

Palliative Sedation at the End of Life:
A Way To Ease the Dying Process Without Resorting To Assisted Suicide?

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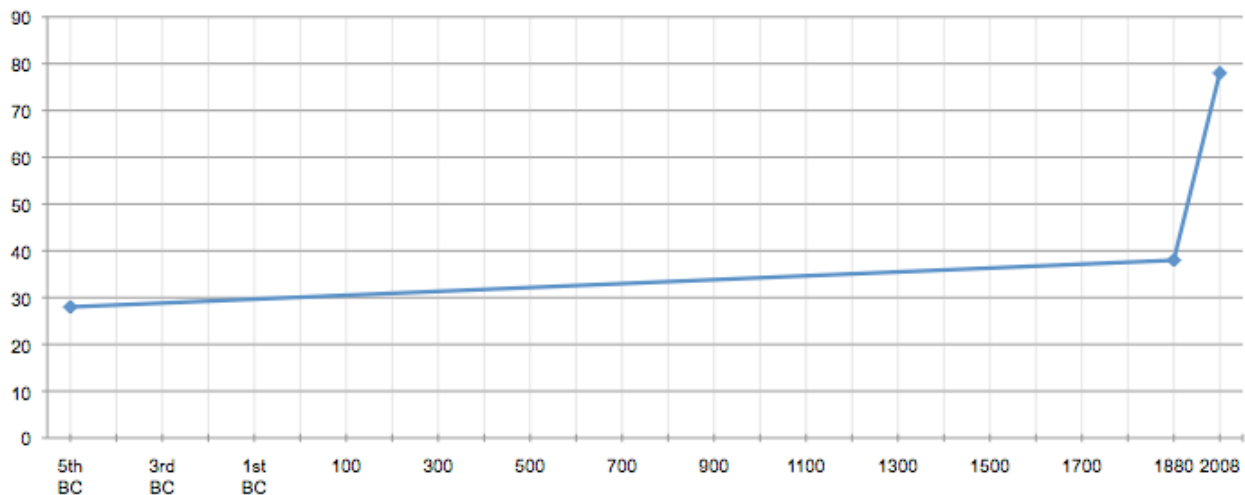
Abstract

A number of developments in right-to-die policies and procedures have emerged in the last four decades as medical technology has advanced to the point where biological life can be extended beyond the point where patients (or their family members) consider the quality of extended life to be life worth living. Today, the rights of patients (or their surrogates) to decide to forgo life-sustaining treatment at the end of life has become well accepted both in law and in the medical community. This is true even when it comes to forgoing artificial nutrition and hydration, and even when family members must make end-of-life decisions for their incompetent loved ones. There have been some successful efforts to push beyond this general consensus to legitimize assisted suicide (Oregon, Washington state, Switzerland, the Netherlands, and Belgium), but there is little evidence to suggest that assisted suicide will become more widely accepted and legalized in the immediate future. Palliative sedation -- sedating end-of-life patients to the point of unconsciousness, if necessary -- represents a middle ground between passively forgoing medical treatment on the one hand, and actively assisting dying patients to end their lives on the other. As such, palliative sedation seems to be gaining some traction in western medicine as an acceptable alternative way ease the dying process and manage suffering at the end of life.

Advances in Medical Technology Change the Face of Dying

The number and significance of advancements in modern medical technology have been nothing short of breathtaking in the last one hundred years. Life expectancy in ancient Greece was approximately 28 years, and increased only ten years in the ensuing twenty-four centuries. Beginning in the late nineteenth century, however, a relative flat life expectancy curve took a sharp turn upward, climbing from 38 years in 1880 to an all-time high in the U.S. of 78 years in 2008.¹ Prior to 1880, life expectancy increased about a day-and-a-half for every passing year, but that rate showed a 78-fold increase thereafter, during which time life expectancy began increasing nearly four months for every passing year (see Fig. 1). Though this rate of increase can be attributed to a number socioeconomic and geopolitical factors, much of this dramatic change is owed directly to the increasing skill and technology associated with advances in modern medicine.

Figure 1: Life expectancy from 5th century BC to present



The obvious benefits associated with increased life expectancy have not been appreciated universally, however. In addition to questions raised about the increasing financial cost and decreasing access to state-of-the-art health care for some populations, more general questions have been raised about the quality of life for those whose lives have been extended by medical interventions. We are all living longer on average, but the quality of life in those last weeks, months, and sometimes years is oftentimes severely degraded, leading some to question whether all the extra days of life afforded us by modern medical technology are actually days worth living.

The percentage of Americans with progressive neurological disorders has increased three times faster than the general population over the last one hundred years. Today, one in eight Americans sixty-

¹ The life expectancy leader in the world, at 84 years, is Macau, a special administrative region of the People's Republic of China. Life expectancy is also currently higher in Japan (82 years), Canada (81 years) and in most of Western Europe (80 years). (Central Intelligence Agency, 2009).

five years and older, and nearly half of all Americans eighty-five and older suffers from Alzheimer's disease or one of its pathological cousins (Hoefer, 1997). Twenty-five percent of older Americans suffer through a stage of severe dementia before they die; a phase of life typically marked by incontinence, the inability to speak, decreased mobility, and the loss of the ability to swallow (which often requires that the patient be feed artificially via a permanently implanted feed tube). Psychosis, anxiety, loss of memory, and personality changes are common in this cohort as well. These individuals would have died of "natural causes" in an earlier time, probably from pneumonia or some other infectious disease (infectious disease was the leading cause of death in 1900). But today, advances in modern medicine have saved older Americans from that fate, enabling them to live longer, and eventually die a longer, more protracted death from a chronic condition that slowly but surely erodes the quality of life they are able to enjoy.

Others, saved for a time from bouts of heart disease, cancer, stroke, and lower respiratory disease, also face a questionable quality of life as death approaches. Whereas most Americans in the late-eighteenth century died a few days, or at most, a few weeks after contracting the illness that finally killed them, Americans today live on an average of several years with the condition that finally proves fatal for them. Those early months of chronic illness may well be marked by a reasonable quality of life, but the later months and weeks are often much less satisfying. It is perhaps ironic that despite tremendous advances in medical technology, the quality of life that most people have as death approaches in the twenty-first century still leaves much to be desired. Despite the very best interventions palliative care has to offer, modern death is still often marked by moderate-to-severe pain, difficult or painful breathing, fatigue, profound confusion, and/or intense anxiety (Quill and Byock, 2000). Much can be done today to sustain the life of mortally ill patients, but given the degraded quality of life that some of them must endure, questions inevitably arise regarding when to say "enough is enough."

Modern Medicine Leads To Attempts To Manage Death

It should come as no surprise that the most recent advances in what might best be called "rescue medicine" in the last forty years have been accompanied by a variety of developments aimed at putting patients in control of what, if any, heroic measures are used at the end of life to sustain their existence. For example, cardiopulmonary resuscitation (CPR) was developed and began widespread practice in the 1960s. At that time, nearly all patients who arrested at the end of life received CPR. Slowly but surely, the medical community came to the realization that not all patients would benefit from aggressive attempts at resuscitation at the end of life, and started quietly deciding on their own when to provide a real attempt at resuscitation (a *full code*) and when to take their time (a *slow code*) in hopes that the patient would die without the futile attempt at rescue. By the end of the 1970s all states and the medical community had come to consensus on the value of patient-initiated Do Not Resuscitate (DNR) orders, medical orders requested by patients or their family members instructing caregivers not to make heroic attempts at resuscitation at the end of life.

The development and proliferation of the hospice concept provides another good example of the shift away from the rescue, curative-oriented practice of medicine. Hospice is a care-based medical model shifts emphasis of medical interventions from *curing* to *caring*, putting more emphasis on the quality of life at the end of life rather than focusing on the quantity of time one can forestall an inevitable death. The concept traces its modern roots to St. Christopher's Hospice in southeast London, where in 1967, British physician Cicely Saunders established a place where specialized care could be provided for dying patients. The hospice concept, with its interdisciplinary approach to aggressive symptom management, spread west (and around the world) in the ensuing years to the point where today, 27% of Americans die with support of one of the over 4,000 certified hospice programs in the U.S..

By the 1980s, with DNR orders and hospice care both well established and accepted, the states began pushing out further into the area of "managed death" with a proliferation of advance directive statutes that would provide patients or their surrogates with the opportunity to prescribe what, if any, medical measures should be taken to stave off an inevitable death once they were deemed to be terminally ill. Today, all fifty states and the District of Columbia recognize some form of advance directive, and approximately 30% of Americans have availed themselves of the opportunity, under state law, to plan the medical management of their own deaths.

Toward the end of the 1980s and into the early 1990s, the medical community's professional associations, one by one, adopted professional codes of ethics that reaffirmed the rights of patients to forgo treatment at the end of life. These codes included statements reaffirming the right to forgo medical treatments at the end of life, or if a patient is in a persistent vegetative state (PVS, a state of complete and permanent unawareness, despite continuation of basic bodily functions to include respiration, eye movements, and sleep-wake cycles). This broad consensus included the right to forgo any treatment, including artificially provided nutrition and hydration, even when the patient was incompetent to speak for him- or herself (see Figure 2).

Figure 2: Professional medical community consensus on end-of-life treatment

	American Medical Assoc.	American College of Physicians	American Thoracic Society	American Nurses Assoc.	Catholic Health Assoc.
Family members have the right to make end-of-life decisions for incompetent patients.					
Forgoing treatment at the end of life and providing pain medication that may incidentally hasten death is not considered assisted suicide.					
There is no ethically important difference between withholding and withdrawing medical treatment at the end of life; both are acceptable.	1990, 1991	1989, 1992	1991	1992, 1994, 2001	1993
It is morally acceptable to withdraw treatment from patients who are deemed to be in a persistent vegetative state.					
It is acceptable to withdraw artificially provided nutrition and hydration.					

This all brings us to 1990, a particularly pivotal year in the right-to-die debate for three reasons. In addition to the American Medical Association (AMA) going on record in support of patient's rights to direct their own care at the end of life, 1990 was also the year the U.S. Congress passed the Patient Self-Determination Act (PSDA). The PSDA required all health care institutions receiving federal funding to inform their patients, upon admission, of their right complete an advance directive. 1990 was also the year the U.S. Supreme Court handed down its landmark decision in the case of Nancy Cruzan. While that court gave the states wide berth when it came to setting standards by which to judge whether family members could make end-of-life decisions for their loved ones, the court left no doubt as to the basic constitutionality of the right to control one's treatment at the end of life. Writing for the majority, Chief Justice Rehnquist noted, almost dismissively, that that:

The Fourteenth Amendment provides that no State shall "deprive any person of life, liberty, or property, without due process of law." The principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions (*Cruzan v. Director*).

The right to refuse treatment via DNR policy, state sanctioned advance directive, or under the supervision of hospice personnel, all of which enjoy full support of the professional medical community, was thus firmly established by the end of this watershed year. And it was during this year that momentum toward the next major effort to shape right-to-die policy – advocacy for the right to assisted suicide – began to pick up steam. It was in 1990 that Dr. Jack Kevorkian provided services to his first (and perhaps, most controversial) assisted suicide patient: Janet Adkins, who suffered from the early stages of Alzheimer's disease. The initiation of Dr. Kevorkian's activities were followed closely by Dr. Timothy

Quill's open letter to the *New England Journal of Medicine* in 1991, where he admitted to providing a mortally ill patient of his with an overdose of drugs after this patient requested his assistance in ending her life (Quill, 1991).

While Kevorkian was viewed as somewhat radical (even by assisted suicide advocates) and well outside the mainstream of medical practice (Kevorkian was a research pathologist without an active clinical practice), Quill was a well-respected clinical practitioner, palliative care specialist, and professor of medicine at the University of Rochester School of Medicine. As such, his admission opened a door to debate on the merits of assisted suicide in the professional community that continues unabated, today.² 1991 was also the year Derek Humphry published *Final Exit*, a self-help book on how to take one's life, which spent several weeks on the best seller lists. (Dr. Quill had initially directed his patient to seek guidance on assisted suicide from Humphry's Hemlock Society at just about the time Humphry's book was coming out.)

A number of attempts made to legalize the practice of assisted suicide in the ensuing decade (see Figure 3). All such attempts in the U.S. and Canada failed, with the lone exception of Oregon, where physician assisted suicide became legally available in 1997.³ The decade ended where it began, with Jack Kevorkian. By this time Kevorkian had assisted in the suicides of approximately 130 patients and being acquitted of violating Michigan's assisted suicide prohibition in several jury trials, despite his open admissions of guilt. In 1998, Kevorkian decided to push the envelope a bit further by providing euthanasia to Thomas Youk. Youk suffered with Amyotrophic Lateral Sclerosis (ALS, more commonly known as Lou Gehrig's Disease) and had come to Kevorkian for assisted suicide, but Kevorkian convinced him that euthanasia would be preferable in his case. Kevorkian video taped the act and sent a copy to *60 Minutes*, which broadcast it on November 22 of that year. Kevorkian was subsequently arrested, tried and convicted of second degree murder, and sentenced in 1999 to a term of 10 to 25 years in Michigan state prison system.

² A grand jury was eventually convened to consider bringing charges against Dr. Quill, but failed to bring an indictment despite his open confession of complicity in an act that was clearly illegal under New York State law. Shortly thereafter, the New York State Health Department's Board for Professional Medical Conduct declined to bring charges of professional misconduct against Quill for his actions.

³ Under the *Death With Dignity Act*, Oregon residents 18 years of age or older may request an overdose of medication from a physician (1) if they are certified by two physicians to have a life-expectancy of six months or less, (2) if they make a repeated written and oral request (at least 15 days apart), and (3) if it is determined that they are not suffering from depression.

Figure 3: Selected worldwide developments in the right-to-die 1990-2000

Year	Locale	Issue	Development
1990	Michigan	assisted suicide	Dr. Jack Kevorkian assists in the death of his first <i>patient</i> ; Janet Adkins, a middle-aged woman with Alzheimer's disease.
	New York		Dr. Timothy Quill describes his provision of lethal drugs to a leukemia patient in an open letter to the in the <i>New England Journal of Medicine</i> .
1991	U.S.		Derek Humphry publishes <i>Final Exit</i> , a how-to book on <i>self-deliverance</i> . The book spends several weeks on the bestseller lists.
	Washington		Voters reject ballot initiative to legalize physician-assisted suicide (PAS): 46% - 54%.
1992	California		Voters reject ballot initiative to legalize PAS: 46% - 54%.
1993	Canada		Canadian Supreme Court (5-4) rejects petition of Sue Rodriguez, 43, an ALS patient asking for the right to PAS. Rodriguez took her own life 4 months later.
1994	Oregon		Voters approve ballot initiative to legalize PAS: 51% - 49%. A U.S. District Court judge issues injunction preventing the state from implementing the law.
			Court challenges are disposed of and voters reject a referendum to repeal the original PAS measure (40% - 60%), clearing the way for implementation law.
1997	U.S.		Supreme Court reverses lower courts in <i>Washington v. Glucksberg</i> and <i>Quill v. Vacco</i> , upholding constitutionality of state statutes barring assisted suicide.
	Australia		Australia's Northern Territories enact a provision to legalize assisted suicide which is rescinded by the full Australian parliament several months later.
1998	Michigan	Voters reject ballot initiative to legalize physician-assisted suicide: 30% - 70%.	
	Switzerland	DIGNITAS is founded, the first Swiss group to assist members from abroad; approximately 800 DIGNITAS patients end their lives in the ensuing ten years.	
1999	Michigan	euthanasia	Dr. Kevorkian sentenced to 10-25 years for the 2nd degree murder of Thomas Youk after video of death by injection airs on the <i>60 Minutes</i> TV program.
2000	Maine	assisted suicide	Voters reject ballot initiative to legalize PAS: 49% - 51%.

The New Millennia: Attempted Steps Backward

The first decade of the new millennia saw some attempts to step backward on right-to-die policy, and several more steps to move forward on a variety of fronts. The attempts to step backward took place in Florida, with the case of Terri Schiavo, ending in her death in 2005, and in Italy, with the case of Eluana Englaro, ending in her death in 2009.

Terri Schiavo (U.S.). The case of Terri Schiavo is instructive for the degree to which the law on forgoing treatment was tested, and as such it deserves some elaboration. Schiavo suffered respiratory and cardiac arrest in her home on February 25, 1990. Although an imbalance of electrolytes in her blood appeared to precipitate the initial event, the exact cause of Schiavo's collapse was never determined. Schiavo suffered extensive brain damage prior to her resuscitation and was eventually determined to be in a persistent vegetative state.

After numerous failed attempts at rehabilitation, Schiavo's husband Michael filed a petition in the state courts to have her feeding tube removed in May of 1998. That action triggered a long legal battle with Terri's family, most of whom wanted to continue feeding and rehabilitation efforts. Michael Schiavo testified at trial that his wife would not want not be kept alive in her present circumstance, but Schiavo's sister and parents contested this point, and further argued that Schiavo's mental condition was not as bad or as hopeless as physicians appointed by the court testified that it was.

The district court in Florida where the case was adjudicated found that a surrogate or proxy may exercise the constitutional right of privacy for an incompetent person who, while competent, expressed his or her wishes to discontinue artificial life-prolonging procedures. As such, continued utilization of life-prolonging procedures -- specifically, tube feeding -- violated the right to privacy guaranteed to Mrs. Schiavo by the Florida constitution. Further, the court found Schiavo's husband to be acting in good faith on his wife's behalf, and accepted the findings of court-appointed physicians that Schiavo was in a PVS, without reasonable hope of recovery. The Florida Supreme Court refused to hear appeals of this ruling brought by members of the family on three separate occasions and withdrawal of tube feeding was authorized and commenced on October 15, 2003.

Almost immediately thereafter, the Florida legislature passed and the governor signed an emergency bill that authorized the governor to issue a one-time stay to prevent nutrition and hydration from being withdrawn for patients in a PVS (pending appointment of a guardian ad litem to consider the interests of the patient) when there was disagreement among immediate family members about the decision and there were no written directives in place. Governor Jeb Bush exercised his authority under the new law forthwith and forced reintroduction of tube feeding for Mrs. Schiavo on October 21, 2003.

The law was ultimately ruled unconstitutional by the Florida courts but legal wrangling over whether Terri Schiavo was actually in a persistent negative state, the suitability of her husband to serve as guardian, and what the wishes of Terri Schiavo would have been regarding continued tube feeding persisted for another year-and-a-half.

In March of 2005, the U.S. Congress passed and President Bush signed a private bill into law that gave Terri Schiavo's parents the right to have their case heard in the federal courts when it appeared, at last, that all state court options had been exhausted. But federal judges in the 11th circuit and ultimately, the U.S. Supreme Court, refused to hear the case. Terri Schiavo's feeding tube was removed (for the third time) on March 18, 2005. She died of dehydration 13 days later.

Eluana Englaro (Italy). Eluana Englaro's situation was in many ways similar to that of Terri Schiavo, and likewise deserves some elaboration. Englaro fell into a persistent vegetative state after being involved in a serious automobile accident in 1992. Several years later, Beppino Englaro, Ms. Englaro's father and legal guardian, petitioned the Italian courts to have her feeding tube removed, arguing that "If she couldn't be what she was [before the accident in 1992] then she would not have wanted to live" (Guardian, Feb. 9, 2009). After several conflicting rulings at the lower court level, Italy's highest court awarded Mr. Englaro the right to stop his daughter from being tube fed in November of 2008.

In February 2009, Prime Minister Silvio Berlusconi, with vocal support from the Roman Catholic Church, introduced an emergency measure that would have forced the continuation Englaro's tube feeding. But Italian President Giorgio Napolitano refused to sign the decree, thrusting Italy into something of a constitutional crisis.

Eluana Englaro died on February 9, 2009, as the Italian senate was preparing to debate a measure that would have required that her tube feeding be continued. The Italian flag was lowered to half-mast over the senate when the news of her death arrived. Thereafter, some Italians, prompted by this case and the fact that Italy has no official provisions for living wills and no legislation on end-of-life issues, began using YouTube to post their own living wills (NY Times, Feb. 9, 2009).

The New Millennia: Attempted Steps Forward

Attempts to legalize assisted suicide continued throughout the first decade of the twenty-first century, but failed to get much traction in the U.K. or in the U.S.. Washington state proved to be the only exception, which in 2008 became the second U.S. state to successfully pass a public initiative on physician assisted suicide. Meanwhile, the Netherlands legalized the practice of assisted suicide and euthanasia in 2002. Both practices had been decriminalized and tolerated since a Dutch ruling in 1984 (provided that physicians adhered to published guidelines). Belgium quickly followed suit passing provisions that legalized the practices of euthanasia and assisted suicide very similar to the Dutch versions in the same year (see Figure 4).

Figure 4: Selected worldwide developments in the right-to-die 2000-2009

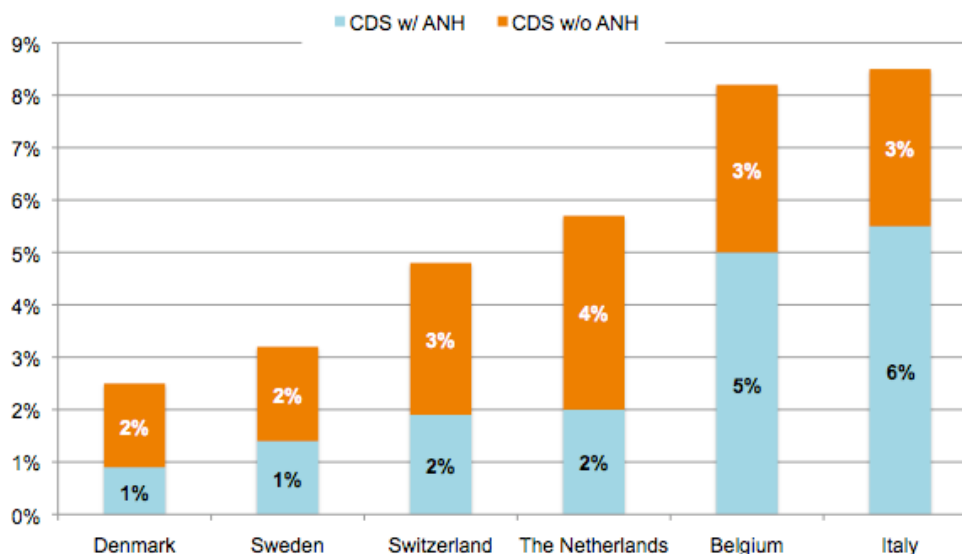
Year	Locale	Issue	Development
2001	U.K.	assisted suicide	M.S. patient Diane Pretty asks court to allow her husband to help her commit suicide. The House of Lords (and the Court of Human Rights, in Strasbourg), all reject her request (she died in hospice a few weeks later).
2002	Netherlands	euthanasia & assisted suicide	Dutch law allowing PAS and voluntary euthanasia takes effect, legalizing procedures that had been decriminalized and tolerated for 20 years.
	Belgium		Belgium passes law similar to the Dutch provisions, allowing both PAS and voluntary euthanasia.
	Hawaii	assisted suicide	Bill to legalize PAS, pushed by then-Governor Cayetano, passes in the Hawaii state house but falls one vote short in the Hawaii state senate.
2003	U.K.		Parliament rejects a patient assisted dying bill identical to the Oregon law.
2005	Florida	forging treatment	After a long legal battle and 15 years in a PVS, Terri Schiavo's feeding tube is removed (for the 3rd time); she dies of dehydration 13 days later.
	Netherlands	palliative sedation	Royal Dutch Medical Association issues national guidelines and the practice of palliative sedation.
2006	U.S.	assisted suicide	The US Supreme Court refuses the U.S. Attorney-General's application to repeal the Oregon <i>Death With Dignity Act</i> .
2007	Michigan	euthanasia	Dr. Jack Kevorkian released on parole after 8 years in prison.
2008	U.S.	palliative sedation	The AMA issues an ethical opinion obligating physicians to offer palliative sedation when symptoms cannot be diminished through other means.
	Washington	assisted suicide	Voters approve ballot initiative to legalize PAS: 58% - 42%. Former Gov. Booth Gardner, who suffers with Parkinson's disease, supported the initiative.
	U.K. and Switzerland		Craig Ewert, a retired professor with motor neuron disease, travels from UK to Zurich where DIGNATAS provides assisted suicide. Ewert's journey and death are broadcast on British television and YouTube.
2009	Italy	forging treatment	Eluana Englaro dies after her feeding tube is removed as the Italian senate prepares to debate a measure to require that her tube feeding be continued.
	Montana	assisted suicide	District Court Judge McCarter rules in a case brought by a man with terminal cancer that the state's constitution gives a mentally competent person who is terminally ill the right to assisted suicide. The state is appealing the ruling.
	Georgia		4 members of the <i>Final Exit Network</i> are arrested for providing assistance in suicide, which is illegal under Georgia law.

The final right-to-die development worthy of note in the current decade is in the area of palliative sedation. Palliative sedation involves sedating end-of-life patients to the point of unconsciousness, if necessary (possibly hastening the patient's death as an unintended consequence). Despite the widely recognized right to forgo medical treatments that would prolong the dying process, despite the proliferation and increased use of hospice, and despite advances in palliative care more generally, it is widely acknowledged that not all symptoms can be adequately managed at the end of life. According to one particularly well cited report published in the *Annals of Internal Medicine*, between 5% and 35% of hospice patients suffer from intractable symptoms in the last week of life (Quill and Byock, 2000). The most common intractable symptoms include pain, dyspnea (air hunger), myoclonus (muscular twitching), nausea, fatigue, and delirium. Palliative sedation is touted by some as an option that offers end-of-life patients who are suffering with refractory symptoms the opportunity to die a more peaceful death, if they so chose.

The procedure, widely studied in the last ten years, has been sanctioned as a legitimate medical course of action by the American Academy of Pain Medicine (1998) and the American Academy of Hospice and Palliative Medicine (2006). The AMA (2008) went one step further in their published ethics guideline, stating that physicians are *obligated* to offer palliative sedation as a last resort when symptoms suffered at the end of life cannot be diminished through other means (O'Reilly).

The procedure is not without its critics, however, and some have gone so far as to refer to palliative sedation as "slow euthanasia." These skeptics argue that few if any symptoms are actually intractable, and that better symptom management education and training would obviate the need to sedate patients, sometimes to the point of unconsciousness (typically referred to as *continuous deep sedation, CDS*; Claessens, 2008). Meanwhile, there has yet to be much discussion about the ethics or legality of this procedure in public policy forums, despite that fact that some reports suggest that palliative sedation is increasingly becoming a part of regular medical practice in end-of-life care. While there is no data on the incidence of palliative sedation in the U.S., one recent study of CDS suggests that this practice is has gained some level of acceptance and respectability in Western Europe (see Figure 5).

Figure 5: Incidence Continuous Deep Sedation in Six European Countries*



*ANH = Artificial Nutrition and Hydration. Data from Miccinesi G, et al. Continuous deep sedation: Physicians' experiences in six European countries. *Journal of Pain and Symptom Management*. 2006;31:122-129.

Medical Literature on Palliative Sedation

Although a number of articles on palliative sedation have been published in peer reviewed medical journals in the last ten years, two stand out as especially illuminating. Claessens (2008) conducted a comprehensive review of the literature, including thirty-three peer reviewed articles on palliative sedation in clinical practice. Rietjens (2008) conducted a more recent and much more in-depth study of continuous deep sedation in one country, the Netherlands (see Figure 6). The results of these two studies, and several others (most notably Miccinesi, 2006; AMA, 2008; RMDA, 2005; and Hasselaar, 2009), are summarized below.

Prevalence: Reported prevalence of palliative sedation varied between 3% and 51% across all studies reviewed, but some of the studies (mostly those with the highest reported prevalence of palliative sedation) only reported on use of sedation for a subset of patients already suffering from intractable symptoms. The study of continuous deep sedation in six European countries noted in Figure 3 above may be the best indicator of palliative sedation use at the end of life to date given that it assayed over 20,000 medical records, a random sample of all deaths in each of the six countries studied (Miccinesi, 2006). Here, rates of continuous deep sedation varied between a low of 1:30 (Denmark) and a high of 1:12 (Italy).

Sedation depth: Palliative sedation drugs can be titrated to yield a variety of different levels of sedation, although these three levels were most commonly mentioned:

- *mild sedation*: patient appears to be sleepy or drowsy; he or she can continue to communicate at some level.
- *moderate sedation*: patient appears to be in a stupor; he or she is asleep, but can be woken to communicate briefly.
- *deep sedation*: patient appears to be comatose; he or she is unconsciousness and unresponsive.

Sedation continuity: Sedation can be intermediate or continuous. At one end of the scale, patients might be mildly sedated for intermittent periods, as symptom management allows. At the other end of the scale, patients might be deeply sedated continuously until death (CDS). In a number of cases, physicians reported needing to move patients from intermittent sedation of the mild or moderate variety to continuous deep sedation in order to adequately manage symptoms (this was the case in between 10% to 27% of patients in the studies Claessens reviewed).

Physical indications: Sixty-eight percent of studies in Claessens review reported use of sedation for management of intractable physical symptoms only, with delirium, breathing problems, and pain being most prevalent symptoms noted. Refractory fatigue, agitation, physical restlessness, insomnia, nausea, and vomiting were also mentioned as reasons for sedation in the studies Claessens reviewed.

Existential suffering: Twenty-seven percent of the studies reviewed by Claessens identified psychological reasons for use of palliative sedation (something the AMA code explicitly rejects as unethical). Anxiety and mental anguish were both mentioned prominently, here, and several authors noted in their papers that the use of palliative sedation for psychological appears to be on the rise. Rietjens reported the existence of anxiety (5%) and depression (3%) among patients in her study, although it is unclear whether any of the patients in the study were treated with CDS only because of these psychological symptoms, or if these psychological symptoms occurred alongside the more prevalently reported physiological symptoms.

Survival: Mean survival time after initiation of palliative sedation ranged from one to six days. A significant percentage of patients, perhaps a third or more, typically died in the first 24 hours after initiation of palliative sedation (47% in the Rietjens study), and nearly all patients receiving palliative sedation died within a week (94% in the Rietjens study). A small number of patients were reported to survive three weeks or more, but it is not clear which level of sedation these longer-living patients were receiving.

Hastening death: Most physicians (65% in the Rietjens study) estimated that palliative sedation shortened their patients' lives by 24 hours or less, on average, although some estimated that this procedure shortened the life of some patients by a week or more. Interestingly, none of the many studies that compared the survival rates of sedated and non-sedated patients showed any relationship between survival and sedation. As such, and despite physicians' attitudes to the contrary, it is not at all clear that sedation hastens death.

Medications: Use of drugs in the benzodiazepine family are strongly recommended in the palliative sedation protocol issued by the RDMA (2005) and 81% of the physicians in the Rietjens study reported the use of drugs in this family. In one recent report on the use of continuous deep sedation in the Netherlands it appears that use of benzodiazepines is currently up to 90% in that country (Hasselaar, 2009). The more general review of the literature conducted by Claessens suggests that while benzodiazepines are used more often than other drugs, antipsychotics, barbiturates, and opioids are also used, perhaps to the detriment of the patients being treated.

Artificial nutrition and hydration (ANH): The AMA (2008) code suggests that the decision to use artificial nutrition and hydration should be made separately from the decision to proceed with palliative sedation. The RDMA (2005) guidelines come to the same general conclusion, although they go further to point out that ANH is not necessarily indicated, and may be contraindicated in the case of continuous deep sedation. Reports from the general medical literature surveyed by Claessens vary widely, although Rietjens reports that ANH was withheld in 66% of the cases in her study. Clearly no consensus has yet emerged on the value of ANH for patients receiving palliative sedation, though it appears that the trend is against providing ANH, particularly when CDS is employed.

Efficacy: Although there were only four studies in Claessens' review that reported on the efficacy of palliative sedation, between 83% and 92% of physicians in those four papers reported that they were able to adequately manage otherwise intractable symptoms through use of palliative sedation.

Decision making: Nearly all papers in Claessens' review noted that patients or their surrogates had been part of the decision making process (as required by both the AMA code and the RDMA guidelines). While conflicts between medical staff and family members were noted in approximately 10% of cases reviewed, four out of five families surveyed reported being satisfied with the decision to resort to palliative sedation. Those expressing dissatisfactions cited *high levels of persistent distress in patients after sedation, insufficient information, fear of shortening the patient's life, physicians and nurses lacking sufficient compassion, and lack of discussion with patients* (Claessens, 2008, pp. 326-7).

Figure 6: Physician experiences with Continuous Deep Sedation (CDS) in The Netherlands (%)*

		General practitioners	Clinical specialists	Nursing home physicians	All physicians
Drug used	Benzodiazepines only	42	13	44	30%
	Morphine only	11	16	10	13%
	Benzodiazepines & morphine	44	60	43	51%
Symptoms Preceded by CDS	Physiological symptomology	Fatigue			55%
		Dyspnea (breathing problems)			48%
		Unclear consciousness (delirium)			47%
	Psychological symptomology	Pain			42%
		Confusion			18%
		Vomiting			4%
Palliative consultation (in last month before death)		Anxiety			9%
		Depression			3%
Artificial Nutrition & Hydration withheld		20	2	5	9%
Duration of CDS before death	Less than 24 hours	95	30	98	66%
	1 to 7 days	43	50	42	47%
	1 to 2 weeks	52	38	58	47%
	1 to 2 weeks	3	7	0	4%
	More than 2 weeks	2	4	0	2%
Estimated time life was shortened	Less than 24 hours	57	73	64	65%
	1 to 7 days	27	17	18	20%
	1 to 4 weeks	6	3	1	4%
	More than 1 month	0	3	4	2%
	Unknown/missing data	16	4	9	9%

* Data for this table are extracted from Rietjens (2008) Tables 3 and 4.

Summary

The right to forgo medical treatment is now well established in the western world, both in law and in the medical community. This is true even when it comes to forgoing artificial nutrition and hydration, and even when patients are in a persistent vegetative state and family members must make the end-of-life decisions. The well-documented political and legal struggles in the cases of Terri Schiavo (Florida, 2005) and Eluana Englaro (Italy, 2009) are exceptions that mask the legal realities related to individual liberty and the daily realities of medical practice, where the rights of patients or their surrogates to decide to forgo life-sustaining treatment at the end of meaningful life has become well accepted.

Assisted suicide currently sits at the other end of the spectrum of right-to-die policy. There has been some movement in the direction of legalizing assisted suicide in Western Europe. In the Netherlands, where assisted suicide and euthanasia have been tolerated since 1984, both became formally legal in 2002. Belgium followed suit that same year with a very similar law. In Switzerland,

where assisted suicide does not require physician involvement and has technically been legal since 1942, DIGNITAS became the first Swiss organization to make assisted suicide services available to non-residents in 1998, and has helped 800 patients end their lives in the last ten years. In the U.S., Oregon (1997) was joined by Washington State (2008) as the only two other locales in the western world where assisted suicide is openly practiced and clearly sanctioned. Elsewhere, the law is silent, ambiguous, or openly hostile to the concept. The recent arrest in a Georgia sting operation of four members of the Final Exit Network, a nonprofit organization established to assist dying patients with *self-deliverance*, is a stark reminder of that fact. Continued agitation for assisted suicide seems inevitable, even if the prospects of sanctioning this act across a wider swath of jurisdictions seems uncertain at best.

Meanwhile, palliative sedation is seen by many as an acceptable middle ground, more controversial perhaps than forgoing life-sustaining medical treatment, but certainly more acceptable than assisted suicide. Medical societies in the Netherland and in the United States – most notably, the AMA, American Academy of Hospice and Palliative Care Medicine (AAHPCM) and the American Academy of Pain Medicine (AAPM) – have sanctioned the procedure, though the guidelines issued by these groups are somewhat more restrictive than the Dutch protocol. The Dutch have openly embraced the palliative sedation, and the RDMA (2005) has issued clear and unambiguous guidelines for its use. Interestingly, recent declines in requests for assisted suicide and euthanasia in the Netherlands have been attributed by some to the increasing availability of and acceptance of the palliative sedation alternative.

To this point, the public sector has remained relatively silent on the issue of palliative sedation, although one might expect governments to become more involved if the procedure becomes more widely used. While some aspects of palliative sedation seem more medical than legal (e.g., should artificial nutrition and hydration be used in conjunction with palliative sedation, and what drugs are most effective?) other aspects of the procedure, while still basically medical in nature, seem more susceptible to governmental interests. Included here are four key issues that might be expected to attract the attention of public policymakers in the coming years, followed by the existing AMA (2008) and RDMA (2005) guidelines which are relevant in each case.

- ***Who can administer palliative sedation?*** Is palliative sedation a procedure that can be carried out by general medical practitioners, without consultation of a second physician, or without consultation of palliative care specialists?

AMA: Guidelines recommend that palliative sedation be carried out in consultation with a multidisciplinary team of clinicians.

RDMA: Guidelines recommend that physicians planning to employ palliative sedation consult an expert, preferably a palliative care specialist, only if he or she has insufficient knowledge of symptom management or sedative administration.

- **How deep and continuous can sedation be?** Is continuous deep sedation something a patient or family member can request, or is it something of a last resort, used only in cases where lesser amounts of sedation prove inadequate for adequate symptom management?

AMA: Guidelines recommend that proportionality be the watchword; that sedation be only as deep and continuous as needed to manage symptoms, and that *palliative use of sedation to unconsciousness should only be implemented in the rarest of circumstances when symptoms are not relieved by lesser amounts of sedative.*

RDMA: Guidelines recommend a similar *proportionality* approach, although they seem to be a bit more tolerant of and quick to resort to continuous deep sedation than their American counterparts.

- **What symptoms qualify for palliative sedation?** Can palliative sedation be used to manage intractable suffering of the existential type (e.g., death anxiety and mental anguish), or should its use be limited to the management of physical symptoms, only?

AMA: Guidelines argue strongly against use of palliative sedation to manage existential suffering.

RDMA: Guidelines note that refractory pain, dyspnea, and delirium are the most common indications for palliative sedation. No mention is made of psychoexistential suffering, although it is clear from published reports that anxiety and depressive symptoms are present in at least some patients who receive continuous deep sedation. What is less clear is whether these psychological symptoms ever occur in isolation, or if they are only concomitant with the kinds of refractory physical symptomology that is clearly covered by the guidelines.

- **When patients qualify for palliative sedation?** How close to death must a patient be before palliative sedation, especially continuous deep sedation, becomes an option?

AMA: Guidelines recommend that patients should be in the *final stages of terminal illness.*

RDMA: Guidelines recommend that deep and continuous sedation until death should be used only in cases where patients are expected to die within two weeks. The RDMA is also open to use of continuous sedation until death to manage refractory symptoms in cases where the imminence of death is unclear (e.g., as with muscular dystrophy, amyotrophic lateral sclerosis

and cardiac or respiratory insufficiency) if done in consultation with another physician, preferably a palliative care specialist.

In closing, it should be noted that while assisted suicide continues to have modest support in the U.S.,⁴ palliative sedation offers many benefits *vis a vis* assisted suicide. This lesser known option at the end of life has at least two characteristics that make it, perhaps, the better of the two alternatives when the simple forgoing of life-sustaining treatment leads to something well short of a peaceful passing (as it too often does, today):

- First, the current practice of palliative sedation is entirely legal.⁵ As noted above, lawmakers may find an interest in regulating at least some aspects of its application in the not-too-distant future. Even then, though, they will be limited in what they can do given that the courts have already stated that they are relatively amenable to the concept:

A patient who is suffering from terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death (*Quill v. Vacco*, 1997, Justice O'Connor, concurring).

- Second, palliative sedation is theoretically available to 100% of dying patients, including severely incapacitated patients and those who can no longer speak for themselves. This is hardly true for assisted suicide, which is available only to competent patients who can take an active part in the assisted suicide process.

It is for these two reasons that palliative sedation holds some, and perhaps a great deal more promise than does assisted suicide for those who suffer at the end of life. Palliative sedation represents a more proactive approach to end-of-life care than simply forgoing treatment, on the one hand, and represents a less controversial approach than actively seeking death, on the other. As such, acceptance and use of palliative sedation – *the middle way* – may indeed emerge as the next major development in the management of death in the modern age.

⁴ In seven Gallup polls conducted this decade, support for assisted suicide averages 49%, while the percentage of those who oppose it averages 43% (Carroll, 2007).

⁵ Indeed, palliative sedation may be preferable even when assisted suicide and euthanasia are legal. As noted above, some attribute the recent decline in requests for assisted suicide and euthanasia in the Netherlands to increased use of palliative sedation.

References

- American Academy of Hospice and Palliative Care Medicine (AAHPCM) Board of Directors. (2006). *Statement on palliative sedation*.
- American College of Physicians. (1989). American college of physicians ethics manual (2nd). *Annals of Internal Medicine*, 111, 327-335.
- American College of Physicians. (1992). American college of physicians ethics manual (3rd). *Annals of Internal Medicine*, 117, 947-960.
- American Medical Association Council on Ethical and Judicial Affairs. (2008). *Sedation to Unconsciousness in End-of-Life Care*. Approval to cite is pending as of 11 March 2009.
- American Medical Association Council on Ethical and Judicial Affairs. (1990). *Guidelines for the appropriate use of do-not-resuscitate orders*.
- American Medical Association Council on Ethical and Judicial Affairs. (1991). *Decisions near the end of life*.
- American Nurses Association. (2001, 1994, 1992). *Code of ethics for nurses with interpretive statements*.
- American Thoracic Society. (1991). Withholding and withdrawing life-sustaining therapy. *Annals of Internal Medicine*, 115, 478-485.
- Carroll, Joseph. 2007. *Public Divided Over Moral Acceptability of Doctor-Assisted Suicide*. Retrieved March 1, 2009, from <http://www.gallup.com/poll/27727/Public-Divided-Over-Moral-Acceptability-DoctorAssisted-Suicide.aspx>
- Catholic Health Association of the United States. (1993). *Care of the dying: A catholic perspective*. St. Louis: Catholic Health Association of the United States.

Central Intelligence Agency. (2009). *The CIA World Factbook: Rank Order -- Life-expectancy at birth*.

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Claessens, P., Menten, J., Schotsmans, P., & Broeckaert, B. (2008). Palliative sedation: A review of the research literature. *Journal of Pain and Symptom Management*, 36(3), 310-333.

Cruzan v. Dir., Mo. Dep't of Health, No. 88-1503 261 (SUPREME COURT OF THE UNITED STATES 1990).

Day, M. (2009, February 8). A father's plea: Let my daughter die in peace. *Guardian*.

de Graeff, A., & 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.

Donadio, R. (2009, Death ends coma case that set off furor in Italy. *New York Times*,

Hasselaar, J. G. J., Verhagen, S. C. A. H. H. V. M., Wolff, A. P., Engels, Y., Crul, B. J. P., & Vissers, K. C. P. (2009). Changed patterns in Dutch palliative sedation practices after the introduction of a national guideline. *Arch Intern Med*, 169(5), 430-437.

Hoefler, James M. (1997). *Managing Death*. Boulder, CO: Westview Press.

National Ethics Committee, Veterans Health Administration,. (2007). The ethics of palliative sedation as a therapy of last resort. *American Journal of Hospice and Palliative Medicine*, 23(6), 483-491.

O'Reilly, K. B. (2008). *AMA meeting: AMA OKs palliative sedation for terminally ill*.

Quill, T. E. (1991). Death and dignity. A case of individualized decision making. *The New England Journal of Medicine*, 324(10), 691-694.

Quill, T. E., & Byock, I. R. (2000). Responding to intractable terminal suffering: The role of terminal sedation and voluntary refusal of food and fluids. ACP-ASIM end-of-life care consensus panel.

American College of Physicians; American Society of Internal Medicine. *Annals of Internal Medicine*, 132(5), 408-414.

Rietjens, J., van Delden, J., Onwuteaka-Philipsen, B., Buiting, H., van der Maas, P., & van der Heide, A. (2008). Continuous deep sedation for patients nearing death in the Netherlands: Descriptive study. *BMJ (Clinical Research Ed.)*, 336(7648), 810-813.

Royal Dutch Medical Association Committee on National Guidelines for Palliative Sedation. (2005). Royal Dutch Medical Association Guidelines for palliative sedation. Utrecht, December 2005.

Vacco v. Quill, No. 95-1858 793 (SUPREME COURT OF THE UNITED STATES 1997).

Verkerk, M., van Wijlick, E., Legemaate, J., & de Graeff, A. (2007). A national guideline for palliative sedation in the Netherlands. *Journal of Pain and Symptom Management*, 34(6), 666-670.