has focused on how families cope with difficult hospitalizations and their responsibilities towards dying family members. Sharon Kaufman, an anthropologist, observed the course of over 100 critically ill patients who died (and many

[203] Ibid.

more who did not), over a course of two years in three California hospitals.[204] Her perspective is insightful in ways that strictly medical research has not been. As an anthropologist ethnographer, she was both witness (to all that was going on) and scientist (able to ask questions and for clarification) to both families and staff. An example of her view is seen in her understanding of how the hospital is differently viewed by professional staff and patients and families.

> For staff, the hospital is a fixed, permanent place and patients are transitional objects that must be moved along… For patients and families, the hospital is a transitional thing - a stressful limbo - and being there heightens their sense of physical and emotional vulnerability and lack of control.[205]

She states that "patients and families are the real stakeholders - in how death is made and how the hospital makes death."[206] I believe this is true and why it is important that family interests be evaluated. Kaufman found that when patients could not articulate their wishes, physicians usually left final decisions about withholding or withdrawing life-sustaining therapy in the hands of families. She found that often, as is common practice in most hospitals, this decision is requested following one or more family conferences. I have participated in many family meetings and echo Kaufuman's findings that:

> What is spoken by medical staff and what is heard by patients and families are not the same thing, as we have seen in family interpretations of *unlikely* and *never* to mean "maybe." …Patients and families look to doctors for direction, yet doctors do not usually know how to speak to them about death. On the other hand, doctors look to patients and families to learn what they are ready to hear and to know, but what patients and families express is not always helpful for what medical staff want, and feel they need to do. The twin difficulties of speaking and being heard are perhaps most

[204] Kaufman, S. R. (2005). ...*And A Time to Die: How American Hospitals Shape the End of Life*. New York: Lisa Drew Book/Scribner.
[205] Ibid. pg. 14.
[206] Ibid.

> poignant around the issue I call doublespeak – the contradictory directives and explanations that physicians offer, however unwittingly.[207]

An example of the doublespeak Kaufman mentions is when following the important family meeting, physicians request, "Take your time, but make a decision (hopefully one that moves things along) now."[208] In cases that would involve TS, this would almost always be true since the goal would be to provide the patient with the most immediate relief from pain and suffering possible. There is little that effectively captures how difficult it is for families, thrust into a foreign hospital environment, to suddenly make these life or death decisions for loved ones. Kaufman writes:

> ….I observed a striking inability to cope with making "choices" about procedures. Many families demonstrated this inability, regardless of education level or any other sociodemographic feature. ….Families rarely want to shoulder medical decision-making responsibility, and they view procedural choices not as options for managing death but as assuming responsibility for "killing" the patient. [209]

It also seems that once physicians reach a point of accepting that the patient will not survive, they may pressure the family to "make a decision" to withdraw treatment and allow comfort care only.[210] Luce and White completed a small study looking specifically at cases where professional staff and family disagreed, often where the family wished to continue life-sustaining therapy.[211] They found, "Physicians and nurses may not be aware of the pressure some of them exert or appreciate how strong it can seem to family members."[212] Their conclusions stress improved communication, beginning family

---

[207] Ibid. pg. 175.
[208] Ibid.
[209] Ibid. pg. 59.
[210] Luce, J., M. and Douglas B. White. (2007). The Pressure to Withhold or Withdraw Life-sustaining Therapy from Critically Ill Patients in the United States. *American Journal of Respiratory and Critical Care Medicine, 175*, 1104-1108.
[211] Ibid.
[212] Ibid.

meetings early in the admission and discussing the possibility of death from the outset as well as allowing family members more time to speak and addressing their emotional issues.[213] Even when patients may have had discussions with their specialist concerning disease progression and end-of-life wishes earlier, these desires are often not shared with the family members who will be making their final decisions, or passed by their personal doctor to the hospital physician in charge during their final admission.

Although the death of a loved one is known to be one of the greatest stressors one can face, few studies have looked at those making the decisions to forgo or discontinue life-prolonging treatments. One study did examine families making those decisions at both a one-month post death and six-month post death evaluation point.[214] Tilden, et al., found a significant core set of phases families went through as they experienced the process of arriving at the decision to withdraw treatment: recognition of futility, coming to terms, shouldering the surrogate role and facing the question. The first phase is the dawning of the understanding that the patient is unlikely to leave the hospital. This understanding may come following a family meeting with physicians. Tilden, et al., also mention in this phase the problems families may have in "really hearing" what is being said to them. "As the recognition of futility unfolded and the need for a decision became apparent, the family process shifted toward resignation to an unfavorable outcome, which we labeled *coming to terms*."[215]

Even when advance directives were there to assist families, shouldering the surrogate role was reported as tremendously difficult.

---

[213] Ibid.
[214] Tilden, V. P., Tolle, S. W., Nelson, C. A., & Eggman, S. C. (1999`). Family Decision Making in Forgoing Life-Extending Treatments. *Journal of Family Nursing, 5*(4), 426-442.
[215] Ibid. pg. 432.

> With a great deal of spontaneous emphasis, most respondents described accepting this responsibility as the hardest thing family members ever have to do. Again and again, respondents used such terms as 'difficult', intense', 'painful', overwhelming', 'devastating', and 'traumatic.' They often said that words failed to communicate the difficulty. In their words, "Who wants to say to someone you love, it's time to go?"; "I hope I never do anything that hard in my life again."; "It left me feeling like I was telling him life or death…like I was pronouncing his death."; "I didn't want to pull those life supports and I kept thinking every day: maybe, maybe, maybe…" [216]

Although some respondents reported fulfilling the role of decision maker was done in a sense of duty and somewhat of an honor, many used the term "work" and had statements concerning the stress and pressures it puts on the surrogate.[217] At the six-month evaluation most families focused on accessing more information or combining multiple pieces of information to increase certainty in their decision. Reflections then were generally positive with some feeling guilty if they believed they had prolonged patient suffering.[218]

Reducing Decision-Maker Burden through Shared Decision Making

The Tilden, et al., study also supports increasing clear physician communication to families, when patients are unable to participate, and specifically using language that implies shared decision making.[219] That means physicians need to practice using language that combines their medical knowledge ('In my best medical judgment there is no possibility…..') *with* family reported patient values ('of George returning to be able to walk his dog or achieve any level of independence'). These are counseling skills that are routinely taught to therapists and social workers but that do not often make it on the medical school skills list. The neutral stating of medical information and statistics and then telling the family that they need to decide leaves the family with greater burdens

[216] Ibid. pg. 435.
[217] Ibid.
[218] Ibid. pg. 437
[219] Ibid. pg. 439.

they need to face. Physicians are trained to make difficult medical decisions; families have no such preparation. Offering families reassurances and summary statements provides those families with support for their decisions ('It sounds like you are focused on keeping George pain free, and I agree that is important right now since he doesn't have long left. I believe that TS will best allow that for him'). Moreover, as the above research shows, families want more and more clear communication from physicians concerning end-of-life decisions for their dying family members.

At times it will remain impossible to reach family consensus on appropriate patient decisions due to family discord. Even with multiple family meetings and attempts at providing additional information or efforts to identify an agreed upon decision maker for the patient, some situations are simply not able to be resolved within the limited time available. I would recommend a much greater reliance upon the hospital ethics committees to offer physicians assistance when concerns regarding surrogate decisions occur. Ethics committees have the benefit of a wide interdisciplinary knowledge base. Each patient situation is invariably unique and must be evaluated on individual merits.

Benefits of TS for Families

Once TS is initiated, the patient is no longer aware, no longer suffering, and no longer capable of experiencing. All the remaining experience is that of the family. One may then hope that they too experience some relief, brought by the knowledge that their loved one is no longer suffering. Yet, there is no way to ensure that this is their experience. Next, we need to look at how a death by TS may offer similar or different harms and benefits for remaining family members.

Since a patient who is unconscious due to TS would have few demanding care needs staff, TS may permit the staff to direct attention to families. Allowing death to occur with TS could allow staff time to talk with family members, assess their experiences, reassure them that patient needs are taken care of, and allow them to vent feelings and concerns. These sorts of emotional supports provided to families could provide important benefits towards easing their bereavement. In order to accomplish this effectively, staff would require training in providing emotional support and identification of signs in those who need referrals for ongoing professional counseling and support. Short term training goals would be to provide clarification of the medical situation and TS procedure, reassurance that the patient was no longer suffering, and reduction of family guilt/burden over decision making by allowing them to express their feelings. We will now evaluate what I believe may be some other potential benefits of allowing death to occur with TS.

Indirect and Direct Family Benefits

Families are deeply affected by the dying and death of loved ones. Families who are experiencing reciprocal suffering with a patient who has refractory symptoms at the end-of-life may find solace in having the patients suffering eliminated by terminal sedation. By allowing the patient relief, even at the cost of consciousness, an indirect relief of suffering is also extended to the family who has become enmeshed in the patient's experience. A direct benefit is that patients who choose TS can exit the ICU's and eliminate excess monitoring. This allows full family attendance around their bedside and enables families to witness their family member dying peacefully, in a controlled

fashion, with medical care and with a minimum of distancing medical machinery. If TS can provide families an opportunity to see their loved one calmly sedated prior to death rather than suffering in agony, then it can be evaluated as a beneficent action.

Further TS may allow families to be present with their dying relatively undistracted by the burden(s) of providing taxing physical care. By remaining with the patient, even when she is unconscious, families may be able to feel that they are still participating in caregiving by providing emotional presence and caring touch. Often family members spend time talking to sedated or unconscious patients currently in ICU or on ventilators, and they report feeling better in talking to their loved one, even when they know they will get no response.[220] These benefits would exist for those whose loved one receives TS as well. Families can also take time to sleep and rest knowing that twenty-four hour care is provided by the hospital staff. A direct benefit for families comes from having a professional medical staff to take over direct caregiving in a medical situation to provide families with much needed physical and mental respite.

Harms to Families from TS

We will next consider harms families may experience when TS is utilized as a final treatment for a family member. These harms may vary depending on whether TS was utilized as requested by the patient (either during the final admission or in a prior advance directive) or was authorized or requested by a family member acting as patient proxy. Although the patient's burdens and distress will end upon her death, the families

[220] This benefit is also often witnessed in those who spend time holding and talking to their infants following a fetal demise, or when it is known that the infant will not survive. Sharing, even if only one way, appears to offer comfort to the one doing the talking. Similarly, counselors will often recommend to those struggling with relationships that can no longer be repaired to "write them a letter" to express all that needs to be said, even when it will never be sent.

who have sacrificed, jobs, savings and their own health to provide care may never recover.[221] Even in the best of situations, families may also suffer from complex emotions following the patient's death. "After the patient's death, the family member may struggle with intense suffering to do with feelings of loss, loneliness, anger, guilt, and doubts about whether they had done enough for the patient."[222] We cannot hope to eliminate the grief a family will experience following the death of a family member but we ought to attempt to limit additional harms when possible.

Harms similar to suicide in the family & guilt

We know that suicide can leave lasting scars upon the surviving family members. Are there any similarities in choosing TS? Suicide in terminal patients is far from rare and is often viewed positively as a death by choice. This choice has been promoted by groups such as Compassion & Choices[223] and books such as *Final Exit*[224] which give detailed instructions on how to independently end your life. Both terminal sedation and some forms of suicide allow the patient to eliminate her conscious participation in the final dying process. TS may be a type of 'good death' for the patient in that both TS and suicide support patient autonomy and allow the patient some control over their death. But what about those who live on? We do know that those who have to live with the suicide of a family member often suffer from emotional problems such as anger, guilt, and confusion. They often have tremendous frustration and grief over the lack of closure

[221] Milberg, A., Olsson, E.-C., Jakobsson, M., Olsson, M., & Friedrichsen, M. (2008). Family Member's Perceived Needs for Bereavement Follow-Up. *Journal of Pain and Symptom Management, 35*(1), 58-69.
[222] Ibid.
[223] See http://www.compassionandchoices.org/
[224] Humphry, D. (1991). *Final Exit: The Practicaliities of Self-Deliverance and Assisted Suicide for the Dying* (3rd ed.). New York: Dell Publishing

that the manner of death prevented and they may not receive social support due to the taboo nature of death by suicide.

If TS is provided before families are prepared (i.e., before they have had final and meaningful conversations with their dying relative and/or before they have had a chance to question medical staff), they may also suffer due to lack of closure, unresolved guilt, and confusion. It seems plausible then that a possible harm of TS is the potential for complicated bereavement for the remaining family members. How families react and respond to a death with TS may be dependent partly on the ability of the medical staff to provide adequate explanations and an atmosphere of open communication for families to enter into.

It may also be that this concern can be mitigated or is merely irrelevant to many families. Conversations may have been plentiful and TS discussed often and well in advance of any potential to utilize this final treatment. Medical staff can also encourage patients and families to initiate these sorts of meaningful final conversations to allow closure prior to a need for TS. Also, if desired, TS can be delayed by patient consent to allow some final words to be spoken to a family member. Lastly, appropriate sedative medications and pain relievers may be lightened up once started if it is felt imperative to do so by family members or if a less burdensome method to successfully palliate distressing symptom is found.[225] Although lightening up of medication is not the usual course or plan for TS, it is done when sedation is used to allow seriously ill patients

[225] This would not be recommended for those who had competently chosen TS, but could be done if family demanded. Similar to other cases where patients have well documented Advance Directives, if family have strong disagreements their demands are usually followed over patient directives since, "only the living can sue".

respite from their symptoms with the intention of checking back in to see if symptoms have resolved or become more tolerable for the patient.

The situations where I can imagine TS subjecting remaining family members to similar harms as a death by suicide would be: if there had been a prior estrangement, if a relative arrived at a hospital only to find out the patient has already been sedated, if there had been a poor relationship already and once the patient is sedated the family member begins to regret not speaking up earlier, or finally, situations when relatives had not been aware of patient illness or severity of illness until sedation is underway. In those sorts of cases, the patient would have had to be competent to choose to undergo TS. In these cases, the family may not have suffered any caregiver burden prior to the patient's death and the burden of decision making concerning TS has been borne by the patient.

A concern specific to TS is related to the possible guilt or confused emotions that a family member may experience from the days or weeks of simply watching a relative undergoing TS waste away until death. The 'waiting it out' without the ability to interact with loved ones may be torturous to many. Although clearly not the same, imagine the indignation if one took a beloved pet to be euthanized and were then told, the pet will be sedated so as to not suffer and we will just wait for death to occur from underlying disease in a few days or weeks. We would expect this sort of death to be deeply troubling to pet owners, especially to the most caring owners.[226] The deep sharing that occurs between pets and owners is all non-verbal so it is not merely the lack of conversation that is so troubling. One would surmise it has more to do with simple interaction. Those owners who have had to euthanize a pet have often reported some

[226] Special thanks to John Hardwig for this thought and encouraging this line of thinking.

measure of comfort from believing that they had 'prevented needless suffering' in their companion. All two-way interaction is absent in TS, although the one living may still offer kind words and touch, there is no response from the one dying. This may be simply too difficult for some to cope with.

Families who suffer from guilt due to believing that they should have found a way to dissuade the patient from choosing TS would also have been harmed. They may believe that moral harm will come to the patient from choosing this manner of dying. This would be especially true if they believe that significant value comes from enduring suffering. If they have not been involved prior to the patient's decision for TS or have not been able to "hear" what the medical staff have been saying, the family may believe TS is just another form of suicide or PAS.

There are other end-of-life situations which prevent final conversations from occurring. This includes but is not limited to: sudden death, being dependent on a ventilator or in intensive care, being on other medications which cloud consciousness and clear thinking, delirium, dementia, metabolic disorders, and strokes or other types of end-of-life comas. In any of the above situations meaningful end-of-life conversations would also likely be impossible. Family members could still be encouraged to sit bedside and say their final goodbyes to their loved one despite lack of response. This one-sided goodbye could still provide some solace to a family member who arrived too late.

Confusions

Some families could be harmed by confusing a death by TS with a less moral or legal option such as suicide, physician assisted suicide, or euthanasia. Despite the fact

that there are clear differences in the methods and intent involved, those who are not medical professionals may have difficulty distinguishing among these options. Confusions may arise unless time is spent with the family to assure that they understand exactly the intent and methods involved in providing terminal sedation. Since families are under great stress – perhaps even distress – especially if they were thrust in to the decision maker role, they may not have asked all the questions that they have during their initial "family conference" with the doctor. Even though physicians are not reimbursed for time spent in family conferences, it is this time spent (often repeatedly) answering questions, providing reassurances and allowing open communication that remains essential. Reinforcement and reiteration that the goal of TS is titration of medication just until cessation of distressing symptoms occurs and the patient is calmly sedated ought to provide clarification and reassurance. Secondly, to reinforce the point that the providing artificial nutrition and hydration would only serve to unnecessarily prolong the dying process.

It would clearly be a harm to allow family members to believe that they had given consent for a family member to be euthanized and is NOT what terminal sedation provides in end-of-life care. Physicians vary widely in their ability to converse clearly and openly with families in a language that families can understand. Families may also suffer from decreased ability to clearly process information when highly stressed and they may need to hear the same information repeatedly or have the same questions answered again and again to enable the information to sink in. Increased efforts towards effective communication to ensure that all parties are clear on the goals of TS treatment prior to sedation are essential to reduce these harms.

Fears of mercy killings

Although relatively few in number, there are occasionally those in the medical profession – both physicians and nursing staff – who intentionally kill their patients. These persons usually are able to go undetected while taking many lives before they are discovered and stopped. The incidence of medical serial killers reported has continued to increase.

> According to the *USA Today*, cases of medical serial killers were almost unheard of until the 1970's, when four incidents were reported. The number jumped to a dozen in the 1980's and fourteen in the following decade. A 1990 book called *Nurses Who Kill* cites twenty-four nurses and nurse's aides charged with serial murder.[227]

Despite the tremendous media attention these cases inspire, the fears they fuel in the public are wildly out of proportion to the incidences or likelihood it will happen. A frank discussion of these fears is unlikely to occur as I would suspect families that hold these fears would also be afraid that to voice them. I have personally witnessed countless times when families admit to concerns or complaints only after their patient's death. When questioned as to why they didn't voice the concern earlier, the reply was often that they were afraid if they complained it could encourage staff to abuse or ignore their family member. Perhaps the best way to address a concern such as this is to openly state that some people may hold this concern and then reassure families that it is not going to be the case in providing appropriate relief for the suffering of their family member utilizing terminal sedation. Reinforcing the differences in the amounts and types of medications used for euthanasia with the amounts and types of medications used for TS might provide clarification and reassurance. Families must also trust that patients are

[227] Lewis Cohen, *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die*. Harper Collins Publisher, New York. 2010.

being sedated to offer patients, not care givers, relief. As above, open and clear communication done on a consistent basis is essential to an appropriate hospital procedure for allowing TS in patients with refractory end-of-life suffering.

Admittedly, there are a few who act against patient and family wishes and against the law in intentionally terminating the lives of the seriously ill. Their actions are outside of any moral or professional behavior. In order to help to differentiate their acts from that of appropriate TS, proper documentation from physicians and patient/family consent is required prior to initiation of TS.

Complicated Bereavement

Although most persons are able to adapt and make life adjustments following the death of a loved one with the assistance of those around them, some do not. Kramer, et al., did a recent in-depth study of factors contributing to complicated grief in caregivers of persons with lung cancer.[228] Understanding what leads to complicated bereavement will allow us to attempt to limit these factors for those families who are affected by TS. Kramer, et al., found that, in general, "complicated grief symptoms were higher among caregivers with less education, among families with lower prior conflict but higher conflict at the end of life, who had family members who had difficulty accepting the illness, and who were caring for patients with greater fear of death."[229]

We may foresee that if a patient suffering at the end-of-life cannot be adequately treated with traditional measures then it may increase the family conflict and lead to

[228] Kramer, B. J., Kavanaugh, M., Trentham-Dietz, A., Walsh, M., & Yonker, J. A. (2010-2011). Complicated Grief Symptoms in Caregivers of Persons with Lung Cancer: The Role of Family Conflict, Intrapsychic Strains, and Hospice Utilization. [Death and Bereavement]. *OMEGA--Journal of Death and Dying, 62*(3), 201-220.
[229] Ibid.

higher rates of complicated grief. In this situation perhaps TS would be able to address the intolerable suffering and offer the patient and family a more peaceful end-of-life scenario. However, the provision of terminal sedation may increase the likelihood of complicated bereavement for the surviving family members, especially if there is family conflict concerning TS. Kramer also cites evidence that communication and "end-of-life discussions may have cascading benefits for patients and their caregivers including better caregiver bereavement adjustment."[230] Encouraging or even assisting family members to talk openly with their dying relative would then be beneficial to both parties.[231]

Moral objections

There will be families who object to TS on the vitalist and theist moral grounds we have previously mentioned. As Terri Schiavo's parents did, they may view any discontinuation of any available medical treatment as a form of killing. Those with very strong religious views may also deny any form of withholding or withdrawal of medical treatment, especially artificial nutrition and hydration, as taking the decisions for life and death out of God's hands and therefore unacceptable. If the patient holds the same belief system as the family, this patient would not be likely to choose TS and there will be no family conflict.

But if the patient and family have differing belief systems then these differences must be addressed and the issue of patient advance directive or surrogate decision making will need to be decided upon. Often where value conflict does exist, health care

[230] Ibid. pg. 205.
[231] This may not be an option for many due to the increasing preponderance of those who also have severely dementing illness.

professionals can achieve family support by stating the need to direct family focus on the patient's values and preferences rather than what they themselves would want done. Even when families do not share patient values they may be able to separate out what they would want done from what they believe the patient would choose if able to do so. Using what the patient's viewpoint would have been, if she could have participated in the decision, will help to determine the most ethical action. Again, it is appropriate to offer empathy to families about just how difficult it is to be in these end-of-life situations. If no agreement can be obtained, Ethics Committee consultation should be requested by the physician in charge to allow full discussion and attempts to understand all viewpoints in an effort to reach a treatment plan agreeable to all. This is undeniably a difficult situation and one that can sometimes be avoided by early and clear communication of wishes by the terminally ill patient to her family.[232]

Need for Additional TS Specific Research

The good intention and benefit of TS that one would like for families is the impression of a peaceful, calm death of their loved one. Unfortunately, little empirical research on TS has been able to confirm that this does in fact occur, let alone occurs most often. I do not believe that this is because this hoped-for perception of a good death does not occur; rather, it is likely due to the lack of focus *on the family* during TS. I have found no research done on specifically American families who had relatives dying with TS. Of course, even if there are harms to family members when relatives die using TS, these harms may not be of sufficient weight to override the benefit that the dying patient

[232] One must note that in clinical practice it is doubtful that TS would occur if there was family disagreement with that decision, even if TS was the patient choice and had the endorsement of the Ethics Committee, due to overriding concerns of litigation by hospital administration.

may receive. Yet, they do deserve careful consideration, if for no other reason, to identify what these harms are and how we might reduce them if possible. We would thereby strengthen the reasons to allow greater use of TS use for those who are suffering intolerably at the end of life.

Families are 'caught up' in our hospital institutions. That fact cannot be disputed, but the nature of its impact upon them is yet to be clearly identified in the ethics literature. Most available studies on bereavement have not focused on the method of dying or on an individual's participation (such as having to make decisions to forgo treatment or requesting TS) in the method of a family member's death.

Culture has dramatic impact upon how individuals assign values to important life events. The death of a family member is an important event and it is not unreasonable to predict differences in the American culture from those of European or Asian cultures. Research on terminal sedation, specifically as it relates to families in the United States, is still desperately needed. The research that has been done on how TS affects families has been conducted in Japan and The Netherlands.

In Japan, Tatsuya Morita has done considerable research in the field of palliative sedation and has begun to take an investigative look at the potential for distress for families.[233] Although cultural difference may exist, these studies are illuminative. Morita found significant concerns:

> Family members reported guilt, helplessness, and physical and emotional exhaustion when patients received palliative sedation therapy. They were concerned about whether sedated patients experienced distress, wanted to know that the maximum efforts had been made, wished to prepare

[233] T. Morita, et al, "Concerns of family members of patients receiving palliative sedation therapy", *Support Cancer Care,* Vol. 12,(2004). pp. 885-889.

> for patient death, wished to tell important things to patients before sedation, wished to understand patients' suffering, and wanted medical professionals to treat patients with dignity.[234]

In a recent study from The Netherlands, looking at concerns of the relatives during the continuous palliative sedation of a family member, van Dooren, et al., found that over half of the relatives expressed concerns after sedation was started.[235] The Netherlands study found concerns grouped into three primary areas: concerns about the aim of continuous sedation (27%), concerns about the well-being of the patient (29%), and concerns related to the well-being of the relatives themselves (18%).[236]

Of the concerns regarding the aim of continuous sedation, 29% expressed concerns about the patient's possible continued suffering.[237] This concern was increased if there was a need to increase the dose of midazolam to control symptoms or a change in the patient's condition such as breathing or groaning. This study was done in a country where euthanasia is legal but cannot always be initiated (if patient condition worsens prior to the ability to meet requirements for euthanasia) and some families were frustrated that euthanasia could not be provided for their patient. This also clarifies one of the differences in the appropriate *intentions* for TS, to provide medication *just until unconsciousness* and the cessation of noxious symptoms. Therefore, families may retain concerns about ongoing patient suffering since the intention in TS is not to hasten or deliver immediate death through medication as would be the case when utilizing euthanasia or PAS.

---

[234] Ibid.
[235] van Dooren, S., van Veluw, H. T. M., van Zuylen, L., Rietjens, J. A. C., Passchier, J., & van der Rijt, C. C. D. (2009). Exploration of Concerns of Relatives During Continuous Palliative Sedation of Their Family Members with Cancer. [doi: DOI: 10.1016/j.jpainsymman.2008.11.011]. *Journal of Pain and Symptom Management, 38*(3), 452-459.
[236] Ibid.
[237] Ibid. pg. 455.

Concerns about the well-being of relatives themselves included feelings of great burden on themselves, feelings of exhaustion because of sleep deprivation and "unbearable feelings of watching their family member die."[238] Van Dooren, et al., conclude that family concerns included:

> The fact that the relatives cannot communicate with their ill family members anymore may strengthen their possible doubts about the opinion of their family members regarding the decision to sedate and the level of symptom relief actually achieved. In fact, some signs that usually occur during the dying process, for example groaning or altered breathing, may be interpreted by the relative as waking up or the recurrence of symptoms and, therefore, upset them.[239]

To address these concerns, van Dooren, et al., also recommend "proactively, repeating information or providing additional information could effectively resolve the expressed concerns."[240] They also stress allowing the relatives to ventilate regarding their own well-being. Thus, beneficence directed towards the family members while loved ones are dying is clearly within the duties of those caring for the dying patients and it may reduce their distress. Van Dooren, et al., endorses "continuous monitoring of not only the patients' symptoms, but also the concerns and needs of the relatives."[241] That family members expressed "doubts about the opinion of family members regarding the decision to sedate" could indicate that there has not been enough time for full discussion or that there are some who are in disagreement with the decision to utilize TS. This would be another important area for further study. I would hypothesize that when there is an increase in staff/family discussions earlier in hospitalizations and more time allowed for talking together, that there would be a corresponding decrease in conflict.

---

[238] Ibid. pg. 456.
[239] Ibid.
[240] Ibid. pg. 457.
[241] Ibid. pg. 457.

Morita, et al., completed a follow-up study in Japan that was done over two years following the TS of a family member showing that although 78% of families were satisfied with the TS treatment, 25% expressed high level of emotional distress.[242] This was a large study looking at 764 patients who had died from cancer in their institutions. Of those, 41% received sedation.[243] This Japanese study does differ: they differentiated between those who received intermittent sedation alone (to offer respite from symptoms) prior to death (7.9%) and those who received continuous-deep sedation with or without intermittent sedation (33%).[244] Usual statistics report the incidence of TS as occurring in between 10-50% of deaths due to terminal cancer. Some of the variance in reporting is due to confusions on reporting intermittent versus continuous sedation.

Some of the family burdens were related to responsibility for making decisions and conflict in the decision making process. "Conflicts in the opinions were observed among family members in 15%, between the patient and family in 7.6%, and between family and medical staff in 9.75%."[245] The families in the study perceived that 69% of the patients were considerably or very distressed before sedation. This may lead one to question if there are differences between professional evaluation of 'intolerable distress' as required for TS and the family evaluation of distress. In this study, 55% reported that the patient had made an explicit request for sedation.

Additionally, the timing of starting sedation was evaluated as appropriate in 78% of families, too early in 1.6 %, maybe too early in 7.6%, maybe too late in 7.0% and too

[242] Morita, T., Ikenaga, M., Adachi, I., Narabayashi, I., Kizawa, Y., Honke, Y., et al. (2004). Family Experience with Palliative Sedation Therapy for Terminally Ill Cancer Patients. *Journal of Pain and Symptom Management*, *28*(6), 557-565.
[243] Ibid.
[244] Ibid.
[245] Ibid. pg. 561.

late in 2.7% and .4 % unsure, of the evaluated cases.[246] Although patient distress went down in a majority of cases (11% still stated observing patient distress following sedation), family emotional distress was related to those cases where patients remained distressed or it was felt sedation came too late.[247]

Even when sedation appeared to be meeting patient and family needs, "half of the families reported that they were distressed they could not communicate with the patient."[248] Additionally, "About one-third of the families reported taking responsibility for the decision as a burden and were concerned that sedation might shorten the patient's life."[249]

> Compared with the family members with low distress, highly distressed families were significantly more likely to have concerns that sedation might shorten the patient's life, feel there might be other ways for symptom relief, feel the burden of responsibility for the decision, feel unprepared for changes of patient condition, think the physicians and nurses were not sufficiently compassionate, feel they still had something more to do, and have legal concerns; they were less likely to have a prior discussion with physicians.[250]

Once again, it appears that many of these concerns could be addressed with adequate or additional communication, and that physician communication is especially important to reduce family distress. When evaluating the concerns listed above, one may wonder why it is that families remain concerned that TS may shorten relative's lives. Is it perhaps because of the issue of not providing artificial feedings? Harboring the old concerns of not wanting to starve the patient to death? Or that TS *really* is a form of euthanasia?

I am coming to believe that regardless of how many times families are told some well accepted medical and ethical precepts - such as "the dying do not feel hunger the

[246] Ibid.
[247] Ibid.
[248] Ibid.
[249] Ibid.
[250] Ibid. pg. 562

same as you and I" or "it is just as ethical to withdraw care as it is to withholding care in most situations" or "there is difference in intent and medications between TS and euthanasia" - they don't buy it. There are things in life that, as my grandmother would say, "Just don't sit right" even when they have been explained to you again and again.[251] These concerns, and the others that Morita has uncovered, deserve more full evaluation for the impact that they have upon families. Nonetheless, as ethicists we need to develop better ways to educate others on complex moral issues which will result in more confidence in making these difficult decisions.

Given the high preponderance of families who must, in the end, take responsibility for making terminal sedation decisions, it is important to retain concern for the families and focus on reducing the harm they may incur. In this study, 89% of the families were clearly informed of sedation therapy to be used on their family member. It is reasonable to hope that if 100% were informed prior to sedation that the percentage of families who reported being satisfied with the care could then go above the 78% Morita found in this study.

These studies are only just a start; they confirm concerns about family suffering are not unfounded. Further philosophical and empirical study into how families cope with the palliative sedation of a loved one could illuminate multiple concerns and the harms families may endure which have yet to be identified. The striking conclusion that is in virtually every current study on the effects upon families from terminal sedation or

[251] A similar concern regarding physicians and concerns about withdrawal versus withholding treatment is addressed in Chapter 5.

other hospital deaths is the need for greater communication between physicians, medical staff and families during the dying process.

Need for Improvement in Communication

Most deaths now occur in institutions such as hospitals and nursing homes. A large study, involving over 1.97 million deaths, completed by Teno, et al., in the year 2000 showed that 67% of deaths occurred in an institution.[252] Billings, et al., state, "We would compare the imprinting that occurs between a family and a hospital at the time of a birth with a family's lasting impression of how the hospital manages a death."[253] The Teno study showed that 76% of family members had contact with the patient all 7 days in the last week of life. Even though most people die in hospitals or other institutions, "family members of descendants who received care at home with hospice services were more likely to report a favorable dying experience."[254] Over one third of families with institutional deaths reported one or more concerns with family emotional support.[255]

The Teno, et al., study "Family Perspectives on End-of-Life care at the Last Place of Care" showed four of five results for better quality end-of- life care results focused on health care professionals' attention to families concerns. This included 1) ensuring desired physical comfort and emotional support, 2) promoting shared decision making, 3) treating the dying person with respect, 4) providing information and emotional support to family members. With this in mind, health care professionals can work towards

[252] Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., et al. (2004). Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA: The Journal of the American Medical Association, 291*(1), 88-93.
[253] J. Andrew Billlings, and Ellen Kolton, "Family Satisfaction and Bereavement Care Following Death in the Hospial", Journal of Palliative Medicine, Vol. 2, No. 1, (1999), pp. 33-49.
[254] Teno, et al., 2004.
[255] Ibid.

providing better care for the family members who die with TS. TS has the ability to work towards achieving these measures. The first, (1) ensuring the physical comfort of patients, is done in TS by elimination of their suffering. I have earlier detailed some ways that physicians and health care professionals can address families to work towards (2), more shared decision making, and included a template for "Conducting Family Meetings When the Patient is Unable to Participate" in Appendix 3. I have addressed in Chapter 3 how TS can be evaluated as achieving (3) in respecting the autonomy of the dying patient. Lastly, I list several suggestions below to offer measures to meet (4), offering families of patients undergoing TS with additional information and emotional support.

Conclusion

Increased communication is paramount in mitigating many of the potential harms to the families. While the value of communication cannot be underrated, prior to having these discussions, physicians need to be educated about talking about death and talking about death to families. Society also needs to be open to talking about death. Discussions about dying preferences among family members ought to begin prior to any illness, this open forum of discussions can allow one to then return to talking about what one "really wants" if a terminal diagnosis is received.[256] I believe having greater openness in discussions of death and dying issues generally will allow families to have

[256] I envision these sorts of discussions to be similar to the ongoing dialogue daughters have with their parents about the topic "When I get married…" and how the dream wedding is continually changing in minute or large ways until the actual event occurs. One notable difference is that although one may have multiple weddings in a lifetime we only get one chance to die well.

greater comfort that they are allowing a good death for loved ones if they are called to authorize TS to alleviate intolerable suffering.

TS deaths are events that come with at least some advanced warning: we plan the sedations, and medication orders are first written and then carried out. I believe that much harm to families could be mitigated by not only increasing the communication by physicians to families and nursing staff to families but by including protocols which mandate the inclusion of additional team members (chaplains and social workers) to specifically address the psychosocial and bereavement needs of the family.

A good protocol would include a family-team meeting to discuss the process, or possibility of utilizing TS prior to the actual need. When discussions of TS as a possible treatment are brought up by hospital staff or physicians early in the course of terminal illness,[257] it will allow patients and families to plan in advance for the occasion and address needed conversations – about dying, forgiveness, thankfulness and permission – to happen earlier in the dying process. In the case that started this chapter, a family meeting held even in the emergency ward could begin to alert the son that even if current infection cleared, his mother would likely not have any great improvements due to her wishes to refuse artificial feedings. A meeting could also assure family that all efforts were being made to keep the patient pain free and comfortable. Words of compassion for her sad situation could go a long way towards supporting the family. It would also begin to open a path for future communication between the family and hospital staff providers.

[257] By "early in the course of terminal illness" I mean when the patient has begun to show signs of the progressive decline in functional abilities and advancing disease. This may be accompanied by more frequent hospitalizations, increasing need for assistance, increasing time spent in bed during the day and other such signs of approaching death. It would be better if the concept of TS was discussed with families prior to the last hospitalization, to allow them time to explore the concept with medical professionals and discuss with family members in a non-urgent situation.

Another option to reduce emotional harms would be a hospital sponsored support group for the family members. This group (similar to other hospital support groups for stroke survivors, parents of fetal demise, or widow/widower groups) would encourage ventilating feelings and provision of education on the medical techniques involved and the grieving process. It seems intuitively right that encouraging discussion of feelings, fears and concerns about the patient's upcoming death would be beneficial and not only for patients. This communication would aid in establishing trust with the professional care team to allow the family to relinquish provision of burdensome direct care and focus their own emotional needs, saying goodbye and preparing for living without their loved one.

It is appropriate to show concern for the harms others may suffer and attempt to reduce them where possible. Since families may suffer harms related to having a loved one die while undergoing TS treatment for intolerable suffering the medical professionals ought to act to reduce their burdens where possible. This may be done in part by

-increasing physician and nursing counseling skills to work with families;

- increasing staff time to allow family and staff discussions regarding the patient, the process of TS, and to encourage family questions;

- ensuring family support if possible, via social worker and chaplain services;

-allowing increased family participation in deaths and education on dying; and

- offering hospital support groups to allow families to share with others who have been in similar situations and ventilate emotions related to the family stress involved in enduring a relative death by TS.

In summary, although there are some significant potential burdens for families when TS is utilized at the end of patient life, many of these burdens may be mitigated or

eliminated by increased focus on ensuring clear communication between medical staff and family prior to and during the process of terminal sedation.[258] Beneficence towards families, even when it came in the last few days of the patient's life, would be a result of allowing TS in the current standard I have proposed. This beneficence would be extended to more families if the TS standard were augmented in the future to encompass those with other progressively debilitating diseases. The benefits to families of knowing that the patient's suffering has been eliminated and the potential to witness a calm death may be considered, by many if not most, to be overriding benefits.

Case Resolution:

Allowable TS with family acting as appropriate surrogate decision maker for patient and family is in agreement. Son confirms a close relationship with mother and reports similar shared religious views and values. He believes that his mother would not want to continue dialysis were she able to evaluate her current situation and wants to relieve her obvious pain and suffering.

1- *Hemodialysis is life prolonging technology and may be terminated upon patient or appropriate surrogate request. Betty appears to be reaching end-stage dementia illness. Pt. refused feeding tube when she had more capacity. Pt. appears to be suffering due to ongoing moaning, wincing with any movement and has obviously painful decubitus.*
2- *Pt. appears to be suffering from painful decubitus ulcers, and has high care burden to endure from dialysis. Has little to no ability to interact with family members nor to provide input as to her current desires. Pt. had earlier independently refused artificial feeding and will surely die from malnutrition without additional nutrition.*
3- *Current fever could be harbinger of death. Would be ethical to discontinue IVAB if family desires, or to provide if short course to see if improvement is possible or may have been already completed. Regardless, would anticipate death in 10-14 days after withdrawal of dialysis, death could be sooner due to poor nutritional state and if no IVAB are provided for the infection.*

[258] This will require additional changes to normative practice of staff in hospitals and clinics as well as requiring families to be receptive to the additional services and communication offered for their benefit.

CHAPTER 5

ETHICAL BENEFITS AND HARMS TO HEALTHCARE PROFESSIONALS

Case example:

Donald is a 88yo retired attorney, he is married, Catholic and has severe cardiomyopathy, CHF, and COPD. He is currently hospitalized in ICU on a dopamine drip to keep blood pressure stable and Bi-Pap for positive lung pressure and oxygen. He will need to go on the ventilator soon if things do not improve. He previously made an advance directive stating that he did not want life prolonging treatments or CPR if it was known he was terminally ill. Prior to admission he was on home oxygen, but independent and still driving. Pt. entered hospital 3 weeks ago with a pneumonia and has failed to improve despite aggressive antibiotics resolving the pneumonia. Lung condition has deteriorated and CHF has worsened. His wife is his POA, she has some dementia and does worse outside of their home environment. The couple's son died several years ago in an automobile accident. Conversation with patient is difficult concerning his condition due to pain medication, anxiety medication and his difficulty breathing. The patient is currently too ill to determine if he is competent to either refuse the ventilator or request TS, but he clearly appears to be suffering at this point. If he were to go on the vent and continue aggressive care, he could survive this assault of illness but it will likely be many weeks if not months before he would be able to wean from the vent, and nursing home placement would be likely. The wife is crying and confused, stating she doesn't know what to do, or what her husband would "really want" and states, "Doctor, do what you think is best". The doctor is Catholic and believes that everything should be done, including putting the patient on the ventilator. A nurse who had cared for him last year strongly disagrees and has been sharing her thoughts with the other nurses in the unit.

Introduction

It is appropriate that my primary concern about harm related to TS is focused on those most directly involved, the patient and her family, but they are not alone. Those attending the death - nurses, physicians, and other staff members - also deserve close evaluation for potential harm. Terminal sedation may provide a good death to patients and this knowledge can be seen as a benefit to physicians and nurses who are obligated, due to beneficence and compassion, to provide care to the dying. Those who best attend to the sick and dying must surely do so not merely out of need for financial gain, but also as part of a larger calling to provide care and compassion towards others. They witness firsthand what most of us seek to ignore: that we all must face our death. When, in the call of a physician's duty, it becomes apparent that cure is no longer possible, it remains a

moral call for physicians to prolong life where possible (and is what the patient desires) and to reduce suffering. These duties are often in difficult balance with the competing duty of nonmaleficence, to do no harm.

There is little discussion of the coping skills utilized and emotional burdens borne by the healthcare profession when faced with patient death. Often we hear the clichés: "there was nothing more we could do"; "it was just time"; or "we all have to die sometime" that healthcare professionals repeat to explain to themselves and others the dying of patients. Doctors are educated early that having patients die "is just part of if" and "happens all the time". They are even told, "You'll get used to it." This is true in some aspects; the human condition is a temporary one and we all must die sometime, someplace, and in some way. It is easier to do your job in a hospital if you don't take every death personally; it might be impossible to do your job if you did. Yet, having spent a large part of over twenty-five years working closely with physicians and nurses in acute care hospitals, I know that it does affect you. I've witnessed and at times joined in the tears when patients have died, either expectedly or unexpectedly.

How someone dies matters, at least sometimes and these memories often affect those who are providing care. This is why it is important that we attempt to evaluate what affect death with TS may have, not just upon the patients and families but also, upon health care professionals. To do this I will first establish the lack training most physicians obtain in death and dying skill sets, share physician attitudes specifically concerning withholding and withdrawal of treatment and explain how Mark Bilton has attempted to evaluate the cognitive disjuncture between the logic and emotions of

physicians when removing life support from patients.[259] Next, I will explore physician attitudes towards various end-of-life treatments, including TS. The emotional burden of nurses who participate in TS, and their special concerns, will be iterated as well since they are the ones most closely caring for those who die. I will next evaluate concerns related to litigation. Then I will make the argument that the way care is currently provided in hospitals with the dual mandates of managed care and evidence based practice have changed the milieu of healthcare in the last 20 years and may impact the provision of TS in either positive or negative ways. Lastly I will address issues of personal conscience.

Problem Number One….Lack of Training in Care of the Dying

The SUPPORT study was completed almost 20 years ago and clearly showed that American healthcare was not doing a great job of caring for the dying, with pain in dying identified as a primary concern.[260] Since then the specialty of palliative care has developed and these specialists have made strides to address this deficit in providing specialized care to those with terminal illness. Although palliative care specialists exist, they remain a relatively new specialty area of medical practice and they are not available in all hospitals, or even all metropolitan areas. Even when available, they are a consult service that many physicians do not refer to or, like hospice, the referrals may come too late to be of optimal benefit for anyone involved.

---

[259] Bilton, M. J., & Finder, S. G. (2002). Traaversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports. *Theoretical Medicine, 23*, 233-258.

[260] Connors, A. F., Dawson, N. V., Desbiens, N. A., Fulkerson, W. J., & al, e. (1995). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. *JAMA, 274*(20), 1591-1598.

One might believe that since death has always been a part of life and medicine, all physicians are trained in providing care to those who are dying. Alternatively, one may have hoped that since there were numerous studies done in the mid-to-late 1990's following the SUPPORT study looking at various issues surrounding care of the dying that it would have prompted immense changes in our care of the dying.[261] Sadly, neither has come true with the notable exception of the burgeoning of hospice organizations. As of 2000, only 5 of 126 medical schools in the United States offered a separate, required course in the care of dying patients.[262] A study done in 1998 with a primary investigator from the Center to Improve Care of the Dying found that oncologist, pulmonologist or critical care physicians had the most frequent contact with death but that "most physicians have little experience with dying, and physicians' experience with death has little effect on patient outcomes."[263] Another study done with housestaff (medical residents and interns providing hospital in-patient care) found that, "About half the residents described themselves as poorly prepared or not at all prepared for dealing with

[261] Billings, J. A., Kolton, E. (1999). Family Satisfaction and Berevement Care following Death in the Hospital. *Journal of Palliative Medicine, 2*(1), 33-49, Block, S. D., & Sullivan, A. M. (1998). Attitudes about End-of-Life Care: A National Cross-sectional Study. *Journal of Palliative Medicine, 1*(4), 347, Ferris, T., G.G., , Hallward, J. A., Ronan, L., & Billings, J. A. (1998). When a Patient Dies: A Survey of Medical Housestaff about Care after Death. *Journal of Palliative Medicine, 1*(3), 231-239, Layde, P., Beam, C., & Broste, S. (1995). Surrogates' predictions of seriously ill patients' resuscitation preferences. *Arch Fam Med, 4*(518), 518-523, Lynn, J., Zhong, Z., Dawson, N. V., Connors, A. F., & Phillips, R. S. (1998). Physician Experience Caring for Dying Patients and Its Relationship to Patient Outcomes. *Journal of Palliative Medicine, 1*(4), 337.

[262] Carver, A. C., & Foely, K. M. (2000). The Wein Article Reviewed. *Oncology 14*(4), 598-601.

[263] Lynn, J., Zhong, Z., Dawson, N. V., Connors, A. F., & Phillips, R. S. (1998). Physician Experience Caring for Dying Patients and Its Relationship to Patient Outcomes. *Journal of Palliative Medicine, 1*(4), 337.

the tasks of care after a death when they entered internship."[264] In the same study researchers also found that:

> Residents recalled deaths that occurred after starting opioids and worried that they had hastened dying or might be blamed for contributing to the death. Several housestaff mentioned difficulties with their own grief, particularly when the patients were young or when life supports were withdrawn.[265]

The above finding would help to explain why so many physicians would be hesitant to provide TS to those suffering during their dying experience. Physicians are like the rest of us and feel better when they are confident about the treatments and services and have knowledge that they are providing good medical care. The current lack of hospital protocols and policies to support and establish appropriate provision of terminal sedation restricts the ability of new residents to become trained and more comfortable providing this treatment.

There exists a values conflict for physicians in end-of-life care that is difficult to both clearly articulate and to negotiate. It involves in part, the difficulty in accurately predicting when death will occur, even given a terminal prognosis, and when to stop using medicine to aggressively battle death and also the emotional component with concerns about "giving up" on your patient. As mentioned above, almost all medical training is addressed to teaching how to diagnose and treat illness and very little on how to treat the dying. In addressing the moral distress in palliative care, David E. Weissman, MD, states the values conflict includes concerns of patient comfort, autonomy, quality, and dignity versus perceived professional duty to preserve life, emotional impact, ethical

[264] Ferris, T., G.G., , Hallward, J. A., Ronan, L., & Billings, J. A. Ibid.When a Patient Dies: A Survey of Medical Housestaff about Care after Death. (3), 231-239.
[265] Ibid. pg. 235. It would be interesting to have data on when during the internship these doctors were questioned. It is expected that one of the things they will learn during an internship is how to approach death and dying issues. It is highly variable what each will learn during "on the job" training.

propriety, and potential malpractice risk of withholding or withdrawing life sustaining treatments.[266] When the topic of TS is not one that is openly discussed and appropriate protocols advanced it can leave too many questions unanswered. The option of providing appropriate TS may then fall into the category of "not worth the risk" for a physician to attempt to provide this specialized treatment for those with exceptional suffering at the end-of-life.

Of course, some value conflicts might be lessened if the physician were certain that she was following patient wishes for end-of-life care. But, early studies show that patient wishes were charted less than one-third of the time in the medical record (29%) and that medical professionals believed treatments such as mechanical ventilation (67%), CPR (64%), artificial nutrition and hydration (54%), dialysis (51%), antibiotics (42%) and pain medication (35%) are used inappropriately at the end-of-life.[267] Physicians may not be aware of your preferences and, therefore, go with over treatments even when they believe such treatments may be inappropriate. This overtreatment is consistent with the overarching medical goal of preserving life and appropriate when one is unaware of patient preferences and/or the outcome is unknown. It is also consistent with most ethical evaluations as being in the patient's best interests (to preserve life) and the most beneficent action when the patient and therefore the patient interests and values are unknown.

---

[266] Weissman, D. E. (2009). Moral Distress in Palliative Care. *Journal of Palliative Medicine, 12*(10), 865-866.

[267] Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfoy, V., Koch-Weser, D., & Donnelley, S. (1993). Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments. *American Journal of Public Health, 83*(1), 14-23.

What if you do have an advance directive? A much more recent study shows little improvement and that end-of-life care still depends more on the doctor you have than your stated desires.[268] A recent National Institute of Health (NIH) study done in Pennsylvania found that variations between physicians "attributed to intrinsic characteristics - such as religious beliefs, beliefs about when a patient is 'dying,' beliefs about quality of life, and tendency to personalize patients' deaths - and extrinsic forces - such as training, role norms, experience and incentives"[269] - often determined the end-of-life care one received. They showed concern that:

> If the use of life-sustaining treatments depends on the doctor, then they do not - as they ought - depend on patient and family preferences. The hypothesis that patients select doctors whose substituted judgment they endorse is tenuous given that hospital-based physicians are often complete strangers. [270]

Further,

> The literature on practice variations hypothesizes that greater uncertainty about the "right" treatment allows physician beliefs and prevailing social norms to dictate care. With the exception of brain death, there are no guidelines for the use of life-sustaining treatments for patients who may be near the end-of-life.[271]

This can add to the confusion for physicians on when to appropriately utilize treatments like terminal sedation, especially when most of them have had little or no training in the appropriate methods for providing this treatment. If physician practices are developed over time based upon hospital and community norms and beliefs on what is the "right" thing to do then it becomes important to attempt to ascertain what those beliefs and attitudes are concerning end-of-life care, particularly treatments for the imminently dying

---

[268] Larochelle, M. R., Rodriguez, K. L., Arnold, R. M., Barnato, A. E. (2009). Hospital Staff Attributions of the Causes of Physician Variation in End-of-Life Treatment Intensity. *Palliative Medicine, 23*(5), 460-470.
[269] Ibid. pg. 8.
[270] Ibid.
[271] Ibid. pg. 9-10.

such as withholding and withdrawal of life sustaining treatments and terminal sedation. Why would physician beliefs about other end-of-life treatments affect the potential for harms or benefits related to TS? Because TS involves, in part, the acceptance of death as imminent and the refusal or discontinuation of other life sustaining measures. Looking at the research on physician attitudes concerns withholding and withdrawal of other end-of-life treatments will allow us a baseline for assessing the effects on TS.

Health Care Professionals Attitudes and Beliefs about End-of-Life Care

As evidenced above, while technical skills and knowledge about medicine cannot be underrated in health care, it is often physicians' beliefs that drive the care you receive (or do not receive) when you are dying. The beliefs and values that physicians and nurses hold affect your care and are also affected by what underlying ethical beliefs they hold. I will refer again to an older study done in 1993, *Decisions Near the End-of-life: Professional Views on Life Sustaining Treatments*,[272] because I believe it highlights one of the primary concerns that has yet to be addressed in healthcare. This concern is the disjunction between nationally accepted ethical precepts, often developed by academic ethicists and the ethical beliefs used in practice by doctors and nurses. This study surveyed 687 physicians and 759 nurses on their views concerning end-of-life care. Almost half (47%) stated that they had acted against their conscience in providing care to the terminally ill, this included 70% of housestaff, 50% of nurses and over a third of

[272] Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfoy, V., Koch-Weser, D., & Donnelley, S. (1993). Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments. *American Journal of Public Health, 83*(1), 14-23.

medical and surgical attending (38%, 34%).[273] Most believed that they provided treatments that were overly burdensome to their patients.

The researchers also investigated medical caregivers' views on key ethical issues such as patient rights to refuse treatment and found 87% in agreement with patient refusal rights and similar (87%) agreement that "to allow patients to die by forgoing or stopping treatment is ethically different from assisting in their suicide."[274] That is reassuring but other findings give reason for concern. Virtually all practicing ethicists are aware of the shift towards moral evaluation of specific treatments based upon determinations of the burdens or benefits of proposed treatment as perceived from the viewpoint of the patient or surrogate. Surprisingly, "No one in (the) subsample explicitly used the benefits and burdens formulation advanced in the literature."[275] For those working in hospital care and included in the survey, "with few professional differences (between nurses, housestaff, medical and surgical attending), 74% reported that (it is) the distinction between extraordinary measures and ordinary treatments" that is helpful in making termination of treatment decisions.[276] This proportion had dropped to only 69% in a similar study looking at the same issue in 2000.[277] This belief can have marked affect on decisions related to the provision of nutrition and hydration. It was apparent in the related item where 42% believed that "even if life supports such as mechanical ventilation and

[273] Ibid. pg. 16.
[274] Ibid.
[275] Ibid. pg. 20
[276] Ibid.
[277] Dickenson, D. L. (2000). Are Medical Ethicists out of Touch? Practitioner Attitudes in the US and UK towards Decisions at the End of Life. *Journal of Medical Ethics, 26*(4), 254-260.

dialysis are stopped, food and water should always be continued."[278] If one believes that food and water should *always* be given, it would then include those who elected TS. This belief could prompt the use of more artificial nutrition and hydration being given to those who would utilize TS thus artificially prolonging their death.

Similarly concerning was the finding that only 34% overall, agreed that, "there is no *ethical* [emphasis in the original] difference between forgoing (not starting) a life support measure and stopping it once it has been started."[279] This means most respondents believed that withdrawing treatment *is ethically different* than deciding not to start a treatment. This erroneous belief was unchanged in a 2000 study.[280] Potential results could be some patients not getting "trial periods" for treatments that may be beneficial to them as well as allowing some patients to be "stuck" on medical treatments that they may not have wanted. It could also result in appropriate patients being prohibited from obtaining TS because it may involve the withdrawal of various life supporting treatments, including nutrition and hydration. Follow-up interviews with a small subset of respondents identified some reasons for believing withdrawal of treatment was ethically worse included uncertainty about what the law, ethics, and respective professional standards were, as well as:

---

[278] Solomon et al., 1993. pg. 17. They also questioned a small subsample to determine if responses would have been different if the question had read "medically supplied nutrition and hydration should always be continued" and the respondents reported that they had indicated that in the context "assumed that the statement referred to medically supplied nutrition and hydration and would not have answered differently." Ibid. pg. 18.

[279] Ibid.

[280] Dickenson, D. L. (2000). Are Medical Ethicists out of Touch? Practitioner Attitudes in the US and UK towards Decisions at the End of Life. *Journal of Medical Ethics, 26*(4), 254-260. "All national recommendations hold that the same reasoning used to withhold treatment can be used to withdraw it: the patient or surrogate's own assessment of the relative benefits and burdens to the patient, not the timing of the decision, should be determinative." Solomon et al 1993. Pg. 19.

> psychological discomfort with actively stopping a life-sustaining intervention; discomfort with the public nature of the act, which might occasion a lawsuit from disapproving witnesses even if the decision were legally correct; and fear of sanction by peer review boards. Moreover, some of the physicians expressed discomfort about openly soliciting patients' views on what would constitute an acceptable quality of life[281]

The early Solomon, et al., study recommended bioethicists increase education to practitioners about national ethics guidelines. Unfortunately, as was apparent in the 2000 Dickenson study, there was little change in the attitudes and beliefs of health care professionals concerning how to evaluate end-of-life care options or on differences between withholding or withdrawing care at the end-of-life. I suspect a new study would still show little movement in practitioners' ethical beliefs. This leads Dickenson to conclude, "We need to know more about why practitioners differ from bioethicists, and from each other, in their attitudes towards decisions near the end-of-life."[282]

Cognitive Dissonance in Withdrawal of Care

In efforts to better understand the differences between practitioners and bioethicists, Mark Bilton and Stuart Finder undertook a closer philosophical investigation of the moral experience of physicians when withdrawing ventilator care and the "boundary between the cognitive and the performative as experienced in the acts of withdrawing medical interventions."[283] This is a crucial component to attempt to understand since many who undergo, or would be appropriate to undergo TS, do so prior to or concurrent with removal from ventilator support. In attempting to define the

[281] Solomon et al., 1993. pg. 19.
[282] Ibid. pg. 259.
[283] Bilton, M. J., & Finder, S. G. (2002). Traaversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports. *Theoretical Medicine, 23*, 233-258.

conflicting emotions between what one may know is the "right thing" to do and how it feels to do it, Bilton & Finder write:

> Inescapable ambiguity often characterizes the acts associated with end-of-life decisions. For example, in the attempt to distinguish between treating pain and killing, the appeal to the rule of double effect-while an attempt to chose the 'right' words, or identify an appropriate rationale-does not transform, nor alleviate the moral ambiguity contained in these situations. Caught in the transition between treating illness and caring for the dying, and confronted with feelings that one might be killing, the anguish of caregivers - in particular, nurses, physicians, and others - can become especially acute in large part because such ambiguity cannot be easily dismissed or avoided.[284]

This may illuminate why even though bioethicists may claim that there is moral equivalence in the withholding and withdrawal of care to those actually doing the work, it feels worse to withdraw.

Bilton and Finder correctly identify these feelings as an appropriate moral issue for further ethical study but admit difficulty in attempts to truly understand the differences for others between the moral experiences of withholding or withdrawing. The moral anguish regarding concerns about how one *feels* about being *the one* responsible to withdraw certain treatments is, I believed, shared with concerns that many health professionals have concerning the provision of terminal sedation. "Involvement in situations of dying and death are reflexive for all involved, reverberating to and with the moral experience of each participant, in distinctive ways quite as much as each participant's experience has its own kind of effect on the other clinical participants."[285] Part of this experience is an attempt to understand that it is the patient who will face and directly experience death and we cannot be objective about that for them.

[284] Ibid. pg. 234.
[285] Ibid. pg. 240.

What does it mean to be the one responsible for saying, "We need to stop medical treatments" or in the case of TS, "We are going to sedate your family member until death occurs?" In terms of the boundaries of relationships and changes, this is a unique situation, to say the least. Deciding upon TS would have the same outcome as withdrawal of ventilator support with the important outcome, as Bilton and Finder note "that among the possible futures for that individual - right there in front of you - he or she has no future other than death (whether that occurs immediately after withdrawal, a few minutes or hours later, or the next day; death is the result)."[286] In the case of TS, the physician could *feel* like the one responsible for elimination of a patient's consciousness and ability to interact with other humans ever again once TS was initiated. This feeling may persist even when doctors have the intellectual knowledge that they are following patient wishes and even though death would result as a consequence of the underlying disease process and withdrawal of nutrition and hydration. The biographical interaction and participation in communicating with others would end for the patient as soon as sedation started with the physician's orders.

Bilton and Finder attempt to unpack the cognitive dissonance in these situations as having to do with when you recognize that the role you are in (such as physician and healer) leads you to a role experience (futile care situations or intolerable suffering) that exceeds your usual role (being unable to heal or required to act to allow death). These difficult situations do not have easy solutions. Bilton and Finder recommend, rather than cutting off discussion of the difficulty that exists both in actions and feelings that one

[286] Ibid. pg. 254.

find, "a vocabulary, some way to talk about and acknowledge the astonishment, even awe, in this sort of experience".[287]

This finding, "a vocabulary", seems an intuitively right solution yet one that Bilton and Finder leave for others to resolve. Once again, it seems that it is the communication about death, allowing, assisting, easing or removing one's direct consciousness of it happing to them, that is too often left too little discussed with those most closely involved. Family members often seem unaware that the option of 'not doing everything' is even available or suffer guilt for being the ones to suggest such an option to the doctors in charge. TS *allows* death to occur, it is not intended to hasten this occurrence, merely to relieve the patient of her conscious suffering as death occurs. Society is currently very open about discussing the many problems in healthcare today and it tops many political agendas. Yet, openly discussing the possibility of perhaps not extending someone's dying experience still seems taboo.[288]

There are many options for progress; I believe more open discussion of limiting or removing treatments to allow death to occur for terminal patients in a compassionate manner ought to be encouraged. Even among health care professionals these discussions are sheltered, whispered with an almost secretive air, and an almost palpable hesitance to be 'the one' to bring up *allowing* death to occur, as if talking too loudly about death might bring it about much more often. I doubt that this is the case. Allowing open discussion for physicians and nurses on how it feels to participate in TS could demystify

[287] The idea of encouraging doctors to 'discuss and share' their emotions would be difficult to put into action inside hospitals and their time is admittedly so valuable that it may be difficult to arrange an outside support group situation where voluntary attendance could occur.
[288] The provision to allow physicians to discuss advance care planning in the Obama health plan was called "Death squads", by those opposing his plan, to pay doctors for holding these important conversations with patients. This plan has yet to reach approval.

the practice and works towards congruence between what ethicists promote as moral and what practitioners believe is true by allowing airing of concerns and debriefing. The inclusion of ethics committee members in this discussion would further approach this goal.

For both the general public and hospital staff, open discussion of what *exactly* constitutes TS is needed. Fear and myths commonly accompany new and rarely used practices, open discussion about the ethical differences in intention and methods will go far to limit the current fears (of promoting euthanasia or hastening death) associated with TS. Open discussion about death and dying issues will help to reduce the taboo character and restore death and discussion of death back towards its essential nature - a natural event we all must face.

Attitudes towards TS Specifically and Emotional Burdens of Healthcare Workers

If open discussion is not promoted in healthcare practice when TS is utilized, other harms may increase for those workers involved. One of the possible harms that may increase due to TS is that it may increase the emotional burdens that our healthcare professionals carry. A study published in 2004 found that although 93% of physicians polled said that there were conditions under which they would use TS, almost 45% reported that there were conditions where it would violate the physician's personal religious beliefs, professional ethics, or believed it was inconsistent with a physician's role of preserving life. [289] Although this was a small, single-state study (fewer than 600

[289] Pomerantz, S., Bhatt, H., Brodsky, N., Lurie, D., Ciesielski, J., & Cavalieri, T. (2004). Physician practices related to the use of terminal sedation: Moral and ethical concerns. *Palliative and Supportive Care, 2*, 15-21.

polled in New Jersey), it highlights the issue that some physicians are experiencing conflict between acceptance of TS as a legitimate method for treating intractable end-of-life suffering and their personal and professional belief systems. In the same study, "Of those who used terminal sedation, 64% agreed it can be used as covert euthanasia, as compared to 71% of those who had not used terminal sedation."[290] This fairly recent study can also be interpreted to illuminate that there still does not exist many (if any) clear policies or protocols for physicians to follow to justify their orders and actions as patient directed beneficence authorized by the patient or appropriate surrogate. The lack thereof may leave them open to the misinterpretation of their actions by fellow professionals or others. These conflicts can lead to moral distress and burnout, two factors which can negatively affect patient care and lead to reduction in qualified healthcare workers. Concerns about potential harm to healthcare workers and burnout are not restricted to physicians. In fact these potential harms may be greater for nursing staff that have less decision making control and often must carry out the medication orders involved in decisions to allow terminal sedation.

In our hospitals and many others, nurses often are the ones carrying out the TS mediation orders. They often follow orders for TS even when they may not understand or support the decision, and this can lead to emotional harm.[291] The pressures of providing quality end-of-life care in a pluralistic society is a challenging aspect of nursing care and moral distress is becoming an issue of notice in nursing practice. Moral distress does not *only* affect those providing TS, but the effects may be accentuated in

[290] Ibid. pg. 19.
[291] Judith AC Reitjens, et al, "Having a difficult time leaving: experiences and attitudes of nurses with palliative", Palliative Medicine, Vol 21., (2007) pp. 643-649. Also, Tatsuya Morita, et al., "Emotional burden of nurses in palliative sedation therapy", Palliative Medicine, Vol. 18 (2004) pp. 550-557.

those providing TS. In the case example to start this chapter one can easily imagine heated discussions amongst nurses at the station. Nurses are affected by the care decisions physicians make and have definite perceptions on whether or not they agree with a physician order as being towards optimal patient benefit.

In one of the largest studies in Japan done by Morita, "*Emotional Burden of Nurses in Palliative Sedation Therapy"*, one of the factors associated with high emotional burden was nurse-perceived insufficient time for caring for patients.[292] Other notable factors which may indicate emotional harms to caregivers associated with TS include nurse-perceived inadequate coping with their own grief, belief that sedation would hasten death, and personal values contradictory to sedation therapy.[293] Often their input on end-of-life decisions and education about TS policies is lacking and may not only be harmful to them but also to their ability to provide compassionate end-of-life care to those dying. Cynda Rushton addresses the ethics of caregiver suffering and states, "Enforcing rules and policies that discount the role of nurses or other health professionals in decision-making processes renders them powerless, suppresses their values, and undermines their capacity for compassion."[294]

An extensive literature search did not discover any specific research on American nurses' experiences with utilizing terminal sedation. But, several countries who allow practices of euthanasia, physician assisted suicide and/or terminal sedation offered

---

[292] Tatsuya Morita, et al., "Emotional Burden of Nurses in Palliative Sedation Therapy", Palliative Medicine, Vol. 18, (2004), pp. 550-557. This may be due to high patient case load which may not be entirely related to TS issues.
[293] Ibid. pg. 554.
[294] Cynda H. Rushton, "Caregiver Suffering: Finding Meaning when Integrity is Threatened", in Nursing and Health Care Ethics. Ed. Winifred J. Ellenchild Pinch and Amy M. Haddad. (2008) Nursesbooks.org, American Nurses Association.

nursing perspectives on these end-of-life care options. Once again, a Morita et al. study in Japan was one of the first large investigations into how TS affects nursing staff in a survey of over 3000 nurses who care for the dying. In *Emotional Burden of Nurses in Palliative Sedation Therapy*, she found a significant number of nurses felt serious emotional burden.[295] "Thirty percent reported that they wanted to leave their current work situation due to sedation-related burden (answering occasionally, often, or always)."[296] Some of the other factors Morita found that contribute to feelings of burden related to TS were shorter clinical experience, perceived lack of time to care for patients, lack of understanding about TS between physicians and nurses, and lack of team conferencing opportunities, as well as conflicts with personal values.

A study in 2007, in The Netherlands found conflicting beliefs of nursing staff as to whether TS accelerated death or was close to the practice of euthanasia, even when they also believed that TS contributed positively to the quality of the patient's dying.[297] Nurses are also concerned that physicians are not prepared to listen to their opinions about terminally ill patients. This concern was found in 50% of the nurses who completed a Belgian study on nurses' attitudes towards end-of-life care (which included dying with terminal sedation) in 2009.[298] As I have stated earlier, it is of utmost importance that any decision for TS be supported by all team members (this includes other interdisciplinary members such as social workers and therapists) prior to initiation. Nurses emotional

[295] Morita, T., Miyashita, M., Kimura, R., Adachi, I., & Shima, Y. (2004). Emotional burden of nurses in palliative sedation therapy. *Palliat Med, 18*(6), 550-557.
[296] Ibid.
[297] Rietjens, J. A. C., Hauser, J., van der Heide, A., & Emanuel, L. (2007). Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliat Med, 21*, 643-649.
[298] Inghelbrecht, E., Bilsen, J., Mortier, F., & Deliens, L. (2009). Nurses attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. *Palliative Medicine, 23*(7), 649-658.

distress would be greatly increased if they are not in agreement with the provision of TS, yet they are often not included in full in the discussions between patients/families and physicians on direction of care. This may be because it happens "on the fly" during physician rounding or due to nursing turnover and at shift rotation times.

Regardless of precipitating reasoning, it will be important to reduce the emotional distress of nursing staff and to include them more fully in creating hospital policy regarding TS initiation. Hospitals may also allow those nurses (and other team members) who hold objections to providing TS to be reassigned to other patients, similar to what is done when nurses object to assisting with pregnancy terminations. The incidence of TS occurring on a particular ward will likely remain low, since there are usually only a few deaths a week on any particular floor and I would not anticipate a reassignment to be unduly difficult. This difficulty in reassignment could likely be offset by increased employee satisfaction when their values or feelings are respected by the organization.

A small, descriptive, exploratory study about TS was completed in Canada with a sample of palliative care nurses.[299] This study focused on nurses' perceptions on the utilization of terminal sedation. "Nurses emphasized that their comfort level with implementing [terminal] sedation depended on their personal knowledge of the patient. The essence of knowing the patient as a person is a central aspect of nursing practice."[300] This is a key concept to which I will return later in this chapter when discussing how the

[299] Beel, A. C., Hawranik, P. G., McClement, S., & Daeninck, P. (2006). Palliative sedation: nurses' perceptions. *International Journal of Palliative Nursing, 12*(11), 510-518.
[300] Ibid.

current changes in hospital care may affect the harms to workers when providing terminal sedation.

Overall, in the surveys looking at nurse perceptions when involved with provision of terminal sedation, it appears that, although most nurses believe TS allows patients a 'good death', they are often involved in conflicts or experience emotional distress when there is a lack of clear communication or involvement of the interdisciplinary team in the decision making process to initiate TS.[301] Therefore, again, one must emphasize that extensive and clear communication is essential to the provision of TS, not only for patients and families, but also for the healthcare workers involved.

Fear of Litigation

Despite the best intentions of many physicians and nurses to provide compassionate care to those who are dying in accordance with the principles of beneficence, nonmaleficence and the autonomy of patient's wishes, careers have been destroyed by claims of wrongdoing related to end-of-life care. This is a realistic potential harm to be incurred by healthcare workers involved in TS. It is of little matter that rarely do the claims of wrong-doing ever prove successful in court. Once charges have been leveled and the litigation begins, it is often the beginning of the end for either nurses or physicians involved in the dispute. The court of public opinion can be swayed by the mere hint of scandal and caregivers are labeled with a scarlet letter warning others that

[301] Claessens, P., Genbrugge, E., Vannuffelen, R., Broeckaert, B., Schotsmans, P., & Menten, J. (2007). Palliative Sedation and Nursing. *J of Hospice and Palliative Nursing, 9*(2), 100-106, Inghelbrecht, E., Bilsen, J., Mortier, F., & Deliens, L. (2009). Nurses attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. *Palliative Medicine, 23*(7), 649-658, Morita, T., Miyashita, M., Kimura, R., Adachi, I., & Shima, Y. (2004). Emotional burden of nurses in palliative sedation therapy. *Palliat Med, 18*(6), 550-557.

they are not to be trusted. Frequently charges are not even brought by those most closely involved with the case in question, but rather come from others who may be on the edges of the case or not even involved.

Registered nurses, such as Sharon LaDuke, from Ogdensburg, NY, have been prosecuted when acting in accordance to MD order, with family support and following a patient's advance directive.[302] Sharon was an intensive care nurse who was following physician orders to provide narcotic pain medication to keep a patient comfortable following removal of the ventilator. The patient had an advance directive stating she did not want to remain on a ventilator; family was aware and supportive of her wishes and authorized the removal with the caveat that "she be kept comfortable and free of pain". Sharon was formally accused of euthanasia by a hospital nursing administrator and fired from her job. Although she was eventually vindicated, it was only following a lengthy and prolonged civil lawsuit.[303]

The television show *60 Minutes* also highlighted a case in March 2002, where Dr. Robert Weitzel was also accused of murdering terminally ill patients.[304] He, too, was eventually acquitted but in the mêlée lost his career, savings, and reputation. Dr. Lloyd Stanley Naramore faced similar accusation related to ending life support and was convicted in 1992.[305] His case has been documented on an A&E cable show and

---

[302] LaDuke, S. (2000). The Effects of Professional Discipline on Nurses. *AJN The American Journal of Nursing, 100*(6), 26-33.Lewis Cohen, *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die.* Harper Collins Publisher, New York. 2010.
[303] Ibid. pg. 151-152.
[304] Ibid. pg. 156-160. Also confirmed on website for attorneys representing Dr. Weitzel.: Bugden & Isaacson, L.L.C. http://www.bilaw.net/practice-areas/criminal-law/cases/ accessed June 15, 2011.
[305] Fisher, F., B., M.D. (2004). Evaluating the Risks of Unwarrented Prosecution. *Journal of American Physicians and Surgeons, 9*(4), 114-117. and Cohen, L. (2010). *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die*. New York: Harper Collins Publishers.

highlights a juror stating that he determined that Dr. Naramore was guilty because he didn't like his personality and didn't want him practicing medicine.[306] This physician was sent to a maximum security prison in Kansas where he remained until a 1998 court of appeals reviewed the case and reversed his conviction. Further, the justices expressed their indignation and stated

> …With no direct evidence of criminal intent, it is highly disturbing that testimony by such an impressive array of apparently objective medical experts, who found the defendant's actions to be not only noncriminal , but medically appropriate, can be dismissed as 'unbelievable' and not even capable of generating reasonable doubt.[307]

These are true harms to medical practitioners that come from false or untrue accusations. Most accusations are unfounded but vindication is little salve to a shattered career and life. It is of little wonder that those who work with the dying tread so carefully and would want to eliminate any and all concerns or appearances of hastening a dying patient's death. Although there will always be the ill-advised family member, rogue staff member or religious zealot out to make wild accusations, it seems to happen more often in cases where patients are dying.

One approach to rectification is to again ensure a clear hospital policy on TS, adequate communication and education on all end-of-life care, including withdrawal of aggressive treatments and terminal sedation with medication. These discussions need to include all family members and all staff involved in patient care whenever possible. This will allow more opportunity to answer questions, discuss possible alternatives, and when necessary to delay making any actions. The inescapable potential harm in this tactic is that it may increase patient suffering through the delays required to follow the above

[306] Cohen, 2010. pg. 167.
[307] Ibid. pg. 168-9.

recommendations and the time involved in seeking consensus. Or worse, the lack of consensus may prevent patients who ought to be eligible for TS from receiving it.[308] This may be a case of conflicting principles between what is most beneficent for the patient verses what is least maleficent for the physician and care providers.

Other countries have included these factors in their protocols and policy. The formal policy developed in Belgium demands both a waiting period and interdisciplinary involvement. Claessens, et al., state that, "A 24-hour period between the request for terminal sedation and its final execution [is needed]. This period gives the patient and family the opportunity to consider fully the treatment, perhaps make certain [final] arrangements, and part from loved ones."[309]

And regarding the interdisciplinary requirement,

> The decision to initiate palliative sedation is always taken at a multidisciplinary level. It can never be an individual decision taken by one member of the team alone. The patient and entire team must agree once all attempts to treat the refractory symptoms have been made. The family must be closely involved or at least be fully informed of the decision process.[310]

It may be possible to shorten the time period between patient request and TS if that patient has made his desire for TS known in advance to his family and physician should a situation develop where the treatment would be appropriate. Interdisciplinary team meetings as a routine morning staffing update could encourage early identification of TS as a possibility and allow discussion of concerns early in the hospitalization. The inclusion of desire for TS, if appropriate, could be added into an advance directive form as requested treatment, similar to a patient refusal of other treatments such as ventilator

[308] Thanks to John Hardwig for pointing this out in an earlier version of this paper.
[309] Claessens, P., Genbrugge, E., Vannuffelen, R., Broeckaert, B., Schotsmans, P., & Menten, J. (2007). Palliative Sedation and Nursing. *J of Hospice and Palliative Nursing, 9*(2), 100-106.
[310] Ibid. pg. 104.

support or dialysis. One may consider TS as assumed to be requested if the patient has checked the option for "all care related to pain control and comfort measures to be continued" but given concerns of clarity and since TS removes a patient's consciousness, I would endorse an additional statement of patient desire for TS be added to her advance directive.

Physicians may be left in a most difficult situation when attempting to discern what is in the patient's best interest. Consider for example, the physician in the case at the beginning of this chapter where the patient values are unable to be discerned from neither the patient himself nor the family present.

Systems-Based Practice

Contemporary medical practice in a hospital environment is a complex situation to examine. I will argue that the current focus on systems-based practice may negatively affect physicians' ability to provide optimal end-of-life care; this includes the option of TS, unless explicit steps are taken to prevent this from occurring. Reduction in the ability to provide quality end-of-life care may result in additional harms to physicians' emotional role fulfillment. Role fulfillment is the sense of accomplishment one obtains from doing their job and believing they are doing it well and for good reasons. Positive role fulfillment combats burnout and emotional distress while negative role fulfillment contributes to burnout and emotional distress.

Since the 1950's modern medical care has made a dramatic shift. In times past, the family doctor handled almost all of his patient's care needs, and trusting relationships developed over years of learning about one's health conditions. Currently, if you have

any "conditions" at all you likely see a specialist to manage that disease and often one may have many specialists to see each year in addition to a family doctor. If hospitalization is required then you may not see any of your personal specialists nor your family doctor but rather, a hospitalist who only sees current hospital inpatients. This allows both primary care doctors and specialists to see more chronic care patients in their offices and the hospitalists who specialize in acute health care to focus on the more urgent needs of those patients who are hospitalized.

Where physicians used to be in private practice and had individual focus on the treatment of those persons and families who were under her care, nowadays many, if not most, work in practice groups, or are employees of large health care organizations. This is what is termed Systems-Based practice (SBP). Systems-based practice focuses on looking at the interrelationship of the complex systems of individuals, systems and networks and the conflicting goals involved in meeting healthcare needs.[311]

Physicians work as part of larger healthcare systems and may interact with others who are part of the same or different larger systems at times. The physician, employed by the hospital or HMO, now has a primary focus on the organizational mission to provide healthcare to the community rather than the individual patient's benefit.[312] Physicians' groups are responsible for groups of enrollees. This often translates into doctors 'on call' for the day seeing whomever comes in rather than allowing individual

[311] Mills, A. E., Chen, D. T., Werhane, P. H., & Wynia, M. K. (Eds.). (2005). *Professionalism in Tomorrow's Healthcare System: Towards Fulfilling the ACGME Requirements for Systems-Based Practice and Professionalism* Hagerstown, Maryland University Publishing Group, Inc.

[312] This larger focus is necessary if physicians are to make decisions about how to contain cost and ration expensive treatments. This is a controversial stance and supported by those who fear the alternative would be rigid practice guidelines developed by folks who don't know the patients at all. Admittedly health care in our nation is still undergoing great change and I will watch this with ongoing interest.

practice relationships to develop by allowing patients access to the same physician routinely.

Patient records are mostly electronic and allow data to be transferred easily. This allows each successive physician to add to patient progress notes or read past history. This change in methods has, as predicted, reduced insurance costs and allowed physicians paid in capitated HMO arrangements to see more patients and thus increase their income and spend fewer hours on call. However, it has left some physicians feeling more dissatisfied and less like patient advocates.[313] Importantly, this shift in physician practice (seeing more patients and spending less time per patient) was motivated not by physicians and surely not by patients, but by the large group insurance providers to reduce costs.

The Accreditation Council for Graduate Medical Education (ACGME) began the Outcome Project in 1999 to launch six general areas of expertise or core competencies that resident training programs needed to ensure physicians were prepared to practice in this new environment. Many were the expected competencies in patient care, medical knowledge, practice based learning, and interpersonal communication that we have all come to expect from our doctors. Two new competencies were added, that of professionalism which includes "a commitment to ethical principles pertaining to…business practices"[314] and systems-based practice. Business practices includes things like cost containment as well as methods to serve the uninsured and knowledge about

[313] Steven Z. Pantilat, Ann Alpers, and Robert Wachter, "A New Doctor in the House: Ethical Issues in Hospitalist Systems", *JAMA*, Vol. 282, No. 2 (1999) ,pp. 171-174.
[314] Mills, A. E., Chen, D. T., Werhane, P. H., & Wynia, M. K. (Eds.). (2005). *Professionalism in Tomorrow's Healthcare System: Toward Fulfilling the ACGME Requirements for Systems-Based Practice and Professionalism*. Hagerstown, Maryland: University Publishing Group.

how prescribing and ordering practices affect the larger system; these responsibilities are new additions to the physician role. Many now believe that these changes will affect the patient-physician relationship. "Taken together, these two competencies move professionalism from its traditional focus on the individual physician to focus on how the individual physician interacts with, and is influenced by and through, the systems that deliver healthcare."[315] These competencies now require the physician to assume some responsibility for the appropriate functioning of the system as well.

Physicians are now routinely hired by hospital systems to work solely within the hospital inpatient environment. These hospitalist doctors are employees of the hospital and charged with providing care for those patients admitted to their service only during the acute care hospital stay. Often, these are recently graduated medical school residents who are well aware of the requirements of systems-based practice. They do not expect to develop a lingering relationship with the patients that they serve; the goal is effective treatment and discharge from the hospital.

"Increasingly in healthcare, relationships are formed at the point of illness."[316] For those dying this means they may not meet the physician directing their death until their last hospital admission. What sorts of potential harms may occur due to this new method of healthcare practice? I can foresee potential harm to the physician-patient relationship and also harms to the physician providing care. If upon meeting a patient it is apparent that this patient will not survive and you will be the last doctor to care for her,

---

[315] Ibid. pg. ix.

[316] Stanley J. Reiser, "Technologic Environments as causes of Suffering: the Ethical Context", The Hidden Dimension of Illness: Human Suffering, Editors, Patricia L. Starck and John P. Mc Govern, National League for Nursing Press, New York,(1992). pp 43-52.

one can easily imagine that, even if only for emotional self-protection, it would be easier to distance oneself from developing a meaningful relationship with that patient.

What effects may this have to those in medicine over time? Some may fear that it could result in overuse of TS due to the lack of personal relationships between patients and hospitalists and because hospitalists are more used to having their patients die. I do not see this as the likely outcome, as it has been well-documented there is a much greater tendency towards the overtreatment of those in the last days and weeks of life. I will argue that this may affect physicians in ways that could limit TS being utilized as an appropriate option for some as end-of-life care.

A focus on atomization, begun with the advancement of medical science and diagnostics, has lessened in some ways; the ancient art of healing that began with listening to your patient. It has also allowed many physicians to escape actually being with patients at the time of their death. Where in days past, physicians knew death well; they now have a much more distant and often adversarial relationship. How has this manifested itself in to the patient-physician relationship? Part of the requirement on Systems-Based Practice includes the use of Evidence Based Medicine (EBM) which supports using treatments that have been proven by empirical evidence to be most effective in treating the ailment you are addressing. This has lead to great advances in treatment of things such as heart attack, heart cauterizations, stroke and GI bleeding, to name just a few. EBM and critical care pathways lead physicians and nursing staff to precision care that has been empirically validated to reduce both cost and waste while allowing the best potential for good medical outcomes. It works well for specific identifiable disease processes or treatments. Most of these pathways are built into the

Medicare Diagnostic Related Groups (DRG's) that control hospital and physician payment for caring for those who are admitted under each diagnosis. Hospitals attempt to reach the JACHO standards to become a "center of excellence" verifying outstanding compliance to specific illness pathways and meeting patient care and payment goals. This can be a major marketing tool for the hospital system since patients who can choose would want to go to the "Center for excellence in heart surgery", for example, over merely the "other hospital."

Those working in hospital environments now routinely accept that a hip replacement is a three-day DRG. With EBM one expects patients to be up in the afternoon following surgery, in the hall on day 2 and out the door on day 3 going home. If a patient is not moving along fast enough and passes their DRG days, then they are usually transferred to a lower level of care such as a nursing home. There are books and logs listing the time and payment allowed for each diagnosis and no one is paid if a patient stays longer without appropriate and verified complication codes.[317] There are physician review boards for exceptional cases but the time and effort involved to reach a review level make it a path less taken in many cases. It's easier to follow the EBM pathways and move forward and move the patients through the system. Physicians are rated as to how well they can follow prescribed EBM pathways and keep down in-patient hospital days. Moreover, if they fail to keep within the guidelines they may be released from the insurance companies covered physicians list if they are too much of an "outlier" in costs or inpatient days.

[317] These additional complications may be for things such as unanticipated bleeding, fever, sepsis, or illus and will allow additional payment for hospitalization until patient is stable for release.

Sadly, dying has a much less predictable pathway. Dying remains a unique and individual trail that one must meander along. I have yet to hear of any hospital vying to become a "center of excellence for dying". Obviously all EBM has failed when your patient dies. Another problem is that there is no DRG for dying and this complicates the process when physicians are attempting to get a patient admitted for end-of-life care. While there is one for uncontrollable symptoms, if your symptom (dyspnea, pain, bleeding, or vomiting, etc.) can be controlled, unless there is another new problem, once under control, a patient is expected to be discharged. No matter that one is actively dying. If there is nothing that can be specifically coded and fixed, there is "a problem with the admission." If the patient is admitted for symptom control and it comes under control but the patient is actively dying or too weak to be moved the doctor may be informed by the insurance company or case manager that her patient "fails to meet criteria" for continuing stay.[318] Thus, the doctor is caught between doing what is best for their specific patient and what is best for the business of the hospital. The new ACGME competencies require that they be committed to both. It may come down to where the closest relationship is established between the doctor and patient or doctor and hospital. Or, it may be decided upon by physician practice group norms, or how strongly the case manager pushes for discharge, or what sort of bed crunch the floor is having that day. The ancient priority of physician-patient relationship now has a great deal of competition.

Has the era of the specialists, who compartmentalize patient illness into specific fixable or non-fixable ailments eliminated or reduced the function of caring? When your

[318] There is coding for patients who are unstable for transfer but even then one is expected to be documenting what is being done to *attempt to stabilize* those patients. For many dying, there may be nothing more, medically, to be done to counter the march towards death, or those efforts may not be the wishes or appropriate for the patient.

pulmonologist is concerned only about listening to your lungs and your oncologist about beating your cancer who is there to listen to your heart? Not the beating in your chest, but the aching of your soul when facing death, a pain that is only cured with compassion. Multiple studies show that residents receive little training on caring for the dying patient or coping with death.[319] They have advanced skills as medical technicians but may lack the simple compassion required to sit silently beside a dying patient. How has this lack of training in coping with death affected the satisfaction of care providers? One can surmise that it might be decreased and further, this increased their ethical burdens as,

> Residents recalled deaths that occurred after starting opioids and worried that they had hastened dying or might be blamed for contributing to the death. Several housestaff mentioned difficulties coping with their own grief, particularly when the patient was young or when life supports were withdrawn.[320]

There is reason to believe that harms do occur as stated by Stanley Pantilat, et al.,

> Thus, the technology of healthcare, by fragmenting its delivery among a spectrum of specialists and codifying its view of illness in the form of ciphers and graphs, created as an unintended by-product the patient as stranger. Such detachment of the life from the illness of the patient has as its effect suffering.[321]

Harms to the ancient physician-patient relationship seem apparent due to systems based practice and the advancement of specialist care. The primary harm being the lack of "relationship" when relationship infers a mutual caring that has developed over time. This is not possible in many situations today when patients are assigned to whatever hospitalist happens to be "on" when they are admitted.

---

[319] Joanne Lynn, et al., "Physician Experience Caring for Dying Patients and Its Relationship to Patient Outcomes" *Journal of Palliative Medicine*, Vol. 1, No. 4, (1998) pp. 337-346. See also, Timothy G.G. Ferris et al., "When the Patient Dies: A Survey of Medical Housestaff about Care after Death", *Journal of Palliative Medicine*., Vol. 1, No. 3. (1998). pp 231-239. And, Marc R. Larochelle et al. "Hospital Staff Attributions of the Causes of Physician Variation in End-of-Life Treatment Intensity". *Palliative Medicine*, Vol. 23, No. 5 (2009). Doi:10.1177/0269216309103664.

[320] Ibid. pg. 235.

[321] Pantilat, et al., (1999) pg. 48.

These harms may result in increased emotional burdens for both sides (primary care physicians and hospitalists) of physicians practicing in SBP. Further, it may also affect the appropriate provision of end-of-life treatments such as TS to the persons for whom it would be appropriate. The hospitalist forced to care for dying patients that they have had no prior relationship with may be reluctant to allow TS due to fears of litigation if there is any misunderstanding of orders by any family members or hospital staff. They may also feel a need to try additional treatments to reduce patient suffering since they have not been involved in the past attempts to resolve intolerable symptoms, thereby potentially lengthening the time that the patient is forced to suffer the intolerable symptoms. Or, if they do allow TS to relieve patient suffering they may have lingering concerns about either giving up too soon or hastening death with the use of opiates if the patient dies quickly. Either way, they may have to face case managers, hospital administrators, and insurance companies who will require justification for inpatient hospitalization for patients who are not undergoing any diagnostic procedures and are not meeting acuity of care needs (utilizing only one IV medication) and once the patient has been 'stabilized' they will press for discharge regardless of nearness of death.

If patients linger prior to dying there may be the dreaded "unreimbursed days" the hospital system must absorb for those undergoing TS and physicians may be asked to "justify" the additional days by utilization review boards. Prior to the 1980's there was not such an intense focus on the number of hospitalized days and physicians were given great leeway in keeping patients in the hospital. With the advent of DRG's patients must now meet in-patient acuity to have each hospital day reimbursed. Since close monitoring of IV medications is required during TS to ensure that the patient remains adequately

sedated without breakthrough of noxious symptoms, I believe that continued physician monitoring is appropriate in a hospital setting and that reimbursement ought to be allowed for terminal care to the dying.

Finally, on the other side of the systems based care issue is the primary care physician who loses the opportunity to provide end-of-life care to the very patients that they have been following in their practice with a terminal illness. They may suffer from feelings of having abandoned their duty or failing to complete final care for their patients and families. Alternatively, those primary care physicians who are unprepared to cope with the death of their patients will be relieved from providing TS and other end-of-life care.

Especially for the hospitalist assigned, the final hospitalization for a terminal patient with intolerable suffering, it appears the current use of TS is fraught with potential problems. This may encourage them to not utilize TS even when appropriate.[322] Given that hospitalist can expect to care for more dying patients, advanced training in hospice and comfort care would be appropriate. Would all of these issues be resolved if the primary care physician were following or involved during the last hospitalization? Surely not, TS is still a treatment for refractory suffering and not to be used as routine end-of-life care. Intentionally medicating a patient to unconsciousness while knowing they will die soon from underlying illness will and ought to prompt moral hesitancy.

There are times when the primary care physician, although not the admitting hospital physician, can be involved. They are able to offer counsel to both the hospitalist

[322] Again, the converse is less likely but it may also be the case unless carefully monitored that TS may be inappropriately overused. TS would be both cheaper and easier than attempting to control noxious symptoms while maintaining consciousness. This comment is thanks to John Hardwig.

about the patient's history and wishes and also to provide that compassionate relationship interaction to offer closure to families, reassuring them that TS was an appropriate method to allow a peaceful death for the patient. The point is merely that the current focus on SBP does not encourage the sorts of relationships that would easily support the provision of TS since physicians may not have a good understanding of patients' or families' desires for end-of-life care or how to provide TS treatment.

EBM will also be complicated by attempting to develop a specific empirically validated formula for TS. This task, although difficult, would be possible since most protocols currently state a starting dose of Midazolam of 10mg, and then increasing by 1.5 to 2mg./hr. titrations until patient appears to be resting comfortably. This dosage can then be adjusted by physician orders until the patient is resting comfortably and showing no outward signs of distress. This ongoing titration is best done in the hospital since it is not uncommon for patients to require ongoing adjustments of medications due to breakthrough distress and dosage requires direct physician involvement so as to not over-medicate the patient and inadvertently hasten death. The time until death will continue to be variable as it is always dependent on the multiple variables of patient condition and disease process.

The potential harms from SBP and EBM will require additional work from physicians to resolve successfully the competing responsibilities assigned by ACGME regarding professionalism and SBP when utilizing TS. I believe that it will be possible but will require physicians to acknowledge their coexisting priority to excellent patient care. This includes treating intolerable suffering at the end-of-life, and utilizing advocacy for those dying who require careful monitoring of medication to assure that suffering

does not return until they succumb from their disease.[323] This process may not be able to fit into an easily codeable DRG[324] but one would hope that it could be assessed on a daily basis as an exception and allowed as a billable day. Having the clear daily assessment included in hospital policy and protocols for TS would assist in education of insurers to become aware of TS as a valid treatment for a minority of patients who experience intolerable suffering at the end-of-life.[325] This process will not be an easy one to address and will take considerable time and effort yet the steps can be envisioned as beneficial to the insurance companies and the goal is worthy.

Palliative Sedation as a Practice against Personal Conscience

A final harm for physicians and nurses involved in TS is the emotional distress that comes from acting against one's personal conscience for those who do not support the treatment. At times physicians may be supporting patient autonomy in providing TS but suffering personal distress from acting against their conscience.[326] A recent study shows that factors such as religious affiliation and ethnicity may affect the end-of-life

[323] I believe that, at this time, physician monitoring of medication is required due to the complex factors involved in monitoring for breakthrough pain without over medicating to hasten death or worse to cause death. I can envision a time in the future once TS becomes a more routine treatment for those close to death when specialized training may be given to advance practice NP, PA's and palliative care nurses to allow physician extenders to monitor this treatment to allow greater flexibility in place of death with TS.
[324] If the patient has enrolled in Medicare Hospice benefit or a private insurance hospice benefit then in patient hospitalization could be allowed for symptom control for up to two weeks. It varies as to if patients can be changed over to the general hospice benefit during an inpatient hospital stay and it is sometimes discouraged by hospital administration because the reimbursement is lower. This is not always the case though, because if the patient has exceeded her DRG then the hospital may not be receiving any insurance coverage and then the daily $100 hospice rate would be better than no payment.
[325] It seems likely that insurance companies will embrace the concept of TS once they are educated on the practice since it reduces more expensive hospital treatments at the end of life.
[326] Farr A. Curlin, et al. "To Die, to Sleep: US Physicians' Religious and other Objections to Physician-Assisted Suicide, Terminal Sedation, and Withdrawal of Life Support", *American Journal of Hospice and Palliative Medicine*, Vol. 25, No. 2. (2008) pp.112-118.

decisional support one receives from physicians.[327] The fact remains that patient autonomy and family pressuring may force the physician at times to go against his own beliefs and choose reluctantly to participate in actions to which they object. There is also the concern of some that medicine is designed to treat illness and promote health and healing and not to aid or abet the process of death. For some even the practice of withdrawal of medical treatments goes against the personal morals of physicians. This appears to be the case with the physician in our case example for this chapter. One would not expect him to be forced to go against his personal religious or other moral convictions towards promotion of life at all costs. His provision of care could be endorsed by the wife's request that he do what he believes is 'best'. What if an Ethics Committee consult was called by nursing staff and the Committee endorsed withholding of ventilator care and TS?

These issues of moral distress and harm are only now beginning to be evaluated in health care practice. To those physicians and nurses who have significant moral prohibitions against participation in TS, further education on the practice and its moral allowability may not change their sensibilities. They ought to be allowed to remove themselves from the case and find other caregivers to support patient and family wishes when a patient meets the requirements for allowing TS as end-of-life care. In the case example for this chapter, the physician could request a second physician opinion or review of the case, that an Ethics Committee consult review the case for recommendations or that another physician take over the case.

[327] Ibid.

A final concern relates to the perception of physicians as healers and that participation in TS may afford some public misperception of their identity or harm to their professional status or lead to litigation. The answer to this concern is clear communication to all those involved and clear policies. Public education of any new medical treatment requires considerable time and effort to assure an accurate understanding of both the potential benefits and harms involved. This process is assisted by the stories told by the families who have undergone the procedure or treatment and shared their experiences with others in the communities in which they live. TS can provide valuable solace to families who have been watching a loved one suffer. The decision to utilize TS is one which must be made carefully and with the support of both the health care professionals and families involved with appropriate education provided to allow clear understanding of the treatment.

Conclusion

The benefits of endorsing TS would be to allow health care professionals a sense of being able to offer their patients and families a peaceful and quiet death. The skills required in administering sedatives and continuing to provide comfort care could endorse their personal satisfaction in a much needed skill set to aid those facing death. It could also ease the harms of those who have been suffering moral distress due to believing they are torturing patients by prolonging suffering and dependence on advanced technology when no cure is possible. These concerns may be those similar to the nurses in the case example.

As in other areas, many of the harms can be addressed by insisting on frequent and clear communication amongst all involved parties. The hospital systems and administration as well as insurance companies and their advocates must be somehow included and this will at times complicate the process of providing TS to patients.[328] This fact in no way deters the beneficence of the outcome. The new ACGME standards requiring physician competency in ethical business practices may even be interpreted to demand that physicians become better advocates at a systems level to allow dying patients greater access to inpatient hospitalization and care in dying.

It is moral to show concern for the harms others may suffer and attempt to reduce them where possible. Since caregivers (physicians, nurses, social workers, and other hospital staff) may suffer harms related to providing TS treatment for intolerable suffering the health care professionals ought to act to reduce their burdens where possible. This may be done in part by:

> -increasing professional staff (especially physician) education on working with those actively dying and coping with death,
>
> - increasing staff time to allow interdisciplinary discussions regarding the patient, the process of TS, and to encourage questions,
>
> - working to develop relationships with insurers to educate them on the practice and develop appropriate reimbursement, and
>
> -creation of a clear hospital policy for TS that will be followed by physicians and staff, This policy is to mandate interdisciplinary support for TS treatment and allow reassignment for those who have a conscientious objection to providing TS care.

[328] I anticipate these complications to come upon initial development of hospital policy and as insurance companies become more familiar with TS as an end of life treatment and to have an ongoing reduction as time and familiarity with the practice increases.

In summary, although there are some significant potential burdens for professional caregivers when TS is utilized at the end of patient life, many of these burdens may be mitigated or eliminated by increased focus on ensuring clear communication and development of clear protocols.

To resolve the case at the start of this chapter:

Allowable TS - patient would not currently be surviving without significant medical assistance with 2 major organ systems involved in shut-down and prior advanced illness from 2 severe chronic and progressive diseases (cardiomyopathy, COPD).

1) *Assess if any other family or potential surrogates are available to assist this patient*
2) *Hold interdisciplinary team meeting with RN, and other care providers to gather input and consensus on options*
3) *Request Ethics Consult if no consensus is obtained and/or no additional surrogate is located**
4) *Pt. appears to be suffering from severe dyspnea*
5) *Current attack of illness would be fatal without intensive medical intervention including soon ventilator which pt. stated he did not want. Ethical to withdraw dopamine and withhold vent.*
6) *Death would occur within hours to days without treatment*

** Additionally, as family is not clearly able to show competent support, I would involve the hospital ethics committee or an ad-hoc consultation to confirm appropriateness of withdrawal of aggressive measures and intensive comfort to sedation. Physician should document wife's request in quotes, also have ethics committee consult attempt to talk with her. Document and assure all team members are aware of treatment plan and ethics support. Would request SW to work with wife to identify who her support network is and that they will be responsible for assisting her once husband dies. This may all require that patient be maintained on blood pressure support drips and Bi-pap longer (a day or two), it also may not be possible if lung condition deteriorates so that he would require full vent support.*

CHAPTER 6

POLICY GUIDELINES AND FUTURE NEEDS

Introduction

All medical progress deserves careful consideration of both the benefits we hope to obtain and the harms which may accompany this progress. Terminal sedation is a medical treatment for those patients who are actively dying and whose pain and suffering are intractable to traditional treatments. I have attempted to identify relevant benefits and harms for patients, families, and medical professionals to consider related to the practice of TS. It must be acknowledged that persons will vary in their acceptance of specific factors as being either a benefit or a harm given their personal values and philosophical framework. This allows for the benefits and harms in each situation to be judged within their unique circumstances prior to making a decision. For many, I suspect that the desire to eliminate the overwhelming suffering of the patient will be an overriding value and the beneficence of allowing TS will balance concerns about the harm in elimination of the patient's consciousness or harms to others. Since each case will be evaluated on its own particular merit, my inclusion of possible harms and benefits has been meant to allow a more complete starting point for this evaluation, and to include others than just the patient as possibly affected by TS. I anticipate that the specifics evaluated in each situation will vary and grow as the practice continues.

Although terminal sedation has been utilized since the early to mid-1990's this treatment has remained controversial or misunderstood by many in healthcare and simply unknown to most of the general public. This dissertation has attempted to provide a clear

description of the practice (including specifically how it differs from both euthanasia and physician assisted suicide) and to identify and clarify where potential harms not previously identified may exist. The goal of this effort is to assist in allowing clear evaluation for patients, families and medical professionals to make specific case determinations and to assist those in health policy development to create clear policy and protocol for the practice in healthcare institutions.

I will close this dissertation with my thoughts on why policy on TS is important. I will then offer two versions of initial guidelines for development of hospital policy. The first version will outline minimal guidelines that ought to be utilized to allow TS for patients who fit my standard. The minimal guideline is based upon the recommendations of the American Medical Association with some modifications. This guideline is meant to offer relief to those who could benefit from TS while remaining clear of the concerns brought by those who fear TS is too closely related to PAS or euthanasia. The guideline is admittedly restrictive in hopes of gaining wider societal support for a currently controversial practice.

Secondly, I will offer more moderate guidelines for policy that I hope could become a standard in the future. It will maintain the restrictive focus of the minimal guidelines for patients and offer additional education and support to others which has yet to be broadly provided. I view these guidelines as benefiting both patients and those others who may be affected by TS and importantly, also be accepted by mainstream society. The moderate guidelines would mark an important step forward for allowing more choices in dying and offering additional supports to those involved with dying patients. Even the moderate guidelines would entail changes by many parties. Many

organizations and entities, such as insurance companies, hospital administrations, and even society at large would need to make changes towards facing the denial of death, holding open discussions about dying, and a greater commitment towards meeting the needs of those who are dying. Since increasing interest in palliative care shows concern about care for the dying is continuing to grow, it is reasonable to believe that my guidelines could become future policy. Therefore, I will explain what I believe will be important guidelines in development of a TS policy of the future that would better support patients, families, and professionals. These guidelines could gain widespread acceptance to allow a better death for many persons in the near future. It is clearly a step in the right direction to provide patients compassionate care, beneficent treatment and autonomy in their dying. Lastly, I will share ways that TS policies may progress in the future.

Why Clear Policy?

It will be important to create transparent hospital policies and protocols for the provision of TS. The need for clear TS policy is not only due to ethical concerns that appropriate patients receive the treatment but also practical concerns about the way hospitals operate which affect the ability to provide good care to the dying, including TS. Hospital staffs are routinely educated on new procedures by learning and following carefully written hospital policy. Staff must learn the policy and protocols written by doctors in patient orders to properly provide and monitor the treatment. Thus, policies need to include appropriate indications for treatment, drugs used, dosage administration, and patient monitoring during the provision of TS. The process of creating policy and

staff education to advise them of the accepted protocol, will also aid in legitimizing the practice as an accepted end-of-life treatment. A policy will endorse TS as an approved treatment offered by the hospital that has passed through the approval process of the various review committees and gained written approval from each level prior to being accepted as 'hospital policy'. Hospitals that allow the practice of TS without a policy risk encouraging the whispers of the uneducated that may suggest TS as a form of PAS and continue to keep this treatment controversial. Further, policy approval will allow for physicians the confidence that they have administrative support for providing TS as end-of-life treatment to their patients. Policy will also assist in limiting potential for litigation and clarify instances for determining if the policy was enacted incorrectly for physician oversight committees.

There are, however, also drawbacks to establishing a clearly written policy for TS. The primary drawback is that some patients who do not easily fit into the policy guidelines (for example those that have a life expectancy slightly exceeding the one specified by the policy) will not be allowed TS and forced to endure continued suffering. An additional concern is that if the protocol is written too stringently - for example on formulary drugs used - then if a patient cannot tolerate those drugs or has allergies, they may not be eligible for TS using other drugs, or newer drugs not written into the protocol. A final drawback to policy is that due to the necessity for many levels of approval the policy making process can often become a lengthy one, especially if the proposed policy covers a controversial subject like TS. This could then deny patients access to the treatment while awaiting policy development.

Nonetheless, I view the benefits of good policy as outweighing the drawbacks and believe this is especially true for new treatments. Policy is especially needed for treatments like TS when errors (in medications) could inadvertently lead to a hastened patient death. I will now address what I believe would be a minimal standard for hospitals to establish to allow the provision of TS to patients.

Minimal Policy Guidelines

I have stated that TS is the appropriate and intentional use of medications to produce ongoing, deep unconsciousness upon three related conditions: 1) a terminal patient's (or surrogate's) request due to 2) intractable pain or other distressing clinical symptoms and when 3) death is expected within hours or days (less than two weeks) due to terminal illness, injury, or disease. This is an extremely minimal standard for when TS ought to be clearly ethically allowable. In order to translate mere ethical allowability into policy one must then work to flesh out guidelines to describe more fully when it would be appropriate to enact the treatment of TS and when it is not appropriate to utilize the treatment following the policy developed.

Good policy will clearly delimit who is appropriate for TS treatments and who is not. Since TS has been a controversial issue and has not yet gained wide support for end-of-life care, I support a restrictive initial policy based upon a set of minimal guidelines. These initial minimal guidelines have a focus exclusively on the patient. They are admittedly conservative in nature. The goal of the minimal guidelines is to allow TS for those patients who clearly meet a minimal set of guidelines to receive TS as an appropriate and acceptable treatment for intractable pain and suffering at the end-of-life.

Obtaining minimal hospital policy on TS will be important to allow compassionate end-of-life care to those who have urgent need for relief of pain and suffering.

These minimal guidelines, once TS is established as an accepted end-of-life treatment, can be revised to more moderate guidelines allowing support to others affected by TS deaths, the families and healthcare professionals. The next step would be revising again towards future guidelines including a larger range of patients who could be appropriate for TS. I define where I would limit this 'larger range of patients' in a later section on 'Future TS Policy'. In the following pages I will address the first two stages, the minimal and moderate guidelines for establishing a justifiable balance towards allowing TS for those patients whom it would benefit and appropriate safeguards against misuse.

The American Medical Association (AMA) – Council on Ethical and Judicial Affairs (CEJA) authored a report on the topic of TS in 2008 entitled, "Sedation to Unconsciousness in End-of-Life Care".[329] This report is supportive of using TS and states, "The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients."[330] The AMA–CEJA report recommendation ends with a listing of eight ethical guidelines to be considered when considering the use of palliative (what I have called terminal) sedation. This report is an initial attempt towards encouraging physicians to adopt more routine standards, if not policy, on providing TS. I applaud their effort. That their recommendations address only the physician's role is appropriate given their constituency, but physicians do not practice

[329] Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care* (No. CEJA Report 5-A-08): American Medical Association
[330] Ibid.

in isolation. Most who would utilize TS will be doing so within a medical institution where policy is mandated for most, if not all, medical treatments and is also required for most insurance reimbursement. Therefore I propose more moderate guidelines in the next section.

I believe that the AMA recommendations are a good initial starting point for a minimal TS policy (see Figure 2, next page). However, I cannot wholeheartedly endorse this policy as I believe it is often too vague and also too restrictive in several instances to be appropriately helpful. I have stated throughout that one of the primary methods to address potential harm is through clear communication and this must include the policy recommendations and guidelines that we endorse. Still, the AMA-CEJA recommendation does provide a huge boost for better care for the dying by the public endorsement from the largest physician group on the United States. Or, it would if these recommendations were more widely acknowledged and utilized. I will address my concerns starting at the top and moving down from the initial paragraph following the introductory sentence.

In the first sentence of the initial paragraph, the AMA endorses relief of pain and suffering as rightly within the physician role. Next, they provide their explanation of palliative sedation to unconsciousness(PSU), this is what the AMA calls the treatment I have called terminal sedation.[331] I will continue to use TS for purposes of continuity. In the third sentence, they state that PSU is to be used as an "intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond

[331] Recall the table in Chapter 1 addresses the issue of the practice of TS being called by various names as one of the issues yet to be addressed.

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 5-A-08 RECOMMENDATION

The Council on Ethical and Judicial Affairs recommends that the following be adopted and that the remainder of this report be filed.

The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients. Palliative sedation to unconsciousness is the administration of sedative medication to the point of unconsciousness in a terminally ill patient. It is an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond to aggressive symptom-specific palliation. It is an accepted and appropriate component of end-of-life care under specific, relatively rare circumstances. When symptoms cannot be diminished through all other means of palliation, including symptom-specific treatments, it is the ethical obligation of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms. When considering the use of palliative sedation, the following ethical guidelines are recommended:

(1) Patients may be offered palliative sedation when they are in the final stages of terminal illness. The rationale for all palliative care measures should be documented in the medical record.
(2) Palliative sedation to unconsciousness may be considered for those terminally ill patients whose clinical symptoms have been unresponsive to aggressive, symptom-specific treatments.
(3) Physicians should ensure that the patient and/or the patient's surrogate have given informed consent for palliative sedation to unconsciousness.
(4) Physicians should consult with a multidisciplinary team, including an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed and that palliative sedation to unconsciousness is now the most appropriate course of treatment.
(5) Physicians should discuss with their patients considering palliative sedation the care plan relative to degree and length (intermittent or constant) of sedation, and the specific expectations for continuing, withdrawing or withholding future life-sustaining treatments.
(6) Once palliative sedation is begun, a process must be implemented to monitor for appropriate care.
(7) Palliative sedation is not an appropriate response to suffering that is primarily existential, defined as the experience of agony and distress that may arise from such issues as death anxiety, isolation and loss of control. Existential suffering is better addressed by other interventions. For example, palliative sedation is not the way to address suffering created by social isolation and loneliness; such suffering should be addressed by providing the patient with needed social support.
(8) Palliative sedation must never be used to intentionally cause a patient's death.

(New HOD/CEJA Policy)

Figure 2. AMA-CEJA Policy

to aggressive symptom-specific palliation."[332] I admit that inevitable vagueness is *required* when attempting to cover an amazingly large array of potentially intolerable and distressing symptoms from which dying patients may suffer. One may never know what sorts of individual or combinations of pain and distress may be suffered or how refractive to treatment any one individual may be. In this instance, I endorse the intentionally vague wording.

It is the "intervention of last resort" that has a more troubling prospective for me to accept. Does this mean that the directing physician has tried all the medications and treatments to resolve the distressing symptom that she *usually* uses to treat end-of-life distress? Or, perhaps, all that she has *heard about or read about* from texts and colleagues before resorting to TS? Or even, all treatments that are known, including a pub-med search and internet query world-wide? This may have the potential to do more than just delay a patient's relief from suffering, by lending potential for patients to be forced to suffer needless attempts of useless medications or treatments that turn out to fail when a known treatment (TS) is and ought to be used.

Admittedly, one does not want to enact the treatment of TS hastily. But I would argue that a more ethical standard for the use of TS would be one that has a focus on the patient's autonomy and willingness to endure additional attempts at other methods of palliation.[333] Some patients may tolerate multiple attempts of various other, less sedating medications or periods allowing intermittent rather than total sedation while others will

[332] Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care* (No. CEJA Report 5-A-08): American Medical Association

[333] One would only consider TS after traditional palliative measures have failed to offer relief of symptoms. It would be inappropriate for TS to be considered upon a patient request without any efforts at traditional palliation.

be less tolerant. Utilizing a patient focused measure for stating an "inability to tolerate additional attempts at symptom palliation" would both support the principle of autonomy and more direct beneficence. We allow patients to choose when to stop aggressive treatment in terminal disease routinely in the name of autonomy and patient rights. Allowing them to have self-determination in choosing when to resort to TS (especially when relief is possible via TS) seems a more appropriate measure of offering respect to individuals than requiring them to endure an imprecise number of failed attempts by their doctors.

The next two sentences in the initial paragraph offer similar vague, yet overly demanding restrictions on TS.

> It is an accepted and appropriate component of end-of-life care under specific, *relatively rare circumstances*. When symptoms cannot be diminished through *all other means* of palliation, including symptom-specific treatments, it is the ethical obligation of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms.[334]

I would hope that TS does remain a treatment choice that is not often required, for this will mean that more persons are dying without great suffering. Further I both hope and expect that medical science will develop better symptom-relieving pharmaceuticals and that this will allow a reduction in the need for TS to occur in the future. Yet if we now are not routinely offering this end-of-life care to those who are suffering intolerably, how do we know what to expect in terms of the appropriate frequency of use? The SUPPORT study indicated clearly that too many patients were dying with unresolved pain. I agree

[334] Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care* (No. CEJA Report 5-A-08): American Medical Association

that TS, as is the case with all other treatments, should only be used in 'specific' circumstances. These are circumstances in which suffering has been unable to be otherwise relieved to the patient's satisfaction. But, I do not believe we currently have the empirical data to verify how frequently those circumstances obtain. Recall that the data found TS occurring with great variance: from 5% to 52% of deaths.[335] It is imperative that we continue to develop research on the use of TS to better define the appropriate parameters for use. Let us now move on to the eight specific AMA-CEJA guidelines.

(1) Patients may be offered palliative sedation when they are in the *final stages of terminal illness*. The rational for all palliative care measures should be documented in the medical record.

My concern here is about the vague phrase "final stages of terminal illness." It is well known that persons today are surviving not only months but years with terminal illness. I have a general understanding of 'final stages' as being anytime during the anticipated last six months of a terminal illness. That is the period during which one is eligible for insurance hospice care benefits. But others may judge 'final stages' differently. There is no widely-accepted standard for this phrase, so using 'final stages' may allow patients to undergo TS who have several months left of life. This would include what I have called ETS (Early Terminal Sedation) in the category of TS and would have the potential to allow patients to die due to lack of nutrition and hydration rather than due to their underlying disease process. I would rather endorse using the phrase "actively dying" to

[335]Barreth, A., Fainsinger,R., Oneschuk, D., Pritchard, Z. (2003). The Challenge of Communicating Intent of Sedation in Advanced Illness. *Journal of Palliative Care, 19*(3), 217-219. Rousseau, P. (2000). The Ethical Validity adn Clinical Experience of Palliative Sedation. *Mayo Clinical Proc, 75*, 1064-1069.

delimit the time period when the use of TS in a minimal guideline would be appropriate. Although the phrase "actively dying" is also imprecise, it is generally understood as a period when specific biological changes (lower urine output, respirations, and blood pressures for example) can be identified as precursors to death and is usually limited to a period of hours or days before death occurs.

(2) Palliative sedation to unconsciousness may be considered for those terminally ill patients whose clinical symptoms have been *unresponsive to aggressive, symptom-specific treatments.*

(3) Physician should ensure that the patient *and/or* the patient's surrogate have given informed consent for palliative sedation to unconsciousness.

Regarding the second and third guidelines I have no major changes although I might offer a couple of clarifications. In the second, "unresponsive to aggressive, symptom-specific treatments" could be clarified to state treatments that have failed to be ameliorated to the patient's perception of comfort. It is appropriate that TS not be considered as a first line of action since there are less burdensome treatments available that may have success in providing the patient with relief. In the third guideline I would clarify that the patient consent is required if the patient has capacity and that surrogate consent is only appropriate if the patient lacks capacity. The current AMA-CEJA guideline could lead to instances of confusion, or worse circumstances where patients and surrogates may not agree and the "and" could become contentious. Respect for patient autonomy allows for her consent to suffice for all medical treatments when capacity is established. For the minimal guidelines I endorse retaining this standard along with the surrogate to act only

in absence of patient capacity. In a more moderate policy the "and" would acknowledge that TS may have effects upon family members that ought to be considered.

(4) Physicians should consult with a *multidisciplinary team*, including an *expert in the field of palliative care,* to ensure that symptom-specific treatments have been *sufficiently* employed and that palliative sedation to unconsciousness is now the *most* appropriate course of treatment.

Although I endorse this statement for my moderate guideline[336] for TS, I believe that it is unduly restrictive for the minimal guideline and will disallow TS treatment from too many who could otherwise benefit. What defines acceptability as a *multidisciplinary team*? Does the inclusion of a single additional discipline, such as nursing, count? Or does multidisciplinary require nursing, social workers and pastoral care as well? I agree that in the best of situations it would be in the patient's best interest to have the full endorsement of all team members but admittedly this may not always be possible. The same is true for the *expert in palliative care*. Although this medical specialty is increasing, those certified as a specialist in palliative care are not yet available in all communities or in all hospitals and home-care hospices. I also have concerns about the vagueness of exactly how to determine if other treatments have been *sufficiently employed* and in difficult end-of-life situations how to know for certain that TS is *the most appropriate* course to take. As above, I would endorse using a patient-centered guide for these determinations.

(5) Physicians should discuss with their patients considering palliative sedation the care plan relative to degree and length (intermittent or constant) of

[336] My moderate guideline is detailed in the following section.

sedation, and the *specific expectations for continuing, withdrawing or withholding future life-sustaining treatments.*

To this my initial reply would be, "Isn't this the usual standard for care involved in any treatment?" But, I would also make changes to include this discussion to occur with a patient's surrogate if the patient lacks capacity to engage in such discussions since, as we know, many patients are unable to participate in their final end-of-life decision making. For clarity's sake I would also alter *specific expectations for continuing, withdrawing or withholding future life-sustaining treatments* to end-of-life wishes or advance directives for life-sustaining treatments. That would clarify that the focus is on the patient's *specific expectations* rather than the physician's or family's. This would include patient directives on artificial nutrition and hydration as an important factor to discuss prior to TS.

(6) Once palliative sedation is begun, a process must be implemented to monitor for appropriate care.

I would encourage a specialized monitoring system for assessing patient response to treatment such as the Critical-Care Pain Observation Tool (CCPT - in Appendix 1). A clearly written TS protocol will establish TS as a medical treatment that follows physician orders for medications to be administered and carefully monitored to allow full relief of patient symptoms and complete unconscious sedation. It should include medications authorized by the hospital formulary for medications to be utilized in TS treatments. The policy should include initial medication dosages as well as a range for hourly increases in administration and 'push' orders for breakthrough pain. The goal to

provide the minimal effective dose to offer relief of symptoms is consistent with good medical practice and minimizes the risks of respiratory complications.

(7) Palliative sedation is not an appropriate response to suffering that is *primarily* existential, defined as the experience of agony and distress that may arise from such issues as death anxiety, isolation and loss of control. Existential suffering is better addressed by other interventions. For example, palliative sedation is not the way to address suffering created by social isolation and loneliness; such suffering should be addressed by providing the patient with needed social support.

I find it interesting, yet appropriate that this guideline in the AMA-CEJA is both the longest and offers the most clarity. I support both their definition of existential suffering and the specification that suffering is not *primarily* existential. This guideline accepts that for many patients who are suffering, such as the patient I describe in the start of Chapter 3, there may be components of both great physical and mental anguish. Now, some may want to argue that the term "primarily" is also too vague to be effectively utilized. This may be true and I would agree that further clarification could be made by changing *primarily* existential suffering to *only* existential suffering. This restriction would in no way diminishes the reality of those whose suffering is primarily existential but states TS is not the most appropriate method for treating that primary form of suffering.

(8) Palliative sedation must never be used to intentionally cause a patient's death.

To this final guideline I endorse the brevity and clarity in a minimal guideline for maintaining the physician's role for relief of suffering while maintaining an oath of

nonmaleficence in not intentionally causing death. The policy ought to clearly state intent as elimination of suffering and consciousness with the minimal effective dose and not to hasten death. But, for the sake of clarity, I would not oppose adding to the phrase by stating "never be used to intentionally cause *or hasten* a patient's death." Having a transparent policy with protocol stating a minimal starting dosage of medication and carefully monitored administration only until symptoms are eliminated establishes the intent to relieve suffering. This sentiment is echoed by the AMA in their preface to the CEJA recommendations:

> Although intent cannot be observed directly, it can be gauged in part by examining the medical record. Repeated doses or continuous infusions are indicators of proportionate palliative sedation, whereas one large dose or rapidly accelerating doses out of proportion to the level of immediate patient suffering may signify lack of knowledge or an inappropriate intention to hasten death. These questions about intent demonstrate the importance of careful documentation in the medical record of purpose and strategy for patients receiving any palliative care including palliative sedation to unconsciousness.[337]

Moderate Policy Guidelines

I have defined the above guidelines as "minimal guidelines" primarily because they address only the physician and the patient and establish some minimal safeguards for the appropriate use of TS. These safeguards are admittedly minimal in order to allow TS to provide relief to dying patients. The minimal guidelines have only a few restrictions: that the patient have a terminal illness, be actively dying and that traditional palliative measures have failed. I could not justify requiring those who are close to death and are suffering to be forced to endure additional time in intolerable pain to meet additional bureaucratic safeguards such as written request or second opinions. I agree and support patient's thinking about what their dying needs may be and including written

[337] Ibid.

requests for TS should it become appropriate in their advance directives. I also support requesting the assistance of palliative care specialists in treating refractive pain when they are available to consult. These are both recommendations in my moderate guideline, but requiring them in a minimal guideline would unduly force many patients to suffer. Denying patients who could be effectively relieved of their pain and suffering using TS would be maleficent since it could be prevented following the minimal guidelines for TS I presented above.

Throughout this dissertation I have maintained that when medical treatments have important effects upon others, and specifically potential to cause harm, it is both ethical and important to attempt to reduce this harm where possible. It is not the usual practice of those in medicine to incorporate policy to include persons other than patients, and even less usual to include any reference to care of the medical professionals. I believe that inclusion of these "others" will push institutional policy towards a new level of more ethical practice.

I have termed this section "Moderate Policy Guidelines" in an attempt to distinguish the minimal policy above to one that, while still maintaining rather strict parameters for allowable TS, does include a significant addition towards efforts to reduce harm to others and further to attempt to provide others benefits. I have three sets of guidelines listed below. The first retains focus upon the patient. This is appropriate since TS is for the patient and remains as the primary focus for the moderate guideline. The first moderate guideline incorporates most of the minimal guidelines above and expands them for clarification. The second and third guidelines offer ethical guidance in the provision of TS with an enlarged focus to include families and professional caregivers.

1. It is within the physician's role to reduce the suffering of those who are dying and TS allows this beneficent action.

1. (a) Thoroughly assess requests for TS to ensure that they meet the Standard for TS.

i) ***a terminal patient's (or surrogates) request*** **due to**

ii) ***suffering intractable pain or other distressing clinical symptoms*** **intolerable to the patient when**

iii) ***death is expected within hours or days[338] (less than two weeks)*** **due to the terminal illness, injury, or disease.**

If they do not meet the above standard, then it may be appropriate to offer intermittent sedation to allow periods of symptom relief and respite while continuing to pursue other aggressive treatment options for the patient.

I focus explicitly on symptoms being intolerable to the specific patient involved. This perception of the patient's experience shows respect for the patient and is the appropriate viewpoint for which to direct our efforts of amelioration. I (as does the AMA) will exclude those symptoms which are only existential in nature but accept that suffering at the end-of-life often includes suffering that is both physical and existential in nature. Those symptoms that are commonly difficult to treat are cancer pain, dyspnea, delirium, myoclonus, or vomiting but may include many others. As I have previously discussed, I also delimit TS to those who are actively dying is defined as a death expected to occur in hours to less than two weeks. This is admittedly an inexact measure but one that is commonly understood in medical practice.

[338] The prediction of an anticipated death is always inexact but ought to be anticipated to occur within two weeks to meet my understanding of actively dying.

1. (b) The AMA-CEJA guidelines are appropriate to include in this section.
1. (c) Special effort to clarify patient consent/prior wishes (include copy of patient advance directive if available) and capacity needs documented. Need to document who (patient or surrogate) has requested or consented to TS.
1. (d) Clear documentation of surrogate/proxy selection if patient does not have capacity.
1. (e) Clearly document prior efforts to treat distressing symptoms in the medical record.

Proxy selection, if not designated by the patient, ought to follow state statutes for physician assignment of surrogate. If no surrogate is available physicians ought to follow institutional policy for decision making on medical necessity for patients without family or surrogates.

1. (f) TS ought to be patient motivated for symptom relief and not payer, institution, or financially motivated.
1. (g) TS ought not be sought by family or caregiver unless the patient is unable to advocate for herself and must rely on surrogates.

Guidelines (f) and (g) above are included in attempts to ensure that TS is enacted for the intention to relieve patient suffering and is primarily patient motivated whenever possible. TS ought to be provided when it is in the best interest of the patient and free from any financial considerations. It is natural to assume that a patient's family is going to act in their best interest and this is usually, but not always, the case. In cases where TS is authorized by the family's or surrogate's additional attempts are warranted to assure clear communication that the surrogate is acting in the patient's best interest.

2. **It is moral to show concern for the harms others may suffer and attempt to reduce them where possible. Since families may suffer harms related to having a loved one die while undergoing TS treatment for intolerable suffering the medical professionals ought to act to reduce their burdens where possible. This may be done in part by:**

2. (a) Increasing physician and nursing counseling skills to work with families.
2. (b) Increasing staff time to allow family and staff discussions regarding the patient, the process of TS, and to encourage family questions.
2. (c) Ensuring family support if possible, via social worker and chaplain services. Allowing increased family participation in deaths and education on dying.
2. (d) Offering hospital support groups following deaths to allow families to share with others who have been in similar situations and express emotions related to the family stress involved in enduring a relative death by TS.

As stated in guideline one above, the appropriate primary goal is the relief of patient suffering. Yet, as I described in Chapter 4, family members may also be affected in significant ways by patient suffering and may be suffering in significant ways themselves. The patient will remain the primary focus of concern but once her needs are adequately met, or in addition to meeting patient needs attention may be given to the attending family. Guideline 2 (a), relates to the need for additional skills in counseling for doctors and nurses so that the help offered to families will be more effective. There are specific skills involved in empathetic listening, reframing losses, and identifying those who will require ongoing therapeutic counseling following a death or who may suffer a complicated bereavement. This training can be done using workshops or in-service training. Both are routine methods for gaining professional skills while maintaining daily employment. The next guideline refers to the additional time that will be required to allow the aforementioned counseling to occur. This may require additional staffing for those floors where TS deaths are occurring. Admittedly, this will be an administrative issue and one that may be difficult to achieve in many institutions.

Guideline 2 (c) is focused upon providing the family with additional support at the hospital while their loved one is dying. Almost all hospitals have social workers and chaplains on staff and they are highly trained in providing family support and community referrals for ongoing support. These individuals could easily be added as a routine referral when TS is being utilized for patient treatment. This guideline also encourages providing families with a designated role in supporting patients during the dying process. This may be simply playing music that the patient may enjoy in the room, providing mouth care or repositioning, or perhaps holding a hand. Family members should be educated as to the common signs that death is approaching and advised when the death is close to allow them to be present if desired.

The final guideline in this section is to offer additional support to family and friends of those who have died using TS. A support group for those who have endured the dying of a loved one by TS would allow participants to express their emotions following the experience and to obtain support from others who have had similar experiences. It may also be helpful in reducing complicated bereavement for many who had been primary caretakers for terminally ill loved ones and lose their primary role when the patient dies. Although this will require some additional staffing support from our hospitals, it is not unheard of for social workers or nurses to add group facilitator to their job function or do as a volunteer. Similar hospital groups exist for example, for those have miscarried or had a stillbirth, child deaths, or who have had transplants.

3. **It is moral to show concern for the harms others may suffer and attempt to reduce them where possible. Since medical professionals involved in TS may suffer harms related to providing TS treatment for intolerable**

suffering the hospital and staff ought to act to reduce their burdens where possible. This may be done in part by:

3. (a) Ensuring that TS is done with the support of an interdisciplinary team when possible, rather than the MD acting alone.
3. (b) Increasing training for staff in palliation in end-of-life care.
3. (c) Encouraging MD's to advocate in hospital systems (including with insurers) to allow TS to occur in a supportive environment.
3. (d) Creating a clear hospital policy for TS that will be followed by staff. This policy is to include physicians, nursing, chaplains, and social worker on care teams whenever possible to support families, when patient families are involved.

Medical care is not provided by physicians alone. Orders are carried out by nursing and other ancillary staff in all hospitals today. TS requires that the patient be rendered medically sedated to unconsciousness. This precludes most of the usual interactions that occur between patients and those who provide them with care. It is these patient/staff interactions that provide a great deal of the professional and emotional gratification for those who work in medical care. Providing ongoing care to those receiving TS will require additional skill sets, including assessment skills for the unconscious, careful medication monitoring and skills in communication with family members and teaching about TS and dying.

Guideline 3 (a), focuses on the entire interdisciplinary team involved with the patient. Ensuring that those others who are treating the patient are supportive of the decision for TS is important in respecting those others involved in patient care. It will also encourage mutual support of team members who are providing specialized care to the dying. This may involve palliative care specialist, if available in the hospital, nursing and other ancillary staff. While complete team endorsement may not be available at all times, the effort to obtain full support will increase communication and work towards a

more holistic team approach. Where significant disagreement exists I would recommend referral to a hospital ethics committee for further evaluation. Further, reassignment of duty is appropriate for those with a conscientious objection to participation in TS.

Guideline 3(b) is to encourage additional training for hospital staff (physicians and others) in palliative and end-of-life care. This would include learning how to talk to both patients and families more directly about dying, advance directives, and what is important to each individual concerning their dying. This may be done by multiple methods such as attendance at workshops, in-service training by qualified professionals, as well as grand rounds or discussions about medical journal articles on death and dying issues.

Guideline 3(c) addressed the work that physicians will need to do both within their hospital institutions and with their affiliated insurers to obtain both the staff time for work with the dying and their families and also insurance reimbursement for this work. As addressed in Chapter 5, evidence based medicine (EBM) has yet to accept the treatment of TS and studies completed in the United States are needed to develop the data required for EBM endorsement of this practice. The last guideline 3 (d) reiterates the need to develop clear policy for the ethical use of TS as an end-of-life treatment for patients. Policy will provide needed guidance in the provision of TS as well as organizational legitimacy. As we get better at treating the pain and suffering at the end-of-life, the need to utilize TS will diminish. This would be a welcomed goal for the future.

Future TS policy

Both the minimal and the moderate guidelines for TS that I laid out above are fairly restrictive in that they have narrow recommendations for identification of patients who are appropriate for the treatment. I have purposely kept my current focus on a narrow range for allowable TS. My reasons for this are primarily to work towards obtaining a more general *social acceptability* for the practice. The practice of TS is clearly an ethical practice, yet it has not obtained wide social acceptance. Allowing women the vote was always an ethical practice, as was allowing freedom to all persons. Yet it was years before social acceptability for these practices was accomplished. My guidelines are admittedly narrow, I accept this criticism and counter that they are an important step towards allowing better care for the dying while obtaining social acceptance for the practice.

One could endorse a much greater focus on the autonomy of the patients to determine when TS ought to be allowed. They might hold that those persons who have progressively chronic diseases such as ALS or cerebral palsy (CP), and many other medical problems ought to be allowed TS. I admit that I have great sympathy for the use of TS for those with ALS, locked-in syndromes, those who have suffered severe stroke, brain, or spinal cord injury and many others who could not meet my requirement of "actively dying." I also believe that the practice of TS could be enlarged in the future to include some of those in the above sorts of conditions. Even allowing early TS, (ETS) could be ethically permissible in some situations. But this is not the place to make the case for a greatly expanded use of TS.

If the practice were enlarged to allow ETS I would suggest that at least two levels be developed. One for those who do have a terminal diagnosis (of less than six months) whose death is still assured and who could understandably be suffering and ought not to be forced to await the "actively dying" phase. Another level of evaluation would be required for those who do not have a terminal diagnosis but may have severe chronic pain or may have primarily existential suffering without pain, such as those who are locked-in or have ALS.

If some ETS was allowed, I would then require additional restrictions. One such restriction would be that any ETS not be done immediately, upon patient request. Since chronic patients are not actively dying, they would have more time to attempt other options to relieve their symptoms. Less drastic attempts to ameliorate the pain or other distressing symptoms ought still to be considered prior to any requests for TS even for those with a terminal diagnosis. These attempts ought to be well documented efforts for attempting alternative methods for alleviation of patient distress prior to using ETS. It may also be appropriate to require an additional physician concurrence, similar to the requirement for PAS in Oregon.

I would include a mandate for those requesting ETS that a prior advance directive address this request in writing. For ETS, I would also require a psychological evaluation to assure that requests were not being made by those suffering a treatable depression or other mental illness. This measure is included in many countries that allow other forms of assistance in dying. If ETS were to be allowed, I believe it would then fall into the category of assistance in dying and ought to require some if not all of the additional safeguards I have outlined.

Lastly, I would not allow TS for those who are suffering only from dementia and who have TS requested for them by a proxy. I agree that a long dying process from Alzheimer's disease or other dementias is a particularly sad way to die. I also agree that it is agonizing for loved ones to watch the person that they love both cease to exist and continue to go on living. But, I have not been convinced that there is extreme suffering for the patient who has the dementia. If they have no concurrent disease or illness then TS is not an appropriate treatment. Demented patients who do have additional illness or suffering ought to be evaluated by the prior guidelines, including proxy consent, for consideration of TS treatment.

I can foresee larger practice parameters for ETS in the future, including those with grave disability or terminal but not imminently dying persons who request assistance in having a peaceful, arranged dying process. This would need to be accompanied by legal developments, for legal and moral reasons. Concerns of slippery slopes will surface and progress will be slow, given the close moral evaluation that not only ethicists, but the public continues (and rightly) to focus on medical practice and especially on end-of-life issues. This work is only one step in that process.

Future Needs & Conclusions

Ethicists are not immune to the need to identify where the communication breakdowns are occurring and to have a role in repairing them. There exists a barrier between widely accepted ethical precepts and the practice beliefs of those involved in direct patient care. Intense and ongoing discussions between ethicists and practitioners need to occur much more often to discover where these barriers exist and work to

develop methods to overcome them. Further work is needed to develop TS policy with transparent language to assist both medical professionals and the general public in understanding the concepts involved in TS. We must work toward establishing both a clearly transparent policy and a willingness to reexamine such policy when needed. Medical progress will continue to occur and we can hope for better methods which will reduce the need for such extreme treatments in the future.

I have argued that terminal sedation is the appropriate and intentional use of medications (benzodiazepines and/or narcotics) to produce ongoing, deep unconsciousness upon 1) a terminal patient's (or surrogates) request due to 2) suffering intractable pain or other distressing clinical symptoms intolerable to the patient when 3) death is expected within hours or days (less than two weeks) due to terminal illness, injury or disease. I have also argued for working toward wide social endorsement of my minimal guidelines as both appropriate and ethical care for the dying and have offered moderate guidelines for additional support to patients and others who are affected by TS deaths.

This is a much needed step forward. That there will be other cases that vary just enough to fail to meet these guidelines is certain, just as it is now certain that there are cases where PAS or euthanasia would be welcomed as an appropriate death by many. Yet, in most of our nation, we have not allowed physicians to participate in PAS or euthanasia. The moral conversations about allowing persons the full dignity and right to choose the manner and timing of their death are far from over, but allowing TS under the conditions I have specified is a step in the right direction. I have argued that the thoughtful provision of TS, following written hospital protocols, is morally allowable and

is a beneficent action. TS is, in final evaluation, an ethically beneficent and compassionate treatment for the dying.

BIBLIOGRAPHY

Aries, P. (1981). *The Hour of Our Death* (H. Weaver, Trans.). New York: Alfred A. Knopf.

Aries, P., translated by Valerie M. Stannard. (1974). The Reversal of Death: Changes in Attitudes toward Death in Western Societies. *American Quarterly, 26*(5 Special Issue: Death in America), 536-560.

Barreth, A., Fainsinger,R., Oneschuk, D., Pritchard, Z. (2003). The Challenge of Communicating Intent of Sedation in Advanced Illness. *Journal of Palliative Care, 19*(3), 217-219.

Battin, M., P. (2005). Euthanasia: The Way We Do It, the Way They Do It. In M. P. Battin (Ed.), *Ending Life: Ethics and the Way We Die* (pp. 47-68). Oxford, New York: University Press

Beauchamp, T., L. , & Childress, J., F. . (1994). *Principles of Biomedical Ethics* (Fifth ed.). New York, Oxford: Oxford University Press.

Beel, A., McClement, S. E., & Harlos, M. (2002). Palliative sedation therapy: a review of definitions and usage. *International Journal of Palliative Nursing, 8*(4), 190-199.

Beel, A. C., Hawranik, P. G., McClement, S., & Daeninck, P. (2006). Palliative sedation: nurses' perceptions. *International Journal of Palliative Nursing, 12*(11), 510-518.

Berger, J. T. (2010). Rethinking Guidelines for the Use of Palliative Sedation. *Hastings Center Report, 40*(3), 17-21.

Billings, J. A., Block, S. (1996). Slow Euthanasia. [Forum]. *Journal of Palliative Care, 12*(4), 21-30.

Billings, J. A., Kolton, E. (1999). Family Satisfaction and Berevement Care following Death in the Hospital. *Journal of Palliative Medicine, 2*(1), 33-49.

Bilton, M. J., & Finder, S. G. (2002). Traaversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawal of Life Supports. *Theoretical Medicine, 23*, 233-258.

Block, S. D., & Sullivan, A. M. (1998). Attitudes about End-of-Life Care: A National Cross-sectional Study. *Journal of Palliative Medicine, 1*(4), 347.

Braun, T. C., & Hagen, N. A. (2003). Development of a Clinical Practice Guideline for Palliative Sedation. *Journal of Palliative Medicine, 6*(3), 345.

Byock, I. R. (1996). The Nature of Suffering and the Nature of Opportunity at the End of Life. *Clinics in Geriatric Medicine, 12*(2), 237-252.

C. Peruselli, e. a. (1999). Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliat Med, 13*, 233-241.

Callahan, D. (1992). When Self-Determination Runs Amok. *The Hastings Center Report, 22*(2), 52-55.

Carr, M. F., & Mohr, G. J. (2008). Palliative Sedation as Part of a Continuum of Palliative Care. *Journal of Palliative Medicine, 11*(1), 76-81.

Carver, A. C., & Foely, K. M. (2000). The Wein Article Reviewed. *Oncology 14*(4), 598-601.

Cassell, E. (1991). *The Nature of Suffering and the Goals of Medicine*
New York, Oxford: Oxford University Press.

Cellarius, V. (2011). 'Early Terminal Sedation' Is A Distinct Entity. *Bioethics, 25*(1), 46-54.
Chater, S., Viola, R., Paterson, J., & Jarvis, V. (1998). Sedation for intractable distress in the dying- a survey of experts. *Palliat Med, 12*, 255-269.
Cherny, N. I., & Portenoy, R. K. (1994). Sedation in the management of refractory symptoms: guidelines for evaluation and treatment. *J Palliat Care, 10*(2), 31-38.
Claessens, P., Genbrugge, E., Vannuffelen, R., Broeckaert, B., Schotsmans, P., & Menten, J. (2007). Palliative Sedation and Nursing. *J of Hospice and Palliative Nursing, 9*(2), 100-106.
Cohen, L. (2010). *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die*. New York: Harper Collins Publishers.
Cohen, L., Ganzini,L., Mitchell, C.,Arons, S., Goy, E.,Cleary, J. (2005). Accusations of Murder and Euthanasia in End-of-Life Care. *Journal of Palliative Medicine, 8*(6), 1096-1104.
Committee, o. N. G. f. P. S. (2009). *KNMG Guideline for Palliative Sedation 2009*: KNMG.
Connors, A. F., Dawson, N. V., Desbiens, N. A., Fulkerson, W. J., & al, e. (1995). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. *JAMA, 274*(20), 1591-1598.
Cowan, J. D. a. D. W. (2001). Terminal sedation in palliative medicine –definition and review of the literature
Support Care Cancer 9, 403-407.
Craig, G. M. (1994). On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? *Journal of Medical Ethics, 20*(3), 139-145.
Dickenson, D. L. (2000). Are Medical Ethicists out of Touch? Practitioner Attitudes in the US and UK towards Decisions at the End of Life. *Journal of Medical Ethics, 26*(4), 254-260.
Domino, K. B., Posner, K. L., Caplan, R. A., & Cheney, F. W. (1999). Awareness during Anesthesia: A Closed Claims Analysis. *Anesthesiology, 90*(4), 1053-1061.
Emmanuel, E. J., & Fairclough, D. L. (2000). Understanding economic and other burdens of terminal illnesses: The experience of patients and. *Annals of Internal Medicine, 132*(6), 451-459.
Enck, R. E. (1991). Drug-induced terminal sedation for symptom control. *American Journal of Hospice and Palliative Medicine, 8*(5), 3-5.
Fainsinger, R. L., Landman, W., Hoskings, M., & Bruera, E. (1998). Sedation for uncontrolled symptoms in a South African hospice. *J Pain Symptom Manage, 16*(3), 145-152.
Ferris, T., G.G., , Hallward, J. A., Ronan, L., & Billings, J. A. (1998). When a Patient Dies: A Survey of Medical Housestaff about Care after Death. *Journal of Palliative Medicine, 1*(3), 231-239.
Fisher, F., B., M.D. (2004). Evaluating the Risks of Unwarrented Prosecution. *Journal of American Physicians and Surgeons, 9*(4), 114-117.
Ganzini, L., M.D., M.P.H., Goy, E., R., Ph.D., R.N., Harvath, T., A., R.N., Ph.D., Jackson, A., M.B.A., & Delorit, M., A., B.A. (2003). Nurses' Experiences with

Hospice Patients Who Refuse Food and Fluids to Hasten Death. *New England Journal of Medicine, 349*(4), 359-365.
Garlan, R. W. B., Lisa D.; Rosenbaum, Ernest; Seigel, Alison;Spiegel, David. (2011). Perceived Benefits and Psychosocial Benefits of a Brief Existential Family Intervention for Cancer Patients/Survivors. *Omega, Journal of Death and Dying, 62*(3), 243-268.
Graeff, A. D., & Dean, M. (2007). Palliative Sedation Therapy in the Last Weeks of Life: A Literature Review and Recommendations for Standards. *Journal of Palliative Medicine, 10*(1), 67-85.
Green, W. R., Davis, W.H. . (1991). Titrated intravenous barbituates in the control of symptoms in patient with terminal cancer. *Southern Medicine Journal, 84*, 332-337.
Humphry, D. (1991). *Final Exit: The Practicaliities of Self-Deliverance and Assisted Suicide for the Dying* (3rd ed.). New York: Dell Publishing
Inghelbrecht, E., Bilsen, J., Mortier, F., & Deliens, L. (2009). Nurses attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium. *Palliative Medicine, 23*(7), 649-658.
JW.Levenson, Carthy, E. M., Lynn, J., Davis, R., & Phillips, R. (2000). The Last Six Months of Life for Patients with Congestive Heart Failure. *J Am Geriatr Soc, May, 48*(5 Supp), 101-109.
Kaufman, S. R. (2005). *...And A Time to Die: How American Hospitals Shape the End of Life*. New York: Lisa Drew Book/Scribner.
Kramer, B. J., Kavanaugh, M., Trentham-Dietz, A., Walsh, M., & Yonker, J. A. (2010-2011). Complicated Grief Symptoms in Caregivers of Persons with Lung Cancer: The Role of Family Conflict, Intrapsychic Strains, and Hospice Utilization. [Death and Bereavement]. *OMEGA--Journal of Death and Dying, 62*(3), 201-220.
Kubler-Ross, E. (1969). *On Death and Dying* (Touchstone 1997 ed.). New York: Simon and Schuster
LaDuke, S. (2000). The Effects of Professional Discipline on Nurses. *AJN The American Journal of Nursing, 100*(6), 26-33.
Larochelle, M. R., Rodriguez, K. L., Arnold, R. M., Barnato, A. E. (2009). Hospital Staff Attributions of the Causes of Physician Variation in End-of-Life Treatment Intensity. *Palliative Medicine, 23*(5), 460-470.
Layde, P., Beam, C., & Broste, S. (1995). Surrogates' predictions of seriously ill patients' resuscitation preferences. *Arch Fam Med, 4*(518), 518-523.
Leske, J. S. (1998). Treatment for Family Members in Crisis After Critical Injury. *Americn Association of Critical Care Nurses, 9*(1), 129-139.
Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*
CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care (No. CEJA Report 5-A-08): American Medical Association
Luce, J., M. and Douglas B. White. (2007). The Pressure to Withhold or Withdraw Life-sustaining Therapy from Critically Ill Patients in the United States. *American Journal of Respiratory and Critical Care Medicine, 175*, 1104-1108.

Lynn, J., Zhong, Z., Dawson, N. V., Connors, A. F., & Phillips, R. S. (1998). Physician Experience Caring for Dying Patients and Its Relationship to Patient Outcomes. *Journal of Palliative Medicine, 1*(4), 337.

Magnusson, R., S. . (2006). The Devil's Choice: Re-Thinking Law, Ethics, and Symptom Relief in Palliative Care. *Race & Ethcnicity, Fall*, 559-569.

Milberg, A., Olsson, E.-C., Jakobsson, M., Olsson, M., & Friedrichsen, M. (2008). Family Member's Perceived Needs for Bereavement Follow-Up. *Journal of Pain and Symptom Management, 35*(1), 58-69.

Mills, A. E., Chen, D. T., Werhane, P. H., & Wynia, M. K. (Eds.). (2005). *Professionalism in Tomorrow's Healthcare System: Toward Fulfilling the ACGME Requirements for Systems-Based Practice and Professionalism*. Hagerstown, Maryland: University Publishing Group.

Mills, A. E., Chen, D. T., Werhane, P. H., & Wynia, M. K. (Eds.). (2005). *Professionalism in Tomorrow's Healthcare System: Towards Fulfilling the ACGME Requirements for Systems-Based Practice and Professionalism* Hagerstown, Maryland University Publishing Group, Inc.

Morita, T., Ikenaga, M., Adachi, I., Narabayashi, I., Kizawa, Y., Honke, Y., et al. (2004). Family Experience with Palliative Sedation Therapy for Terminally Ill Cancer Patients. *Journal of Pain and Symptom Management, 28*(6), 557-565.

Morita, T., Miyashita, M., Kimura, R., Adachi, I., & Shima, Y. (2004). Emotional burden of nurses in palliative sedation therapy. *Palliat Med, 18*(6), 550-557.

Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (1999). Do hospice clinicians sedate patients intending to hasten death? *J Palliat Care, 15*(3), 20-23.

Morita, T., Tsunoda, J., Inoue, S., & Chihara, S. (2000). Terminal sedation for existential distress. *Am J Hosp Palliat Care, 17*(3), 189-195.

Muller-Busch, H. C. C., Andres, I., & Jehser, T. (2003). Sedation in palliative care- a critical analysis of 7 years experience. *BMC Palliative Care, 2*(2).

Norwood, F. (2009). *The Maintenance of Life: Preventing Social Death through Euthanasia Talk and End-of-Life Care- Lessons from The Netherlands*. Duram, North Carolina: Carolina Academic Press.

Orentlicher, D. (1992). The Illusion of Patient Choice in End-of-Life Decisions. *JAMA: The Journal of the American Medical Association, 267*(15), 2101-2104.

Orentlicher, D. (1997). The Supreme Court and Physician-Assisted Suicide- Rejecting Assisted Suicide but Embracing Euthanasia *N Engl J Med, 337*(17), 1236-1239.

Peppin, J., F. (2003). Intractable Symptoms and Palliative Sedation at the End of Life. *Christian Bioethics: Non-ecumenical Studies in Medical Morality, 9*(2/3), 13.

Pomerantz, S., Bhatt, H., Brodsky, N., Lurie, D., Ciesielski, J., & Cavalieri, T. (2004). Physician practices related to the use of terminal sedation: Moral and ethical concerns. *Palliative and Supportive Care, 2*, 15-21.

Porta Sales, J. (2002). Palliative sedation : Clinical Aspects. In C. Gastmans (Ed.), *Between Technology and Humanity: The Impact of Technology on Health Care Ethics* (pp. 219-238): Leuven University press.

Quill, T. E. (1993). Doctor, I want to die. Will you help me? *JAMA, 270*(7), 870-873.

Quill, T. E., Byock, I. R., & For the American College of Physicians-American Society of Internal Medicine End-of-Life Care Consensus, P. (2000). Responding to

intractable terminal suffering: The role of terminal sedation and voluntary refusal. *Annals of Internal Medicine, 132*(5), 408-414.
Quill, T. E., Dresser, R., & Brock, D. W. (1997). The rule of double effect--a critique of its role in end-of-life decision making. *N Engl J Med, 337*(24), 1768-1771.
Quill, T. E., Lee, B. C., & Nunn, S. (2000). Palliative treatments of last resort: choosing the least harmful alternative. University of Pennsylvania Center for Bioethics Assisted Suicide Consensus Panel. *Ann Intern Med, 132*(6), 488-493.
Quill, T. E., Lo, B., & Brock, D. W. (1997). Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *Jama, 278*(23), 2099-2104.
Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting Family Caregivers at the End of Life. *JAMA: The Journal of the American Medical Association, 291*(4), 483-491.
Rady, M. Y., & Verheijde, J. L. (2010). Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death? *American Journal of Hospice and Palliative Medicine, 27*(3), 205-214.
Rietjens, J. A. C., Hauser, J., van der Heide, A., & Emanuel, L. (2007). Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliat Med, 21*, 643-649.
Rousseau, P. (2000). The Ethical Validity adn Clinical Experience of Palliative Sedation. *Mayo Clinical Proc, 75*, 1064-1069.
Seymour, J. E., Bellamy, G., Gott, M., Ahmedzai, S. H., & Clark, D. (2002). Good deaths, bad deaths: older people's assessments of the risks and benefits of morphine and terminal sedation in end-of-life care. *Health, Risk & Society 4*(3), 288-302.
Solomon, M. Z., O'Donnell, L., Jennings, B., Guilfoy, V., Koch-Weser, D., & Donnelley, S. (1993). Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments. *American Journal of Public Health, 83*(1), 14-23.
Starck, P. L., & Mc Govern, J. P. (Eds.). (1992). *The Hidden Dimension of Illness: Human Suffering*. New York: National League fro Nursing Press.
Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA, 284*(19), 2476-2482.
Sullivan, R. (1993). Accepting death without artificial nutrition or hydration. *Journal of General Internal Medicine, 8*(4), 220-224.
Teno, J. M., Clarridge, B. R., Casey, V., Welch, L. C., Wetle, T., Shield, R., et al. (2004). Family Perspectives on End-of-Life Care at the Last Place of Care. *JAMA: The Journal of the American Medical Association, 291*(1), 88-93.
Tilden, V. P., Tolle, S. W., Nelson, C. A., & Eggman, S. C. (1999`). Family Decision Making in Forgoing Life-Extending Treatments. *Journal of Family Nursing, 5*(4), 426-442.
Timmermans, S. (2005). Death brokering: constructing culturally appropriate deaths. *Sociology of Health & Illness*, 993-1013.
Tschann, J. M., Kaufman, S. R., & Micco, G. P. (2003). Family Involvement in End-of-Life Hospital Care. *Journal of American Geriatric Society, 51*(835), 835-840.

van Dooren, S., van Veluw, H. T. M., van Zuylen, L., Rietjens, J. A. C., Passchier, J., & van der Rijt, C. C. D. (2009). Exploration of Concerns of Relatives During Continuous Palliative Sedation of Their Family Members with Cancer. [doi: DOI: 10.1016/j.jpainsymman.2008.11.011]. *Journal of Pain and Symptom Management, 38*(3), 452-459.

Ventrafridda, V., Ripamonti, C., & DeConno, F. e. a. (1990). Symptom prevalence and control during cancer patients' last days of life. *Journal of Palliative Care, 6*, 7-11.

Way, J., Back, A. L., & Curtis, J. R. (2002). Withdrawing life support and resolution of conflict with families. *BMJ, 325*(7376), 1342-1345.

Wein, S. (2000). Sedation in the imminently dying patient. *Oncology (Williston Park), 14*(4), 585-592; discussion 592, 597-588, 601.

Weissman, D. E. (2009). Moral Distress in Palliative Care. *Journal of Palliative Medicine, 12*(10), 865-866.

Young-Eisendrath, P. D., Polly (1996). *The Gifts of Suffering: Finding Insight, Compassion and Renewal*. Reading, Massachusetts; Menlo Park, California, New York: Addison-Wesley Publishing.

APPENDIX

Appendix 1 Critical-Care Pain Observation Tool

Appendix 3: Scales to help assess distress in patients with lowered consciousness

Critical-Care Pain Observation Tool (CCPOT)

Indicator	Description	Score	
Facial expression	No muscular tension observed	Relaxed, neutral	0
	Presence of frowning, brow lowering, orbit tightening and levator contraction	Tense	1
	All of the above facial movements plus eyelid tightly closed	Grimacing	2
Body movements	Does not move at all (does not mean the absence of pain)	Absence of movements	0
	Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements	Protection	1
	Pulling tube, attempting to sit up, moving limbs, thrashing about, not following commands, striking at staff, trying to climb out of bed	Restlessness	2
Muscle tension (evaluate by passive flexion and extension of upper extremities)	No resistance to passive movements	Relaxed	0
	Resistance to passive movements	Tense, rigid	1
	Strong resistance to passive movements, inability to complete them	Very tense or rigid	2
Compliance with the ventilator (for intubated patients)	Alarms not activated, easy ventilation	Tolerating ventilator or movement	0
	Alarms stop spontaneously	Coughing but tolerating	1
Or			
Vocalization (for non-ventilated patients)	Asynchrony: blocking ventilation, alarms frequently activated	Fighting ventilator	2
	Talking in normal tone or no sound	Talking in normal tone or no sound	0
	Sighing, moaning	Sighing, moaning	1
	Crying out, sobbing	Crying out, sobbing	2
Total possible score (range)			0–8

Note that the higher the total score, the greater the pain level.
Adapted from: Gelinas C, Fillion L, Puntillo KA, Viens C, Fortier M. Validation of the critical-care pain observation tool in adult patients. Am J Crit Care 2006; 15: 420–427 with permission from the American Association of Critical-Care Nurses.[81]

Appendix 2 AMA Policy on Palliative Sedation

CEJA Rep. 5-A-08 American Medical Association Council on Ethical and Judicial Affairs[339]

The duty to relieve pain and suffering is central to the physician's role as healer and is an obligation physicians have to their patients. Palliative sedation to unconsciousness is the administration of sedative medication to the point of unconsciousness in a terminally ill patient. It is an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond to aggressive symptom-specific palliation. It is an accepted and appropriate component of end-of-life care under specific, relatively rare circumstances. When symptoms cannot be diminished through all other means of palliation, including symptom2 specific treatments, it is the ethical obligation of a physician to offer palliative sedation to unconsciousness as an option for the relief of intractable symptoms. When considering the use of palliative sedation, the following ethical guidelines are recommended:

(1) Patients may be offered palliative sedation when they are in the final stages of terminal illness. The rationale for all palliative care measures should be documented in the medical record.

(2) Palliative sedation to unconsciousness may be considered for those terminally ill patients whose clinical symptoms have been unresponsive to aggressive, symptom-specific treatments.

(3) Physicians should ensure that the patient and/or the patient's surrogate have given informed consent for palliative sedation to unconsciousness.

(4) Physicians should consult with a multidisciplinary team, including an expert in the field of palliative care, to ensure that symptom-specific treatments have been sufficiently employed and that palliative sedation to unconsciousness is now the most appropriate course of treatment.

(5) Physicians should discuss with their patients considering palliative sedation the care plan relative to degree and length (intermittent or constant) of sedation, and the specific expectations for continuing, withdrawing or withholding future life-sustaining treatments.

(6) Once palliative sedation is begun, a process must be implemented to monitor for appropriate care.

(7) Palliative sedation is not an appropriate response to suffering that is primarily existential, defined as the experience of agony and distress that may arise from such issues as death anxiety, isolation and loss of control. Existential suffering is better addressed by other interventions. For example, palliative sedation is not the way to address suffering created by social isolation and loneliness; such suffering should be addressed by providing the patient with needed social support.

(8) Palliative sedation must never be used to intentionally cause a patient's death.

[339] Levine, M. A., Chair. (2008). *REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS CEJA Report 5-A-08 : Subject: Sedation to Unconsciousness in End-of-Life Care* (No. CEJA Report 5-A-08): American Medical Association

Appendix 3 Recommendations for Conducting a Family Meeting When the Patient Is Unable to Participate Prepare for the Meeting

Review medical issues and history.
Coordinate health care team.
Discuss goals of meeting with team.
Identify a meeting leader among the health care team.
Discuss which family members will be present.
Arrange a private, quiet location with seating for all.
Try to minimize distractions: set aside adequate time and seating, turn off pager if possible.

Open the Meeting

Introduce all in attendance.
Review the medical situation.
Establish the overall goal of the meeting, by saying something like: *"Today I'd like to make sure everyone understands how [the patient]is doing and answer all the questions that you have,"* or *"We wanted to meet today to discuss how [the patient] will be cared for at home."*
Be prepared for the goals of the meeting to change based on family's desires.

Elicit Family Understanding

Ask family members questions, such as *"What have you been told about [the patient's] condition?"*
After hearing from the family, a helpful follow-up question is *"Is there anything that isn't clear that we can help to explain?"*

Elicit Patient and Family Values and Goals

Elicit goals of all those present, especially if multiple perspectives are held.
Begin with an open-ended question, such as, *"Given what's gone on, what are your hopes for [the patient]?"* This may be followed by more specific suggestions for the family: *"Sometimes getting home is an important goal for someone. Sometimes seeing a certain family member or friend is an important goal: are there things like this that you imagine are important for [the patient]?"*
Understand ethnic and cultural influences on communication styles, family relationships, medical treatments, and end-of-life care by asking: *"Can you please help me to understand what I need to know about [the patient's] beliefs and practices to take the best care of [the patient]?"*
Maintain focus on the patient's perspective. Often this can help to relieve guilt that family members may feel over making decisions.
Such questions could include *"What do you imagine [the patient] would have done or wanted in this situation?"* or *"Our goal is not so much to think about what you would want or not want but to use your knowledge of [the patient] to understand what he or she would want in this situation."*

Deal With Decisions That Need to Be Made

Achieve a common understanding of the issues.
Find out if the patient had made his or her wishes about the decision known by asking, *"Had [the patient] ever discussed what he would want or not want in this kind of a situation?"*
Reassure family members that they are making a decision about what is in the best interests of the patient, not necessarily what is in their own best interests.
Begin with open-ended assessments and then turn to specific interventions if necessary.
Offer clear recommendations based on patient and family goals, by suggesting, for example, *"Given our understanding of the medical situation and what you've told us about [the patient's] goals, I would recommend not pursuing dialysis."*
Seek consensus whenever possible, agreeing on the decision or on the need for more information.
Use summary statements, such as *"It sounds like we are coming to an understanding that [the patient] would not want to continue on the ventilator. Is that how everyone understands his or her wishes?"*
Consider the possibilities of seeing the decision as a "therapeutic trial" or as a health care team recommendation that requires only family assent.
Check for understanding of the decisions made, by saying something like, *"I want to make sure everyone understands that we've decided to . . . ."*

Close the Meeting

Offer a brief summary of what was discussed.Ask for any final questions. Offer a statement of appreciation and respect for the family: *"I appreciate how difficult this must be, but I respect everyone for trying so hard to do right by [the patient],"* or *"I want to thank everyone for being here and for helping to make these difficult decisions."*Make a clear follow-up plan, including plans for the next family meeting and how to contact the health care team.

Follow up on the Meeting

Document the meeting in the chart. Follow up with any information or reassessment agreed upon during the meeting, by saying, *"When we last met, you were going to talk with your brother about our meeting. How did that go?"*[340]

---

[340] Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting Family Caregivers at the End of Life. *JAMA: The Journal of the American Medical Association, 291*(4), 483-491.

VITA

Karen Smith

Karen L. Smith was born in Blue Island, Illinois and raised in Warsaw, Indiana where she graduated from Warsaw Community High School in 1982. From there, she went to Indiana University where she obtained a BSW in social work in 1987 and a MSW in 1990. Ms. Smith worked in hospital social work for over 20 years prior to returning to school to obtain her Ph.D. in philosophy from the University of Tennessee in 2011.