A GOOD DEATH:

THE POLITICS OF PHYSICIAN ASSISTED SUICIDE IN HAWAI`I

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A dissertation is a marathon, a work of art that takes time and a deliberate speed.

Mahalo Nui Loa

To all who stayed the course with me,

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And the one just starting,
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ABSTRACT

This dissertation analyzes the politics of the conflict between the advocates of physician-assisted suicide in Hawaii and their opponents. The first part of this dissertation examines the role of society in deciding whether the individual's decisions regarding end of life treatment should be governed by morals, ethics and beliefs maintained under the status quo or whether such decisions should also include the option of physician assisted suicide under strict conditions. This part of the study seeks to answer the questions, "What are the end-of-life options that define a "good death" and what are the arguments imbedded in the issue of physician assisted suicide?

The second part of this dissertation addresses the politics of winning the battle of physician assisted suicide legislation in Hawaii. The empirical focus is a small group of individuals joined together by their beliefs in choice and autonomy and who propose legislation to legalize PAS. They are opposed by a bigger and better financed group with ties to organized religion, to health care professionals and to groups whose members have disabilities. In 2002, except for three votes, the advocates almost win.

Despite their continued attempts, the advocates have not repeated their "near win." Challenged by the death of their leader, the lack of financial resources and a declining membership, the sustainability and viability of the advocates are in question. This dissertation concludes by proposing a strategy that may further their attempts to win.

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LIST OF ABBREVIATIONS

DWD	Death with Dignity
HDWDS	Hawaii Death with Dignity Society
HFF	Hawaii Family Forum
ODWDA	Oregon Death with Dignity Act
PAD	Physician Aid in Dying
PAS	Physician Assisted Suicide
POLST	Physician Orders for Life Sustaining Treatment

CHAPTER 1
THE POLITICS OF PHYSICIAN ASSISTED SUICIDE

Introduction

On November 4, 2008, Washington became the second state to pass a Death with Dignity Act which would allow certain competent, terminally ill adults to request and self administer lethal medications prescribed by a doctor. In effect, Washington legalized "physician assisted suicide" (PAS). This event was expected to spark excitement among the PAS advocates in Hawaii and renew their efforts to pass a PAS bill. However, except for an article in the editorial page of the local Hawaii newspaper, there appeared to be no other reaction from either its supporters or opponents. The local papers gave the event scant coverage and reported the event matter-of-factly. A few weeks later, when Montana's state court declared PAS legal, the news media was quieter yet. There was still no hoop-la from the members of the Hawaii Death with Dignity Society (HDWDS) and other advocates who supported PAS or even denunciations from the Hawaii Family Forum, an organization of the Hawaii Catholic Conference, the political policy arm of the Roman Catholic Church.

It had been ten years since Oregon became the first state to legalize PAS. The legalization of PAS by a second state was to have been very significant for PAS advocates in Hawaii. It was to have been a rallying point for them, igniting a resurgence of interest and energy that would mobilize the troops. They had hoped to ride Washington's coattails in passing PAS legislation. The virtual non-response indicated to the author that the issue of PAS had become more centrist over the years due in large part to medical advances that had occurred since the Supreme Court upheld the right to die in the Cruzan and Quinlan cases. Further, the dramatic efforts by Congress and the President of the United States to “save” Terri Schiavo from having her feeding tube removed and the refusal of the courts to buckle under pressure had acquainted the public with end-of-life medical treatment decisions. But more pointedly, the passive response to the news also had indicated a decline in the strength of the PAS advocates. In 2002 the HDWDS had claimed a membership of 2,500, by 2009 that number declined to a base of 500 and an active core of six.

Despite their loss of membership, the HDWDS still can cause bills to be introduced in the legislature and incite their opponents to mobilize and lobby their legislators in protest. The most recent example was reported on February 18, 2009 on the Hawaii House blog, that described how the 2009 Death with Dignity bill was “fast tracked” to bypass the House Health Committee where it had been routinely killed and jumped over to the House Judiciary Committee, where it had a better chance of being passed. The Hawaii Family Forum tightened its guard, mounted a phone and e-mail campaign and heavily lobbied against the bill. This led House Judiciary Chairman Jon Riki Karimatsu, to decide not to hear HB 806 which would legalize PAS. He announced, “At this time, the committee has not received a strong push from advocates to hear the bill, therefore, given the full plate before the Judiciary committee, I have decided to not hear the bill this year. I am open to hearing the bill in the future.” (Hawaii House Blog: News and Comments from the Majority of the Hawaii House of Representatives, 2009). The bill died in committee. The Hawaii Family Forum had won again. Having lost their opportunity to have the bill heard, PAS advocates were disappointed and frustrated. Questions and doubts about their viability attested to the group's decline. If the news of Washington and Montana did not spark the PAS cause, what would? How many more defeats could HDWDS sustain before it gave up? What would it take for HDWDS to win? And what was the PAS conflict about?

The Issue

This dissertation attempts to answer these questions by analyzing the conflict between Hawaii Family Forum, which opposes to PAS on moral, ethical, religious and legal grounds and HDWDS, which supports the right to allow personal choice and control over one's death and dying. While advocates argue that the individual has the right to choose and control his or her very personal and very profound act of death and dying, their opponents argue that death by self administered lethal medication violates morals, ethics and society's duty to preserve life.

The PAS issue is salient, controversial, hot-button, and timely. It has the power to summon the Bishop of Honolulu to the legislature. It stops legislators from supporting it for fear of losing their elected seats. It causes Catholics, doctors and groups whose members have disabilities to mobilize in protest. And it compels a small group of advocates, year after year, to engage in a David and Goliath battle to try to change public policy to allow an individual, under strict safeguards, the ability to choose to control his or her death and dying.

The PAS Proposal

Before analyzing the politics of PAS, it is important to analyze the most current legislative proposal. The 2009 Hawaii Death with Dignity proposal is patterned after Oregon's Death with Dignity Act. It gives 1) certain competent adults, 2) who are terminally ill, 3) the ability to choose to end their lives by 4) self-administered lethal medication 5) prescribed by a physician. Each of these clauses is bracketed for emphasis. Read without the brackets, the statement is compact, simple, straight-forward and makes sense. Read with the brackets, the statement contains compromises, deals, buy-ins and a mutual adjustment of differences. The underlying intention of each of these clauses is to ensure that the proposal makes sense, is politically acceptable and safe for the stakeholders, the ones affected by the proposal and those implementing the proposal. Some of the clauses of the most recent PAS proposal are the following:

1. Certain, competent adults—this eliminates children, non-adults and persons who are mentally incompetent. This requirement is inserted to protect individuals and to deflect fears of the slippery slope. The term "certain" is used to describe the individual adults contemplating PAS who have qualified and met the requirements. These requirements are safeguards that protect patients from depression, one of the main causes of suicide and to ensure that the patient is making a deliberate choice. Patients are required to make both an oral and a written request to their physicians twice, the second time at least 15 days after their initial oral request.

2. Terminally ill— PAS applies only to certain terminally ill individuals; those determined by a physician to have 6 months or less to live. This clause was debated endlessly. The more liberal factions had wanted PAS to apply to chronic conditions such as persons suffering from advanced Parkinson's disease. Too many variables arose. To avoid accusations of initiating "the slippery slope," the clause is very narrowly constructed.
3. The ability to choose to end their lives by—this clause is inserted to ensure that individuals have the competency to choose. This clause ascertains voluntarism and informed consent. It ensures that the individual is not subject to undue influence, force or inducements.
4. Self-administered lethal medication—this clause reflects the efforts to make the proposal "safe" for doctors. The term, "self-administered," means that the patients themselves not their physicians, would administer the lethal dose. This clause had been debated vigorously in 1992 when lethal injections applied by a doctor were advocated by Derek Humphrey and his followers. Humphrey was ousted from Hemlock in part because of this position as lethal injections were thought to infringe on self-determination.
5. Prescribed by a physician—this is an extra step that the patient takes to obtain the lethal medication. It assures that the drugs meet medical standards.

The full script of Hawaii's 2009 proposal, HB 806, is found in the appendix.

The difference between Hawaii's bill and Oregon's are the residence requirement and Hawaii's requirement for a monitor. Oregon has a residency requirement but does not define it. In Hawaii, it is six months. When the bill was brokered in Oregon, it was thought that residency requirements were not relevant to the issue of PAS. However, to allay fears that Oregon might be overrun with people seeking death with dignity, a residency clause was included, but no term was specified. Hawaii's requirement reflects the fear that Hawaii might become a Mecca for PAS if it did not have a residency requirement. The second difference is that Hawaii would require a "monitor" who does not have to be a licensed physician. A monitor was included as a precaution for those who might change their minds at the last minute and to attend persons who might physically react badly to the medication, such as gag or vomit. Oregon is silent about this requirement.

Theories

Various approaches can be taken to study the politics of PAS. Although the approaches may be characterized by tremendous diversity, they produce a kaleidoscope of patterns that reflect the dynamic efforts to legalize PAS.

The PAS contest itself can be framed in the style of Madison's classic contest among factions competing to advance their own interests. His theory allows for the various interests to battle in the legislative arena. Even though they may represent powerful interests, that power is dispersed by the sheer number of interest groups and their different positions. The traditional outcomes of the contests can include compromises, and in the case of PAS, such provisions as legal instruments that promote autonomy yet stop short of PAS, better palliative and hospice care that assuage suffering yet prolong life and even attempts at deals and coalitions that among unlikely groups.

While Madison provides a model for the role of interest groups in a democracy, a rational choice theory can better explain what motivates individuals and interest groups to push forward their own agenda. This theory advances the notion that individuals choose according to how much it would benefit themselves even at the expense of others. One of these theorists is Mancur Olson who applies this notion to organizational behavior. He debunks the assumption that individuals in large organizations are united in collective action. Instead, he reasons that individuals are driven by personal gain. For example, in the politics of PAS, for some legislators, voting for PAS would have cost them their seats. For others, having the support of the Catholic Church would provide many more benefits. To demonstrate the power of rational choice, a bishop's letter circulated the night before the vote to legalize PAS, reminded state senators of the church's position and caused three senators to switch their votes and defeat PAS.

However, for many individuals, PAS does not involve wealth or power but deep seated values and strong beliefs. It is a hotly contested issue that seems to be favored by the majority of those polled. It would seem logical that the great number of personal choices in favor of PAS would become the aggregate of societal choice. Kenneth Arrow's book, *Social Choice and Individual Values, Second Edition,* (1963), demonstrates the difficulty of making personal values into a societal choice. Arrow demonstrates mathematically that in a capitalistic society, the ranked preferences of individuals cannot be converted into a societal choice unless power and economics drive the choice. For example, personal values and choice underlie concerns such as abortion, school choice, civil unions, healthcare, choice of candidates in voting and choice to prolong life or to hasten death. In some of these concerns, strong support by labor unions or organized interest groups that represent wealth and power can push to advance or block an individual choice from becoming a societal choice.

While Arrow provides an understanding of how wealth and power can drive societal choice in a capitalistic society, he also recognizes that in a capitalistic society, there exist groups that are governed by a strong religious code (p. 1). He compares these groups to dictatorships where one person's values become a societal choice. In the PAS contest, the choices that opponents make are dictated by centuries of strong religious codes. These values seem to have become and are sustained as societal choices by wealth and power evidenced by the physical and financial assets and the large number of members belonging to these groups. In the case of PAS, some of those most likely to be affected are legislators who have the most to lose should they vote against the wealth and power represented by members adhering to a strong religious code. Thus, PAS faces great difficulty in advancing beyond a legislative hearing before becoming a societal choice.

Another classic theme that appears in the study of PAS is Maslow's theory about the hierarchy of needs that have at its very foundation the individuals' instinct to survive. It surfaces in the arguments of opponents who point out that life is sacred and PAS defies this basic human instinct. Although many more people have requested PAS, perhaps, the fact that only 15 in 10,000 deaths in Oregon have occurred through its Death with Dignity Act is testimony to the human survival instinct. It is reported, however, that the many more who have requested it, find comfort in having the lethal medication at hand.

It seems to serve as an assurance that if the probability of a bad death marked by intolerable suffering, is overwhelming, one is secure in the knowledge that he or she has the means, to end suffering. When Father Marc Alexander, Vicar General of the Roman Catholic Church in Hawaii, posed the rhetorical question, “Why PAS? We don’t need it,” the answer just as spontaneously rises, that, “Yes, we need it to put an end to needless suffering.”

In addition to classical approaches, the politics of PAS can also be understood through “historical institutionalism,” an approach that explains specific real world political outcomes that an empirical study produces. Paul Pierson and Theda Skocpol in their article, “Historical Institutionalism in Contemporary Political Science,” (2002), explain this approach: “Historical institutioanalists analyze organizational configurations while others look at particular setting in isolation; and they pay attention to critical junctures and long-term processes where others look only at slices of time or short-term maneuvers” (p. 1). The scholars further explain that historical institutionalists “take time seriously specifying sequences and tracing transformations and process of varying scale and temporality (p. 3).” They use this method to link and trace events to causes and outcomes and discover where and how their paths intersect, evolve or affect each other.

A concept related to historical institutionalism is the concept of path dependency. Pierson and Skocpol (ibid. p. 6) explain that “it refers to the dynamics of self-reinforcing or positive feedback processes in a political system—what economists call ‘increasing returns’ processes… Outcomes at a ‘critical juncture’ trigger feedback mechanisms that reinforce the recurrence of a particular pattern into the future.” The authors further comment that when an object is on a dependent course, it is difficult to reverse the course; moreover, other alternatives may have been lost in the process.

The notion of path dependency may provide an explanation of why and how the leaders of physician groups resisted PAS even though it was common knowledge that PAS was being performed "underground." According to Pierson and Skocpol, (*Ibid*.), dependent paths are created when behavior is reinforced by positive feedbacks. For those physicians who opposed the PAS, personal beliefs and motives, professional hubris, and the prevailing political ethos may have created positive feedbacks that created a path dependency. Arguments opposing PAS were rife with reminders of the healing power of physicians, their early links to the priesthood and their sacred oath of Hippocrates. Hawaii's plantation ethos had also engendered great respect for many physicians who, through their own personal sacrifice, cared for those who were denied or had limited access to healthcare providers and facilities.

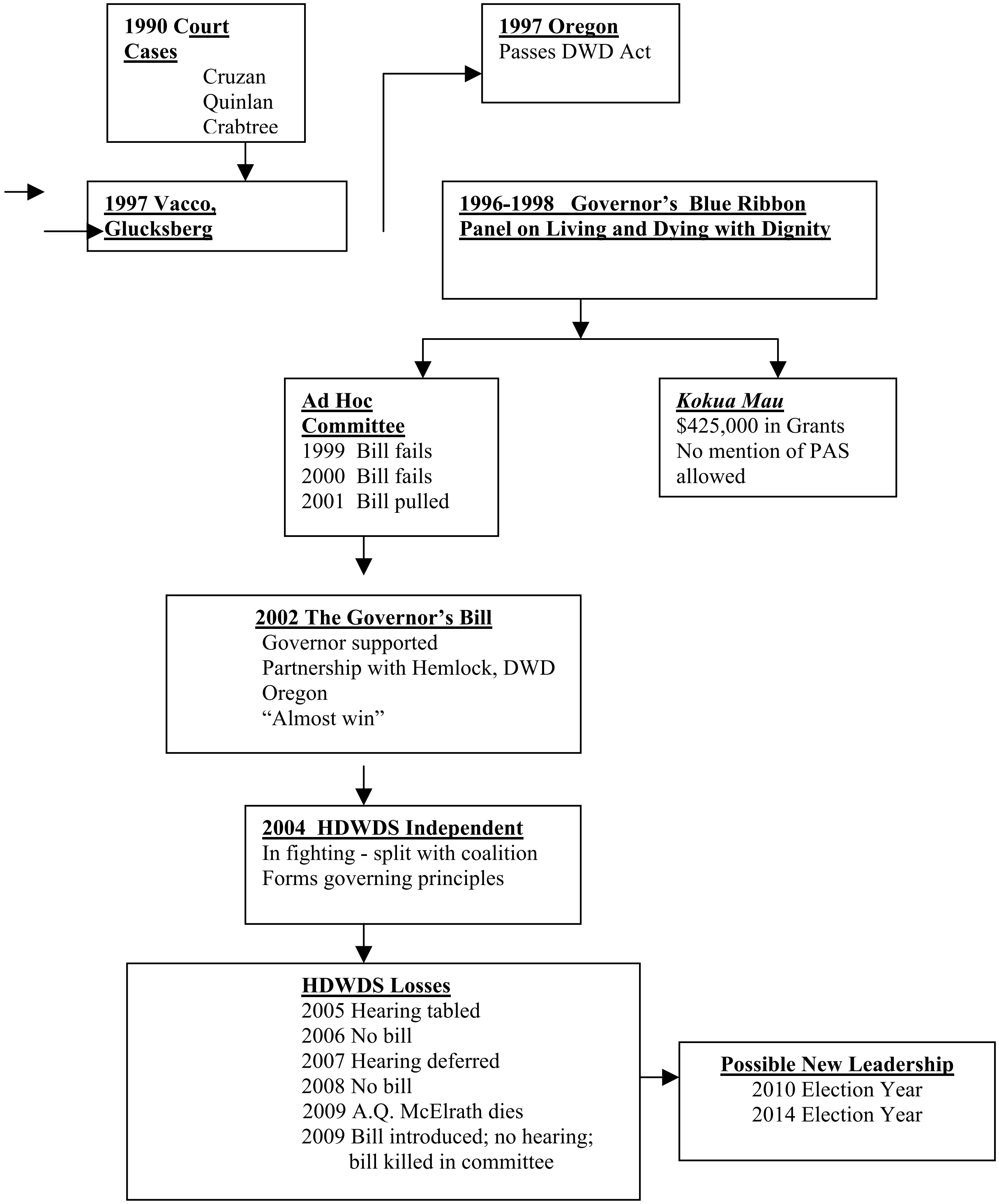
A critical juncture in the PAS movement occurred when physicians are asked to support PAS, a notion imbued with individual choice and autonomy and contrary to the history of the medical profession and foreign to the plantation ethos. When the physician groups and other healthcare groups joined with the Hawaii Family Forum, also with links to tradition and religious codes, the medical profession was committed to oppose PAS. The Hawaii Family Forum became a vehicle that promoted those in the medical profession as heroes who saved and prolonged lives and framed advocates of PAS as instigators of the slippery slope. The outcome of this critical juncture doomed the PAS bills but enhanced the role of the physicians. The early legislative successes scored by the medical profession were repeated in subsequent bills. These successes were reinforced by the chair of the health committee, also a physician, who blocked attempts to hear the PAS bill or when heard, justified killing it.

Using the historical institutional method is well suited to this particular case study. The chapters that follow are laden with human motives, ambition, idealism and power that provide further explanations of the difficulty of changing institutions and the status quo.

The following chart illustrates the path of the PAS movement in Hawaii. It provides a skeleton of boxes into which historical institutionalists can fill with the convergence of motives, outcomes, causes and the intersection of persons, ideas, and action. Historical institutionalism may provide a rich context of understanding but still fails to satisfactorily answer a nagging question, “What sustains the small band of six individuals in their fight to legalize PAS and why do they think they can win against a larger, better organized and better financed foe?

A noted political science professor provided the answer. He reminded me that the power of ideals and ideas had inspired a small band of men filled with the desire for a better life and prompted by ideals of democracy, to defy the majesty of Great Britain and win the War of Independence. So it is not unimaginable that there were only six individuals (and now five) who were pursuing another ideal, that of a better way of living and dying. And like the small band of revolutionists, they also think they can fight against centuries of tradition and win.

Figure 1. The PAS movement timeline.



Methodology: Empirical Framework

I was given the unique opportunity to access the inner workings of HDWDS and meet its members. I found the members open, generous with their time and politically savvy. I was not surprised that they had great confidence in themselves and in their ability to change public policy.

I participated as a member of its steering committee, attended meetings and legislative hearings, attended some events and hosted others. My experiences, observations, interviews with advocates and opponents formed the empirical framework that guided my study in analyzing the politics of the PAS in Hawaii.

Interviews

When I began writing this dissertation, I sought out A.Q. McElrath. One of the questions I asked her was, “How large is the right to die group in Hawaii?” She paused and thoughtfully counted the number of members on her fingers. “Six,” she said. “Bud has died. Ruth has died. Andi is very ill. So there are about six of us who are active.” When I related this information to the members of my dissertation committee their first response was, “Surely, there must be more.” “There must be an underbelly of maybe 500 members who make up the group.” All of us were right. It depended on how one counted.

Indeed, the controversial nature of the issue, the annual plethora of PAS bills unfalteringly introduced by HDWDS, the sound bites of testimony carried on the news channels and the condemnation of PAS by the Bishop of Honolulu, the clergy, doctors and those who had disabilities had magnified the size of the group. According to Scott Foster, Director of HDWDS’ Communications, HDWDS consisted of about 2,500 members in 2002. The numbers had shrunk over the years to about 500 people whom HDWDS could currently count on to support legislation and donate money. Out of the 500, HDWDS could depend on perhaps a dozen to give testimony at legislative hearings and maybe six to do all of the above and more. These six actively beat the bushes for member participation, button-holed legislators, finagled for free publicity and put on a show of strength and numbers. They were the late A.Q. McElrath, Scott Foster, Juliet Begley, George Fox, Andi van der Voort, and Eve Anderson. I was a late comer, a neophyte, who had been given a seat on the steering committee because one summer day I showed up to interview Foster. My job was to help out as best as I could and, left unsaid, not to betray any secrets.

McElrath had said there were six active members, but I discovered that there were not six, but only one, Ah Quon McElrath, better known as A.Q.. She was the leader of PAS, founded the *Ad Hoc* Committee on Death and Dying, pushed the governor to form the Governor's Blue Ribbon Panel on Death and Dying and drove the issue onto the legislative agenda by her iconic reputation and personality. As Foster, the Director of Communications for HDWDS, explained to me, HDWDS existed for McElrath. She told them what to do.

The late McElrath was a social worker for ILWU, a former University of Hawaii Regent and has admitted to have joined the Communist party. During the McCarthy "witch hunt" in the 50's, a cross was burned on her front lawn and her children taunted because of her political beliefs. The other five members are the following individuals: Foster and Begley who had supported same sex union, car insurance reform and medical marijuana and other liberal legislation; Fox, retired, had been a representative for Compassion and Choices; van der Voort who had founded Hemlock in Hawaii and then broke away from Hemlock to join Derek Humphrey to lead Final Exit in Hawaii, a group that helped people with end-of-life matters; and Anderson, a former state Representative from Waimanalo, whose house, at one time, served as the set for the television show, Magnum PI. Each one of the six was liberal in thinking, held strong opinions, was highly educated and articulate. Half were atheists, who like the early Greeks, may not have believed in an afterlife, but recognized that we are all connected by a human spirit. Except for McElrath and me, all the others were white. The characteristic they had in common was a steadfast confidence in themselves and in their ability to change what they believed was not right.

Their stories of how they cared for their loved ones, some of whom suffered immeasurably at the end of life, illustrated why they were in favor of PAS and why they believed that public policy ought to be changed to allow PAS. They sincerely believed that death was personal and that the individual should have a choice and being in control of their living and dying. In their battles, they were David-like in facing the Goliaths of conservative church organizations, doctors and groups whose members have disabilities.

Participation

To find out what people thought about PAS, how much support the issue generated, and the urgency of the issue, I participated as a volunteer in the HDWDS's booth at the Senior Fair held at the Neil Blaisdell Arena on a Sunday afternoon in late September 2007. Of the thousands of people who streamed through booths that sold medical devices, assistive aids, long-term-care nursing plans and senior residences, few came by our booth. The purpose of our being there was to recruit new members as well as to dispense information about end of life choices. About 30 people left information about themselves; more stopped by out of curiosity; some took our brochures and explained that they were Catholics and did not believe in PAS. The HDWDS stalwarts had expected a response from the public that was equal to or more than the previous years when they had collected hundreds of names at similar public events. However, they were pleased with the names they collected and that the people they spoke with seemed genuinely interested.

Other Interviews

While writing this dissertation, I met and interviewed persons who were passionate about PAS. When asked, “Why do you favor PAS?” the answers centered on shared experiences of bad deaths and a deep personal convictions of autonomy, independence and choice. Some of these answers were:

“My wife died of bone cancer. Do you know what bone cancer is? Do you know how she suffered?” “My brother died of cancer. They wanted to operate on him and he is 96 years old.” “I was a nurse and I saw how people suffered. Did you know that pain sedation doesn’t hasten your death? It only stops the pain.” “My father wanted a pill so he could die.” “I don’t want to wear diapers. If I can’t function mentally, sign me out.” “I don’t care what other people believe; I want to be able to choose.”

I also interviewed opponents, including Father Marc Alexander, Vicar General of the Roman Catholic Diocese of Honolulu and several physicians who were active in opposing PAS. They were as adamant in their stand as were the HDWDS members in their stand on PAS. The physicians, whom I interviewed, seemed to instinctively refer to the Hippocratic Oath and to the slogan most heard in the opponents' campaign messages: "Physicians heal, not kill." I also sought information regarding the perspective of the group that ultimately must decide, namely legislators. I attended legislative hearings on the bill presided by Representative Josh Green, Chair of the House Health Committee where the PAS bill was routinely routed and killed. At a *Kokua* Council meeting on May 14, 2007, he defended his stance against PAS. He was not so much concerned about religious arguments but with physicians who testified and who were adamantly against the bill. In addition he was influenced by the testimony of groups whose members had disabilities and felt a genuine fear that they would be targeted by insurance companies to use PAS. I also interviewed and communicated through e-mail with others include the former Director of *Kokua Mau*, Rachel Wong, the representatives of Compassion and Choices, Roland Halpern and Kathryn Tucker and a former representative of the public relations team who had worked on the California's assembly proposal in California in 2007.

During the interviews, I listened to criticism that our island politics can be static; that there was no inclination to change the status quo and that there was no momentum to support PAS. I heard Representative Josh Greene recount a similar sentiment at a meeting with *Kokua* Council right after the 2007 legislative session. I heard the same lament from a member of the media team of Compassion and Choices of California, who had moved back to Hawaii. However, all were gracious and interested in my study.

The methods of finding those who were actively involved in PAS to interview involved two methods: the snowball technique and word of mouth. Persons would suggest other persons who would lead to yet another. Also, colleagues would hear about my study and would suggest others to interview. In addition to obtaining different perspectives, I became friends with some of the members of the HDWDS and with some of the opponents. Each generously shared his or her stories, opinions, and even secrets. These interviews used open-ended questions such as the following:

Why PAS?

What is your view on PAS?

What role do you play?

Tell me about the 2002 almost-win.

What strategy did you use? What about future strategies?

Have you thought about joining with Compassion and Choices?

What will it take to pass PAS legislation in Hawaii?

Meetings

To decide on strategy, what to do next and how they could win, I gathered the members of the HDWDS together twice. We met for dinner and conversation on January 12, 2008 to plan strategy for the legislative session which was about to start. No action was taken.

A year later, on March 8, 2009, we met another time with about 30 other advocates to plan strategy for 2010, the year when a Democratic governor had a strong chance of being elected. One of the advocates was Eli Stutsman from the national Death with Dignity organization. He was direct and candid in the discussion of how HDWDS could win. In the conclusion to this dissertation, I used his thoughts and my observations about local politics in proposing a winning strategy.

Literature Review

In doing a literature review, I discovered extensive writings and studies on the issue of PAS. A classic work was Derek Humphrey's *Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying* (1991). It described what it meant to be terminally ill, despaired of medical treatments and longing for death to end intractable suffering. Other books that described the salience of the right to die issue, the ethics of passive and active euthanasia and the interrelationship of ethics and the law in the emerging field of bioethics were the works of such writers as Jerry B. Wilson, author of *Death By Decision: The Medical, Moral, And Legal Dilemmas Of Euthanasia* (1975) and Henry Robert Glick, author of *Right To Die: Policy Innovation And Its Consequence* (1992). Margaret P. Battin, Rosamond Rhodes, and Anita Silvers, editors of *Physician Assisted Suicide: Expanding The Debate* presented the essays of philosophers and scholars on the moral issues of PAS, the principle of the double effect, the concept of rationing or practicing the stewardship of resources, the differentiation between active and passive euthanasia and the importance of autonomy in decision-making at the end of life. Interestingly, in the collection of essays, studies showed that the Bible did not condemn suicide, even the suicide of Judas.

Those who wrote about contemporary issues and solutions were people like Daniel Hillyard and John Dombrink who gave a detailed account of the politics of

Oregon's Death with Dignity Act in *Dying Right: The Death with Dignity Movement* (2001). Another person is William H. Colby, the attorney who represented Nancy Cruzan whose parents wanted her unplugged from her respirator. Colby was the author of *Unplugged: Reclaiming our Right to Die in America* in which he described his role in the Cruzan case. Similar writers were Joanne Lynn, author of *Sick To Death And Not Going To Take It Anymore!: Reforming Health Care For The Last Years Of L*ife (2004) and Peter G. Filene, author of *In The Arms Of Others: A Cultural History Of The Right-To-Die In America* (1998). They looked at the problems of death and dying that ignited the right to die movement. As they compared medical technology and demographics of the 40's and 50's, were expressed amazement at the advances in technology and noted that the movement was only 30 years old, a short length of time for a radical societal change to happen. They linked key court cases to the different laws and programs that emerged from the cases. They also linked the decline of the doctor's authority over the medical treatment of patients to the rise of patients' rights and the growing demand for individual autonomy.

In addition to these books, volumes have been written about the significance of the benchmark cases decided by the Supreme Court of the United States. I have referenced these materials in my discussion of judicial, ethical and historic influences.

There were more extant materials on the websites of the Hawaii Death with Dignity Society, www.hawaiidwdsociety.org/
Compassion and Choices, (formerly National Hemlock Society)
www.compassionandchoices.org//home.jsp and the Death With Dignity National Center

http://www.deathwithdignity.org/. The website for the opponents of PAS is at Hawaii Family Forum www.hawaiifamilyforum.org/ . In addition to the various websites, newspaper articles listed on the web are helpful in tracing action taken on the various PAS bills in the legislature. The editorials of the late A.A. Smyser in the Honolulu Star-Bulletin that favored PAS, are balanced by articles in the Hawaii Catholic Herald that opposed PAS.

While there were shelves of books on the pros and cons of the so-called "right to die," scant attention was paid to the politics of PAS especially in Hawaii. Although the advocates in Hawaii consistently kept their presence in the public's eye, just a small mention was given to them on various websites and in the news media. Some of the material on the politics of Hawaii, though written long ago, was still relevant in providing historical background. These were classics like Tom Coffman's *To Catch a Wave* and The *Island Edge Of America: A Political History Of Hawaii* (2003), Hubert Kimura's *Akamai Strategist* (1982), Patricia G. Steinhoff's and Milton Diamond's *Abortion Politics: The Hawaii Experience* (1977); each provided insights into events that wend their way into the whys and how's of politics in Hawaii. A book that filled the void in the literature on the issues of death and dying in Hawaii was *Cultural Issues In End-Of-Life Decision Making* (2000) edited by Kathryn L. Braun, James H. Pietsch and Patricia L. Blanchette. This book contained a collection of essays written by practitioners, physicians, academicians and other professionals in Hawaii about the attitudes, beliefs and cultural practices at the end of life held by the various ethnic groups in Hawaii. Other classics that gave insight into interest groups include Mancur Olson's *The Logic of*

Collective Actions (1971), Floyd Hunter's, Community *Power Structure; a Study of Decision Makers* (1980) and James Q.Wilson's, *The Amateur Democrat; Club Politics in Three Cities* (1966). Finally, Maryann Barakso's case study, *Governing NOW: Grassroots Activism in the National Organization for Women,* resonated with the politics of HDWDS, as a small interest group.

My Interest Physician-assisted Suicide

My interest in the politics of PAS in Hawaii stemmed from three experiences. My work as a paralegal for a legal services provider with the elderly has made me aware of the need to prepare for death and dying, the urgency for a solution to living longer in poor health, outliving resources, and enduring a potentially bleak quality of life, plus a wish to not suffer needlessly and a fervent desire not to end up in a nursing home, the victim of a brain robbing disease.

I was an eyewitness to Hawaii's first "death and dying" court case. Although my role was minimal, I was greatly moved by the experience. I saw Mrs. Shirley Crabtree suffering at the end of her life and the struggle that medical legal and social work professionals went through to determine what she might have wanted or what might be in her best interest. I later witnessed over the years how advocates and legislators tried to make things better for those who might face the same difficulties as Mrs. Crabtree. She did not have at the time of her accident a "living will" to show her preference whether or not to be kept on a feeding tube. I assisted the g*uardian ad litem*, representing the interests of Mrs. Crabtree, in providing evidence in court that Mrs. Crabtree's would most likely not have wanted to be kept alive in a persistent vegetative state. I accompanied the guardian *ad litem* to Chaminade University to look up the works of French Catholic philosopher, Pierre Teilhard de Chardin, that Mrs. Crabtree, a Catholic, often quoted. The works of this particular philosopher was used to link her wishes to end heroic methods to keep her alive. I was also involved in some of the legal preparation to have a guardian *ad litem* appointed and ultimately to see the court process to its end. Finally, as part of the legal team representing the interests of Mrs. Crabtree, I experienced the tension and the gravity of letting a person go and was privy to the bioethical debates about ethics and morals in not prolonging life. These debates were in their nascent stages twenty-five years ago. How informed consent could be construed, whether removing the feeding tube violated laws, ethics and morals, whether a guardian could make life and death decisions—had never before been adjudicated in Hawaii and I was part of this "right to die" movement.

And like many of my friends, I experienced "bad deaths." I saw my aunt, consumed with cancer, suffer and die. I took care of my father who suffered immensely from cancer. He suffered so much that he prayed for a pill so he could die.

When asked whether I support PAS, I answer "yes" and "no." I had attended a Catholic school. And, as often the case, the nuns were right—a Catholic education follows you like the "Hound of Heaven" (Francis Thompson). And even though I am not a Catholic, I was schooled in Catholic beliefs and rituals and its respect for life. But, at the same time, I believe that suffering is not a requirement for salvation. At some point, I believe it is alright to end suffering or even to let go what I may believe to be a diminished quality of life. I believe that I have the right to choose how and when I wish to die. I say this now, but know that at the end, I may let the “Hound of Heaven” take me at its own “deliberate speed” rather than exercise an option I will have fought for others to have.

But I am sure of one thing: I want choice. I want the assurance that if my suffering is too intractable or if I am no longer functioning, I want to be able to know that I have a choice to not continue suffering in that particular state. It will be my way of conquering death by making it very personal, and thus, very profound.

Overview of Chapters

I have designed this dissertation in two parts. The first part covers the definitions of death and dying and the moral, ethical and bioethical issues that make “a good” death very personal and very profound. The second part is focused on a particular interest group in Hawaii, the Hawaii Death with Dignity Society that struggles to change public policy to allow another type of “good” death, one through physician assisted suicide. The chapters in my dissertation proceed as follows:

Chapter 1 provides an introduction to the issue of PAS, its advocates and opponents, and a detailed explanation of the proposed legislation. In addition, this chapter presents theories grounded in political science that offer explanations, revelations and understandings of human endeavor to seek a good death. It describes the methodology used which includes using empirical and theoretical frameworks and comprehensive research in the literature on the right to die. The chapter concludes with a description of my motives for choosing this topic and an overview of the chapters.

Chapter 2 demonstrates the moral, legal and bioethical conundrums of PAS. It explores the various end-of-life options, benchmark court cases and individual experiments in expanding the right to die. The chapter concludes by examining Hawaii's laws that could have allowed physicians to use PAS without criminalization.

Chapter 3 explores and traces the arguments of advocates and opponents of PAS. It describes how they are framed with Biblical references, Greek mythology and American values and concludes that framing constructs personal and profound beliefs about death and dying.

Chapter 4 links the previous chapters with the politics of PAS. It examines how culture, religion and ethnicity may determine a person's views on PAS. It analyzes the Hawaii's ethos of diversity to explain why it was conducive and yet at the same time contrary to PAS.

Chapter 5 describes the conflict between the contestants in the right to die, namely, the HDWDS and the Hawaii Family Forum. It begins with the formation of The Governor's Blue Ribbon Panel on Living and Dying with Dignity that divides the panel members and spawns *Kokua Mau* an end-of-life organization. The advocates make several strategic mistakes that result in failure to pass PAS legislation. Coplin and O'Leary's model of power assessment is used to analyze how difficult it would have been to sway physician groups. The chapter concludes with a description of the professional handling of the bill and the almost win.

Chapter 6 analyzes the sustainability and viability of HDWDS. HDWDS currently appears at a low point of its career cycle and needs to renew itself, its mission and goals, find executive leadership, attract big donors, and prepare diligently to campaign in 2014, a time when a second term governor has less risk in supporting a controversial measure.

Chapter 7 concludes that only time, place, intention and manner separate the meaning of a good death for the advocates and opponents of PAS. It also presents a practical strategy that might help the PAS advocates win.

CHAPTER 2
PHYSICIAN ASSISTED SUICIDE DEFINED

This chapter examines the various definitions of euthanasia and their relationship to the positions held by the PAS advocates and their opponents. It then proceeds to examine benchmark court cases that define the right to certain end-of-life medical treatment, but not PAS. It concludes by describing current Hawaii laws which might have been the basis for legalizing PAS in Hawaii.

Medical Terminology Used at the End of Life

Physician Assisted Suicide (PAS)

PAS is shaped by legal and medical definitions and has elements of euthanasia and suicide. The word, euthanasia, itself, is made up of two Greek words, meaning "good death," coined by early organizations in England that advocated the concept of ending suffering through lethal medication and mercy killing. The more commonly understood meaning of euthanasia today is nuanced with dying an easy or peaceful death as opposed to a prolonged or bad death.

Euthanasia, as commonly used, means giving active assistance to a patient who is terminally ill and wishes to die in order to end intractable suffering. It can be categorized as active or passive, voluntary or involuntary and can include elements of suicide, assisted suicide and physician-assisted suicide. Voluntary active euthanasia occurs when a patient asks another person or doctor to terminate his or her life by means of the provision of a lethal medication for self-ingestion, (suicide). Involuntary means that the person's life is being ended without his or her knowledge or consent. In practice, it generally means that the person is unconscious, unable to communicate, or too sick or weak to know what is happening.

PAS describes a type of voluntary euthanasia, where a competent, terminally ill individual under strict rules, asks a physician to prescribe lethal medication that the individual administers himself or herself to take his or her own life. In self administering the lethal medication, PAS differs from voluntary euthanasia in which a physician or other person directly administers a lethal injection or other medication to end a person's life. This difference is reflected in Oregon's Death with Dignity proposals which did not include lethal injections. Hillyard and Dombrink (2001) explains, "An injection required direct aid in death; putting prescription medicine in one's own mouth and swallowing it puts the final act of inducing death in the hands of patients" (p. 29).

Although PAS has elements of suicide, which is commonly defined as the intentional taking of one's own life, Compassion and Choices' attorney, Katherine Tucker, (2008) adamantly declares that "it is inaccurate to consider this choice to be 'suicide.'" Tucker states that "from a mental health perspective, 'suicide' and the choice of a dying patient to hasten impending death in a peaceful and dignified manner are starkly different" (p. 3). She insists that value-neutral terms such as "aid-in-dying" or "physician-assisted dying" replace the term "assisted suicide."

The predominant view of modern medicine is that suicide is a mental health concern, associated with psychological factors such as the difficulty of coping with depression, inescapable suffering or fear, or other mental disorders and pressures. Suicide is sometimes interpreted in this framework as a "cry for help" and attention, or to express despair and the wish to escape, rather than a genuine intent to die. To prevent individuals suffering from depression or mental stress from choosing PAS, under Oregon's Death with Dignity Act, strict safeguards and procedures requiring counseling and two written requests 15 days apart are in place. Individuals must also undergo a psychiatric examination and be counseled on other alternatives to PAS.

Active or Passive, Voluntary or Involuntary Euthanasia

While PAS is a type of active euthanasia, passive euthanasia is used to describe the act of withdrawing or withholding medical treatment, in which the disease or injury is allowed to take its course, with only "comfort care" provided by hospital or hospice staff. Terminating life-sustaining treatment generally is acceptable by medical societies and legal under the law. Frolick (2005) comments on its similarity to PAS, "The difference between active and passive euthanasia is between allowing a person to die and killing that person, albeit at his or her request" (p. 613).

The Crabtree case is an example of passive euthanasia where the patient's feeding tube is removed and the patient allowed to die. Other examples are removing life support equipment, turning off a respirator, stopping medical procedures or medications, stopping food and water and allowing the person to dehydrate or starve to death, not delivering cardiopulmonary resuscitation and allowing the person whose heart has stopped to die.

Generally, there is no legal and ethical difference between stopping and not starting medical treatment, including life-sustaining medical treatment. Nevertheless, withholding treatment is often seen by doctors to be more defensible than withdrawing treatment and most court cases involve withdrawal of treatment. Although decisions by a capacitated individual to withhold or withdraw medical treatment are less complex than similar issues relating to incapacitated individuals, most state laws, such as Hawaii's surrogate decision-making law found in Hawaii Revised Statutes § 327E-5 (2007), provide for a mechanism to make medical treatment decisions under either circumstance. This was evidenced in hearings for the passage of the "living will", supporters of the bill emphatically stated that "this bill does not condone "euthanasia" or "mercy killing." "Nothing in this chapter shall be construed to condone, authorize, or approve mercy killing or euthanasia…" (State of Hawaii, *Conference Committee Report House Journal*, 1997, p. 91).

Doctrine of Double Effect

Passive euthanasia also includes interventions that do not have the intent of causing the death of the patient but nevertheless results in the death of the patient. One of these is called the doctrine of "double effect" which is used to justify the use of large doses of medication to control pain, even if it may act to suppress respiration and cause death to the patient. This concept is said to originate with Thomas Aquinas in the 13thth century in his writings in the *Summa Theologica* (II.-II, Qu.64, Art. 7, as cited by Battin, 1982) to justify pursuing a moral good even though the side effect may be harmful. In the Roman Catholic tradition, the conditions for applying the double effect depend on the intention, the means and the end of the action to be taken. Battin (1982), explains how the double effect is formulated.

According to the doctrine of double effect, an action is permitted if:

(1) the action itself is morally good or neutral;

(2) The evil effect is not directly intended, although perhaps foreseen;

(3) The good effect follows directly from the action and not from the foreseen evil effect; and

(4) There is grave reason for allowing the evil to occur (p. 66).

Battin further explains that the doctrine of double effect provides a way for those physicians who object to euthanasia or assisted suicide to provide adequate pain relief without fear of wrongfully killing their patient. Thus, palliative use of palliative drugs are morally permissible even though euthanasia and assisted suicide are illegal and possible morally offensive to the individual physician.

Quill, Dresser, & Brock (1997), are critical of this rule and point out the difficulties of assessing intentions. Intentions cannot be validated or measured, and are "… multilayered, ambiguous, subjective, and often contradictory" (*Ibid*.) Quill and others point out that some physicians have been reluctant to prescribe medications precisely because the interpretation of intent can be ambiguous and troubling. They fear overmedication might be interpreted as an intention to kill rather than an intention to treat. They conclude that the ambiguities and the inability to quantify a treating physician's intentions make the principle of the double effect dubious as a guide in medical practice. If intent were ambiguous, the double effect would be legitimate if the good of the action outweighs harm caused by the action. This leads the writers to state that "[i]t is the principle of proportionality that determines when the risk of undesirable consequences is justified" (*Ibid*.). In other words, the good and the bad effects must be weighed and the good effects must outweigh the bad effects.

Terminal Sedation or Palliative Sedation

The concept of "terminal sedation," also called palliative sedation, is a combination of medically inducing a deep sleep and stopping other treatment in a terminally ill patient.   It is considered to relieve intractable pain when specific pain relieving protocols or interventions are ineffective or where there is not medical treatment to provide a cure. During the dying process, active treatment is stopped, the patient's vital functions are not supported and patients are given sufficient drugs to render him or her unconscious. The intent is not to cause the death of the patient and when death occurs, it is attributed to the patient's underlying fatal illness.

Like the doctrine of the double effect, in palliative sedation, the intent of the physician is extremely important and distinguishes it from euthanasia and PAS. In euthanasia, the patient who is severely suffering requests medication to produce death and the doctor may comply by administering a lethal injection. In PAS, a terminally ill person under strict rules, requests lethal medication which he or she self administers. In terminal sedation or palliative sedation, the process could be described in the following manner: the patient who is in severe pain requests to be sedated, gives instructions through an advance directive to refuse food and hydration, have the palliative drug administered by the doctor, is sedated and slips into a coma, hydration and nutrition would be stopped as he or she had consented to in an advance directive, and life is ended. The intent is to relieve pain and suffering by causing unconsciousness and death is not the intent. Thus, having informed consent and clear intentions are foremost in considering its ethical implications.

Acts and Omissions, Informed Consent

Early proponents of allowing withdrawal of life support confronted the legal distinction between acts and omissions. Omissions has limited liability under the theory that unless that person has a legal duty to act, a person is not liable for failure to act. A doctor who turned off the respirator of a person with no brain activity should be treated as having omitted to care for the patient rather than having caused death. This was confirmed in a precedent-setting 1983 case when a doctor was prosecuted for turning off the respirator of a patient in a persistent vegetative state (*Barber v. Superior Court*)[1]. Although the family had given consent, the state charged the doctor with murder. The Court reversed the conviction accepting the argument that the doctor had omitted to act when he had no duty to act since the patient would never recover substantial brain function. Issues regarding the provision, withholding or withdrawing of medical treatment are centered on the concept of informed consent and the constitutional right of an individual to accept or refuse medical treatment. A refusal to accept medical treatment is not usually considered a form of homicide or suicide even if it should lead to death. In an early precedent setting case, a New Jersey Court in the 1970's tried to strike a balance between the privacy interests of an individual and the state's interest in the preservation of life.[2] Besides asserting individual rights to privacy, informed consent is also dependent on meeting the rules of evidence as required in each state. In the Cruzan case,

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[1] Barber v. Superior Court, 147 Cal.App.3d 1006 (1983).

[2] *In Re* Karen Ann Quinlan, 355 A 2d 647 (New Jersey, 1976).

the Missouri court required “clear and convincing evidence” that she did not want her life prolonged if she became incapacitated before her feeding tube was removed.

Hawaii has adopted a patient-oriented standard applicable to the duty to disclose risk information prior to treatment.[3] The patient-oriented standard of informed consent focuses on what reasonable patients objectively need to hear from the physician to allow them to make informed and intelligent decisions regarding proposed medical treatment.

Stewardship of Resources

Another concept that is often used to justify the termination of futile medical treatment or to end extraordinary means to keep a person alive is the concept of “stewardship of resources.” This concept, attributed to Thomas Aquinas, is extant to the principle of the double effect. This was argued in the Karen Quinlan case under the first amendment, the right to religious freedom. The Quinlans were Catholics and their argument of the stewardship of resources stemmed from their religious beliefs. At the time of the case, Catholic moral theology viewed respirators as “extraordinary means” used to keep the patient alive and could be removed. This is in contrast to the moral obligation of providing ordinary means, such as food and water, to keep the patient alive. However, in 2004, in the Terri Shiavo case, Pope John Paul II seemed to have reversed this teaching. He declared that “The administration of water and food, even when provided by artificial means, always represents a natural means of preserving life and not a medical act” (Colby, 2006, p. 173). Thus, some have interpreted the Pope’s teaching to

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[3] Carr v. Strode, 904 P.2d 489 (Haw. 1995).

mean that a person in a vegetative state must be given artificial hydration and nutrition. Colby concludes that currently, there are on-going are efforts by right to life groups to require tube feeding for all who have not made an advance directive.

The following chart compares the definitions of PAS and the legalities of voluntary, involuntary, and active and passive euthanasia. These definitions may appear ambiguous and have shortcomings as a practical guide to medical treatment. However, it demonstrates that both the supporters of PAS and the opponents of PAS are very close in agreement about medical treatment at the end of life except for PAS.

Rational Suicide

In addition to the end-of-life medical options that were previously discussed, “rational suicide” is also a subject of much debate. Like other end-of-life options, it is also characterized by ambiguities in ethics, bioethics, morals and the law. The concept of rational suicide differs from suicide in that it is not considered a mental disorder and may be permissible under certain conditions. The term, “rational,” suggests that mentally competent individuals, possibly in good health, can “objectively weigh the pros and cons of continued life, and then decide in favor of death” (Lerner, 2004).

Clear guidelines have not been established to distinguish what makes a “rational suicide.” Rich and Butts (2003) cite Werth and Cobias’s (1985) study of psychotherapists’ attitudes. They found that 88% of the respondents indicated that they approved rational suicide when “a) there is a feeling of unyielding hopelessness in the condition of the suicidal person according to their perception; b) they are not coerced and they make a free choice about suicide and; c) they exercise sound decision making in the process" (p. 272). Other characteristics are decision-making that has been deliberated over a period of time and involvement of the suicidal person's significant others when possible. Citing Siegal (1986), Rich and Butts add that a rational suicide is characteristic of "suicidal persons (who) have a realistic assessment of their life circumstances, are free from psychological and severe emotional distress, and have motives that would be understandable to uninvolved observers within the suicidal person's community" (p. 272).

Debates arise whether the refusal of life-sustaining treatment and withdrawal of life support can be considered "rational suicide," including the voluntary stopping of eating and drinking. Questions also arise as to whether PAS should be included in the definition. Finally, relating to the topic of this dissertation, these ethical dilemmas supporting and opposing rational suicide and whether PAS can be considered as rational suicide are subjects for future examination.

Figure 2. Compares the definitions of end-of-life options, their legality and relationship to PAS arguments.

Medical treatment forms of euthanasia	Example	Legality	PAS Advocates Position	Opponents Position
Active euthanasia or, voluntary euthanasia	A terminally ill, competent person requests medication to produce death, the physician administers a lethal injection.	No	No	No
Physician assisted suicide	A terminally ill, competent person requests PAS in accordance with the law. The lethal medication, prescribed by a physician is self-administered under stringent conditions.	Legal in Oregon, Washington & Montana	Yes	No
Passive	Withhold treatment, withdraw treatment.	Constitutional right	Yes	Yes
Withhold	Omit treatment.	Constitutional right	Yes	Yes
Withdraw	Turn off respirator.	Constitutional right	Yes	Yes
Double effect	Intent to treat but medication might result in death.	Legal medical treatment	Yes	Yes
Terminal sedation or palliative sedation	Intent to end suffering but as a palliative care treatment, results in death.	Legal medical treatment	Yes	Yes
Stewardship of resources	Use no extraordinary means to keep terminally patients alive.	Legal medical treatment	Yes	Yes
Surrogate decision making	Substituted decision making for incompetent person with advance direction.	Legal medical treatment	Yes	Yes
Surrogate decision making	Substituted decision making for incompetent person without advance directive.	Legal medical treatment	Yes	No
Involuntary Euthanasia	World War II Nazi atrocities.	Illegal	Condemned	Condemned

Death Defined

Death in ancient times seemed simpler when people lived shorter lives, died more quickly and did not face the dilemma of being kept alive artificially. Today, death is defined in terms of legal, religious and cultural and clinical terms as well as philosophical, ethical and social terms. Death is commonly defined as a state in which,"… in the absence of life support technology, a patient is pronounced clinically dead when respiration ceases and the heart no longer beats" (Braun K., Pietsch J.H., Blanchette P., (Eds.) 2000, p.21). In Hawaii, death is legally defined as "irreversible cessation of spontaneous respiratory and circulatory functions" (Hawaii Revised Statutes, 2004, § 327C-1).

This definition is now challenged by terms such as brain death, brain stem death, whole brain death, living cadaver, passive euthanasia, active euthanasia, excessive care, and vegetative state. These terms are a product of modern medicine that illustrates the complexity of death. Those who have the power and responsibility of declaring a person dead are now challenged by the various states of death. To complicate matters more, not all state laws accept brain death, which can be defined as the irreversible cessation of brain activity, as "death." Since a person can remain permanently unconscious with total or partial brain death, ethical and legal confusion about when death occurs is problematical. Those who are in a persistent vegetative state and suffer complete loss of cerebral function but whose brain stem continues to operate may not be considered "dead." This notion was put forward by Shiavo's parents in contesting Shiavo's husband's efforts to withdraw her feeding tube.

CBC News Online March 22, 2005 in reporting news about Terri Shiavo, described patients in a persistent vegetative state who appear to function normally:

> …Patients in a persistent vegetative state are bedridden and require feeding because they cannot feed themselves. They may open their eyes spontaneously; they may grunt or scream, smile briefly and move their limbs. They may cry or grimace occasionally. But while they may blink their eyes if stimulated, they are not doing so as a response to a visual threat. Some may chew or clamp their teeth. They are incontinent, as well….

To get around the ambiguous definition of death, New Jersey's Declaration of Death Act permits a person to choose an alternate meaning of death. Under New Jersey Revised Statutes § 13:35-6A.6. The law describes are several exemptions to accommodate personal religious beliefs, as follows:

> …Death shall not be declared on the basis of neurological criteria if the examining physician has reason to believe, on the basis of information in the patient's available medical records, or information provided by a member of the patient's family or any other person knowledgeable about the patient's personal religious beliefs, that such a declaration would violate the personal religious beliefs of the patient. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria….

Religious and cultural beliefs also present conundrums in the definition of brain death. For example, Japanese debate over brain death and organ transplants illustrate the cultural, ethical, bioethical debates about death. Traditionally, death in Japan is recognized as a secession of heart and lung function. However, a change in the law in 1997 permits the definition of brain death when organ transplants are involved. Further, culture plays an important role in the meaning of death. Death is a family matter, rather than a process. In many cultures, the family, rather than the individual, is in control in making end-of-life decisions and decides when death has occurred (Braun, *et al,* Eds., 2002). A later chapter will show that this notion could be a conundrum in building a campaign message to legalize PAS.

Quinlan, Cruzan and Crabtree: Defining the Right to Die

As death grows increasingly complex, courts are petitioned to decide when the issue cannot be resolved. When the court becomes involved in a public policy debate on PAS, the debate changes as rights are argued; for example, individual rights, the right to privacy and right to commit suicide, the right to refuse treatment, the right to liberty rights, and the right to die (Schnieder, C., 2002). As demonstrated in the Quinlan and Cruzan cases, the right to privacy, the right to due process, and the right to have medical devices withdrawn were argued and upheld.

Karen Ann Quinlan

The case of Karen Ann Quinlan[4] marks the beginning of the right to die movement. Briefly, in 1975 in New Jersey, Karen Ann Quinlan collapsed after attending a party where she had been taking alcohol and tranquilizers. She suffered brain damage and lapsed into a "persistent vegetative state." She was kept alive through a respirator and

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[4] *In Re* Karen Ann Quinlan, 355 A 2d 647 (New Jersey, 1976).

feeding tube implanted into her stomach. Her parents, realizing she could be kept alive for 50 or 60 years, went to the New Jersey trial court to remove her respirator. The hospital had refused to remove the respirator unless they had a court order.

Her parents lost at the trial level and appealed to the superior court. After much legal maneuvering, the case wound its way to the Supreme Court of New Jersey. In 1976, basing its decision on the 14th Amendment, the constitutional right to privacy, the court ruled for the Quinlans who were permitted to remove the respirator. Doctors at the hospital had weaned their daughter from the respirator and she was able to breathe on her own. Although the Supreme Court of New Jersey permitted the hospital to remove her feeding tube, her parents decided not to do so. She continued to live for another nine years.

This case was significant for several reasons. First, it was one of the first cases in which a state Supreme Court grappled with allowing the withdrawal and withholding of life sustaining treatment from a person who was not terminally ill, but in a vegetative state. Braun, *et al.,* Eds., (2002) described this state as being "unaware of the self and the environment, accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain stem autonomic function" (p. 28). Second, the case involved an incompetent person where a guardian was appointed to make a decision on her behalf for end-of-life medical treatment. Third, the case established the precedence of arguing the 14th amendment, the right to privacy in right to die cases. And fourth, the meaning of death expanded from cessation of vital organs to brain death.

As the first high profile case in withholding or withdrawing life-sustaining treatment, there were protests and confusion among doctors, lawyers and various advocate groups. Religion had played a major role in the arguments. The Quinlans had argued the first and eighth amendments. The first amendment, right to religious beliefs and the eighth amendment, protection against cruel and unusual punishment were deemed irrelevant to the case. The Quinlans had argued that the extraordinary medical treatment was not sanctioned by their Catholic faith as it would put too great a financial burden on the individual. The court agreed with the Quinlans and held that a respirator was deemed an extraordinary measure in an irreversibly unconscious patient. The court ruled against the 8th amendment argument by reserving it to those convicted of crime (Hillyard & Dombrink, 2001).

Quinlan's case spurred the spread of advance directives for healthcare. With these documents, an individual could declare whether he or she wanted to have his or her life prolonged through artificial means or not, whether to stop artificial nutrition and/or hydration, whether pain relief should be applied even if death resulted, and whether to appoint an agent to make end-of-life decisions. Spiritual guidance could also be included as in the current "Five Wishes," a national advance directive created by the non-profit organization, Aging with Dignity. Advance directives vary in each state and in Hawaii, an optional form is available under Hawaii Revised Statutes § 327E-16.

The Patient Self-Determination Act was passed as an amendment to the Omnibus Budget Reconciliation Act of 1990. It required federal funded healthcare institutions to make available information about advance directives for healthcare for in-coming patients. The advance directives called attention to the importance of making end of life choices ahead of time and the need for better end-of-life care.

Nancy Cruzan and Shirley Crabtree

The following two cases, The Nancy Cruzan Case in Missouri (1983 – 1990) and the Shirley Crabtree Case (1990) in Hawaii are similar.[5] The Nancy Cruzan case was decided by the U.S. Supreme Court on June 25, 1990 and the case of Shirley Crabtree was decided by Family Court Senior Judge Daniel G. Heely in Hawaii on April 26, 1990, two months prior to Cruzan's case. The Cruzan and Crabtree cases both happened because of terrible accidents—one, a car accident in Missouri and the other, a hiking accident in Hawaii. Both involved vibrant women who suffered extensive brain damage, which caused them to be mentally and physically incapacitated and legally incompetent. Prior to each of their respective destinies in court, Cruzan existed in a vegetative state for seven years and Crabtree for four years. Both Cruzan and Crabtree were in nursing facilities paid for through Medicaid. Cruzan's family found legal counsel through William Colby and the Legal Aid Society in Missouri. Crabtree's son, Jeff Crabtree, was an attorney in litigation practice in Honolulu. Both had to resort to judicial means to uphold the patient's right to die. The cases were similar but more even more significantly, they each set public policy on death and dying, one on the national level and the other in Hawaii.

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[5] *See,* Cruzan v. Director, Missouri Department of Health*,* 497 U.S. 261 (1990).

See also, *In Re* Guardianship of Crabtree, No. 86-0031 (Haw. Fam. Ct., First Cir., April 26, 1990).

In both the Cruzan and the Crabtree case, the United States Supreme Court and the Hawaii Family Court, respectively, set out the criteria for informed consent in making medical treatment decisions at the end of life. Neither woman had executed an advance directive nor possessed any formal written documents that demonstrated how they wanted to be treated at the end of life. Like Quinlan's case, the right to privacy was argued in both the Cruzan and Crabtree case to allow them to refuse medical treatment. In Cruzan's case, the Missouri court required "clear and convincing evidence" that she would not want to be kept alive indefinitely in a vegetative state. In Crabtree's case, the Hawaii court also relied on evidence, expert testimony and testimony of friends and family. It ruled in favor of substituted judgment, in other words, a guardian could be appointed to make decisions that the individual would have made. Although Crabtree's case deserves recognition as an important case in the right to die movement, it was not appealed in the higher courts and remains a Hawaii case.

Nancy Cruzan

When Cruzan's parents sought permission to withdraw her feeding tube, they took their case through the Missouri courts system and up to the United States Supreme Court. A state trial court had authorized the termination, finding that a person in Cruzan's condition had a fundamental right under the state and federal constitutions to direct or refuse the withdrawal of death-prolonging procedures. The court also ruled that her expression to a former housemate that she would not wish to continue her life if sick or injured unless she could live at least halfway normally, suggested that she would not wish to continue on with her nutrition and hydration.

The Missouri Supreme Court reversed the lower court's decision. While recognizing a right to refuse treatment embodied in the common-law doctrine of informed consent, the court questioned its applicability in this case. It also declined to read into the state constitution a broad right to privacy that would support an unrestricted right to refuse treatment and expressed doubt that the federal constitution embodied such a right. The court then decided that the Missouri's "living will" statute embodied a state policy strongly favoring the preservation of life, and that Cruzan's statements to her housemate were unreliable for the purpose of determining her intent. It rejected the argument that her parents were entitled to order the termination of her medical treatment, concluding that no person can assume that choice for an incompetent person in the absence of the formalities required by the "living will" statute or clear and convincing evidence of the patient's wishes (Braun, *et al*, eds., 2000).

The case ultimately went to the U. S. Supreme Court which declared that a competent patient had a liberty interest in refusing unwanted medical treatment, including tube feeding, which it considered for purposes of the opinion, as medical treatment. The Court, however, upheld the decision of the Missouri Supreme Court. In doing so, it held that states have the right to require by "clear and convincing" evidence that a patient would want life-sustaining treatment withheld or withdrawn. The parents returned to the Missouri courts for a determination of what Cruzan's wishes actually were. After further testimony, the Missouri courts found that there was enough evidence to conclude that she would wish the feeding tube withdrawn. With the court's order, the feeding tube was removed amid protests and vigils. Religious groups tried to storm the facility in which she lay dying. A nurse appeared at the hospital to re-insert the feeding tube which had been removed following the court order. For protection, the family had to be ushered into the facility through the back door. She died 10 days later.

Shirley Crabtree

The Shirley Crabtree case is significant because it applies directly to Hawaii's laws and to the "right to die movement." Like Cruzan, Crabtree was diagnosed as being in a persistent vegetative state, unable to give "informed consent." She had not executed a "living will" nor were there any existing laws pertaining to what the "living will" could do. Further, the court had to decide what constituted informed consent and informed refusal by authorized decision makers. The case also illustrates the difficulty of assessing the capacity of a person in a persistent vegetative state but who exhibited a certain level of cognition. Doctors had declared Crabtree "incompetent" and unable to make decisions and unable to give informed consent. However, an elder law attorney was able to elicit eye movements from her which was presented to the court as potential evidence of a minimum level of capacity.

The case begins while Nancy Cruzan's case was being argued in the Missouri and in the federal courts. It also ends before the Cruzan case. In 1986, Shirley Crabtree, a 59 year old woman, while hiking on a trail above Aiea, Hawaii lost her footing and slipped and fell down a steep slope. She suffered serious head injuries and was initially in a coma and then in a vegetative state. She remained in that condition—with sleep and wake cycles and her eyes responding to light and dark. She blinked in response to loud noises. She was totally physically dependent and was fed by a nasal-gastric tube. Every hour or so, nurses came by to turn her. Family members and friends visited and left. She was in this condition for four years when her guardian requested that her feeding tube be withdrawn. As in the Cruzan case, the healthcare facility refused to remove Crabtree's feeding tube without a court order. Crabtree had not executed a "living will," and, at the time of her accident, there was no legislation in Hawaii's supporting such documents (Pietsch, 1999).

Her son petitioned the court for and was granted a successor guardianship. (His father was the original court-appointed guardian but had died.) He asked for court permission to remove the feeding tube and gathered supporting evidence of the law and what her philosophy of life was and what her wishes were or might be. The family searched among her writings and belongings. They contacted friends and her priest. One of her friends recalled that she was one who read the writings of the French Priest Pierre Teilhard de Chardin and commented upon them. She had also written to her daughter about an article on "living wills," suggesting that they were a good idea. A paralegal recalled her conversation at a holiday meal prior to her accident in which she had voiced her opinion about brain injury, quality of life and end-of-life decisions. Using all of this as evidence regarding her beliefs, the guardian indicated to the court that she would not want to be kept alive in such a state and that he should be permitted to have her feeding tube removed.

Hawaii's laws were not clear on this matter. Neither were the standards in the medical community. Accordingly, experts were requested to provide testimony. Her neurosurgeon, a very well respected physician, had declared her to be mentally incapacitated and unable to make or to communicate decisions. He described her as being in a persistent vegetative state without the ability to sense stimuli such as pain much less to interact with her environment or people. Nurses provided a different perspective. They were the ones who turned her, bathed her and tried to make her comfortable. One nurse testified that Crabtree responded to loud noises, seemed to become agitated at times because of a urinary infection and seemed to display emotions of sadness, anguish, and anger.

Among the legal experts contacted was an attorney, who was considered a leader in the field of “elder law,” who was at the time an adjunct professor at the law school and a member of a hospital ethics committee. The judge appointed him as g*uardian ad litem* and instructed him to represent her best interests and make a report of his findings and recommendations to the court. He also researched the legal issues relating to informed consent, proxy/surrogate decision-making, withdrawing or withholding of life-sustaining medical treatment, tube feeding as medical treatment, medical futility and the “right to die.” In addition, he reviewed medical, ethical, philosophical, and historical literature on the subject of death and dying. He also interviewed witnesses, including expert witnesses at the trial as well as family members, friends, acquaintances and other persons who might be able to provide pertinent information to the court. Finally, he investigated the financial and familial situation of the parties involved to look for possible conflicts of interest.

He also spent much time with Crabtree. On hearing that she seemed to blink in response to light and other stimuli, that her eyes seemed to follow the action of nurses and doctors and visitors, he decided on a straightforward method of attempting to communicate with her that seemed to escape some of the experts. Among the nurses and other experts, he decided to establish a simple fundamental communication system—asking her to blink once for "yes" and twice for "no" and then reversing the process. Among the most difficult questions asked were:

"Do you understand the condition you are in?"

"Do you want to continue to live like this?"

"Do you trust your son to make the correct decisions for you?"

"Do you want to have your feeding tube removed?"

"Do you understand what happens when the feeding tube is removed?"

A few days into the process, several experts in speech and in ethics formed an opinion that Crabtree had at least moments when she was capable of communicating. Other experts were not sure. Some experts denied that she had any capability to communicate at all.

Her *guardian ad litem* submitted his findings of fact and recommendations to the court. The court found that Crabtree's nasal-gastric tube was medical treatment or medical procedure which 1) merely kept her alive when treatment was futile, 2) did not provide her comfort or pain relief, 3) was contrary to her own previously stated beliefs and desires, and 4) was contrary to the decisions of her family and *guardian ad litem* in consultation with her attending physician.

The court further found that there was nothing under then existing law to prohibit the withdrawal of the feeding tube if her physician and family agreed, and that even if there was some persuasive argument that the law prohibited such removal, she had an independent constitutional right to privacy under the Hawaii constitution. This right to privacy included the right of a person (or a guardian for an incompetent person) to refuse unwanted medical treatment, including an artificial feeding tube, if done consistently under proper medical standards. This state constitutional right prevailed over any conflicting statutory provision.

The court authorized the removal of the feeding tube. The feeding tube was subsequently removed and she died several days later. As noted above, the case was not appealed and no appellate court in Hawaii has addressed the issue.

This case was significant for Hawaii because it was the first case where a facility was authorized by court order to remove a feeding tube. It was especially significant because the judge ruled prior to the decision in the Cruzan case which was still pending at the time. This case was used as a yardstick and example in bioethics in Hawaii to make decisions concerning medical treatment. Because of this case, which was close to home and whose principals were well known in the legal community, it was easier to pass needed healthcare legislation and to advocate in particular for legislative recognition of a person's right to make advance directives and the responsibility of healthcare providers to follow the instructions of authorized decision-makers. The most current statute on healthcare decision making, including advance directives was embodied in the Uniform Healthcare Decisions Act (Modified) UHCDA found in Hawaii Revised Statutes Chapter 327E.

In sum, the Cruzan and Crabtree case involved the following issues and related sub-issues:

1. Informed consent—Individuals have a constitutionally protected liberty interest in refusing unwanted medical treatment and also have an independent right to privacy under the state constitution.
2. Incapacitated individuals—the "living will" (advance healthcare directive) can be used to document and make an individual's intention and informed consent to accept or to refuse treatment even when he/she is no longer mentally capacitated to do so.
3. Evidence of a patient's wishes—although clear and convincing evidence is not necessarily the standard used by all states when determining what sort of medical treatment a person would or would not want, the "living will" (advance healthcare directive) can provide such evidence. (Numerous states such as Hawaii utilize a lower standard of proof, a preponderance of evidence. Also, depending on which state the individual resides in, the individual needs to comply with state law regarding execution of the document, e.g. whether not he/she needs to have his/her signature witnessed and notarized.)
4. Surrogate or proxy decisions—absent state law, no person can automatically assume end-of-life choices for an incompetent person. One needs to look at state law to determine the authority of guardians, agents under powers of attorney and other proxy or surrogate decision-makers. As a consequence of this court

decision, most states have re-evaluated proxy decision making procedures in their healthcare decision-making laws.

5. Patients' rights regarding healthcare decision-making—patients have the right to make advance healthcare directives and healthcare providers must follow the instructions of authorized decision-makers. The Uniform Healthcare Decisions Act adopted in Hawaii, embodies these two core points.

Other Experiments with the Right to Die

While court cases defined the rights of individuals, activity outside of the court pushed for broader rights. In 1991, Derek Humphrey, the founder of the Hemlock Society, wrote a best seller, *Final Exit*. The book detailed the bad deaths of his wife and mother and struck an emotional cord in many who experienced the prolonged suffering of loved ones. But more shocking and controversial were the book's instructions for the terminally ill on how to commit suicide. He was eventually ousted from Hemlock and founded Final Exit.

Dr. Timothy Quill, another classic figure in the right to die movement, put his career in danger when he admitted in an article published in the New England Journal of Medicine, that at the request of a woman patient suffering from terminal cancer, he had prescribed barbiturates and counseled her on how to commit suicide.

Perhaps the most infamous is Dr. Jack Kervorkian, who in 1990 begins his crusade of helping people to commit suicide. He claimed he assisted in at least 15 suicides by using a "suicide machine" that patients used to administer lethal doses of medication to themselves. He was convicted of murder in 1999 when he applied a lethal injection to Thomas Youk who suffered from ALS (Lou Gehrig's disease) at Youk's request. Kevorkian served eight out of 25 years of his sentence and was released June 1, 2007.

Against the backdrop of these extra activities, others experimented with expanding the right to die. Compassion in Dying, a non-profit organization, filed two suits, one in Washington State and the other in New York State, in 1993 to challenge the constitutionality of the Washington law and New York law banning PAS. Five hearings were held at the various judicial levels (three hearings in Glucksberg and two in Vacco) before both cases were combined and decided in the U.S. Supreme Court in 1997 (Hillyard & Dombrink, 2001).

<u>Washington v. Glucksberg</u>

In Glucksberg v. Washington, Harold Glucksberg, a Seattle oncologist who was also a clinical professor at the University of Washington, along with three terminally ill patients and Compassion in Dying, a non-profit organization, filed a suit in Washington's District Court to challenge the constitutionality of Washington's law banning PAS.[6] Glucksberg asserted that an individual had a liberty interest protected by the Fourteenth

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[6] This case wove its way to the United States Supreme Court starting as Compassion in Dying v. State of Washington, 49 F.3d 586 (9th Cir. 1995). The court found for the plaintiffs that Washington's law violated the equal protection clause of 14th amendment. On appeal, the three panel judges of the Ninth Circuit reversed the district court decision finding for Washington State. The Ninth Circuit decided to re-hear the case *en banc*. The *en banc* court reversed the appellate court's earlier decision and affirmed the district court's original decision. The case then went up on appeal to the United States Supreme Court, Washington v. Glucksberg, 521 U.S. 702 (1997). *See also*, Anthony Lim, *Right to Die Movement: From Quinlan to Schiavo*, (2005), at leda.law.harvard.edu/leda/data/732/Lim05.pdf last visited February 27, 2008

Amendment's due process clause to ask for and receive PAS. He asserted that Washington State violated the due process of law when it prohibited competent, terminally ill people the right to hasten death by means of lethal medication prescribed by a physician.[7]

According to the due process doctrine, the government may not infringe on an individual's fundamental rights unless it has a compelling reason to do so (Schneider, Ed. 2004). Thus, in this case, the court was asked to decide on whether Washington interfered with a fundamental right of a terminally ill patient and if Washington did so, was there a compelling reason?

The federal district court judge reasoned that the fundamental rights of terminal patients who are not on life support are "burdened" while those on life support are not so "burdened" since death can be hastened by withdrawal of life support. Having established that the law did not treat the two groups of people equally, she concluded that the Washington's ban against PAS violated the 14th amendment due process clause[8] (Hillyard & Dombrink, 2001).

This ruling was appealed and reversed by the United States Court of Appeals for the Ninth Circuit. Six months later, the proponents won a reinstatement of the first ruling. Five months after that, in October 1996, the United States Supreme Court combined Washington and New York cases.

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[7] Compassion in Dying v. Washington, 79 F.3d 790 (9th Cir. 1996).

[8] Washington v. Glucksberg, 521 U.S. 702 (1997).

Vacco v. Quill

Meanwhile, thousands of miles away, Dr. Timothy Quill and others filed a similar suit, Quill v. Koppell,[9] in the District Court of New York, along with other physicians and three terminally ill patients. They challenged New York's prohibition of PAS and claimed it violated the 14th amendment equal protection clause. Equal protection doctrine requires the government to treat like cases alike and unlike cases differently. According to the doctrine, states must have a compelling reason to grant some persons a fundamental right and deny it to others.

Quill claimed that New York violated the 14th amendment equal protection clause by allowing the terminally ill patients who were dependent on feeding tubes or other forms of life support to hasten their deaths by withholding or withdrawing their medical treatment, but denying a hastened death to those who were not dependent on life support. Quill argued that since New York allows competent, terminally ill patients to refuse life sustaining treatment, it must also allow physicians to help competent, terminally ill patients to hasten death by prescribing lethal medication for patients to self administer.

The District Court upheld New York's ban against PAS declaring that New York did not violate equal protection as everyone had the right to refuse medical treatment and no one is permitted to assist another's suicide. It upheld the clinical and legal traditions that permit withdrawing and withholding medical treatment and those laws that

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[9] Quill v. Koppell, 870 F. Supp. 78 (1994).

prohibited PAS. It said making a person die through PAS and letting a person die through withholding and withdrawing medical treatment were different because intent was different. There was no historic recognition of PAS as a legal right. The ban had existed since English common law and PAS had remained illegal under state laws.

This ruling was appealed and overturned in the Second Circuit Appellate Court on the issue of equal protection argument. Like Glucksberg, it was then appealed and heard in the U.S. Supreme Court.

In 1997 the two cases, (now Washington v. Glucksberg[10] and Vacco v. Quill[11]) were joined and heard in the United States Supreme Court. It determined in Glucksberg that the right to PAS was not a fundamental liberty interest protected by the due process clause. In Vacco, it determined that a state's policy distinguishing between letting a patient die and making a patient die was rational and did not violate the equal protection clause. Both arguments included balancing the interests of an individual against the interests of the state.

The justices also discussed patients' rights to forgo treatment and receive palliative care. Questions of the physician's intent to apply large amounts of medication and whether such application should be considered the cause of resulting death have confounded doctors, lawyers and ethicists. As Justice Sandra Day O'Connor noted in her concurring opinion in Vacco, "[T]he illusory character of any differences in intent or

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[10] Washington v. Glucksberg, 521 U.S. 702 (1997).

[11] Vacco v. Quill, 521 U.S. 793 (1997).

causation is confirmed by the fact that the American Medical Association unequivocally endorses the practice of terminal sedation, the administration of sufficient dosages of pain-killing medication to terminally ill patients to protect them from excruciating pain even when it is clear that the time of death will be advanced" (*Ibid.*). Accordingly, such "terminal sedation" does not seem to be considered PAS when looking at the whole of the Glucksberg and Vacco cases.

While the Supreme Court held that the "right" to assistance in committing suicide neither infringed fundamental rights nor involved suspect classifications, it also held that individual states are free to enact legislation that legalizes PAS.

Oregon Passes Death with Dignity Act 1997

When the Supreme Court returned the right to die to the states, Oregon began its own experiment in enacting legislation. Its efforts marked a cumulative shift in the right to die movement. Legislation stepped up from seeking the right to the passive procedure of withdrawal or withholding of medical treatment to an active right to die through PAS. In Oregon, voters approved Ballot Measure 16, a citizen's initiative to pass the Oregon Death with Dignity Act. On October 27, 1997 Oregon enacted the Death with Dignity Act which passed by a margin of 51% to 49%. Almost immediately, a legal injunction was filed. When the injunction was lifted, voters in Oregon were again asked through another initiative to repeal the Oregon Death with Dignity Act. They rejected this by a margin of 60% to 40%.

Although the Vacco and Glucksberg decisions did not uphold a constitutional right to PAS, public support for the PAS did not wane. Advocates continued to press their states to legalize PAS. Legislation was introduced to legalize PAS in Hawaii in 1997. Attempts were made in Arizona, California, Washington, Maine, Massachusetts and Wyoming. In addition to the efforts to legalize PAS, legal mechanisms were put into place to ensure personal autonomy at end of life and to avoid situations like Cruzan and Crabtree. People were urged to execute written advance directives for health care. The Uniform Health-care Decisions Act was passed in 1993 to conform the advance directives in all the states.[12] When properly executed, these allowed the individual to meet the rules of evidence, give informed consent and use substituted judgment in the event that the or she suffered mental and physical incapacity. Hillyard & Dombrink (2001) observes that the advance directives seemed to have blurred the distinctions between withdraw and withhold medical treatment, extraordinary and ordinary medical treatment, the rights of competent patients versus incompetent patients, the rights of terminal patients versus non-terminal patients, and the distinction between extraordinary treatments and ordinary treatments.

In 1990 Congress enacted the Patient Self-Determination Act (PSDA) as part of the Omnibus Budget Reconciliation Act of 1990 (PL 101-508). This law required all

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[12] The 1999 Hawaii Session Laws Act 169, signed by the governor on July 1, 1999, established the Uniform Health Care Decisions Act (Modified) ("UHCDA"). The new law repealed or changed several provisions of the Hawaii Revised Statutes. The UHCDA takes a comprehensive approach by placing the "living will," the durable power of attorney for health care, a "family consent" or surrogate law, and some provisions concerning organ donation together in one statute. *See* Hawaii Revised Statutes § 327D (2007).

healthcare providers participating in Medicare and Medicaid programs to provide all patients over age 18 with information about advance directives.

Later, in 1998 Congress introduced the Patients' Bill of Rights Act that supported patient's autonomy and privacy in decision making in health care facilities. This act would give patients more autonomy and would have tilted the balance of power in their favor vis-à-vis their physicians.

Test Cases

Two cases, Ashcroft v. Oregon (Gonzales v. Oregon) and the case of Terri Schiavo, appeared to disrupt the advancement of the right to die movement. Even though the Supreme Court had reserved PAS to the states, these two cases demonstrated how the federal government tried to intervene in states' rights to legislate and regulate PAS.

After Oregon's passed its Death with Dignity Act in 1991, the Bush administration and the U.S. attorney general Ashcroft sought to prohibit doctors in Oregon from prescribing federally regulated drugs for use in assisted suicide under the federal Controlled Substances Act. Ashcroft claimed that hastening death is not a "legitimate medical purpose" for the use of drugs under federal law. The Oregon court responded by issuing an injunction against the enforcement of Ashcroft's order.[13]

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[13] The case history is as follows: Oregon v. Ashcroft, 192 F. Supp.2d 1077 (D. Ore. 2002); affirmed, 368 F.3d 1118 (9th Cir. 2003); cert. granted, sub. nom., Gonzales v. Oregon, 543 U.S. 1145 (2005).

The Ninth Circuit Court of Appeals heard the case in 2004. The court decided in favor of Oregon stating that Ashcroft had overstepped his authority in challenging Oregon's law. The U.S. Justice Department asked for a re-hearing that was denied. The U.S. Justice Department then petitioned the U.S. Supreme Court to hear the case, now called Gonzales v. Oregon. The Supreme Court rendered its decision in January 2006. It upheld the assisted-suicide law in Oregon by a vote of 6 to 3 and declared that Ashcroft had overstepped his authority.

The Terri Shiavo case in 2005 proved to be one of the most emotionally charged and divisive issues in recent times in the right to die movement. A domestic feud between Shiavo's husband and her family, the clash of right to die and right to life interest groups, religious factions, the Governor of Florida, the Congress of the United States, the President of the United States and the United States Supreme Court were all involved with how and if to end Shiavo's life.

Shiavo, 41 years old, had lain in a vegetative state for 15 years. In 1990 she suffered a cardiac arrest most likely due to a potassium imbalance brought on by an eating disorder. Schiavo did not have an advance directive or anything else in writing that would indicate what she would want if she ever became incapacitated. After seven years, her husband who was appointed her guardian, petitioned to have her feeding tube removed. The Florida court determined that although Shiavo did not have a written directive, clear and convincing evidence presented by her husband showed that she would not have wanted to continue life sustaining treatment if she could decide for herself. Her parents disagreed and petitioned the Florida court to stop the removal of her feeding tube.

A tug of war between her husband and parents ensued. Her feeding tube was removed after the court had ruled that evidence presented by her husband showed she did not want to be kept in a vegetative state. A public outcry ensued. Four days later, after many political maneuverings and extensive financial and political support from conservative religious organizations, her parents sought help from the Florida legislature. The legislature passed a law, "Terri's Law," signed by Governor Jeb Bush, to prevent the removal of her feeding tube, which was re-inserted.

The law was challenged and the Supreme Court of Florida struck down "Terri's Law"[14] as unconstitutional and determined that there was a breach of the separation of powers inherent in Florida's constitution and an overreaching by the Florida legislators. The Florida Supreme Court refused to hear Governor Bush's appeal and Schiavo's feeding tube was removed for the third time.

The federal government became involved in March 2005, just before the Easter recess. The United States Congress convened to pass a law to give jurisdiction of the case to the federal courts. Called the "Palm Sunday Compromise," the President of the United States flew from his vacation in Texas to Washington to sign the bill that blocked the removal of her feeding tube. The federal court struck down that law and denied the injunction to remove her feeding tube. The appellate court agreed with the federal district

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[14] Terri's Law would have granted jurisdiction to the Florida federal district court to hear the Schindlers' case and ordered the court to look at the claims *de novo*, without regard for prior state court decisions.

court and the United States Supreme Court denied certiorari. Her feeding tube was removed and she died March 31, 2005.

The aftermath of Terri Shiavo and Gonzales cases had an impact on the right to die movement. The Compassion and Choices website reports that 23 states have proposed legislation to make it difficult to remove a feeding tube from those in a persistent vegetative state. These bills, called "health decision restriction bills," "refusal bills," or "conscience bills," allow health care providers or pharmacists to refuse to carry out a medical procedure on moral grounds.

Conversely, the ten-year Oregon report on the Oregon Death with Dignity Act presented data that dispelled the fears of "slippery slope." Data did not seem to support the belief that people would flock to Oregon from other states to commit suicide, or be pressured by families, doctors or insurance companies to kill themselves. Data showed that since the law went into effect in 1997, fewer than 300 patients have chosen to end their lives by taking doctor-prescribed drug—about one in a thousand of those diagnosed with terminal illness in that state.[15]

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[15] During 2006, 65 prescriptions for lethal medications or the provision of the Death with Dignity Act were written. Of these, 35 patients took the medications, 19 died of their underlying disease, and 11 were alive at the end of 2006. In addition, 11 patients with earlier prescriptions died from taking the medications, resulting in a total of 46 deaths attributed to the Death with Dignity Act during 2006. This corresponds to an estimated 14.7 Death with Dignity Act deaths per 10,000 total deaths. Since the law was passed in 1997, 292 patients have died under the terms of the law. *See* Human Services Department, State of Oregon, *Death with Dignity Act 2006 Annual Report*, *available at* http://egov.oregon.gov/DHS/ph/pas/faqs.shtml#whatis (last visited October 31, 2007).

While the right to die movement has been battered by the Bush administration, advocates in states such as Hawaii, California and Washington have continued to push for legislation.

Hawaii's Laws

Hawaii has a reputation of being a progressive and liberal state. The laws that are conducive to PAS can first be found in Hawaii's constitution which states that: "The right of the people to privacy is recognized and shall not be infringed without the showing of a compelling state interest." (Haw. Const. Art. 1, §6). This section has been cited as a basis for upholding the right of a person (or guardian for an incompetent person) to refuse unwanted medical treatment (In re Guardianship of Crabtree, No. 86-0031 (Haw. Fam. Ct., 1st cir. Apr. 26, 1990).

Other progressive individual rights stem from this constitutional provision. One of these rights is the right to having life-sustaining medical treatment withheld or withdrawn. In 1999 Hawaii passed its modified version of the Uniform Healthcare Decisions Act (UHCDA). It had the effect of repealing or changing several provisions of the Hawaii Revised Statutes. The UHCDA takes a comprehensive approach by placing the "living will," the durable power of attorney for health care, a "family consent" or surrogate law, and some provisions concerning organ donation together in one statute. It is found in Hawaii Revised Statutes Chapter 327E.

In § 327E-13 of UHCDA, the law makes clear the effect of the act:

…

> (b) Death resulting from the withholding or withdrawal of the healthcare in accordance with this chapter shall not for any purpose constitute a suicide or homicide or legally impair or invalidate a policy of insurance or an annuity providing a death benefit, notwithstanding any term of the policy or annuity to the contrary.
>
> (c) This chapter shall not authorize mercy killing, assisted suicide, euthanasia, or the provision, withholding, or withdrawal of health care, to the extent prohibited by other statutes of this State….

While UHCDA does not authorize suicide there is no law against suicide in Hawaii. Although the Hawaii Penal Code has been interpreted to prohibit physicians from assisting in suicides or otherwise helping to cause a death, there appears to be no case in which a physician or anyone else has been prosecuted for causing or assisting in suicide. The common law also is the source of other prohibitions against PAS. Professor James Pietsch (2004) comments, "The salient issue is whether the physician by providing the lethal agent commits the offense of manslaughter by intentionally causing another person to commit suicide. Suicide is often treated as mental illness." (321).

Perhaps the most unique and perplexing provision within Hawaii law is HRS § 453-1 that defines the practice of medicine:

> …[W]hen a duly licensed physician pronounces a person affected with any disease hopeless and beyond recovery and gives a written certificate to that effect to the person affected or the person's attendant, nothing herein shall forbid any

> person from giving or furnishing any remedial agent or measure when so requested by or on behalf of the affected person….

The provision could provide the authorization for physicians to actively assist a patient in dying by providing a lethal dose of medication under certain circumstances. The language is explicit in providing protection to a physician when "giving or furnishing any remedial agent or measure when so requested by or on behalf of the affected persons. It may provide the basis for physicians in Hawaii to evade common-law responsibility. What is shown is that existing laws in Hawaii do not provide a clear answer about whether PAS is illegal or authorized. To be more explicit requires the legislature to decide and clarify the issue (Journal of Legal Medicine, 25:303-332 2004).

Governor's Blue Ribbon Panel

While the law in Hawaii had no clear statutory authority authorizing PAS, such as Oregon's Death with Dignity Act, neither did it have any clear prohibitions relating to PAS such as those in New York or Washington. Faced with an unclear law, local PAS advocacy groups pressed for change. An A.A. Smyser, editor of the Honolulu Star-Bulletin (March15, 2004) comments that "A subtle form of assisted suicide is already practiced in hospitals when doctors and nurses halt life-sustaining treatments in hospitals to let a terminally ill patient die. Moreover, as part of palliative care, narcotics administered to relieve pain can occasionally result in sufficient respiratory depression to kill a patient." Bowing to these pressures, Governor Benjamin Cayetano appointed the Governor's Blue Ribbon Panel on Living and Dying with Dignity (hereafter Blue Ribbon

Panel) to discuss PAS as a major policy change in Hawaii and to make recommendations for end-of-life care.

CHAPTER 3
THE MYTHS OF A GOOD DEATH

Chapter 2 defined the terms used when discussing end of life treatment, traced judicial decisions that made legal withholding or withdrawing medical treatment in milestone cases represented by Quinlan and Cruzan, and in Hawaii, Crabtree. It also examined Quinn and Glucksberg, in which the court declared that there was no constitutional right to die but that states were free to enact laws to permit PAS. When the federal court returned the issue to the states, individuals and groups took up the challenge and in their own ways tried to expand the right to die by including PAS.

Individuals including Kervorkian, Quill and Humphreys tried to expand on the right to die in their own ways. States such as Washington and California introduced legislation but failed in their initial attempt to legalize PAS. Oregon, however, became the first state to legalized PAS through their Death with Dignity Act. Hawaii also joined in the quest. Ambiguities in Hawaii's laws and state policy pertaining to end-of- life medical treatment that could have provided the legislative process to legalize PAS hovered in the background. Groups like HDWDS and Hawaii Family Forum formed, gathered momentum, and became contestants in the conflict between maintaining the status quo or changing it to allow PAS.

Framing the arguments to support or oppose PAS became part of the political process. This chapter examines the myths, Christian theology, Greek mythology and American values that are invoked and used to persuade, convince and win.

Framing Arguments

Framing is a device used to “sell” a story. How the issue is presented or framed is central to the understanding of the political conflict and resolution. Debra Stone explains that “frames serve to organize an individual’s thinking, weaving various threads of content and context into a coherent story line that suggests what the controversy is about, the essence of the issue” (Stone, 1980, p. 16).

She observes that, “… myth[s] [are] … credible, dramatic, socially constructed re-presentation of perceived realities that people accept as permanent, fixed knowledge of reality….” She continues, “myths are enduring, widely accepted stories about the “big” aspects of society—its history, institutions and culture” (Stone, 1998, p. 109). Common beliefs and practices of the past may be framed to favor one or the other position. When myths become embedded in the minds of people, they may become a collective belief and are taken for granted.

While there is a proliferation of material about the issues involved in the discussion of PAS, there is much less material about the various historical facts and studies that refute the myths. Perhaps the emotional nature of the issue does not allow corrections. Perhaps ambiguity leaves room for compromise or imagined claims and arguments of legitimacy. But most likely of all, myths are not meant to be rational, objective or necessarily truthful but are part of the politics that seek to control the images of PAS.

Pro and Con Arguments

Opponents of physician-assisted suicide in Hawaii include a coalition of some twelve groups united under the Hawaii Family Forum. Their website at http://www.hpacc.org/positions/hff.php (last visited November 27, 2008) lists the organizations belonging to Hawaii Family Forum as the Hawaii Medical Association, Hawaii Nurses Association, Healthcare Association of Hawaii, Hawaii Cancer Pain Initiative, Not Yet Dead, Disability Rights Hawaii, Hawaii Centers for Independent Living, Hawaii Catholic Conference, and Hawaii Right to Life. In addition to Hawaii Family Forum, other opposing groups include socially conservative religious groups, such as the Roman Catholic Church, Orthodox Jews and evangelical Protestant denominations.

Four themes consistently appear in their arguments: belief in the sanctity of life that allows only a natural death and considers suffering a part of life; imbuing PAS with the suicide taboo as a forbidden and condemned death; invocation of the Hippocratic Oath to prove that physicians are vowed to do no harm, and likening PAS to a slippery slope, from which the elderly, handicapped or infirmed could be easily pushed once PAS is legalized. These arguments reflect a complexity of emotions, the pull of ancient history, the stubborn beliefs of religious dogma and psychological difficulty in changing thousands of years devoted to preserving life.

In contrast, PAS supporters include some more socially liberal Christian and Jewish religious denominations, some civil rights groups and some organizations that advocate on behalf of the rights of patients, particularly the terminally ill. The website of the HDWDS at http://www.hawaiidwdsociety.org/history.php (last visited November 3, 2008) lists as their supporters, Advocates for Consumer Rights, the American Civil Liberties Union, the First Unitarian Church of Honolulu, Free Thinkers Maui, Humanists Hawaii, and Honolulu's *Kokua* Council. The local chapter of Final Exit is an active supporter but independent of the HDWDS. Those opposed to PAS are reluctant to change the status quo while advocates desire to change a policy claimed to be outdated by technology and old world conservatism.

These groups tend to focus on three themes: compassion, choice and autonomy which have at its basis, American values and individual rights. They model their proposals after Oregon's Death With Dignity Act passed in 1997, align the various legal definitions and safeguards to those of Oregon's Death with Dignity Act.

To smooth over the suicide aspect of PAS, one of the current strategies used in framing is the attempt to eliminate the term "physician assisted suicide" and replace it with, "physician-aid-in dying" (PAD), death with dignity, or "peaceful death." Compassion and Choices, formerly Hemlock, has made great efforts to change the term from PAS to peaceful death. Kathryn Tucker (2008), legal counsel for Compassion and Choices, has argued that the word, "suicide," is objectionable and inappropriate when referring to the deliberate choice of a mentally competent person to hasten death. She has argued that the term should be replaced with a more accurate and value-neutral term such as "aid in dying" or "physician-assisted dying."

The importance of avoiding the word "suicide" was demonstrated in the Washington initiative. Fearing that term "suicide" would offend the general public, supporters of the Washington initiative went to court to keep the term "suicide," off the ballot title that summarizes the ballot measure and conveys to the voters what the measure is about. Since many voters depend on the information on the ballot title when voting, it was important to have a more value neutral term. The ballot title did not use the term, "physician assisted suicide," but referred to the measure as "aid-in-dying."

The "Good Death"

The contest between the advocates of PAS and their opponents can be said to center on the meaning of a "good death." Achieving a "good death" has been sought since time immemorial. One of the arguments in support of PAS is that it is a means to a good and peaceful death as opposed to a bad death, intractable suffering or futile and hopelessly incurable conditions. The meaning of a good death is elusive as it varies with each culture and each person's beliefs. In hospital settings where the largest number of deaths occur, hospice nurses who minister to the dying on a daily basis describe a good death as "characterized by physical comfort, social support, acceptance, and appropriate medical care and it should minimize psychological distress for the dying and their families" (Carr, 2003, p. 215-232). A bad death is described as the inability to control pain, psychological distress, fear, prolonged suffering, non-acceptance of death.

On a spiritual level, Reverend Mits Aoki, (n.d.) University of Hawaii, uses the term "appropriate death" rather than a good death. There is a "…greater sense of completeness; resolution of relationships with loved ones; more inner tranquility; less turmoil and agitation, and anguish; and rounding out life with a sense of accomplishment and peace" (at http://www.livingyourdying.com/article5.html last visited November 29, 2008).

Greek Notion of a Good Death

Scherer and Simon (1999) put death and dying in a historical perspective by examining the practices of the ancient Greeks who are credited with defining a good death as a happy, peaceful, even noble death. They state that Greek philosophers believed that one should not suffer unduly in dying and that suicide was justified when death and dying meant undue suffering. Thus, a sick or suffering individual could seek the approval of the state to commit suicide, and if approved, a magistrate would supply the poison. Death by suicide was a morally neutral issue and an accepted part of life. Wilson (1975), Scherer and Simon (1999) agree that suicide or euthanasia was not an issue since death was preferable to suffering.

Although acceptable, the Greeks believed that suicide was an offense against the state and required the state's permission before attempting it. Permission would be granted to those who suffered unbearable pain, physical deformity or the hardships of life. The state also reserved it for those who were judged to have committed a crime against the state. An example is Socrates, who was accused of refusing to recognize the state gods and of corrupting the youth. He was tried for treason, found guilty but chose not to recant. He was punished by being ordered to drink a cup of hemlock, thereby committing suicide and became his own executioner.

Suicide Condemned

Suicide and euthanasia were commonplace methods of achieving a good death until the 4th century AD when Augustine (354-430 CE), Bishop of Rome, interpreted the 6th commandment, "Thou shalt not kill," to include suicide (self-killing), and by definition, euthanasia.[16] He also made clear that the punishment for suicide was eternal damnation. About nine hundred years later, Thomas Aquinas (1225-1274), in his *Summa Theological*, affirmed Augustine's teaching and ban on suicide. He supported the Church's argument that life was sacred and only God can take life away. Suffering must be endured and death was the final act in the Divine Plan. To kill oneself amounted to usurping God's power and resulted in eternal damnation.

Suicide Taboo

The popular notion that suicide is a sin or crime can best be understood against the backdrop of the church's traditional opposition to any form of self-destruction. Battin, (1982) calls this notion "the suicide taboo" (p. 20). She says that this taboo is responsible for our attitudes toward suicide and has an "enormous formative influence on our values and beliefs, and consequently on the institutions, policies, and legal structures we have established to deal with suicide" (p.22).

Battin suggests that suicide should not be viewed as forbidden or morally wrong but whether it is morally permissible. Like Tucker, previously mentioned, she suggests using more neutral terms for suicide to include alternatives like elective death, self-determined death or voluntary death.

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[16] The commandment, "Thou shalt not kill," is the 5th commandment in the Catholic Tradition.

She points to the suicides of Samson, Saul, Abimalech and Achitophel from the Old Testament and Judas from the New Testament to demonstrate that at one time the early Church neither approved nor disapproved of suicide and that the deceased was not punished by eternal damnation. However, for about ten centuries between the time of Augustine and the Renaissance, the Church regarded suicide and euthanasia as sinful and immoral. This dogma was largely unchallenged and unchanged even during the Protestant Reformation. The Protestant Reformation and its emphasis on liberalizing Church domination, however, eased eternal damnation away from the list of punishments but still retained the ban on suicide.

The horror of suicide dominated Catholic thought for many centuries. During the Middle Ages, the punishment for suicides was severe; for example, the estate of the deceased was confiscated, the corpse desecrated and denied a Christian burial and spouse and children were stigmatized. Suicides were often hidden for fear of punishment or being blacklisted. In the feudal system, a person belonged to the Lord of the Manor and killing oneself deprived him of labor and production.

The notion that suicide was a punishable crime was carried over in some state laws. As late as 1963, six states, North and South Dakota, Washington, New Jersey, Nevada, and Oklahoma, still considered attempted suicide a crime. Since 1993, all states decriminalized suicide and three, Oregon and Washington and Montana, have elected to decriminalize assisted suicide. Hawaii’s laws are silent about assisted suicide. In the United States suicide has never been treated as a crime nor punished by property forfeiture or ignominious burial. Contemporary views of suicide regard it as a mental illness, depression, and a "cry for help."

Stewardship of Resources

While there were strict rules against suicide, the Roman Catholic Church accepted the concept of the double effect and the notion of stewardship as end-of-life medical treatments that allow a form of passive euthanasia. Catholic theologians distinguished between a patient's obligation to undergo "ordinary" medical treatment to sustain life and the right to forego "extraordinary" procedures (Wilson, 1975). The notion that ordinary measures must be used to preserve life but extraordinary measures were not warranted comes from the idea that man's dominion is of this world and he is the steward of its resources. This notion is discussed in a conversation with Vicar General Father Mark Alexander on August 14, 2006 at St. Francis Hospital, Geriatric Fellows Grand Rounds. He is of the belief that, under the stewardship of resources principle, futile medical treatment, such as respirators and feeding tubes, can be removed since they are considered extraordinary measures and may require the expenditure of extraordinary resources.

However, two modern events seemingly contradict this practice. In 2004, Pope John Paul denounced removing Terri Schiavo's feeding tube although she was severely brain damaged. During Shiavo's controversy, he stated that hydration and nutrition ought to be provided for patients in a "persistent vegetative state" even if there is no hope of recovery. At the end of his life, the pope chose to be on artificial life support until he died in 2004.

Doctrine of the Double Effect

The Church also was not opposed to the doctrine of the double effect which permits committing a wrong in order to achieve a greater good. The doctrine of the double effect, which was already considered during the time of the Greeks, was upheld by Aquinas in his *Summa Theological* to justify killing in the act of self defense. In medicine, it is used to justify the administration of pain medication even though it may lead to the unintended although foreseen consequences of hastening death. The doctrine of the double effect, as discussed in Chapter 2, is generally accepted by all and often it is one of the provisions of the advance health care directive in which an individual can choose to have pain medication even if it hastens death.

The “Myth” of the Hippocratic Oath

Another popular argument used against PAS is the myth of the Hippocratic Oath and the phrase, “do no harm.” Upon close examination, the Oath and the phrase “do no harm” are 4,000 years old and have strayed from their original meanings. While used extensively in PAS debate, there is no historical evidence that Hippocrates authored the oath although it is widely believed to have been authored by Hippocrates or his students. Markel (2004) explains that the phrase appears not in the oath but in a different writing, cited as *Epidemics, Bk. 1, Sect. XI.* He states that the full phrase is “Declare the past, diagnose the present, foretell the future; practice these acts. As to diseases, make a habit of two things—to help, or at least to do no harm” (p. 2026). It is interesting that the oath was lost during the decline of Greece and the sack of Rome and later revived and made popular by Arabic scholars.

Inconsistencies in the Oath with what was actually practiced also challenge Hippocrates' authorship. Some examples are the Oath's prohibition against abortions and suicides which Greeks and Romans commonly resorted to and its prohibitions against surgical procedures of all kinds, the shedding of blood, abortions, euthanasia and banning women from practicing medicine.

Today there is debate as to the practicality of the Oath. Many regard it as a *pro forma* pledge that is not enforced. Certain parts of the original oath especially the invocations to the Greek and Roman gods at the very beginning of the oath, have been deleted or substituted with more general invocations. Most medical schools administer an oath, usually modified and modernized to better reflect changes in the practice of healthcare.

Do No Harm

On a more contemporary note, Vaux (1992) examines how the words, "do no harm," are used as axioms by many physicians to oppose PAS by underscoring that they are "healers" and not "killers." He writes that those who invoke the Oath of Hippocrates, are seemingly guided by ancient precepts to preserve life. Vaux is critical when these arguments are unchallenged and when there seems to be a sense of the holiness about the work that physicians do. He says that "it is the awareness of death and the privilege and fear of attending dying persons that evokes this sense of the holy" (p. 22).

He also uses the phrase “the holiness tradition” to explain why the medical profession has been successful in blocking PAS. Vaux defines the holiness tradition as “the cultural bias that affirms the authority of God in moral life, the sacredness of human being, the purity obligations of the healing professions, and a derivative secularized, quasi-religious respect for life” (p. 22).

The idea of holy is taken from its themes of awareness of death, confronting the fear, the unknown and the supernatural in the phenomenon of death. Vaux comments that, “Like the pastor or priest, the physician is aware that (he or) she stands on holy ground and that (he or) she handles that which is power-charged—the sacred” (p.23). And, one is led to conclude that like a god, the doctor has power over life and death.

Extant Use of Hippocratic Oath

The following examples show how the Hippocratic Oath has been invoked to oppose PAS. The Hawaii Medical Society Association’s position paper opposing PAS is found at the Hawaii Family Forum website at http://www.hpacc.org/positions/hrtl.php (Last visited, December 3, 2008).

> …Every physician takes the Hippocratic oath when they graduate from medical school. This oath forbids physicians from taking any action, which harms a patient. The act of assisted suicide is in direct opposition with the Hippocratic Oath….

Dr. Lonnie Bristow, past president of the American Medical Association, told the Commerce Committee’s Subcommittee on Health during a hearing held in March 1997, reported in the Honolulu Advertiser, posted February 26, 2002:

> …The AMA believes…that physician-assisted suicide is unethical and… inconsistent with the pledge physicians make to devote themselves to healing…Laws that sanction physician-assisted suicide undermine the foundation of the patient-physician relationship that is grounded in the patient's trust that the physician is working wholeheartedly for his or her health and welfare.
>
> Indeed, physicians are sworn to uphold the ideals of the Hippocratic Oath, to preserve life, "to keep (the sick) from harm and injustice...to give no deadly drug if asked for it...nor to make a suggestion to this effect.,,

At the House Committee on the Judiciary on March 24, 2004, Rich Meirs, President and CEO of Healthcare Association of Hawaii gave the following testimony:

> "…Many physicians strongly oppose physician-assisted suicide on the basis of the historical ethical traditions of medicine. For example, the Hippocratic Oath states, "I will not administer poison to anyone where asked": and 'Be of benefit, or at least do no harm.' Physician-assisted suicide would undermine the integrity of the medical profession.…"

Paradoxically, what Vaux calls the holiness doctrine reveals the tension in the medical model of health care between patients who want more control over their own medical treatment and doctors who are reluctant to let patients do so. Hillyard and Dombrink comment on the change in doctor/patients relations: "As patients have demanded greater parity in the physician-patient relationship, including the right to die on their own terms, physicians have also struggled to preserve a level of nobility and autonomy based on expertise in the practice of medicine" (p. 7).

Another critic, Fox (1999), also recognizes the power physicians have over their patients. Fox says that medical technology, especially, made physicians the primary gatekeeper for cures, medication, health and well being since they were the ones most skilled, could give access to technology, and have the power to cure. Further, physicians are supported by a powerful organization, the American Medical Association (AMA), traditionally a conservative organization which had earlier opposed the "living will,"

Since the physician is deeply involved in life and death, medical models in the United States require that physicians prescribe the lethal medication for PAS. Fox is critical of this model but expresses doubt that a more patient oriented model is feasible. Fox writes that PAS will continue to actively involve physicians for several reasons. Only they can write a prescription for lethal medication, they have expert power conferred on the basis of recognized skills and knowledge and the notion that physicians control the healthcare and medical care and thus, the lives and deaths of their patients.

Patient Bill of Rights 1998

In response to patients' demands, the Patients Bill of Rights was proposed in 1998. One of its goals was to reaffirm the importance of a strong relationship between patients and their health care providers. This seeks to balance patients' power with that of physicians and it is linked to Medicare/Medicaid funding. Its goals are to strengthen consumer confidence, to affirm the importance of patient's rights and to link compliance by hospitals to federal and state Medicare and Medicaid programs. For example, some rights include the ability of patients enrolled in HMO's to access second opinions, women to be able to directly access to obstetricians and gynecologists without going through gatekeepers and patients to have the right to independent review when denied necessary medical care. A bill (S. 1052) was considered in 2009 by both houses. It has prompted legal instruments such as living wills and health care advance directives, durable powers of attorney, comfort care only bracelets, do not resuscitate (DNR) orders, and surrogate decision making.

Let Nature Take its Course

While the AMA currently opposes PAS, it did not always do so. Many state laws allowed doctors to do or administer whatever was needed to relieve pain. It appears that even in Hawaii, although not a state at that time, laws reflected this trend: In an 1896 Hawaiian statute concerning the rights of patients seeking relief from suffering is described as follows:

> …[W]hen a duly licensed physician pronounces a person afflicted with any disease hopeless and beyond recovery and gives a written certificate to that effect to the person afflicted or to his or her attendant nothing herein shall be held or construed to forbid any person from giving or furnishing any remedial agent or measure when so requested by or on behalf of the afflicted person….

A popular treatment for the dying was to "let nature takes its course" rather than to prolong life. The AMA, founded in 1844 and the AMA Journals commented on this practice: "Where there is no hope, it should be the highest triumph of the physician to minister unto the wants of a dying fellow creature by affecting the euthanasia" (Filene, 1998, p. 4).

Mercy killings were also committed by ordinary persons against family members who suffered disabilities, excruciating pain, or hopeless conditions. News of these killings was sensationalized in the press and made a crime by the state legislatures. However, punishment for mercy killing tended to be light as these deaths were felt to be acts of desperation to end suffering (Wilson, 1975).

Although mercy killings continued into the 50's, the interest in euthanasia increased but did not have the force to push through legislation. Even today, as Governor's Blue Ribbon Panel stated, they still occur. However, the Death with Dignity Acts in Oregon and Washington and Hawaii's legislative proposal are adamant in declaring that PAS is not mercy killing.

Mercy Killing Changed to PAS

Incidents of mercy killing started the movement to legalize euthanasia in England and shifted to America when legislation to allow it failed to succeed in England. During the 1930's when The American Society for Euthanasia failed in its efforts to legalize mercy killing in Nebraska, the organization changed the term, "mercy killing," to physician-assisted suicide (PAS). It was thought that PAS was less likely to connote homicide and would re-focus people's attention to the morals of ending suffering (Scherer and Simon, 1999; Hillyard and Dombrink, 2001).

The Second World War also halted the spread of the PAS movement in America. Euthanasia and eugenics were associated with Nazi Germany's practices of putting to death thousands of people because of their religion, race, or physical or mental disabilities. Even today, in Germany, the terms are shunned as grim reminders of the horror and diabolical scenes of Nazi atrocities.

Slippery Slope

The "slippery slope" argument is used to argue that if PAS were legalized, the mentally disabled, blind, deaf or aged persons would be forced to die. It hints of Nazi Germany and Hitler's eugenics and racial purification program in which thousands of were killed or sterilized. Framing PAS in this manner made those with disabilities fear that what happened in Nazi Germany could easily happen to them if PAS were to be legalized.

Even though this argument may not be supported by data, as demonstrated by a study of the Oregon Death with Dignity Act by the Pew Foundation in 2007, ten years after the passage of the act, it is emotional and is a form of persuasion that is generally used in hotly debated social issues. Walton (1992) as reviewed by Bruce Waller (1993) explains that although slippery slope arguments are generally dismissed as fallacious, they "… play an important but limited role: they are not designed to refute the proposed policy as hopelessly flawed but instead to shift the burden of proof back to the proponents of the new policy." By pointing out potential problems of the PAS policy, the slippery slope argument requires that those problems be addressed, thus, shifting the burden of proof back to the proponents of the argument. Groups whose members have disabilities have in fact turned the public spotlight on the problems they face and gained a foothold on the public agenda.

An example of the slippery slope argument appeared at the Hawaii State Senate Hearing on Feb. 24, 2005, as PAS was debated. As reported by Steven Ertel (2009) for Lifenews.com, the disability rights groups had come out in full force to voice their protests and fears. Testimony offered by Michael Tada who suffers from cerebral palsy recounted his difficulties trying to live with the disease. As he read his testimony with difficulty, his independent living specialist interpreted for him. He stated that, "Physician-assisted suicide would open a door that would make suicide seem reasonable." Referring to Hitler's eugenics, he stated that if PAS were legal, he would no longer be alive. "Now life is precious" (*Ibid.*).

Other testimony repeats the theme. Dr. William Petty, an oncologist and one of several Oregon physicians who flew into Hawaii for the hearing to oppose PAS at the hearing, said those facing death "are potential victims of subtle and not-so-subtle coercion." He criticized right to die groups who promote social attitudes that having severe disabilities compromise the quality of life and is reason for PAS. …"Care and treatment can be expensive," he added. "Manipulation of patients is a real problem when physician-assisted suicide becomes an option." (*Ibid.*)

Similar arguments come up on the national level. Disability rights groups such as Not Dead Yet argue that PAS is fine for those who wish to end their lives through PAS. However, their disabilities may cause their quality of life to be underrated and lives to be deemed unendurable. Groups claim that this attitude makes them extremely vulnerable and easily persuaded to end their lives and their misery, as reported:

> "We are living the lives that others fear…" "I depend on others to keep me alive every day. If I'm lucky, I get them to honor my requests—and keep me alive—on the strength of my paychecks and my charms. But money and charms are transient and, at bottom, we need people to know they're stuck with us no matter what and that they'll see us through those days when we feel bad about the pressures we put them under or when we get tired of all the complications" (Corbet, 2003).

Concerns are also focused on the possibility that if PAS becomes a medical option, they would be first to be offered the option of killing themselves especially in the light of government budget cuts in health care. As potential victims of manipulation, they fear they are regarded as unwelcome and costly burdens on society. Further, groups with members who have disabilities, claim they are discriminated against because of an unequal process of law which does not offer suicide prevention, equal mental health care and services for independent living to the disabled. They accuse the courts and media of marginalizing disability and they fear that they will be forced to choose PAS even at a time when they might not mentally competent to do so. While slippery slope arguments play on emotions, proponents of PAS, who may not be disabled, dispute and disapprove of the slippery slope arguments that "conflate disability with illness"(Silvers, p. 133). They criticize disability groups as furthering the stereotype of disabled persons as incompetent, vulnerable and easily coerced to end their lives.

Elders, like disability groups, share the same fear of the slippery slope and the same criticism of using too many resources. This use of resources was studied by Francis who demonstrated that the last six months of an elder's life, when the most care is needed, are the most expensive. The argument is made that elders are a special case because they have lived longer and are closer to death and may want to die more quickly. Although this is not supported by data, “studies of suicide among the elderly do find correlations between physical debility and increased incidence of suicide” (cited in Battin, Rhodes & Silvers, (Eds.) 1998 p. 80).

Personal Dignity and Quality of Life

While groups whose members have disabilities see PAS as a slippery slope, proponents see PAS as a means to preserve personal dignity and the quality of life. Although the concepts of dignity and quality of life may seem simple, desirable and moot, they are divisive among these groups. Dignity, according to Schachter (1983), has psychological significance. He states that “…(N)othing is so clearly violative of the dignity of persons as treatment that demeans or humiliates them…” “…and, perhaps even more insidious, destroying or reducing the sense of self respect that is so important to the integrity of every human” (p.850).

For some, like Janet Good, past president and founder of the Michigan Hemlock, choosing PAS retains one’s dignity and quality of life. She describes how she feels about having disabilities:

“Pain is not the main reason we want to die. It’s the indignity. It’s the inability to get out of bed or get only the toilet, let alone drive a car or go shopping without another’s help. I can speak for literally hundreds of people whose bedside I’ve sat at over the years. Every client I’ve talked to—I call them ‘clients’ because I’m not a medical professional—they’ve had enough when whey can’t go to the bathroom by themselves.

Most of them say, 'I can't stand my mother—my husband—wiping my butt.' That's why everybody in the movement talks about dignity. People have their pride. They want to be in charge" (Washington Post, August 11, 1996).

These sentiments were echoed by the 9th Circuit Court of Appeals when it struck down Washington State's ban on PAS in 1996. In the case of Washington v. Glucksberg, it declared that the terminally ill have a right to a "dignified and humane death." Further, it stated that "a competent, terminally ill adult, having lived nearly a full measure of his life, has a strong liberty interest in choosing a dignified and humane death rather than being reduced at the end of his existence to a childlike state of helplessness, diapered, sedated, and incompetent." It concluded that, in addition to physicians, parties "whose services are essential to help the terminally ill patient obtain and take" medication that will hasten death, "or the persons who help the patient to his death bed and provide the love and comfort so essential to a peaceful death," are covered by the decision and are not subject to prosecution (Pietsch and Lee, 1999, p. 220).

When Washington v. Glucksberg and Vacco v. Quill were combined and argued in the Supreme Court, six contemporary philosophers joined together to file an as *amicus curiae* brief, called the Philosopher's Brief, in which they argued that the right to PAS should be upheld. It argues for a person's right to make decisions regarding life's value. The groups whose members have disabilities should not deny people the right to die even though legalization may make them more vulnerable. And it admits the possible danger of the slippery slope because the cost of care would force them into PAS.

It lists examples of persons with disabilities and their multiple illnesses, is sympathetic to their situation but concludes “there is no data to establish the special vulnerability of people with disabilities” (Silvers, p. 133). The authors of the brief concluded that PAS should be upheld as a right to personal autonomy or the ability to make individual choice even though those with disabilities were at risk. At the conclusion of the combined cases, although the court recognized the dilemma posed by these groups, it did not rule in favor of PAS for reasons other than the arguments posed by these groups.

Those with disabilities argue that the quality of life is personal and healthcare providers should not judge whether certain forms of medical treatment are disproportionately burdensome to the patient, or even whether persons’ life stops being meaningful. Disabilities or illness should not measure a person’s quality of life and should not be the reason for PAS.

Reconciling Disabilities

A study by disabilities rights advocate and scholar, Carol Gill, (2000) interviewed and examined the attitudes of health personnel to those with disabilities. Gill reported that during interviews with people with disabilities, she found that people were horrified at first that they were disabled, but many have later discover a rich and fulfilling life. Some popular examples include Christopher Reeves and Stephen Hawkins.

Moreover, as groups whose members have disabilities gained strength, dignity as framed by PAS advocates appears to have slowly evolved in their favor. They have since joined with Hawaii Family Forum and successfully blocked passage of the PAS bill.

Their strength has affected legislators like Josh Green chair of the Health Committee who after the 2007 session remarked that the disability groups and their fear of the slippery slope had influenced his vote.

Civil Rights and the Right to Die

In turning to the arguments posed by advocates of PAS, the good death is often framed in personal rights. For example, the right to die is often used in PAS arguments in order to mobilize and appeal to people. Hillyard and Dombrink (2001), explains that "The discursive themes proceeding from the "rights movements of the 1960's and 1970's have formed the sociopolitical terrain that has inspired and fueled the contemporary death with dignity movement (p. 8)." This reverberated in women's rights to abortion to which the right to die found a relationship. It is often noted that once the notion of abortions was accepted, the notion of euthanasia was far easier to justify.

Autonomy is another argument put forth by proponents of PAS who argue that 14th amendment due process clause protects their right to choose the means, time and place of death. To that argument, Lynn, (2004) a gerontologist and doctor, responds that the desire for autonomy is not possible. Lynn points out that when a large number of people die in hospitals and an even larger number die in nursing homes, "differential access to care, the problem of the uninsured and underinsured, the wise stewardship of scarce institutional resources and materials are themes that impact dignity, autonomy and compassion. PAS is motivated not only by individual autonomy but by coercion, physician reimbursement policies, HMO's limits of hospital stays and medical care, and family finances"(Braun, *et al.* (Eds.), 2000, p. xi).

Autonomy can also trumped by family wishes for the individual who is nearing death. One such vivid example is A.Q. McElrath, the founder and embodiment of living and dying with dignity. McElrath had voiced in many of her lectures and in private that she did not want to be hooked up to machines. This author had visited her at the hospital on December 10, 2008, the day before she died. She had undergone dialysis the day before and was hooked up to oxygen tubes, heart monitors, and another tube in her groin. Perhaps, it was decided that prolonging her life a few more days gave us, her friends and colleagues, time say goodbye. And, conscious and stubborn to the end, she wished us well as we said our last goodbye. The tubes were most likely removed later because that night she died.

Summary

This chapter exposed various common myths that both advocates and their opponents use to advance their positions in the PAS debate. Myths are necessary. Myths are easy ways tell a story. They hint at truths but may lack the complexities necessary for critical judgment. Framing is a political tool, not an analytical one and the purpose of framing is not to expose or uncover the layers of perceived truths.

CHAPTER 4
HAWAII'S CONDUCIVENESS TO PHYSICIAN-ASSISTED SUICIDE

Hawaii, the island state, was affected by Supreme Court cases and the right to die movement in different parts of the nation. Before Cruzan was decided, in the guardianship of Shirley Crabtree, Hawaii had honored Crabtree's right to end unwanted medical treatment. This case was buttressed by the state's constitution that protected the individual's right to privacy. Although ambiguous and inconclusive laws about medical treatment were not applied, they hovered in the background and could have provided a legislative process to permit PAS. With these events happening, PAS advocates in Hawaii were encouraged to pursue their notion of the "good death." They had counted on Hawaii's diversity, and favorable polls in their quest to legalize PAS. Except for its liberal and progressive reputation, Hawaii's ethos was very different from Oregon's, the only state that had legalized PAS at that time.

Hawaii's Ethos

An astute political strategist is said to have a "good feel" for the "gut-level" values of the electorate (Kimura, 1982). The political strategist should be able to discern how and why a particular electorate feels the way it does and how its sentiments, beliefs, attitudes, frustrations, dreams, and hopes shape its voting behavior. He or she must be sensitive to its collective history, culture, experience and beliefs that make up its ethos. Understanding its ethos enables him or her to answer the how's and why's of voting behavior and select tactics that can best communicate with a particular electorate.

Leaders

The leaders of the PAS movement were old-timers. The late A.Q. McElrath was a near legendary icon, a former union organizer and social worker. The late A.A. Smyser was the former editor of the Star Bulletin and a contributing editor before his death. Andi van der Voort, another old timer, founded the Hemlock Society in Hawaii in the late 80's and thereafter Final Choices in Hawaii. Eve Anderson, was a former Hawaii State Representative from the Waimanalo District. Scott Foster, a political strategist and publicist, worked behind the scenes. Juliet Begley was former nurse and a researcher for the opposition strategist who had worked on Governor Benjamin Cayetano's campaign. There were others. And all understood Hawaii's ethos, embraced it, manipulated it and some had even created it.

When asked why they thought PAS had a chance to win in Hawaii, the themes that surfaced and that were repeated by various leaders of the movement, centered on influences and characteristics that were particular to Hawaii: a population that was aware of national and local court cases and events involving death and dying issues, a population not opposed to making advance end-of-life decisions, diverse in ethnicity and religion, and reputed to have a penchant for liberal and progressive legislation. In addition, national and local polls indicated that people, in general, were in favor of PAS. All these traits made its supporters feel that Hawaii was conducive to PAS and optimistic about winning legislation. As the campaign to pass PAS legislation progressed, advocates and their hopes were challenged by the conundrums in the islands' diverse cultures and religions.

Hawaii's Geography, Diversity, Culture

Hawaii is unlike other state in the nation. Its ethos is infused with an immigrant and plantation history, a strong centralized system of government and small town, face-to-face manner of politics. It is insular and global, open to both trends and to people across the Pacific. It extends *aloha* to a virtual "melting pot" of diverse races, cultures and religions. It is the most Asian of all the states, its population is composed of 40% Asians, a healthy but not dominate number of whites, has the most Buddhists, the most interracial marriages and has a reputation of being liberal, progressive and tolerantHawaii is often envisioned as an exotic, tropical destination described in languid, romantic terms, such as Mark Twain's "the loveliest fleet of islands that lie anchored in any ocean." Maps of the Pacific show that it is thousands of miles from the nearest large land mass. It is over 2,300 miles distant from California, its nearest neighbor, and according to the *U.S. 2000 Census Databook*, has 6,423.4 square miles of land area, a population of just over a million people (1,211,537 in 2000 and 1,275194 in 2005) and is the most diverse of all the states in race, ethnicity and religion.

Its small geographic size affects its politics and ethos, for example, Steinhoff and Diamond (1977) suggests that Hawaii's small size was crucial to the success of abortion legislation. "More than three quarters of the population, however, lives on the island of Oahu, within fifty miles of the state capital in Honolulu. The government is thus physically accessible when people want to express their views. It is also socially accessible because the population is small and the scale of government is correspondingly reduced" (Steinhoff & Diamond, 1977, p. 1). Ease of access to legislators, is illustrated by the comment, "All you need to do is to buy a $25 fundraiser ticket."

Its geographic isolation and small population allow the state to go its own way to be progressive, liberal and tolerant. Popular writer Tom Coffman (2003) describes this trait in the local population: "Those who grow up in the *Aloha* spirit appear to develop a common culture of their own, irrespective of their ethnic backgrounds which are unique, when compared with mainland American culture" (p. 35).

Coffman continues as he describes Hawaii as "the island edge of America" and an extension of national trends (p. 35). As it is both periphery and center, it is a place unto itself. Coffman points out that Hawaii may absorb the trends current in America, yet the histories of its own ethnic groups and its island culture may set it apart from other states.

An example is the Hawaii Medical Treatment Decisions Act passed in 1986. Quinlan and Cruzan both suffered car accidents that left them in persistent vegetative states. As these cases were argued, they raised consciousness of the whole nation on the issue of death and dying. And if the ordinary individual on the street had not heard of Quinlan, Cruzan and Glucksberg, he or she would most likely have been exposed to the televised antics of Dr. Jack Kevorkian and his death machine. Nationally syndicated columnist Abigail van Buren in her "Dear Abby" column described the model document drafted by the Euthanasia Educational Council, 500,000 people sent in requests for a copy. During 1970-1975, the council mailed out a total of 750,000 copies and nine months after the Quinlan trial, another 600,000. In the mail outs, they urged their readers to execute "living wills" to let doctors know what kind of medical treatment they wanted at the end-of-life. Did they want tube feeding and hydration to be kept alive indefinitely like Quinlan and Cruzan or did they want their doctors to "pull the plug?"(Filene, 1998, p. 98).

As news of these events reached the "island edge of America," the Hawaii State Legislature in 1986 passed the Hawaii Medical Treatment Decisions Act (Hawaii Revised Statues 327D-1 et.seq.) Hawaii's "living will" was "a legal document containing instructions for the medical care of an individual if that individual is unable to make such decisions on his or her own behalf.

Hawaii's First Experiment in End-of-Life Issues

When the Hawaii Medical Treatment Decisions Act was passed in 1986, it was Hawaii's first attempt in "right to die" legislation. Advocates faced three challenges that stemmed from the conundrums of its cultural and religious diversity and the traditional respect for doctors: 1) how to accommodate the cultural and ethnic differences in Hawaii; 2) how to assuage any fears that remnants of the Right to Life anti-abortion group, including conservative Catholics harbored, and 3) how to accommodate physicians who were directly involved in determining the medical treatment of patients and who had reservations about patient's autonomy.

Hawaii's Diverse Culture and Ethnicity

The first challenge in Hawaii's experiment in end-of-life issue was to accommodate the various ethnic groups and individuals within the groups. Educational public television programs, special prime time TV panels, talk shows, and outreach by several state agencies targeted the general population. Minority groups were reached by

Japanese language radio programs, Korean language radio programs and Filipino television programs that often featured English speaking persons whose presentation was translated into the native tongues. Public opinion was also shaped by local celebrities. For example, Leslie Wilcox, a television personality, hosted several programs on living and dying. Through a Robert Wood Johnson Foundation grant, a popular radio and TV announcer, who had experienced a heart attack, produced and showed on prime time a program that explained what the “living will” was all about and how people could make end-of-life decisions if they became physically or mentally incapacitated. To ensure that a person’s wishes were carried out in an advance directive, an agent could be named. If there were disagreements among the parties, the law provided that a guardian could be appointed to make the decision. Both sides of the issue were presented and individuals were encouraged to exercise their autonomy and independence in deciding their end-of-life treatment “before it was too late.”

Catholic Church

While the first challenge was easily met, the other two challenges presaged strong opposition to PAS. The second challenge, how to accommodate conservative religious and fundamentalist groups was met through the advocacy of the Vicar General of the Catholic Diocese of Hawaii. Although he was adamantly against PAS, his support of the principal of the double effect and terminal sedation (explained in the previous chapter) affirmed the support of liberal Catholics and calmed the minds of conservative Catholics.

Catholics in Hawaii, as in many other states, were divided between the liberal group and the conservative group. The liberal group favored the advance directive and adhered to the tradition of "the papal allocution" rejecting "extraordinary means" to prolong life." (Filene, 1998, Glick, 1992) The more traditional and conservative group felt that the advance directive was a covert attempt at euthanasia. The more liberal faction relied on the Catholic Church's policy of the "double effect" and the stewardship principal as affirmed by the Vicar General. The conservative faction of the Catholic Church left its imprint on the advance directive by demanding safeguards, such as requiring that a person had to have a terminal condition as distinguished from being in a vegetative state, before the "living will" would take effect.

In the years after the passage of the abortion bill, the religious groups would grow more powerful as coalitions formed, bolstered by generous financial support.

Physicians

The third challenge was to gain acceptance of the advance directive by physician groups. This entailed convincing physicians that patients had the right to determine their own medical treatment at the end of life. Physician groups in California initially objected to the medical treatment decisions document and had reservations about patient's autonomy. The battle had been intensely fought in California. They relented after the American Medical Association (AMA) threw its support behind the advance directive which was then called the "living will" (Hillyard & Dombrink, 2001). The AMA acquiesced to the advance directive as it protected them from liability in malpractice suits when taking a patient off life support. In Hawaii, although the advance directive met some objections by physicians, it was strongly supported by the head of the Hawaii

Medical Association at that time and it passed without strong resistance from the medical community.

The clash between the advocates and opponents of the advance directive was not as long drawn out or as intensely hostile in Hawaii possibly because of distance and geographic isolation from California. Also, the battle in California had been fought since its introduction in 1976 and disagreements had already been negotiated. In the end, objections from pro-life groups and conservative Catholics were minimal and their threat to picket public presentations did not materialize.

Hawaii's Own

Four years later, the Federal Patient Self-Determination Act passed under the Omnibus Budget Reconciliation Act of 1990. It was an attempt to enhance the effectiveness of state laws to ensure patient's autonomy and informed consent. It required providers in all 50 states—hospitals, skilled nursing facilities, home health agencies, and hospice programs—to inform adult patients about their right to make heathcare decisions and to ask whether they had executed an advance directive.

Multi-language programs reached out to minorities, outreach sessions by the University of Hawaii and other groups helped individuals execute the advance directive and favorable pronouncements by the Vicar General and the HMA president had headed off the opposition. The State had gone about its own way to adopt and adapt to federal legislation and avoid the confrontations experienced by other states on the mainland. For example, the State modified the Uniform Health Care Decisions Act that was passed by all fifty states, to be as inclusive as possible. Rather than having a hierarchy of who could make decisions, all interested persons had the same place in line as a spouse or other family members had when making decisions for a person lacking competency. Consensus among all parties was required in making an end-of-life decision for the incompetent person. Appointing a guardian for the incompetent person was required when consensus could not be reached. The advance directive, Hawaii's first attempt in legislating end-of-life issues, had been modified to meet the diverse cultural needs of the people of Hawaii and easily segued into an end-of-life document in its own fashion.

Hawaii Progressive and Liberal Ethos

Abortion Decriminalized

A piece of legislation that especially encouraged PAS advocates and demonstrated to them that Hawaii's ethos seemed progressive and liberal was the decriminalization of abortion. About 25 years had passed between 1971 when abortion was decriminalized and 1996 when the advocates began to mobilize. In the interim, what may have been not so much forgotten, as idealized, were the battles of conscience that took place in the minds of legislative leaders whose religion opposed abortion, the extensive coalition building efforts and the demand for the decriminalization of abortion that underlay this piece of legislation.

The bill that decriminalized abortions was passed two years before the historic court decision, Roe v. Wade decided in 1973. Legalizing abortion in Hawaii was more poignant and dramatic because at the time, Hawaii's Governor, John A. Burns was a devout Catholic whose wife, pregnant with child, had contracted polio. He had been warned by physicians that she might die if the pregnancy were not aborted (Steinhoff &

Diamond, (1977). Rather than abort the fetus, Mrs. Burns was cared for by a physical therapist and carried the child to term. The child was given the middle name Seishiro, in honor of the therapist. In the fight to legalize abortion, Governor Burns had set aside his personal beliefs and declared his neutrality. He refrained from vetoing the bill which would have destroyed any chance of its passing "I do consider the abortion question as a matter involving individual conscience and a proper subject for legislative policy setting and scientific or judicial interpretation" (p. 173).

In addition to Governor Burns, Vincent Yano, chairman of the Senate Health Committee, who was also of the Catholic faith, supported and took charge of pushing the bill through. Tom Coffman describes Yano. "The Catholic bishop was stalking the halls, and Vince was a very big Catholic layperson..." "He read intently on the subject and consulted with many people, eventually reaching the agonizing decision that if he opposed the bill, he would be imposing his personal religious beliefs on others. So, as chair, he moved the bill out of committee, and it was passed by both houses" (Helen Alton, 2005).

The Church and Physicians

This was a time when the Church was not then organized enough to resist the pro-abortion bill. The American Medical Association (AMA) had also supported the bill and Hawaii Medical Association went along with the parent organization. Much effort went into shaping the bill and gaining support. This strategy is further discussed in Chapter 5.

Ethnicity

Ethnicity was important in the abortion issue. The composition of the legislature in the 70's was filled with the new generation of Japanese Americans including those who had fought during World War II in the famous 442nd Infantry Regimental Combat Team. The majority of the legislature during the time in which the pro-abortion bill was considered was made up of persons of Japanese ancestry.

To win over the Japanese vote, the Japanese population was reminded of how World War II governmental actions had violated their civil rights during their internment. It suggested that violating civil rights should not happen to others. They were also reminded that they had fought a war to protect individual rights, freedom and liberty. Drawing from Hawaii's history in World War II and the courage of its famed 442 combat battalion, abortion was framed in personal and civil rights.

This argument was used in the same sex marriage and the PAS issue to joggle the collective memory of individuals of Japanese ancestry especially for those with ties to the 442.nd

Prepaid Health Care Act

Another law that encouraged the advocates was Hawaii's Prepaid Health Care Act. Hawaii was the first state to require employers to offer health insurance to those who worked at least 20 hours for four consecutive weeks through its Prepaid Health Care (PHC) Act enacted in 1974. Hawaii's tradition of large plantations that provided hospitals and physician care for their vast workforces had laid the foundation for this piece of legislation. McElrath, the principle leader in the PAS movement, had worked relentlessly among the plantation workers as a social worker and as a union leader. Even though a large number of the plantation workers were Filipino and Catholic she was confident of their backing.

During a private conversation, she was asked whether they would oppose PAS because of their Catholic religion. She used an example from her experience as a social worker teaching Filipinas about birth control on the plantation camps. She said she went house to house and talked to the wife about the advantages of birth control and showed her how the various devices worked. She said that many were not practicing Catholics and that she was confident that their religion would not be a detriment to PAS legislation. A different point of view was expressed by the director of *Kokua* Mau, who conjectured that this ethos of paternalism in healthcare continued to the present day. People in Hawaii still maintained a huge respect and *aloha* for their physicians and trusted their doctors to take care of their health needs.

Gay Rights Legislation 1998

Again demonstrating its propensity for progressive and liberal social legislation, in 1997, Hawaii was the first state in which gay rights groups campaigned for same sex marriage. However, the conundrums in Hawaii's diversity challenged its supporters. When gay rights activists pushed for legislation to allow marriage between persons of the same sex, they encountered strong resistance from conservative religious groups and others who believed in traditional marriages. With the support of other religious and conservative groups, they raised "big money," hired a national public relations firm to run the campaign, monitored and lobbied the legislature, produced ads for television and newspapers and formed websites and political action groups (Crapo, 1998).

Challenges

The Mormon and Catholic Churches, groups that were traditionally at odds with each other united under the Hawaii Family Forum. An activist for gay rights describes this phenomenon, as the "tipping point," the point at which Christian fundamentalists united in opposition to what was considered moral legislation. Before the Gay Rights marriage issue, they "kind of just drifted around. They weren't united." The same activist continued, "I told them not to call it gay marriage, that it would cause the Church to go ballistic, yet they went ahead and called it gay marriage. If they called it anything else, like "choice," they would have had a chance.

No Statewide Initiative

The second challenge appeared in Hawaii's version of the ballot box, a venue of direct democracy used by states such as Oregon, California and Washington State. The initiative can be a venue for deciding controversial issues when a legislator did not want to be identified with the issue and left the matter to the voters to decide. Unlike many states, Hawaii did not have a statewide initiative or referendum. Voting for an amendment to the state constitution was the closest the voters in Hawaii had that paralleled a statewide initiative.

Amending the constitution is difficult and it is not regularly used. Not only does the legislature need to decide by two thirds vote to put the question before the voters in the form of an amendment to the state constitution, but voters need to approve by a majority of the votes cast to convene a constitutional convention to change the constitution should the measure pass. Another difficulty lurks in the wording of the amendment title which voters tended to rely upon when voting.

In the proposed amendment to legalize same sex unions, the wording of the amendment was thought to have confused many of the voters. The amendment was worded: “Shall the constitution of the State of Hawaii be amended to specify that the Legislature shall have the power to reserve marriage to opposite-sex couples.” A “no” vote could be easily have been interpreted as a “yes” vote. Voting “yes” meant that the voter opposed same sex unions.

This circuitous method of achieving direct democracy seemed to go against the liberal and progressive grain of the state. But perhaps, it was more reflective of the history of Republican rule, immigrant labor from China, Japan and the Philippines, the “Red Scare” that tainted the unions and the other bits of political and social history embedded in the ethos of the islands.

There is scant information about why Hawaii has no statewide initiative and referendum. However, The League of Women Voters studied the issue intensively and captured the thoughts of those who were influential in the move to achieve statehood for Hawaii and those who were involved in forming the constitution for the state. The absence of the initiative and referendum can be traced to the time when Hawaii was annexed by the United States and the President of the United States appointed its governor. During the drafting of the state’s constitution which was a required step that preceded statehood, the Republican Party that dominated Congress felt that people in

Hawaii, especially its immigrant Asian groups, were not ready for direct democracy and were fearful that Communists in the labor unions would take over the islands. At each subsequent constitutional convention after statehood, the issue of the initiative and referendum was brought up and voted down by the dominant party. However, it has been used in the counties for zoning purposes for many years. But this is criticized as a misuse of democracy that goes against the spirit of the initiative (League of Women Voters, 2003).

Hawaii's Conundrums: Culture and Religion

While the state's melting pot had established its reputation for tolerance and harmony, its blend of races and religions posed a conundrum. To reach the diverse groups, PAS advocates in Hawaii had to step a fine line in shaping its message. In a homogenous state like Oregon, where whites made up 96.9% of the population, a single consistent message would appeal to many of the voters. In contrast, the PAS issue had to be framed to appeal to the many ethnic groups in Hawaii. According to 2000 data provided by the U.S. Census Bureau, Hawaii, by contrast, had no majority race—whites made up 24.3% of the population, Hawaiians and other Pacific Islanders made up about 9.4% of the population and Asians as a group made up 41.6%. Among Asians, Japanese predominated at 16.7% and Filipinos at 14%.

The diversity in ethnic composition was reflected in a wide range of values among the groups. Yeo and Hikoyeda report that conflicts occurred in the following areas concerning medical treatment: among those whose values were influenced by Confucian traditions and filial piety, family decision making often trumped individual autonomy. (in

Braun, *et.al*. Eds. (2002) p.103). Asian families hesitated to disclose terminal illness to a family member which was a problem especially when informed consent was required for medical treatment. Advance directives were not widely distributed when families believed it was bad luck to talk about death. Being on life support was also commonly accepted among those who favored longevity over quality of life or the hope for a miracle to happen. Autopsy or organ donations were not favored. Hospice Care might not meet the European model of hospice care because Asian and Pacific Islander families prefer more aggressive care (p. 103-105).

They further found that whereas autonomy resonated with whites, it did not resonate with people of Japanese ancestry. In traditional Japanese culture, decisions at the end of life were made by the consensus of the family rather than an individual. Autonomy also did not resonate well with Hawaiians or Pacific Islanders who also made decisions through consensus. Many Chinese simply did not like to talk about death. And, persons with disabilities tended to feel marginalized when a diminished quality of life became a reason for legalizing PAS.

These differing values among a diverse population made forging a single message such as choice and autonomy difficult. To forge a common message that would link the people and their interests, values, and goals to the PAS movement, the PAS advocates chose to remind people of their collective experience during World War II. It settled on personal choice and a subtle reminder that World War II was fought to protect the freedom to make personal choices. An example of this is the testimony of Reverend John Heidel, a former chaplain at Punahou School. At a legislative hearing, he testified that

“This is primarily a matter of personal choice, “We should have the freedom to make our end-of-life choice. ... We should live with dignity and we should be allowed to die with dignity” (Star Bulletin, February 6, 2005).

When the PAS strategists they decided to frame their message within a civil-rights context, they followed the example of the same sex union advocates. Both PAS and same sex union advocates recognized the difficulty of mobilizing people with this message. The Honolulu Star Bulletin (November 11, 2005) reports that it was a “complex, technical message about government and civil rights” that was “trumped by an easy, emotional message” that marriage was reserved between one man and one woman, or in the PAS context, that “doctors heal, not kill.” Despite the complexity of explaining “personal rights” and “personal choice,” these words continued to be used in PAS arguments.

While culture could matter, religion also could matter. The PAS advocates were optimistic about another characteristic of Hawaii’s ethos, Hawaii’s diverse religions. They were encouraged by the number of Buddhists in the state who seemed favorable to PAS. Although Hawaii and Alaska are generally not included in the U.S. Religious Landscape data or any other survey of religious identity, there is indirect data about their attitudes. Yeo and Hikoyeda reports that a study of the attitudes of Buddhists was done by Ronald Nakasone and reported in the 1996 Annual Reports of the 85th Legislative Assembly of the *Honpa Hongwanji* Mission of Hawaii. He had surveyed a total of 9,414 members, 31 ministers and 36 temples. He described their attitudes as the following: “In Buddhism, a request for euthanasia represents a conflict between respect for life and the compassion to end continued suffering. Despite the prohibition against ending one's life, there can be occasions when the continuation of life might not be the best alternative."… "Devotees understand death to be a part of life because change and suffering are endemic to life, and death is not to be feared" (Braun *et al*., (Eds.) 2000, p. 226). These sentiments led proponents of PAS to believe that members of the Buddhist religion would not be opposed to PAS. Proponents of PAS felt that this attitude might appear among Japanese, including Okinawans who comprise approximately 14% of the collective Japanese population in Hawaii, and other Asians in general (*Ibid.* p. 227).

Polls

In addition to the perception that elements in Hawaii's ethos were conducive to PAS, polls were used to gauge public opinion in favor of and against PAS and to create political strategies. One of the first polls was conducted in 1991 by Timothy Littlejohn and Jeanne Burrows-Johnson, "An Attitudinal Survey of Euthanasia in Windward Oahu: A Cross-Sectional Study of Four Age Groups." Ironically, one of the participants was Jeff Crabtree whose mother, Shirley Crabtree, had suffered massive brain damage, slipped into a vegetative state for four years and died after her feeding tube was removed. Crabtree was subsequently appointed to the Blue Ribbon Panel in 1997.

The authors of the study hypothesized that those favoring PAS were older, in their 60's. Their studies found that age did not make a difference. Education did.

A poll that surveyed residents March 12-17, 1998 was particularly relied upon by the Governor's Blue Ribbon Panel. This was the Honolulu Star-Bulletin's poll was conducted among 419 registered voters statewide (Blue Ribbon Panel Report, 1998, p. 64).

The question asked was:

“Would you favor or oppose a law which would permit physician-assisted death under carefully controlled circumstances in Hawaii?” As reported in the Final Report of the Governor’s Blue Ribbon Panel on Living and Dying with Dignity, (1998, p.64) the results are shown below:

Figure 3. Results of the poll taken May 12-17, 1998 according to general population.

	No. of Persons	% of those surveyed
Favor	281	67.1%
Oppose	82	19.6%
No sure	56	13.4%
Total	419	100%

Figure 4. Results of the poll according to gender.

Gender	Favor	Oppose	Not sure
Male	146 (71.6%)	43 (21.1%)	15 (7.4%)
Female	135 (62.8/%)	39 (18.1%)	41 (19.1%)

Figure 5. Results of poll according to ethnicity.

Ethnicity	Favor	Oppose	Not sure
Caucasian	93 (77.5%)	20 (16.7%)	7 (5.8%)
Japanese	73 (67.0%)	18 (16.5%)	18 (16.5%)
Full/Part Hawaiian	39 (65.0%)	14 (23.3%)	7 (11.7%)
Filipino	37(63.8%)	2 (3.4%)	19 (32.8%)
Mixed Other	22 (55.0%)	18 (45.0%)	0 (0%)
Other	17 (53.1%)	10 (31.3%)	5 (15.6%)
Region			
Oahu	202(67.1%)	60 (19.9%)	39 (13.0%)
Neighbor Island	79 (66.9%)	22 (18.6%)	17 (14.4%)

These polls and the conduciveness of Hawaii to PAS were very encouraging to advocates of PAS. But these characteristics while favorable, rippled with conundrums. Although Hawaii was known for religious tolerance, there was great resistance toward liberal and social legislation as shown by the same sex union proposal and the coalition of conservative groups. The bill to decriminalize abortion demonstrated that social legislation was possible but it necessitated leadership, coalition building and a time when the opposition was less united. Studies about the cultural attitudes toward death and dying tended to show that there could not be a single unified message in framing the PAS message. Hawaii's social and political history and variations within particular cultures had to be considered. The advocates of PAS faced a population with different values, goals, immigrant history and identity and could not easily put forth a singular, emotional message.

Oregon

These characteristics contrasted with the ethos in Oregon, which at that time, was the only state that had legalized PAS. To get a sense of how Oregon's ethos was conducive to PAS, the attitudes and sentiments of its people are aptly described by David Broder. In studying the success of the initiative ballot that won PAS in Oregon, Broder described his experiences: "In Oregon, I quickly learned, the legislators were seen as interlopers, busybodies who had interfered with the sovereign right of people to make their own laws" (Broder, 2002, p.9). Broder also pointed out the independent nature of the voter and distrust of anyone who had the power to make decisions for him or her. The distrust extended not only to legislators but to religious groups. Hillyard and Dombrink (2001), also examine Oregon's ethos that made possible the passage of their Death With Dignity Act. They described typical Oregonians as independent thinkers, critical of the church and distrustful of authority. Although these characteristics fit the pioneer and explorer ethos of Oregon, they seemed alien in the *Aloha* State. The following population chart sharply contrasts the racial composition of Oregon and Hawaii in the year 2000 (U.S. Census Bureau, 2000).

Figure 6. Oregon’s Racial Groups compared with Hawaii’s Racial Groups.

	Oregon total population in 2000	Oregon % of population	Hawaii total population in 2000	Hawaii % of population
One race	3,316,654	96.9	952,194	78.6
White	2,961,623	86.6	294,102	24.3
Black or African American	55,662	1.6	22,003	1.8
American Indian and Alaska Native	45,211	1.3	3,535	0.3
Asian	101,350	3.0	503,868	41.6
Asian Indian	9,575	0.3	1,441	0.1
Chinese	20,930	0.6	56,600	4.7
Filipino	10,627	0.3	170,635	14.1
Japanese	12,131	0.4	201,764	16.7
Korean	12,387	0.4	23,537	1.9
Vietnamese	18,890	0.6	7,867	0.6
Other Asian	16,810	0.5	42,024	3.5
Native Hawaiian and Other Pacific Islander	7,976	0.2	113,539	9.4
Native Hawaiian	2,244	0.1	80,137	6.6
Guamanian or Chamorro	1,015	0.0	1,663	0.1
Samoan	1,124	0.0	16,166	1.3
Other Pacific Islander	3,593	0.1	15,573	1.3
Some other race	144,832	4.2	15,147	1.3
Two or more races	104,745	3.1	259,343	21.4
Race alone or in combination with one or more other races				
White	3,055,670	89.3	476,162	39.3
Black or African American	72,647	2.1	33,343	2.8
American Indian and Alaska Native	85,667	2.5	24,882	2.1
Asian	127,339	3.7	703,232	58.0
Native Hawaiian and Other Pacific Islander	16,019	0.5	282,667	23.3
Some other race	176,866	5.2	47,603	3.9
HISPANIC OR LATINO AND RACE				
Total population	**3,421,399**	**100.0**	**1,211,537**	**100.0**
Hispanic or Latino (of any race)	275,314	8.0	87,699	7.2
Mexican	214,662	6.3	19,820	1.6
Puerto Rican	5,092	0.1	30,005	2.5
Cuban	3,091	0.1	711	0.1
Other Hispanic or Latino	52,469	1.5	37,163	3.1
Not Hispanic or Latino	3,146,085	92.0	1,123,838	92.8
White alone	2,857,616	83.5	277,091	22.9

In comparing religious groups in Hawaii, Oregon and U.S., Oregon has the higher number and Hawaii has a fewer number of persons unaffiliated with any religion compared with rest of the nation.

Figure 7. The 2009 Pew Forum on Religion and Public Life show the religious composition of Hawaii, Oregon and the U.S.

Religious Tradition	**Hawaii**	**Oregon**	**U.S.**
Evangelical Protestant tradition	26%	16%	26%
Historically Black Protestant Tradition	<.5%	1%	7%
Catholic Tradition	22%	14%	24%
Mormon Tradition	5%	5%	2%
Orthodox Tradition	<.5%	<.5%	1%
Jehovah's Witness Tradition	2%	<.5%	1%
Other Christian Traditions	<.5%	1%	<.5%
Jewish Tradition	<.5%	1%	2%
Muslim Tradition	<.5%	<5%	1%
Buddhist Tradition	6%	2%	1%
Hindu Tradition	1%	<.5%	<.5%
Other World Religions	<.5%	<.5%	<.5%
Other Faiths	2%	2%	1%
Unaffiliated	17%	27%	16%

Although Hawaii's diversity contrasted with Oregon's homogeneity, the advocates were optimistic and still saw opportunities in the conundrums posed by Hawaii's ethos. Mindful of the difficulties presented by same sex union proposal, they counted on Hawaii's liberal climate that helped legalize abortion, the mix of cultures where Buddhist sense of compassion mixed with liberal Protestant leanings and the American notions of choice and autonomy. They were further encouraged by the support of the Governor who formed The Blue Ribbon Panel on Living and Dying with Dignity. Most of all, the leaders of PAS were experienced activists, politically savvy and understood Hawaii's ethos. They, after all, had embraced it, manipulated it and had even helped create it.

CHAPTER 5
BUILDING THE PAS AGENDA IN HAWAII

The PAS advocates had found Hawaii's ethos conducive to changing the law to allow PAS under strict conditions. They had formed the Governor's Blue Ribbon Panel on Living and Dying with Dignity in 1997 (hereafter, Blue Ribbon Panel) which drove the PAS movement in Hawaii and set in motion the conflict between advocates and opponent.

This chapter analyzes the significance of the Blue Ribbon Panel, the two competitors in the PAS issue and strategic mistakes made by the advocates. This chapter also points out the role of serendipity, professionalism and money that revive the PAS bill and lead it to a near victory.

Two notions are advanced; the notion of agenda building that sets in motion the events leading up to the creation of the Blue Ribbon Panel and the notion of coalition building as described by Coplin's and O'Leary's PRINCE analysis. Using Coplin's and O'Leary's analysis, this chapter concludes that winning in 2002 could have been possible if the advocates had engaged in coalition building with its stakeholders.

Agenda Building

Henry Glick was one of the few scholars who analyzed PAS through the lens of politics, in particular, the theory of agenda building (Glick, 1992). Under his theory of agenda building, issues concerning death and dying were identified as problems in the modern world of advanced medical technology which can keep a person alive indefinitely. Policy makers, which include government officials, the media, interest groups and academics, paid serious attention to these problems and placed them on the public agenda to be discussed and perhaps acted upon.

Glick pointed out that some agenda building events were the civil rights movement and women's right to abortion movement that laid the groundwork for the right to die movement. Abortion rights were based on individual autonomy and personal choice, the same ideas that were central to the PAS movement. The women's pro-abortion movement made familiar the arguments for the right to personal liberty, personal privacy and due process of the law, all of which were arguments used in the Quinlan and Cruzan cases. In addition to media attention, public sentiment on the right to die, the right to die as a medical topic, the criminal activities of Jack Kevorkian and Derek Humphrey's book, *Final Exit*, commanded public attention and lifted PAS onto public agendas.

Like Glick, Kingdon, another scholar of agenda building theory, believed that agendas, were made up of the list of subjects to which government officials and those around them were paying serious attention. Kingdon, however, observed that even though problems required attention, they remained on the periphery and were not given close attention until they were put on policy makers' agendas. He added that the success of an issue making the political agenda of decision makers often required the perception of political opportunities. These theories and notions are demonstrated in the following section.

The Problem of Dying Badly

The issue of PAS was not new to Hawaii. PAS had hovered on the periphery of public policy in Hawaii for many years. In the aftermath of Quinlan and the prior to the passage of the "living wills" in Hawaii, Representative Howard Oda introduced the first of several PAS bills in the legislature in 1975. The bills languished and were not taken seriously. No hearings were held and few media press releases were announced. (Kirtley, n.d.) (Roland Halpern, private note, July 23, 2008). A few years later, especially after the Vacco and Glucksberg decision, McElrath formed her *Ad Hoc* Committee on Living and Dying with Dignity. It met throughout the Governor's Blue Ribbon Panel's deliberations and would continue to meet after the Governor's Blue Ribbon Panel ended to educate the public and lobby for PAS bills.

Leadership as Catalyst

To gain insight into how the issue of PAS was transformed from a problem that concerned a small group of activists to an agenda setting problem for the Hawaii state legislature, I queried McElrath, the leader of the right to die movement in Hawaii. She replied that because of court cases, bad deaths and healthcare costs, she felt compelled to call the Governor to tell him that it is about time we do something about PAS and that this should be on his agenda.

It is not surprising that the Governor listened. In a classical study of groups and leadership in a community, Floyd Hunter (1953) searched out leaders in the community and rated their power. In his study, he asked people who they thought were community leaders and how they would rank the people they identified. Hunter then asked those identified as leaders to identify and rank others. This resulted in defining a community's "power structure." He defined power as "the act of other men going about the business of moving other men to act in relation to themselves or in relation to organic or inorganic things" (p. 3). Hunter describes an authoritative person as one who either by law or by custom has the legitimate and recognized right to make the decision in question. The individual is reformist in intent and whose goals are the change or maintenance of community-wide institutions or facilities. This definition appears to fit McElrath as demonstrated below.

In discussing PAS with the principals who played key roles in PAS legislation, McElrath's name was foremost. They ranked her above all. McElrath belonged to a group that can be described as "intelligentsia," among whom were A.A. Smyser, editor of the Star Bulletin, the late Oswald Bushnell, local author and historian, and University of Hawaii educators. McElrath had cared for her former husband who had died badly after a prolonged illness and her 96 year old brother who had been subjected to what was perceived as a prolonged and unnecessary medical treatment. Her role as a caregiver, plus her long involvement in social work and advocacy impelled her to form the *Ad Hoc* Committee On Living And Dying With Dignity.

Andi van der Voort, president of the former Hemlock Society in Hawaii and a current Board Director of the Final Exit Chapter in Hawaii, described McElrath's prestige in the community and in both the Democratic and Republican parties. "I would call and make appointments and legislators never kept them; or if they did, they would arrange to be called out have another appointment. I could never get hold of them." Van der Voort further complained that legislators were inaccessible to her. “It is hard to catch them. Even if you have an appointment. They get called away, there’s a meeting or a hearing they have to go to. But not AQ. She would go in there and talk to the legislator and they would listen. She would get to the point.” “She always does her homework.” (Interview, February 10, 2007, at her home.)

Formation of the Governor’s Blue Ribbon Panel

On November 9, 1996 Governor Cayetano Benjamin formed the Governor’s Blue Ribbon Panel. “Society,” he declared, “has a vital interest in protecting life and safeguarding the ability of healthcare providers to cure and care for the ill. On the other hand, it is vitally important to individuals to control every moment of their lives up to the final days” (The Governor’s Blue Ribbon Panel on Living and dying with Dignity: Final Report, 1998, p. 1), (Hereafter, called Blue Ribbon Panel Final Report).

The purpose of the Blue Ribbon Panel was to “…consider the many issues involve in death and dying and to suggest guidelines for our own public policy” (Blue Ribbon Panel Final Report, p. i). It was formed in textbook fashion. Representatives from the fields of medicine, nursing and law, and from churches and temples, foundations, government and the media were called upon to serve on the state’s Blue Ribbon Panel. They were diverse in ethnicity, professions, gender, religion and economic background and resided on various counties in Hawaii (Blue Ribbon Panel Final Report, 1998, p. i).

The Blue Ribbon Panel was comprised of the following individuals listed with their professions and how they voted (* = opposed to PAS).

- *Dr. Naleen N. Andrade, Psychiatrist, Queen’s Medical Center

- Rabbi Stephan Barack, Temple Bet Shalom
- Dr. Max Botticelli, Retired Professor, University of Hawaii, School of Medicine
- Mary Cooke, Community Volunteer
- Jeffrey P. Crabtree, Attorney
- *Reverend Beth Donaldson, Kapaa United Church of Christ
- *Sister Roselani Enomoto, CSJ, Director of the Roman Catholic Church Office for Social Ministry, Maui
- Reverend Yoshiaki Fujitani, Retired Bishop, Honpa Hongwanji Temple
- Dr. Norman Goldstein, Editor, Hawaii Medical Association Journal
- Dr. Lawrence Heintz, Professor of Humanities, University of Hawaii-Hilo
- *Dr. Brian Issell, Director, Cancer Research Center of Hawaii, University of -
- Hideto Kono, Former Director, State Department of Planning and Economic Development, and Former President, Japan-American Institute of Management Sciences (JAIMS)
- *Patricia Lee, MSN, RN, CS, Gerontological Nurse Practitioner
- Dr. Lawrence Miike, Director of the State Department of Health
- *Stephani Monet, Esq., RN, Director of Education and Practice, Hawaii Nurses' Association
- *James Pietsch, Associate Professor of Law and Attorney, Director of the Elder Law Program, University of Hawaii
- A.A. “Bud” Smyser, Contributing Editor and Retired Editorial Page Editor, the Honolulu Star-Bulletin

- Judge Betty Vitousek, Retired Judge, Family Court

*= no.

The Ribbon Panel was an attempt to find common ground and present a united front in creating public policy about end-of-life treatment. The panel's members shared a commonality that consisted of experience with dying people, educational backgrounds, and stature in the community and expertise in their professional fields. The members were hand-picked by McElrath for their expertise in the fields of law, ethics, religion and aging. Although she was the primary link between the Governor and the Blue Ribbon Panel, McElrath declined to be a member and decided she would be more effective by working behind the scenes to organize, advocate and push for its success.

In the best coalition building efforts possible, the Blue Ribbon Panel endeavored to reach common ground in formulating public policy. The eighteen member panel, which included persons from all counties, deliberated a host of issues related to end of life care over an 18-month period. In their report, they wrote, "We began our work by mutually sharing the extensive knowledge and experiences in medical, legal and spiritual fields accrued over the years by the distinguished members whom you appointed to serve on the Panel…." (Blue Ribbon Panel Final Report, p. i). They described their work which led to their conclusion as "listening to, and gathering testimony regarding this issue, both expert and law. As a result we have concluded that many people unnecessarily face lingering, painful and undignified deaths" (Blue Ribbon Panel Final Report, p. i). Further, they sought input from the general public to ensure that the views Hawaii's culturally and ethnically diverse population were taken into account.

The Director of the Executive Office on Aging, a member of the Governor's cabinet, was tasked with holding hearings and educating the public. Nine meetings were held to come up with consensus and to educate and listen to the public. Over 300 people attended. The meetings were considered a successful attempt at creating consensus.

Conclusion of Blue Ribbon Panel

The Panel issued its final report in May 1998. Eleven of the 18 members voted to recommend the legalization of physician-assisted suicide under strict conditions for terminally ill persons or those with an intractable or unbearable illness that cannot be cured or successfully palliated. The remaining seven members concurred with the report in its entirety except for recommendations for PAS and physician assisted death, which was defined by the Blue Ribbon Panel as "the death of an individual that results from the administration of a lethal agent by a physician ((p. 45). Each wrote a dissenting report. The charts on the following page give a picture of how the members of the panel voted. Those in healthcare were divided evenly, three for and three against and one undecided. The members affiliated with religious organizations were also divided, two for and three against. In the Final Report, those who were undecided (a lawyer and a healthcare person who was also a lawyer) were categorized as voting "no."

Among those who opposed, three out of seven were health care professionals. The nurse/ lawyer was undecided. Several felt that although the end-of-life procedures could be improved, the procedures in place were compatible with ethics and morals and adequately met the needs of patients and PAS was not needed. Several members of this group also felt that if PAS were to be legalized, the incentive to improve hospice care and palliative care would be diminished. Lastly, the Hippocratic Oath was invoked to remind physicians about their ethical duty to heal. The conclusions were mixed. No group was overly represented. Although hand picked, AQ was even-handed in suggesting the composition of the panel members, e.g., while two healthcare persons opposed PAS, four did not (one was unsure); two persons with religious affiliations opposed PAS, three favored PAS and one abstained.

Figure 8. Blue Ribbon Panel members who voted in favor of PAS, their profession and residence.

For PAS	Profession	Neighbor Island
Miike	Healthcare	Oahu
Goldstein	Healthcare	Oahu
Boticelli	Healthcare	Oahu
Fujitani	Buddhist minister	Oahu
Barrack	Jewish rabbi	Oahu
Heintz	Christian minister	Hawaii
Smyser	Former news editor	Oahu
Kono	Government, management	Oahu
Cooke	Community volunteer	Oahu
Crabtree	Law	Oahu
Vitousek	Law, judge (retired)	Oahu

Figure 9. Blue Ribbon Panel members who voted against PAS, their profession and residence.

Against PAS	Profession	Neighbor island
Andrade	Healthcare	Oahu
Issell	Healthcare	Oahu
Lee	Healthcare	Oahu
Donaldson	Christian minister	Kauai
Enomoto	Catholic nun	Maui
Oppose/Undecided		
Pietsch	Law	Oahu
Monet	Healthcare and law	Oahu

Figure 10. Those with religious affiliations were divided.

For PAS	Denomination
Fujitani	Buddhist minister
Barrack	Jewish Rabbi
Heintz	Christian minister
Against PAS	**Denomination**
Enomoto	Catholic nun
Abstain	**Denomination**
Donaldson	Christian minister

Although the members who represented the Buddhist, Jewish and Protestant affiliation did not oppose PAS, opposition was strongly voiced by Enamoto, a Catholic nun. She believed that Catholics condemned suicide as morally wrong and detrimental to society and feared that PAS would be abused. She based her arguments on traditional beliefs in the sanctity of life and God's dominion over humans. Donaldson, a Christian minister, feeling more time was needed to decided, abstained from voting.

The attorneys were also divided. Crabtree, an attorney who had been deeply involved in his mother's end-of-life decision, voted for PAS. The other attorneys, Pietsch and Monet, who was also a nurse, felt that the issue had so many varied moral, ethical and philosophical pieces that more time was needed before a decision could be made. They had wanted the Blue Ribbon Panel to continue with the dialogue to find a solution within the law to allow PAS. The law as discussed in Chapter 2 was ambiguous and allowed physicians to administer what was necessary to alleviate suffering.

Although the groups whose members had disabilities, such as Not Dead Yet, had not joined the doctors nor had a place on the Blue Ribbon Panel, they attended hearings and meetings. They raised issues the about limited access to healthcare for the poor, the risk of impoverishment because of the high cost of medicine and healthcare, the fear that pressure to save family assets would lead to a duty to die and the fear that PAS would limit medical access and diminish insurance payments to the disabled. Some felt marginalized by statements about how the quality of life is diminished by disabilities, "the indignity of wearing diapers," or "the indignity of being fed, cleaned and wheeled round." Although they were loosely organized at that time, they would increasingly gain strength and, eventually, join with the physicians to protest PAS.

Final Report: Two Recommendations

In May 1998, the Blue Ribbon Panel issued its final report. The chair recognized the division of beliefs and opinions and concluded that, "The difference is a moral question to some, a matter of choice to others. We respectfully present the positions of both sides in this report" (Blue Ribbon Panel Final Report, p. i). The panel by a majority of eleven members concurring and seven dissenting agreed to recommend legalizing PAS to the legislature. While seven members disagreed, all, however, were in favor of presenting the following six recommendations to the legislature.

The six key points on which all agreed are the following:

- Spiritual counseling should be more available to individuals afflicted with life threatening illnesses and should be integrated into the healthcare system.
- Public and health care professional education should be designed and carried out to increase awareness of the choices available to the dying.
- Advance directives should be more specific and their use more widespread and provisions more binding.
- Hospice care should be made more available and offered more expediently to the dying.
- Pain management programs should be required in all health care institutions.

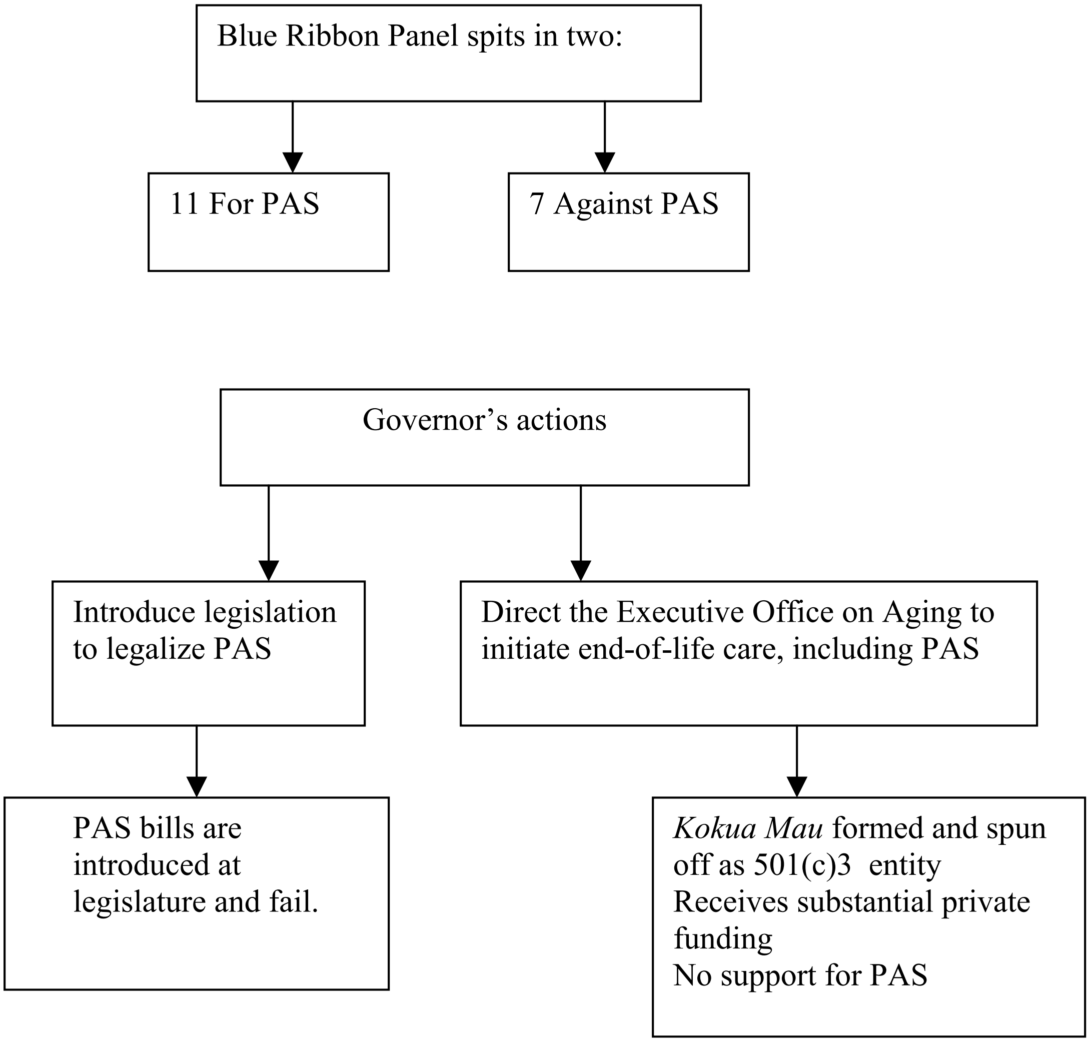
- Involuntary euthanasia should continue to be a crime. (Blue Ribbon Panel Final Report 1998, p. 4 & 5).

Analysis of Blue Ribbon Panel

The majority of the panel who voted for PAS had won an unsustainable victory. Although they were successful in endorsing the recommendation that the Hawaii Revised Statutes be amended to legalize physician-assisted suicide and physician-assisted death, the panel as a whole was no longer united in purpose but, as concluded by its chair, “divided by morals and choice” (Blue Ribbon Panel Final Report, 1998, p.v.).

The groups had polarized into two opposing factions: the PAS advocates arguing for choice, personal rights, dignity in death and its opponents upholding the sanctity of life and the duty of the physician to prolong life and heal. These arguments would surface again and again as the PAS issue was fought.

Figure 11. Outcomes of the Blue Ribbon Panel.



What had started as a textbook attempt at consensus building had unintentionally broken down into two opposing factions that reached consensus by recommending both PAS and end-of-life care. These two recommendations seemed to satisfy everyone and brought to a close the work of the Blue Ribbon Panel. When the panel scattered, little did they realize that their recommendations would have indirect and unintended consequences that would heightened the tension between the advocates of PAS and the advocates of end-of-life care and set the stage for a clash of ideologies and values.

Kokua Mau

When the Blue Ribbon Panel finished its work in May 1998, the governor's office began the task of carrying out its two sets of recommendations. A bill was prepared with the support of the Governor's Office to legalize PAS, and at the same time, the Director of the Executive Office on Aging, a member of his cabinet, was directed to work on better end-of-life care. The Executive Office on Aging, created *Kokua Mau* which later was spun off as a non-profit 501(c)3 entity that received both state and private funding.

To get *Kokua Mau* off the ground, the Executive Office on Aging coordinated the *Kokua Mau* project for three years from 1999 to 2002 under a grant from the Robert Wood Johnson Foundation (RWJ) to assist in coordination, policy analysis, and research about end-of-life care.

As a requirement of the $450,000 grant, the Executive Office on Aging was prohibited from promoting PAS as an end-of-life option. Thus, *Kokua Mau* excluded any mention of PAS in their brochures, website, and other forms of communications (Private conversations with Begley, Pietsch). Other private foundations provided funding and their ideologies for prolonging life through hospice and palliative care were also advanced. Some of these private foundations were organizations such as Archstone, a non-profit with links to the former FHP corporation that provided long term care insurance, RWJ, the non-profit family foundation of Johnson and Johnson, HMSA Foundation, (Hawaii Medical Service Association), St. Francis Health Care, and the Soros Foundation that funds hospice and palliative care. In partnership with these organizations, *Kokua Mau's* mission became one of hospice, end-of-life care, palliative care, and early advance care planning through advance directives.

Kokua Mau won two awards, The 2004 "National Coalition of the Year" Community Coalition Award of Excellence, Statewide Coalition, given by Rallying Points, a Robert Wood Johnson Foundation end-of-life care initiative and the 2002 Innovations in American Government Award, from Harvard University Kennedy School. *Kokua Mau* reported that hospice admissions increased 20% from 1999 to 2001, referrals at the state's largest hospice increased 48% during 2002 and the requests for PAS had decreased (Braun, K.L., Zir, A., Crocker, J., Seely, M.R, 2005).

The study also reported that in the first 3 years of the project: coalition membership grew to 350 members; end-of-life care curricula were developed and offered to various target audiences; 17,000 individuals attended educational events; policy changes were facilitated; decreases were seen in the number of residents supporting physician-assisted suicide; and increases were seen in advance directive completion rates and hospice utilization. Most importantly, after the grant period, coalition members went on to develop and implement new programs to improve care to the dying.

Later, *Kokua Mau* created partnerships with the University of Hawaii School Of Public Health, the St. Francis Healthcare Systems of Hawaii and the Hawaiian Islands Hospice Organizations. As other organizations joined in, *Kokua Mau*, eventually grew to 300 members made up of public agencies, health care providers, and community groups but without PAS advocates and right to die organizations.

The original intent of the Blue Ribbon Panel from which it was created, receded as more organizations partnered with *Kokua Mau*. Its work with private foundations and with organizations that opposed PAS created a countermovement of prolonging end of life rather than hastening end of life. Currently, the PAS movement has come to be seen as aberrant in the midst of the 300 organizations that support "natural" end-of-life care. (Interview with, Rachel Wong, its Executive Director, on July 3, 2008). The mission of the coalition would be to do the following:

- Increase public & professional awareness,
- Increase access to spiritual/cultural resources,
- Improve pain management efforts,
- Increase hospice utilization,
- Increase completion and use of advance directives.

Figure 12. A partial list of organizations that funded *Kokua Mau.*

Evidence of moneyed interest in *Kokua Mau*	1999-2008 Amount	Business
RWJ	$450,000	Pharmaceuticals
Archstone (formerly FHP Foundation)	$200,000	HMO provider Medicare contractor
HMSA	$25,000	Health care insurance
Soros Foundation		
Atherton Foundation	$5,000	
McInerney Foundation, G.N. Wilcox S.W. Wilcox, Freer Eleemosynary Trust	Combined contribution of $105,000	
UH Center on Aging	$ 710,697	Education on palliative care, hospice education

Kōkua Mau's mission statement, "To ensure that Hawaii's people may die in the place of their choice, free of pain and suffering, and treated according to their beliefs and values," was uncontroversial and appealed to many but took the wind out of the sails of the PAS movement. Although silence about PAS as an end-of-life option ensured more political opportunities for *Kokua Mau,* it increased the tension between *Kokua Mau* and the right to die advocates. It was criticized for not participating in hearings or giving support to PAS for fear of losing its grant from RWJ.

However, the tension that had arisen over the different end-of-life philosophies provided a foil for the right to die advocates who saw themselves as the main drivers of better care in Hawaii. They claimed that without the tension between the groups, hospice and palliative care in Hawaii would not have advanced as quickly nor would have been as widespread. In a private conversation, advocates viewed *Kokua Mau* as "red herring" whose purpose was to detract from the purpose and need for PAS. They argued that hospice and palliative care did not always work and for those who became so immune to pain medication, there was no relief from suffering.

Politics of PAS: Failed Legislation

While *Kokua Mau* was being launched, the *Ad Hoc* Committee on Living and Dying with Dignity, headed by McElrath, continued to meet and plan its own educational campaign. To keep the issue alive and before the public, Smyser continued to write editorials, McElrath appeared in videos and talk shows and continued to lobby the legislature and the governor. Dr. Norman Goldstein, a former member of the Blue Ribbon Panel wrote articles for the *Hawaii Medical Journal* in support of PAS. However, the momentum had slowed at the termination of the Blue Ribbon Panel and the launching of *Kokua Mau.*

Once the issue of PAS left the Blue Ribbon Panel and was introduced as a piece of proposed legislation, it was no longer about consensus and finding common ground. As a bill, it had the effect of separating and defining the positions of the different factions. The ground rules had changed, the cast of characters had changed, and the issues were framed in a different light. Now what mattered were political opportunities, getting re-elected, carrying out the perceived will of constituents and recognizing and managing the risks of supporting a controversial bill.

When the advocates began their quest at the legislature, they were optimistic because the Blue Ribbon Panel had recommended legalization of PAS, Hawaii's ethos was still considered progressive and liberal, and just the year before in 1999, legislators had expanded and revised provisions in the "living will" that would allow a more comprehensive approach to end-of-life care by including the "living will," the durable power of attorney for health care, a "family consent" or surrogate law, and some provisions concerning organ donation together in one statute. The law was purposely written "as an open end option" to accommodate PAS if and when it passed. In fact, the law was left unchanged in the expectation that PAS would pass. (See Uniform Health Care Decisions Act (Modified) ("UHCDA") in Hawaii Revised Statutes Chapter 327E.)

However, when the PAS bill was introduced by House Majority Speaker Calvin Say (Democrat, Palolo) in 1999 and again in 2000, it did not pass. Legislators who did not see political opportunities in supporting a controversial issue stayed away from it. Further, the bill seemed flawed as it did not provide strict protections and was criticized for engendering a "slippery slope" that targeted the elderly and disabled.

A.A. Smyser, in an editorial to the Honolulu Star Bulletin, on April 14, 1999, explains why safeguards were not put into the bill and expresses his disappointment at the bill's failure to pass:

> …The Legislature would leave these rules to the Department of Health to adopt subject to approval by the governor. This would transfer the long haggles over details from the limited 60-day legislative session to a forum able to operate without time limits.

> Our 1999 Legislature, perhaps bloodied by the 1997-98 fights over same-sex marriage, had no wish to even look at the details of the assisted-death law proposed by Governor Cayetano's Blue Ribbon Panel on Living and Dying With Dignity, on which I served. Neither the Senate nor the House invited testimony from the chairman of the panel!
>
> Committees in each house ran through the charade of listening for a few hours to anyone who wanted to speak, then shelved the bills at least until next year. Only a single senator listened most of the time.

What Smyser failed to mention was the huge showing of the strong and vocal religious and medical groups. When the bill was heard, the PAS advocates were overwhelmed by a sea of physicians in white coats and clergy in Roman collars. The PAS advocates were a small group made up of McElrath's *Ad Hoc* Committee on Death and Dying and supporters from liberal organizations such as the ACLU, Unitarian Church, and Hemlock. PAS advocates claimed they had about 2,500 members but were not able to rally their supporters to speak for the bill. During hearings, they filled up half a row of seats and could not compete against the organized and vocal opponents.

First Tactical mistake: No Safeguards

While the low turn out of PAS supporters may have influenced the outcome of the bill, not having specified safeguards in the bill became a costly tactical error as it gave the perception that the bill was flawed rather than flexible.

Smyser had explained that the bill did not contain protections in order to keep it flexible so that the details would be hammered out by the legislature and Department of

Health. By wanting to keep the bill flexible, the Blue Ribbon Panel advocates left themselves open to criticism from elderly and disability groups. There were accusations of engendering a slippery slope, fostering feeling of a duty to die among the elderly and comparing PAS to Nazi tactics. Proposed bills also failed in 2000 and were pulled in 2001. These flaws would not be mended until 2002 when it was modeled after Oregon's Death with Dignity Act that detailed and defined the purpose, processes and protections under PAS.

A Second Tactical mistake: No Coalition with Physicians

Another tactical mistake was made when the PAS advocates underestimated the resistance of the physicians and the need to have their support, or at least their neutrality. The seemed to be lulled by three events: the history of decriminalizing abortion in Hawaii in 1976, the non-opposition by doctors in Oregon and polls that showed physicians in Hawaii favored PAS.

The importance of having the physicians' approval, or at best neutrality, was critical as demonstrated by Oregon's experience. There the physicians had agreed to not testify for or against the bill and to leave it up to the voters. Support from the physicians was crucial to the success of PAS because they were directly involved as gatekeepers to pain relief, medications, end of life care and, if legalized, as gatekeepers to PAS. Although the patient must self administer the lethal medication, a doctor was involved in prescribing the lethal dose. Doctors also were involved in assessing the medical states of their patients and determining that the patient was terminally ill and of sound mind. As the bills underwent change to provide more protections, the doctors' role grew more involved. Under the Oregon law and the proposed Hawaii law, the patient seeking PAS must undergo a mental evaluation twice, the second time, 15 days after the first assessment. The patient must also be offered counseling to determine if he/she was suffering from emotional despair. Only after lengthy involvement by a doctor, can the patient be prescribed the lethal medication.

The PAS bill was written to place a huge responsibility in the patient's attending physician, the gatekeeper to PAS. That physicians were crucial in legislative hearings is well demonstrated in the passage of the abortion bill in Hawaii in 1976. The PAS advocates reasoned that since doctors favored the abortion bill, they would also be amenable to PAS. But, they failed to duplicate the efforts that were made to reach a consensus from the doctors regarding the abortion bill. The omission to involve the physicians who would be affected by PAS legislation contrasted with the great effort that went into building consensus among the medical community in the abortion decriminalization bill.

The strategy to achieve consensus to decriminalize abortion was long in building, carefully nurtured, and media supported. For example, the AMA favored reform and doctors and the legislators had collaborated in framing the abortion bill. The ABA had already drafted a model reform bill which was used as a model in drafting the Hawaii version. Further, doctors also were performing abortions "underground". Others openly referred patients to known doctors in Japan where abortions were legal.

Having doctors on their side produced positive and convincing testimony for the supporters of the abortion bill. The legislators' own evaluation of what influenced their decision also clearly points up the importance of physicians' support of repeal. Legislators reported that the testimony of physicians at the hearing was most influential to their decisions "... because it demonstrated that reputable physicians would perform abortions and that their colleagues would support them.…" "Without such evidence of how abortion would actually be made available to the public if the law were changed, it is doubtful that the repeal bill would ever have come out of committee" (Steinhoff and Diamond, 1977, p. 70).

In Oregon, advocates sought support from physicians and a "neutrality" was negotiated. Debate was held at an AMA meeting where the head of the Oregon Medical Association had favored the bill while the body of the AMA did not. An agreement was formed with the AMA to not oppose the bill. The rationale was that since the doctors themselves could not agree what choice to make, they decided to let the people make their own choice (Hillyard &Dombrink, 1999) .

Without an agreement to remain neutral, testimony from Hawaii's physicians was damaging. Dr. Brian Issell, a member of Cayetano's Blue Ribbon Panel disagreed with the committee's majority's support for legalizing doctor-assisted death and testified, "A physician does not need to prescribe or otherwise administer a treatment with the primary intention of killing his or her patient and should not be permitted to do so. The present incompetence of our health delivery system in respect to end of life care should not be corrected by legalized killing" (Blue Ribbon Panel Report, 1998, p. 37).

The HMA president also did not back PAS. Inam Rahman, M.D., a Kaneohe resident and president of the Hawaii Medical Association in 2002, declared that Hawaii's doctors oppose physician-assisted suicide. The Honolulu Advertiser reported that at the hearing on February 6, 2005, Dr.Rahman gave the following testimony:

> …I believe I can make that statement as president of the Hawaii Medical Association. While roughly 50 percent of all doctors in Hawai'i are members of HMA, I believe I speak for most because the mainstream medical community is united and of one voice on this issue…

PAS advocates such as McElrath in a private conversation rebutted these statements with the observation that "only 30% of all doctors belong to HMA." Since only one third of doctors belonged to HMA, They were optimistic that the other two thirds could be convinced to favor PAS. Furthermore, Dr. Norman Goldstein, a Blue Ribbon Panel member and editor of the *Hawaii Medical Journal,* in defense of PAS, devoted an issue of the journal to articles written by physicians favoring PAS.

Even a poll conducted in 1999 by S.Y. Tan, M.D., a professor of medicine at the John A. Burns School of Medicine, University of Hawaii, a strong opponent of PAS showed that 25% of the doctors would be in favor of some form of euthanasia. In 1996 he polled 3017 doctors and medical trainings in Hawaii to determine their attitudes towards physician-assisted suicide, euthanasia and other end-of-life medical issues. With 34% responding, 15.6% willing to assist a terminally ill patient to commit suicide, 9.8% would perform active euthanasia, 97% favored withholding life support, 78.6% favored withdrawing life support, 88% were willing to administer high does of narcotics for pain relief even if such therapy hastened death (Siaw, L.K., Tan, S.Y., 1996).

Third Tactical Error: Timing and Disability Groups

A third error involved timing. Kimura says that “Do not underestimate the importance of timing. Strengths and weaknesses often vary over time so you must strike when your opponent is vulnerable and be prepared for attack from your opponent when your campaign is vulnerable” (p. 21).

For PAS, perhaps the time to have wooed the physicians or obtained a tacit agreement not to oppose the bill, like Oregon had done, might have been before or during the Blue Ribbon Panel discussions. It would be too late by the time the bill was introduced. By then, the group whose members had disabilities had joined with the doctors in opposing the bill. By attaching themselves to the doctors, they strengthened their position as well as the doctors’ position.

The groups whose members had disabilities had badgered the panel at the meetings and at hearings but were not yet organized nor had a place on the panel. Nationally, the disability activists were formed in 1996 under, Not Dead Yet. According to its founder, Diane Coleman, the group takes its name from the “Bring out your dead,” scene in *Monty Python and the Holy Grail*.

Although they would oppose PAS in subsequent legislative hearings, they were not yet a force in 1996-2000. Heidi Singh, HMA director of legislative and governmental affairs, acknowledged that her organization, which represents physicians, was linked to the disability group. She remarked that although they were not traditionally aligned with the disability group, which generally had liberal leanings in contrast to the more conservative leanings of the doctors. Both the physicians and the disability groups realized that they have shared interests and issues. While physicians were in favor of prolonging life, disability groups argued for equal access to health care and health insurance and expressed fear that they would be encouraged to use PAS as a means of saving money. When this group joined forces with the physicians, it strengthened their position.

Using the PRINCE Analysis

At this juncture, one can speculate if the healthcare providers, especially the doctors, could have been won over to support PAS, or at least, could have agreed not to oppose PAS. When the author queried a former member of the Blue Ribbon Panel about the possibility of neutralizing or winning over the healthcare providers, the former member felt there was a good possibility that could have happened if they were wooed and enough time had been given to forging the relationship. McElrath also felt that the majority of the doctors supported PAS even if the leadership under Hawaii Medical Association (HMA) did not. As pointed out earlier, the poll conducted in 1996 by L.K. Siaw and S.Y. Tan indicated that 25% of the doctors polled favored some form of active euthanasia, and between 78.6% to 97% of the doctors polled favored some form of passive euthanasia.

Another indication that the healthcare providers could have been persuaded to support PAS is the example of Dr. Brian Issell. During the discussions of the Blue Ribbon Panel in 1998, Issell, a highly respected oncologist, had indicated that if improved palliative care were better promoted, he might have been persuaded to back the PAS proposal. It can be speculated that if Issell had supported PAS, other healthcare providers on the Blue Ribbon Panel might have followed suit and a consensus might have been reached among the physicians.

Coplin and O'Leary designed a model that might help analyze Issell's issue position with respect to supporting PAS. Although it is a highly simplified model of political activity that leaves out many important elements,[17] it is a tool that can be used to analyze or confirm the probability of how the actors or decision makers will behave on the issue. The model uses a ranking system that rates and combines elements of the actor's position on the issue, the salience of the issue to the actor, and the actor's power in convincing others to adopt his or her position. After generating and comparing data, an expected outcome may indicate the actor's likeliness to support or oppose the issue. Various strategies can then be formulated to meet the actor's needs and increase the chances of support for PAS. Or, on this particular issue and in this instance, the expected outcome may explain why Issell continued to publicly oppose PAS.

To begin the analysis, information was gathered from members of the Blue Ribbon Panel and the news media that reported on the public positions the doctors and other healthcare providers (or "actors") took relative to PAS. This information was used to rank the issue positions of the doctors and other healthcare providers, from -5 (strong opposition) to +5 (strong support), their potential power to influence legislation from +1 (little influence or power) to +5 (great influence or power), and salience of the issue from +1 (little importance) to +5 (great importance), Two terms used in this model are "output

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[17] Coplin and O'Leary (1976) describe in greater detail several other models based on interest group theory in *Everyman's Prince: a Guide to Understanding Your Political Problems; Rev. Ed.*

actor," the authoritative decision maker, and "reference actor(s)," an actor(s) who can influence the output actor and other doctors and healthcare providers.

In this particular example, attention is focused on Dr. Brian Issell, who is designated as the output actor. At that time he was a practicing oncologist and a nationally recognized clinical researcher and head of the University of Hawaii Cancer Research Center. Although he opposed PAS, during the meetings of the Blue Ribbon Panel, he had indicated to the members that if better palliative care were available and supported, he might back PAS.

The reference actors for the purpose of this analysis are the other doctors and healthcare providers on the Blue Ribbon Panel. In addition to Issell, the other doctors were Dr. Max Botticelli, a physician teacher at the John A. Burns School of Medicine at the University of Hawaii, Dr. Norman Goldstein, a practicing dermatologist and editor of the *Hawaii Medical Journal,* Dr. Naleen Andrade, Professor and Chair of the Department of Psychiatry at the John Burns School of Medicine at the University of Hawaii and Dr. Lawrence Miike, Director of the Department of Health. Botticelli, Goldstein and Miike favored PAS and Andrade, along with Issell opposed it. None of the doctors, except Issell, was perceived as having expertise in pain management or providing direct care to dying patients. Even though Botticelli and Goldstein were well known in the community and publicly supported PAS, neither appeared to be able to give the assurance that palliative care would be supported and improved. Goldstein was editor of *The Hawaii Medical Journal* and Botticelli was a member of McElrath's *Ad Hoc* Committee and well known in local circles for his advocacy for healthcare. Dr. Lawrence Miike, as the

Director of the Department of Health, might have had a bargaining chip as Cayetano's appointee but could not offer the assurance of better palliative care. *Kokua Mau*, the state's hospice and end-of-life care agency was not yet established. When established, it operated independently as a non-profit entity. Andrade, a psychologist was absent on many occasions. She opposed PAS but was not publicly vocal about her stance. Patricia Lee was a gerontological nurse practitioner and a social worker and feared the possible slippery slope. Monet, a nurse and lawyer, was Director of Education and Practice for the Hawaii Nurses' Association and was equivocal about PAS.

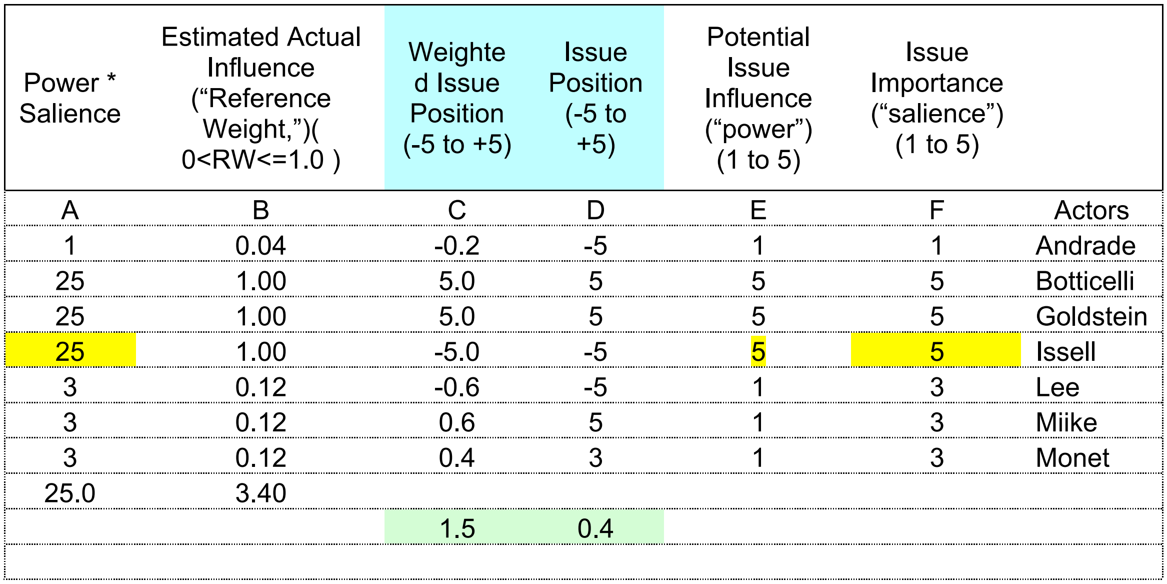
The expected outcome of the Coplin and O'Leary's model is two fold: 1) to obtain a value that would indicate Issell's support or non-support of the issue, and 2) to assess whether Issell can be moved from his negative position by the Botticelli and Goldstein. It is assumed that Issell will adopt an issue position that is a weighted average of the issue positions of all doctors, as it is defined by the data supplied. It may be conjectured that the closer his weighted average position is to the weighted average position of the group, the greater the likelihood he could be moved from his position to the group's position. And the farther away his weighted average position was from the group's, the more difficult it would be to persuade him to move to the group's position.

To generate the expected outcome requires two calculations: the first calculation of the expected outcome will include data from all the doctors and healthcare providers. The second calculation will be independent of Issell's data. These two expected outcomes can be compared and used to confirm his position.

The following charts show the calculations.

Figure 12. Coplin and O’Leary’s PRINCE model applied to the Blue Ribbon Panel.

The shaded values above show the expected outcome (“weighted issue position”) of 1.5 and the unweighted average position of 0.4.



Power * Salience	Estimated Actual Influence (“Reference Weight,”)(0<RW<=1.0)	Weighted Issue Position (-5 to +5)	Issue Position (-5 to +5)	Potential Issue Influence (“power”) (1 to 5)	Issue Importance (“salience”) (1 to 5)	
A	B	C	D	E	F	Actors
1	0.04	-0.2	-5	1	1	Andrade
25	1.00	5.0	5	5	5	Botticelli
25	1.00	5.0	5	5	5	Goldstein
25	1.00	-5.0	-5	5	5	Issell
3	0.12	-0.6	-5	1	3	Lee
3	0.12	0.6	5	1	3	Miike
3	0.12	0.4	3	1	3	Monet
25.0	3.40					
		1.5	0.4			

Figure 13. Coplin and O'Leary's PRINCE model applied to the Blue Ribbon Panel without Issell.

Power * Salience	Estimated Actual Influence ("Reference Weight,")(0<RW<=1.0)	Weighted Issue Position (-5 to +5)	Issue Position (-5 to +5)	Potential Issue Influence ("power") (1 to 5)	Issue Importance ("salience") (1 to 5)	
A	B	C	D	E	F	Actors
1	0.04	-0.2	-5	1	1	Andrade
25	1.00	5.0	5	5	5	Botticelli
25	1.00	5.0	5	5	5	Goldstein
3	0.12	-0.6	-5	1	3	Lee
3	0.12	0.6	5	1	3	Miike
3	0.12	0.4	3	1	3	Monet
25.0	2.40					
		4.2	1.3			

The shaded values above show the expected outcome ("weighted issue position") of 4.2, and the unweighted average position of 1.3.

The calculations were made as follows:

<u>Column A</u> is the multiple of power and salience (the more salient an issue, the more influence is likely to be fully used).

<u>Column B</u> is the Reference Weight – Column A "normalized," i.e., divided by the maximum power x salience score

<u>Column C</u> is the Weighted Issue Position of each actor, i.e., the original issue position multiplied by the reference weight. The weighted average of all the weighted issue positions is shown at the bottom of the column. It is the sum of the weighted issue positions of the actors, divided by the sum of the

reference weights to preserve the range of the issue position scale so the outcome position could theoretically vary between -5 and +5. This weighted average at the bottom of the column is the expected outcome taking into account all three factors (issue position, relative power to influence the outcome and relative salience of the issue

Column D is the initial issue position of the actor ranked from -5 to +5. The Mean issue position without weighting is the average of the issue positions of the actors, shown at the bottom of the column.

Column E is the potential issue influence or "Power" ranked from +1 to +5.

Column F is the issue importance of the issue to the actor's "Salience" ranked from +1 to +5.

Column G identifies the actors.

Conclusions

The result of the group's position *independent from Issell's position* is a weighted issue position supporting PAS of 4.2. Issell's position (-5) is clearly far from the average and weighted position. It would appear that Issell's position is too far to be moved. Goldstein and Botticelli will have a difficult time convincing his to change his position.

An astute political observer (private communication, June 14, 2009) made the following observation:

> (A person like) Issell is clearly the odd man out because he is so opposed and simultaneously so influential. So not only is it harder for Issell to move ideologically, but also not neither necessary nor desirable politically. First, two of

his opponents are weak and relatively uncaring, hence can be dismissed. Second, his two strong opponents would carry the day (recall 4.2 above) if he weakened his position or withdrew from the conflict. Very little wiggle room. It pays (for him) to stand tall just to neutralize the overall influence (recall the weighted average of 1.5 with him vs. 4.2 without him).

Aftermath

In the matter of PAS, the goal was to achieve consensus which needed time to find compromises and negotiate differences. If the panel had continued to meet, there was a strong possibility that coalitions and agreements might have been possible. Pietsch wanted to have assurances of greater protections and resources for vulnerable populations, such as the elderly. He tried to find a way under the law that allowed PAS by implication and broad interpretation without changing the law. As reported in Chapter 2, Hawaii’s law was ambiguous and could have allowed PAS as a lawful method of treatment. Pietsch sought this solution in the law which would have avoided the split in the groups. As with Pietsch, Monet’s legal training may have also found reconciliation in the law. Legalizing PAS had already been floated at the legislature in anticipation that PAS would pass. If PAS advocated wanted to win, this would have been the time. However, Pietsch was not able to convince members to return to the table after they left in the summer of 1998.

Issell was not convinced to support PAS nor to be neutral on the issue. He later publicly testified against PAS and advocated strongly for better end-of-life care through improved hospice and palliative care. Advocates, unable to convince the doctors or other healthcare providers to support PAS, unsuccessfully introduced bills to allow an alternate doctor to replace the attending doctor if latter declines to prescribe and proposed having a monitor present who did not need to be a licensed physician at time of taking the lethal dose. In addition, the attempt to establish a process in the Department of Health to regulate PAS and to add a third option in the advance directive to allow PAS were unsuccessful.

When the group disbanded, each member went his or her own way and did not want to reconvene. Pietsch's strategy was moot. McElrath regrouped her committee as policy advisors. The efforts to mobilize the grassroots included Smyser's editorials at the Star Bulletin, Goldstein's included favorable articles in *The Hawaii Medical Journal* and other advocates who appeared in talk shows, *Olelo* and Public Television.

During the initial attempts at passing PAS legislation, the opposition united under Hawaii Family Forum, which, after supporting and defeating the same sex marriage issue, was in place to oppose PAS. They were joined by healthcare groups, the local branch of the American Medical Association, and other conservative groups. The members of the group with disabilities gained prominence and strength. In response to the attempt to pass PAS legislation, the opponents mobilized their forces, spent $40,000 on ads, which at that time was a large sum, built a website, and exhorted their grassroots to lobby their legislators. The bills failed to make it out of committee and the PAS bill in 2000 was pulled by the governor for non-support.

Professional verses Amateur

In the intervening years between the time the Blue Ribbon Panel ended, and 2002, PAS legislation was introduced at the legislature in 1999, 2000 and 2001 only to meet failure. New coalitions had been formed: physicians and disability groups, Catholics and Mormons. Moreover, a silent *Kokua Mau* funded by grants from corporate interests and pharmaceuticals became the state's hospice and palliative care agency. The Cayetano administration was in its waning days and the windows of opportunity were closing,

Serendipity

The nascent movement for PAS may have ended there but for serendipity. Serendipity is luck. Sally Merry in her book, *Colonizing Hawaii*, uses this phrase to describe a chain of events that led to the discovery of the Hawaiian Islands by Captain Cook. A chain of events happened that revived the PAS bill, put it in the hands of professional politicians and back onto the legislative agenda. Juliette Begley, opposition researcher and Scott Foster, political strategist, both had worked on Governor Cayetano's campaign to get him re-elected were instrumental in doing this.

Begley, the governor's assistant for opposition research tells her story: "I was looking through a pile of rejects and this bill caught my eye. See, I was a nurse and I've seen a lot of suffering and deaths. I know what it means to suffer. So I told the governor with some help, we can revive this bill. And he told me to go with it. He wouldn't actively participate but it was mine to do. Hawaii was in a financial pinch and this bill didn't cost anything."

Another link in the chain of serendipitous events that connected the governor to the bill was governor's father who had Alzheimer's disease. His father would wander off and get lost and the governor would be on television looking for him. As a result, he understood better than most the set of issues facing people in the last chapter of life.

Amateur Politics

Up to now, the bill was in the hands of amateurs. An amateur, according to James Wilson is defined as "… one who finds politics intrinsically interesting because it expresses a conception of the public interest. The amateur politician sees the political world more in terms of ideas and principles than in terms of persons" (1966, p.3). In contrast, the professional is one or two levels removed from the emotions of the bill, are self seeking and realize their private aims and maximize their self interest. Yet in many instances, they become amateurs in their commitment to the issue. They stay on after the issue giving leadership and expertise on the issue.

The word "amateur" is used in similar contexts. Dennis Johnson, (2001) uses it to mean one motivated by issues of public policy and who receives little or no compensation for his/her efforts. Both Wilson and Johnson agree that the term, amateurs, is not disparaging as they can be "dedicated, intelligent, hard working, volunteers who know the dynamics of state or local politics and who can develop an effective campaign message and implement a winning strategy. But their campaigns can be understaffed, unable to rely on volunteers, unable to run an efficient, and strategically smart race and are simply out-gunned when facing an opponent's professionally driven campaign" (p. xv). Thus, both believe that in today's complex, modern elections, professional talent is necessary to fundraise, organize volunteers, shape the message, get out the vote, lobby, compete and win.

When Begley got the approval of the Governor to shepherd the bill, the dynamics changed. She said it was not about the issue as much as about winning. She began by using the power of the Governor's Office to gain access to the media, legislators, and bureaucracy. Begley describes, "You can't imagine the power of the governor. It meant access, it opened doors. I was able to call on Mid-Week magazine and get the front cover. I called up the LA Times and they gave us coverage."

Governor Benjamin Cayetano is described by George Will, a national columnist, as "an American Caesar" because of his power to appoint. "Cayetano, was the most powerful governor in the nation because of the structure of Hawaii's centralized government that keeps most functions and financial revenue streams under the state government, which in other states are directed to county or city jurisdiction. He appoints positions that typically in other states are elected, such as state judges, the state attorney general, his administrators and deputies, and appointees to commissions and boards such as the University of Hawaii Regents. His emergency powers were considerable, with additional powers granted to him by the Democrat-controlled Legislature after the September 11, 2001, terrorist attack" (Zimmerman, Malia, 2002).

Others came on board. Scott Foster, who had worked on the governor's campaign came on board and later, in 2004, assumed the role of Director of Communications for the Hawaii Death with Dignity Society. Working on the belief that "Public Sentiment is

Everything" (a logo on his website), he developed strategy, communication, marketing and spin for all subsequent campaigns.

The message for PAS was simplified and was broken down into 4 parts:

- Compassion,
- Individual choice, not for everyone,
- Terminally ill, six months or less to live
- Adult, competent.

Foster, student of Kimura, who was by profession, a publicist, worked on communications and took a cue from him: (Kimura, p. 20).

- Assure secrecy. In every campaign, the details of your game plan should remain private revealed only to a few trusted campaign workers.
- The reason for secrecy is to keep vital information from reaching your opposition. This will help your strategic moves retain the element of surprise and keep your opponent off-balance. …Your opponent need not be completely unaware of your overall strategy; it is only necessary to conceal your game plan details long enough to deter your opponent from reacting effectively. Secrecy reduces the probability that your opponent's activity can be directed at the vital points in your strategy.

Their strategy was to keep a low profile in order not to let their opponents know the extent of their involvement. Without fanfare, the group called upon Hemlock for help and the Death with Dignity Society in Oregon. Van der Vort, president of Hemlock called the national group, which donated $80,000. She also provided the data base for

Hemlock's members and supporters. Foster was able to do mail outs and grassroots campaigning to ferret out supporters. Oregon's Death with Dignity sent Eli Stutsman, an attorney, who was instrumental in legalizing Oregon's Death with Dignity Act. He provided valuable advice, honed the bill and incorporated missing safeguards to make the bill viable. Roland Halpern from Compassion and Choice (formerly Hemlock) worked on public relations. He effectively worked the grass roots, appeared in ads, gave interviews, and lobbied the legislators.

A professional lobbyist, Robert Toyofuku, was later hired to work inside the legislature. This strategy was necessary as the bill was bi-partisan, formulated top-down and depended on individual votes in the legislature. Once the bill crossed over from the House to the Senate, momentum was built and the Hawaii Family Forum was taken by surprise.

The team's strategy at the legislature was to present a non-partisan bill that had no budget requirements but stressed compassion and choice. Personal stories would be presented to convince legislators of the need for such a bill. Begley described her lobbying efforts. She visited each legislator, talked about the future of Hawaii's healthcare crisis, the scarcity of hospital beds, the high cost of medicine, the role of caregivers, the need for discussion *now*, not later, about the end-of-life and that PAS should be an option. As a result, the bill was approved by the House 20-10 and had crossed over. Toyofuku was then hired to work the legislature.

The bill went to Senate Health Committee chaired by David Matsuura who had the support of the fundamentalist Christian group. He tried to keep the bill bottled in committee and did not report the bill out until governor and the public put pressure on him. He is reported to have said, “Absolutely, I will not hear assisted suicide. This dumb bill wasn’t even on our radar screen. I haven’t even looked at the measure or studied this measure yet. I can’t figure out what assisted suicide is.” (Kirtley, 2003). Matsuura later apologized for these remarks. Governor Cayetano hoped that Matsuura, an evangelical Christian, would rise above his personal beliefs and pressure from interest groups opposing the measure and schedule a hearing.

Timing would prove crucial. Begley said all votes were counted and it was her job to know where the votes would fall. Strategies and contingencies were negotiated. She convinced Filipino legislators to vote as a group if the bill crossed over. It helped that the Governor was Filipino. All seemed accounted for except a legislative rule that required a bill rest for two days before it was voted on. During that time Archbishop Francis Xavier DiLorenzo of Honolulu Catholic Diocese visited each legislator to remind him/her of the Church’s opposition to PAS. (Letter in appendix.) And three legislators, Democrats Rod Tam and Donna Mercado Kim and Republican Bob Hogue, changed their minds. Kirtley (2003) describes the 2002 legislative action:

> The final debate on the Hawaii Death With Dignity bill (HB 2487) took place during the third reading of the bill on Thursday, 2 May 2002, the afternoon of the final day of the session. Senator Jonathan Chun (D-Kauai-Niihau), an attorney, stood in opposition to the bill, charging that it would have an adverse impact on minorities and the disadvantaged. He quoted Diane Coleman, the founder of Not Dead Yet, that the promoters of assisted suicide are primarily “white, well-off,

worried and well." Senator Hanabusa (D-Nanakuli-Waianae-Makaha), also an attorney, spoke in favor of the measure, recalling that during previous debates much was shared, "emotions were high and the stories were moving." Senator Bob Hogue (D-Kaneohe-Maunawili-Enchanted Lake), speaking in opposition to the measure, related that his own family and his community were divided over the issue and that more discussion was needed. Senator Avery Chumbley, speaking in support of the measure, apologized to Senator Matsuura, the speaker, for being emotional. Matsuura rejected his apology, stating, "You don't need to apologize for your emotions." Chumbley then asked Matsuura to relay a message to Ruth Matsuura, the speaker's mother. "She called me and asked me if I would reconsider my position. Please apologize to her because I won't. But I have a tremendous amount of respect for Ruth, both as a doctor and a human being." Senator Chumbley went on to say there was no partisanship in the debate, citing a QMark poll that showed that both Democrats (75%) and Republicans (69%) supported the concept that an individual has the right to end his or her own life. He asserted that the poll showed that you did not have to be white, worried, and well off to support this concept. The same poll showed high levels of support among all ethnic groups.

Senator Robert [*sic*] Tam (D-Nuuamu [*sic*]-Moiliili-Manoa), better known to his colleagues as Mr. Sunshine, spoke against the measure, calling for further discussion among the people of Hawaii on the issue, stating, "Let's talk story. Let us embrace relationships with communication." When the call for the final vote

> came, three members who voted for the measure on Tuesday changed their votes and the Hawaii Death with Dignity Act was defeated by a 14-11 vote.

Although they lost, the PAS advocates, in a spirit of aloha, did not think they could come so close to winning and considered the loss a victory. In the Death With Dignity Society website, (http://www.hawaiidwdsociety.org/, last visited March 9, 2009), Scott Foster describes the aftermath of the near-win:

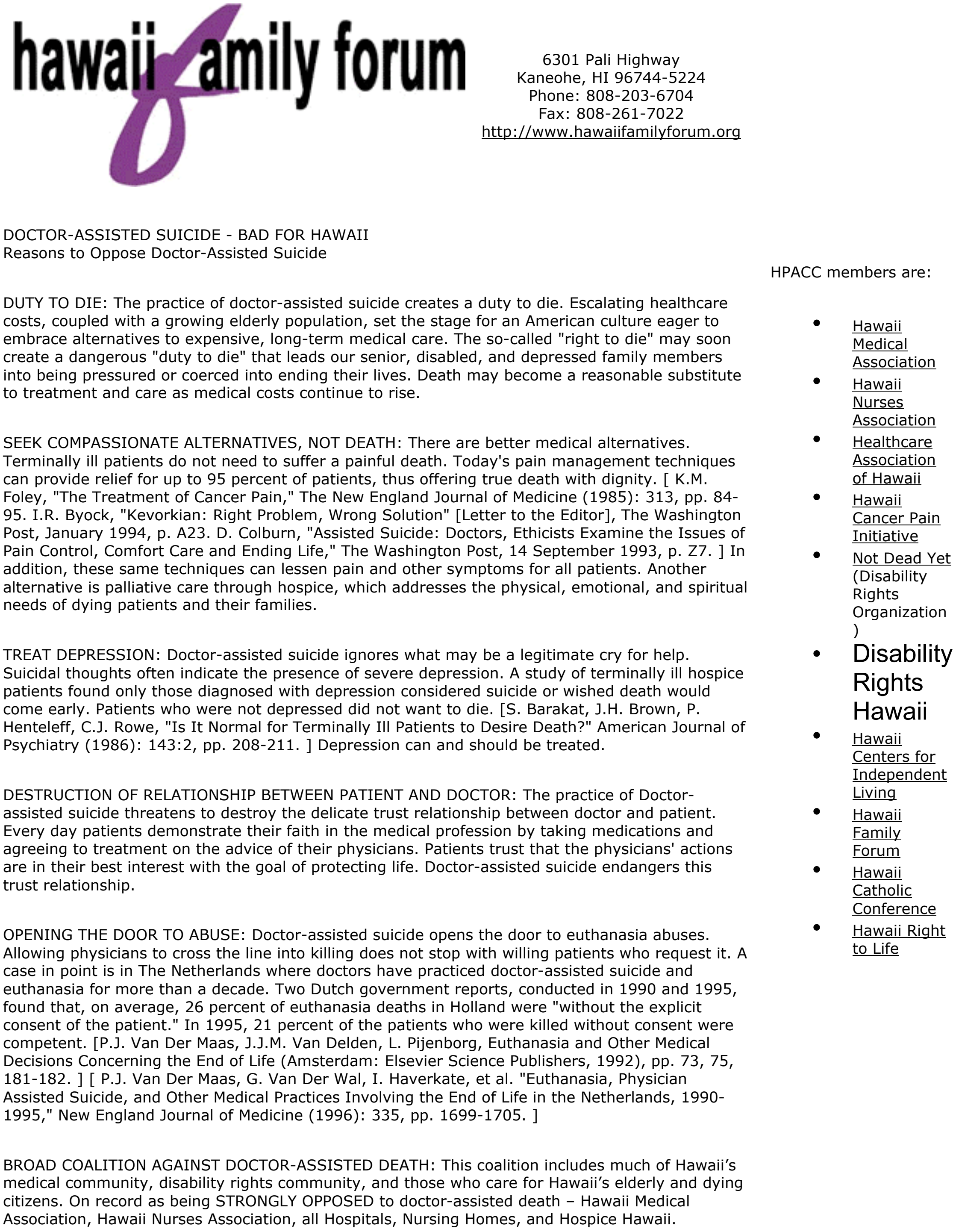
> While we indeed lost in the end by only three votes (14 - 11), we accomplished much. The important public education aspect of this timely issue was moved light-years ahead and the legislators too became much better educated about the issue. With the elections now looming, the Death With Dignity issue will no doubt be on every candidate's and news reporter's mind and the continuing dialog will hopefully assist us to elect more supportive legislator—and with some luck, another supportive Governor.

The Aftermath

In the following election, Matsuura was defeated. The Hawaii Death with Dignity Society later introduced and backed several more bills. In 2003, no bill was introduced as elections were just around the corner. It was felt that the issue was too controversial and threatening to the candidates.

The Hawaii Death With Dignity Society tried again in 2004 but was thwarted by conflicts, a change of administration, and the internal politics of the national organization. As a result, negative sentiments surfaced with allegations of a mainland take over and mishandling of the lobbying efforts. The local Hemlock office shut down and Halpern, its director, was hired away to head a regional office on the mainland. Although the bill had gained the attention of the voters, it had failed to pass. In the following legislative session in 2005, bills were introduced but no hearings were held. In 2006, other bills were introduced, heard, then tabled. In 2007, bills were introduced but hearings were postponed. In 2008, no bills were introduced. In 2009, although several bills were introduced as a tribute to the late McElrath, none were heard.

Figure 15. Hawaii Family Forum position statement on physician assisted suicide.



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DOCTOR-ASSISTED SUICIDE - BAD FOR HAWAII
Reasons to Oppose Doctor-Assisted Suicide

DUTY TO DIE: The practice of doctor-assisted suicide creates a duty to die. Escalating healthcare costs, coupled with a growing elderly population, set the stage for an American culture eager to embrace alternatives to expensive, long-term medical care. The so-called "right to die" may soon create a dangerous "duty to die" that leads our senior, disabled, and depressed family members into being pressured or coerced into ending their lives. Death may become a reasonable substitute to treatment and care as medical costs continue to rise.

SEEK COMPASSIONATE ALTERNATIVES, NOT DEATH: There are better medical alternatives. Terminally ill patients do not need to suffer a painful death. Today's pain management techniques can provide relief for up to 95 percent of patients, thus offering true death with dignity. [K.M. Foley, "The Treatment of Cancer Pain," The New England Journal of Medicine (1985): 313, pp. 84-95. I.R. Byock, "Kevorkian: Right Problem, Wrong Solution" [Letter to the Editor], The Washington Post, January 1994, p. A23. D. Colburn, "Assisted Suicide: Doctors, Ethicists Examine the Issues of Pain Control, Comfort Care and Ending Life," The Washington Post, 14 September 1993, p. Z7.] In addition, these same techniques can lessen pain and other symptoms for all patients. Another alternative is palliative care through hospice, which addresses the physical, emotional, and spiritual needs of dying patients and their families.

TREAT DEPRESSION: Doctor-assisted suicide ignores what may be a legitimate cry for help. Suicidal thoughts often indicate the presence of severe depression. A study of terminally ill hospice patients found only those diagnosed with depression considered suicide or wished death would come early. Patients who were not depressed did not want to die. [S. Barakat, J.H. Brown, P. Henteleff, C.J. Rowe, "Is It Normal for Terminally Ill Patients to Desire Death?" American Journal of Psychiatry (1986): 143:2, pp. 208-211.] Depression can and should be treated.

DESTRUCTION OF RELATIONSHIP BETWEEN PATIENT AND DOCTOR: The practice of Doctor-assisted suicide threatens to destroy the delicate trust relationship between doctor and patient. Every day patients demonstrate their faith in the medical profession by taking medications and agreeing to treatment on the advice of their physicians. Patients trust that the physicians' actions are in their best interest with the goal of protecting life. Doctor-assisted suicide endangers this trust relationship.

OPENING THE DOOR TO ABUSE: Doctor-assisted suicide opens the door to euthanasia abuses. Allowing physicians to cross the line into killing does not stop with willing patients who request it. A case in point is in The Netherlands where doctors have practiced doctor-assisted suicide and euthanasia for more than a decade. Two Dutch government reports, conducted in 1990 and 1995, found that, on average, 26 percent of euthanasia deaths in Holland were "without the explicit consent of the patient." In 1995, 21 percent of the patients who were killed without consent were competent. [P.J. Van Der Maas, J.J.M. Van Delden, L. Pijenborg, Euthanasia and Other Medical Decisions Concerning the End of Life (Amsterdam: Elsevier Science Publishers, 1992), pp. 73, 75, 181-182.] [P.J. Van Der Maas, G. Van Der Wal, I. Haverkate, et al. "Euthanasia, Physician Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," New England Journal of Medicine (1996): 335, pp. 1699-1705.]

BROAD COALITION AGAINST DOCTOR-ASSISTED DEATH: This coalition includes much of Hawaii's medical community, disability rights community, and those who care for Hawaii's elderly and dying citizens. On record as being STRONGLY OPPOSED to doctor-assisted death – Hawaii Medical Association, Hawaii Nurses Association, all Hospitals, Nursing Homes, and Hospice Hawaii.

HPACC members are:

- Hawaii Medical Association
- Hawaii Nurses Association
- Healthcare Association of Hawaii
- Hawaii Cancer Pain Initiative
- Not Dead Yet (Disability Rights Organization)
- Disability Rights Hawaii
- Hawaii Centers for Independent Living
- Hawaii Family Forum
- Hawaii Catholic Conference
- Hawaii Right to Life

Figure 16. HPACC Ad 2002 against physician assisted suicide

Craig Nakatsuka, M.D.

At Issue:

- *Trusting a doctor who is legally able to assist in a suicide;*
- *The 'right' to die becoming the 'duty' to die;*
- *The myths of 'untreatable' pain;*
- *The myth of assisted suicide as a 'free choice.'*

A long-term care Physician talks about the risks of Physician Assisted Suicide:

Doctors and patients both have a lot at stake *in the debate over assisted suicide. As a physician, I'm trained to diagnose and treat illness. But when treatment becomes suicide, I fear for my profession – and my patients.*

Here are a few hard truths you should know as you consider your response to any legislation that would legally allow a doctor to assist patients with suicide. ***Please read this message carefully, then discuss it with your family, with your friends and neighbors, and especially with your doctor.***

The Death of Doctor/Patient Trust

Allowing physician assisted suicide (PAS) will forever change the doctor/patient relationship. My patients trust me to do everything medically possible to heal them, and when that is not possible, to make them comfortable until death comes.

But if I'm given the legal right to kill a patient, that credibility will quickly crumble into distrust.

Imagine discovering tomorrow you have a serious life threatening *(and expensive)* illness. With the intense market pressure on medical cost containment, then how could you ever really trust that your treatment decisions wouldn't be based on their *cost* rather than *your cure*? And just whose side would your doctor really be on?

Assisted suicide ultimately reduces the value of a person to their utility to society. And when medical care is reduced to a cost/benefit ratio like that, helping patients kill themselves will always be cheaper than either curing them or caring for them. And that will be a sad day.

Creating a 'Duty' to Die

Evidence shows that a so-called 'choice' to die that's given to some, will put the most vulnerable among us in even greater danger. *So who's at risk?* Those with terminal illnesses. Those with expensive but treatable diseases like lung cancer or HIV/AIDS. And people with disabilities like cerebral palsy or multiple sclerosis. There's also great risk for the poor and elderly, and those without access to good medical care; likewise for the mentally impaired, and anyone else who places great demands on others.

Their 'quality' of life will be judged to be 'undesirable,' and they'll be made to feel like a burden to their families. Then one day, having done their 'duty,' *they'll be gone.*

Pain Control through Suicide?

In my practice I've observed that one of the greatest fears of patients with life-threatening illness is pain. Yet, with all the advances in pain control today, we can reliably eliminate or significantly reduce any pain they experience.

There is absolutely no reason for a patient to endure unbearable pain, and certainly no reason to kill them by ***a 'legal' overdose just to end physical or emotional suffering.*** That's not compassion...it's violence against life.

Any patient under a physician's care who repeatedly experiences excruciating pain should quickly locate a new physician, one trained in modern pain management.

Hospice care is also widely availability for terminally ill patients as a compassionate in-home service to care for their physical, emotional and spiritual needs.

Dumbing Down a Doctor's Calling

It takes a great deal of effort for a doctor to cultivate and maintain a good relationship with any patient. But for those with terminal or life-threatening illness, it requires an even greater degree of skill to help alleviate their patient's anxieties, control their suffering, and to compassionately invest themselves in their well-being.

While physician assisted suicide might seem compassionate, it's nothing more than abandoning a patient when they need a doctor the most. It's the easy way. It cheapens life, and it diminishes the physician's calling to a higher good.

I urge you to get informed, get involved, and speak up. I oppose physician assisted suicide because it's the highest form of prejudice, and it comes disguised as 'free choice.' Don't be fooled Hawaii. Let's not kill our humanity, because the cost of caring is never too high.

Excerpts from

THE HIPPOCRATIC OATH

I swear that I will fulfill according to my ability and judgment this oath and this covenant:

I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice.

I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect.

Translation from the Greek by Ludwig Edelstein.
From The Hippocratic Oath: Text, Translation, and Interpretation,
by Ludwig Edelstein. Baltimore: Johns Hopkins Press, 1943.

The Cost of Caring is Never Too High.

WWW.HPACC.ORG

Hawaii Partnership for Appropriate and Compassionate Care

Hawaii Medical Association   Hawaii Nurses Association   Hospice Hawaii   Hawaii Cancer Pain Initiative   Hawaii Family Forum
Healthcare Association of Hawaii   Hawaii Catholic Conference   The Arc in Hawaii   ACLJ of Hawaii   Not Dead Yet

CHAPTER 6
THE ADVOCATES

The previous chapter analyzed two catalysts that moved PAS from the periphery of politics to center stage: the Governor's Blue Ribbon Panel and the serendipitous event that placed the PAS bill in the hands of professionals. In the aftermath of the almost-win, the various right to die advocates in Hawaii coalesced under the umbrella of the HDWDS and continued to propose and lobby for PAS legislation.

This chapter examines more closely the HDWDS as the contender in the fight to legalize PAS. It looks at the role of interest groups in the larger landscape of competing "factions," then examines the motives of external parties that have the power to determine who wins, and lastly, it focuses on the inner structure of the HDWDS itself.

The contest between the advocates and the opposition can be likened to a David and a Goliath battle; one, a small group of six activists and the other, an arm of the powerful Catholic Church. This chapter seeks to answer how a small group of six advocates summoned the courage and resources to battle a large entrenched, well-organized and well-financed foe; what makes HDWDS different from other interest groups; and concludes by speculating on the ultimate question, "can HDWDS win?"

Political Theories

The PAS advocates have never duplicated the 2002 almost-win. Why they lost in the years after can be explained through the eyes of various parties. After losing in 2007, in frustration, Foster, Communications Director of HWDS, lamented that HDWDS lost because of the Church, doctors and disability groups. This comment came at the heel of a legislative hearing on February 8, 2007 attended by about 100 people and lasting several hours, with most of the testimony overwhelmingly against the bill. Persons with disabilities, like Kevin Inouye, paralyzed from the neck down because of a motorcycle accident, and testified that “This bill is wrong. It’s taking advantage of the elderly, disabled, sick—kicking a man when he’s down.” (Shikina, Robert, 2007).

The hearing was chaired by Hawaii State Representative Josh Green, M.D., of the House Health Committee, who voted against the bill and who claimed to have received about 300 written testimonies, which ran 10 to 1 against the PAS bill (House Bill 675). At a *Kokua* Council meeting held May 14, 2007, at United Methodist Church, Honolulu, Hawaii, Green explained his objections. “I objected because of the dangers to the disabled. Doctors also strongly opposed it.” Later, in an interview on July 16, 2007 at the Catholic Diocese in Honolulu, Vicar General Marc Alexander commented on the hearing and stated that “their people did not turn out to show support. Why PAS? We don’t need it.”

These comments reveal the role of Madison’s “factions” in a democracy, Olson’s cost/benefit model of political decision making and Barackso’s model of internal governance and guiding principles that may predetermine the path of an interest group.

James Madison

James Madison’s political model describes the pluralistic nature of competing groups are reflected in HDWDS’s contest with the Hawaii Family Forum. While both HDWDS and the Hawaii Family Forum have not compromised their positions, they have forced each other to improve end of life care. The result is public policy that supports *Kokua Mau* as the end-of-life state agency; the teaching of palliative care at the state’s

John Burns School of Medicine; the increased use of hospice care and the creation and legalization of legal instruments that include "do not resuscitate" orders; a surrogate decision making law that allows a surrogate to remove life support and nasal gastric tubes; and a new program called the Physician Orders for Life Sustaining Paradigm (POLST) that would to ensure that a patient's end-of-life treatment decisions are followed.

Mancur Olson

While Madison gives an understanding of the role of interest groups, Mancur Olson (1960) studies the economics that motivates them to compete. He explains that decisions are generally made after weighing perceived costs and benefits and risks and rewards. When deciding whether or not to support a controversial issue, politicians tend to weigh their decision against the goal of being elected or re-elected to office. Olson's model is evident in Green's decision to favor the disability groups who showed up with members of their coalition, the Hawaii Family Forum. In contrast, the core of six activists and perhaps a dozen others who showed up at the hearing made an unimpressive showing.

Maryann Barakso

While Olson's theories of cost/benefits and risk/reward may explain how political decisions are made, Barackso (2004) takes a closer look at the interest group itself and examines their internal structure and their guiding principles to explain their behavior, choice of strategies and destiny. In particular, she studies the National Organization for Women (NOW) and concludes that its decline from the public favor and its inability to win the Equal Rights Amendment are linked to its governance structure and its inflexible goals.

She agrees with Marshall Ganz, who states that "...(although the) organizational form may be a founders' strategic choice, once established, it has a profound influence on subsequent innovation and strategy." (p. 5) She argues the internal structure or "governance structure defines the group's set of legitimate activities, including its tactical repertoire; (and) activities inconsistent with the group's goals and values are unlikely to be seriously considered or pursued (p. 5)." She theorizes that the single-mindedness of NOW's pursuit of the passage of the ERA amendment and its unwillingness to moderate its rhetoric hindered its goals. Barakso's study throws similar light on HDWDS and its internal structure.

Guiding Principles

In studying the internal structure of HDWDS, two guiding principles emerge: avoidance of mainland ties and adherence to mission. Its avoidance of mainland ties appears to be the result of the "interference" of mainland organizers in 2003 in what HDWDS considered their *kuleana* (territory). On the HDWDS website, under the title "History of the Hawaii Death with Dignity Society, (n.d.)" Foster offers the following explanation: "…(W)e feel that after our near success in 2002, we made a great mistake in allowing our local effort to be taken over and directed by the large mainland organizations…."

Resentment was further expressed in the same article: "The confusion caused by the dramatic changes to the large mainland organizations cost us dearly in time and resources. During the past two years, we have seen our support base erode and the opposition become better organized."

For example, although the national Hemlock Society had provided $80,000 in 2002 and a smaller amount in 2003 to pay for professional lobbying and public relations, it did not contribute to Hawaii's other efforts to pass PAS bills. Likewise, HDWDS did not seek their support or any other mainland organization's support. The tense relationship with the national Hemlock Society, re-named Compassion and Choices, can be understood by island attitudes and the personal backgrounds of its members. A perceived superior attitude exhibited by mainland personnel caused resentment among the island advocates who felt they, not mainlanders, had intimate knowledge of the islands and had done all the hard work. The local organization needed to be in control of their issue and their organization. Island pride would not defer to mainland interlopers who attempted to take credit for the almost win. Further, the national Hemlock Society collected dues and donations from the local advocates who were not yet tightly organized. This was fine as a certain percentage of the dues and donations collected from the local advocates were rebated to the local Hemlock organization to maintain its presence in Hawaii. The rebated money stopped after the break with HDWDS and the in-fighting with Derek Humphrey, the founder of Hemlock, began. Without the Compassion and Choices' money and other outside support, HDWDS could not compete with the Hawaii Family Forum and win.

While HWDS lost ground, "dramatic changes to the mainland organizations" and infighting at Hemlock occurred as documented by Derek Humphrey (February 21, 2005).

The national Hemlock Society which had provided funds for the 2002 campaign was itself undergoing a change in leadership. It disagreed with its founder, Derek Humphreys, over his espousal of active euthanasia and his aggressive pursuit of PAS legislation. Its directors were concerned that if he continued with his stand on active euthanasia and self-deliverance, Hemlock would lose its tax exempt status which had brought in $3 million in contributions. To comply with its tax exempt status, the board wanted to stress educational activities rather than political activities. Further, the board felt uncomfortable with the name Hemlock that Humpheys had chosen to symbolize the "rational suicide" of Socrates. The board felt that the name Hemlock gave off the wrong message and fought Humphreys to change it. When Humphey left Hemlock, he left behind $3 million in donations. He next founded Final Exit, named after his book with the same name. With Humphrey gone, Hemlock changed its name to End of Life Choices which lasted until late 2004 when it merged with Compassion in Dying to become Compassion and Choices.

Compassion and Choices assumed the $3 million, re-made the organization and adopted a model which appears to be more business oriented than its competitor, the national Death with Dignity organization. The ERGO website, maintained by Derek Humphrey, reports how Compassion and Choices had caused resentment among the smaller Hemlock organizations by claiming that the name 'Hemlock' was trade-marked in l997 and no other right-to-die group could use it. In 2007, citing loss of identity and membership, Florida, New Mexico and other related organizations which had changed their names, resumed the name, Hemlock, in defiance of the ban (Ergo, 2007).

The power play on the mainland also affected the local Hemlock branch which had changed its name to End-of Life Choices to comply with the name of its parent organization. During the 2003 campaign, the plum job of political relations was given to someone better connected politically. Others, who had been involved in the 2002 campaign and who felt that more lobbying efforts should be aimed at the grass-roots level rather than from the top down, were let go. Although a bill was introduced in the 2003 legislative session, personnel and morale problems led to its failure. Citing the controversial nature of the bill, the upcoming elections, and the non-support by the new governor, the legislators did not hold a hearing on the bill.

After the legislative session, Compassion and Choices closed their local office and left the islands. Left alone, the various cells of the local right to die groups coalesced with HDWD. At this point, their budget consisted of donations from a small local base of members. Having re-structured and trying to re-capture their momentum to put together a winning strategy, HDWDS became the primary spokesman and only organized interest group in Hawaii advocating PAS. Meanwhile, two of its leaders A. Alan Symser, editor of the Star Bulletin and Ruth Lindberg passed away and leadership fell on Foster, Begley, Fox and McElrath.

Very briefly, Compassion and Choices' name changes is summarized below:

- 1980 The Hemlock Society is founded.
- 1993 Compassion in Dying is founded to provide support and advocacy programs for the terminally ill in Washington State.
- 1997 The Hemlock Society establishes the Caring Friends program

- 2003 Hemlock Society changes its name to End-of-Life Choices
- 2005 Compassion in Dying and End-of-Life Choices merge to become Compassion & Choices. The new organization maintains headquarters in both Denver and Portland, and is the largest organization in the United States advocating for patients' rights at the end of life.

With the in-fighting on the mainland, keeping HDWDS local was a lesson learned. This formed one of its guiding principles. Its other guiding principle was formed by AQ McElrath; namely, to pass legislation. This defined and differentiated HDWDS from other right to die groups which may have education, outreach and community service as their mission. Its mission is not self-deliverance, not to just improve end-of-life care and not education. It is a declaration of the refusal to "follow the money." While interviewing its principals, it was sincerely stated many times that, "You must understand, it is not about money, it never was about money. We were poor then but we somehow managed. We won't sell out. Our mission is to pass PAS legislation, not join in some end-of-life care."

When asked, "Would they change their mission in order to appeal to more people?" "Would they change their use of the term, PAS, to peaceful death?" "Would they broaden their mission to appeal to more people, refocus their goals to include education or join with Compassion and Choices?" The answer is no. They eschew the idea and stubbornly refuse to sell out. In the words of its president, George Fox, "We're not some g—d—end-of-life people" (private e-mail to author, 2006).

Internal Organization

While its guiding principles may be strict, its internal organization is loose which seems to fit the informal but dependable support given by liberal organizations such as ACLU, the Unitarian Church, and Humanists Hawaii. This looseness allows for a flexible style of management appropriate for HDWDS' size. To administer its organization, HDWDS has a data bank of contributors but no membership list, no constitution, by-laws, rules, regulations, central office, few overhead expenses, no regular meetings, several appointed leaders and no professional lobbyist. It relies on annual fund drives to pay a small stipend to its Director of Communication and to pay for its website, postage, printing and its membership drive at the Senior Fair.

As a private organization, they do not have to answer to a board or be constrained by rules and regulations. It stands in stark contrast to older, more established organizations, which tend to have a formal governance structure characterized by a division of labor, a hierarchy, by-laws and rules, and elected or appointed officers. The contrast appears dramatic in comparing HDWDS with its entrenched opponent, the Catholic Church in Hawaii, the sponsor of the Hawaii Family Forum. The contrast in the internal structure of a small group of volunteers with a large, highly organized entity provides a clear picture of an organization's strength, the available resources and possible strategies.

Figure 17. Comparison of the organization of HDWDS and Hawaii Family Forum in Hawaii.

Traits	**HDWDS**	**Hawaii Family Forum as part of the Catholic Church in Hawaii**
Division of labor	Volunteers. Overlapping jobs	Paid personnel Clear lines of work
Centralization	Loose	High
Formalization	None	Highly formalized, regulated
Coalitions	Final Exit, ACLU, Unitarian Church	Doctors, Disability groups Conservative religious groups
Bureaucracy	None	Highly organized
Source of income	Unreliable, small donations	Reliable, large donations
Membership	Small	Thousands
Decision making	Bottom up, democratic, consensual	Top down

Unbeholdened to any organization, it has no corporate or moneyed sponsors. It is not a 501c(3) organization that would seem essential in fundraising as it allows tax contributions to be deductible. On the other hand, it is not prohibited from political lobbying nor required to report its finances. When inquired about its tax status, the reply was, "if A.Q. wanted us to be a 501c(3), she would have made us a 501c(3) organization."

As a private organization, it does not need to comply with other requirements such as having a governing board, by-laws and tax and financial oversight. Its loose internal governance structure contributes to its survival, meeting only when there is some business to attend to or when necessary. Its decisions are consensual and democratically arrived at.

SWOT Analysis

Does it have the ability to survive and win? Its viability is best examined through an analysis of its strength, weaknesses, opportunities and threats (also called a SWOT analysis). The SWOT analysis is appropriate for several reasons: A voluntary non-profit organization, like any business enterprise, needs know its mission, goals, strengths and weaknesses, be able to identify its competition and possible partners, know what appeals to its members, what value or reward it can offer, have a realistic understanding of its revenue stream, cost structure and capabilities to make things happen. This type of analysis gives a picture of its leadership, explains why it can do certain things and not others, how it persists as it does and more importantly whether it is sustainable as a viable group.

Strengths

Their strength can be summarized as being the only game in town. As an umbrella for right to die advocates, it is the singular organization in Hawaii actively pursuing legislation to legalize PAS. To keep the organization active, it raises funds from its local base of advocates and often calls upon supporters from organizations such as ACLU and Unitarian Church to give testimony at hearings.

Its loose informal structure is both strength and weakness. As a strength, it fosters camaraderie, loyalty and a feeling of being in the vanguard of society. Further, its loose organizational structure allows for a freer range of personal initiative, unencumbered by tradition, a board of directors or hierarchical approval. More importantly, it allows for stealth, individualism and creative strategies as it tries to out maneuver established giants.

Behind the protests and heated controversy that PAS generates, is a “Wizard of Oz,” Scott Foster. (Baum, L. Frank, The Wonderful Wizard of Oz, 1900). Foster, its Director of Communications manages to sustain HDWD with only a small budget by using the web and electronic mail for advertisement, publicity and professional lobbying. Perhaps for battles that take place in the modern world of cyberspace, media spin and image building, a website and contacts with the media are the smoke and mirrors of a wizard. Foster is a professional writer and communicator. He is seasoned and politically savvy. He has successfully amplified the members’ voices to seem larger than their actual numbers.

Foster uses the Hawaii Family Forum as a foil for HDWDS by planning strategy around the forum’s offense. When there is a legislative hearing, HDWDS members are ready for a huge crowd of protestors and can anticipate arguments from doctors who invoke the Hippocratic Oath, from the disabled who fear PAS will be the “slippery slope” to euthanasia, and from the religious who preach the sanctity of life. The advocates and friends counter with a few short arguments about autonomy, independence and safeguards in the bill. Legislators take note of the small number of advocates and the huge number of Hawaii Family Forum members. Whichever way legislators respond, either by postponing the bill to the following year or defeating the bill, HDWDS has made its point: the issue of PAS is still alive and well. As the press and television crew pick up sound bites from Hawaii Family Forum or HDWDS advocates, PAS is in the eye of the public. Accordingly, the public is given the impression that the HDWDS has hundreds of members, a virtual voice that roars. Give him $65,000, the Director of Communications says, and he can turn public opinion your way.

Internal Weaknesses: Leadership, Funding

If McElrath was strength for the HDWDS, she might be considered its weakness. Very real challenges to HDWDS lie in its leadership and succession. Although there are younger supporters, it is a one person issue. Foster points out that, “If truth be known, we exist for AQ. She is the leader. She tells us what to do” (private e-mail to author, January 13, 2008). He also comments that the problem is that communication with her is difficult. She has no e-mail, no technology, no message recorders, and no cell phone. And she is not well.

He also says, “If you want to know, about politics, it is AQ. We are here to support her.” HDWDS becomes her voice each time the bill is introduced. Each year McElrath visits members of the legislature. When she calls on her friends in the legislature to introduce a bill, they accordingly comply. She says, “that’s the easy part; the hard part is getting a hearing.” Out of respect, friendship, and belief in her cause, the hearing is granted most of the time. When asked about his relationship to McElrath, Senate Majority Leader, Blake Oshiro knows her well, having worked with her on the *Kukui* Garden low income housing deal and has introduced the Death with Dignity bill for six years at her request and expects to introduce the next one.

While McElrath may be the driver of PAS legislation in Hawaii, she is not a recognizable name for fundraising and prefers to work in the background. HDWDS necessarily depends on the good will of volunteers, friendly reporters and friends. Its one paid staff member tracks legislation, organizes grass-roots support, recruits members, organizes fundraisers and masterminds the Internet. The inability to raise big money impacts its ability to lobby, buy ads, create and sustain momentum, fend off attacks and do all the other activities that give safe passage to PAS. One possible reason for HDWDS' paucity is that it is not a 501c(3) tax exempt organization, unlike non-profits such as Hawaii Family Forum, Compassion and Choices, *Kokua Mau*, and the Catholic Church. Not having the tax exempt status makes it difficult to acquire grants from charitable institutions and businesses and donors who contribute in exchange for tax deductions. However, without the tax states, HDWDS has the freedom to lobby and avoids the formality and necessary compliances.

External Threats: Hawaii Family Forum

While leadership and funding are two of HDWD's weaknesses, they are among Hawaii Family Forum's strengths. Even though HDWDS is decidedly the underdog, Hawaii Family Forum is still threatened by its bark. Determined not to be caught off guard again as it was in 2002, it responds with full force when a PAS bill is introduced.

The Hawaii Family Forum as a partner with the Hawaii Catholic Conference, the public policy arm of the Roman Catholic Church in Hawaii, has almost unlimited resources, a communications network that reach at least 65,000 people each Sunday, strong hierarchical leadership, a coalition of doctors, nurses, people with disabilities, and strong moral, ethical beliefs in the sanctity of life. They were led until 2008 by Kelly Rosati, a full time lobbyist for the Hawaii Family Forum and the Hawaii Catholic Conference.

Compassion and Choices

Another threat to HDWDS is its vulnerability to a takeover by a mainland organization such as Compassion and Choices. This organization was the financial backer of the 2002 and 2003 events and is familiar with the leadership of HDWDS and the political landscape of Hawaii. Although Compassion and Choices closed up their office in the islands in 2003, it appears to be still interested in involving itself in Hawaii. Most telling is a line item in their 2007 Financial Statement that lists “plaintiff prospecting in Hawaii” as an $8000 expense in 2007. When the author queried Kathryn Tucker, their legal counsel, about this item, Tucker replied that she had no knowledge of this line item. During a presentation at the William S. Richardson School of Law at the University of Hawaii Law School in April 14, 2007, Tucker was asked if Compassion and Choices would be interested in re-opening its office in Hawaii. She responded by saying that if the grassroots requested a branch they would consider it.

When a bill was presented in 2009 in Hawaii to legalize PAS, Compassion and Choices launched an active campaign with personal phone calls and mailings to solicit donations and to recruit members through their website.

Kokua Mau

A former threat that HDWDS faces is *Kokua Mau,* which is the state’s palliative and hospice care organization. It appears to lean toward framing advance directives, surrogate decision making, do not resuscitate laws in terms of achieving consensus among family members and less as a means to exercise personal autonomy and has sponsored the new POLST policy. It still retains its stance of silent opposition to PAS.

In 2006 there was a change of leadership and sponsors. It is now required to be self–supporting by means of fundraising, charging dues and fees for conferences. Interviews in 2008 with its now former director, Rachel Wong, indicated that any organization capable of paying dues is welcome to join as a member, even HDWDS.

While HDWDS may reject *Kokua Mau's* advances, Compassion and Choices may find it a vehicle to penetrate the network of pro-life organizations. According to its 2007 Annual Report, it has started an end-of-life consultation program that provides information about options including PAS. Its sponsorship of California's new law that requires hospitals to provide information about end-of-life treatment including PAS may make it a good fit for *Kokua Mau's* new direction.

The Future for PAS Advocates

Life Cycles

The notion of life cycles and careers describes the rise and fall of small groups. Examples are neighborhood associations joined in protest of a "nimby' project (not in my neighborhood). The life of some of these groups ends at the conclusion of the issue, whether it is won or lost. Except for the two thousand year old Roman Catholic Church and its religious allies that lay claim to eternal life, organizations and interest groups tend have a life cycle or career cycle that rises and falls. In the PAS controversy, HWDS may appear as a speck in contrast to the steadfast presence of a two thousand year old Roman Catholic Church, its religious allies and the decades old healthcare organizations.

HDWDS appears to be at the nadir of its life cycle. Its membership has declined; its bills at the legislature have been defeated; its finances are not robust; but, it has survived onslaughts from the Church and its allies, healthcare organizations and other opponents. Even at this low point, HDWDS is not to be underestimated. Their political savvy, the salience of their issue, their belief system and their patience to abide until a dramatic event or a crisis shakes them up are similarities they share with other small interest groups that are formed to meet a crisis and then hibernate until the next crisis.

But what differentiates HDWDS is the very nature of the issue. Unlike other issues, the issue of death and dying is very personal and very profound and affects everyman. The salience of the issue is compounded by the fear of losing control over life and death, of intractable suffering and of the unknown. As reported by Oregon's Death with Dignity 2008 report, the most frequently mentioned end-of-life concerns were: loss of autonomy (95%), decreasing ability to participate in activities that made life enjoyable (92%), and loss of dignity (92%). During 2008, more participants were concerned about loss of dignity than in previous years (82%). (http://egov.oregon.gov/DHS/ph/pas/ar-index.shtml, last visited March 27, 2009).

What gave this organization sustainability was the leadership of the late McElrath who persevered and rebuffed attempts to soften its message. PAS was her issue, and even at her death in 2009, it remained her issue. It is claimed that Marcus Oshiro, Hawaii State House Majority Leader and Finance Chair, who was close to her, was one of the last visitors at to see her before she died. Members of HDWDS who knew McElrath conjured images of her scolding Oshiro and reminding him that the time had come for him to support for PAS and universal healthcare. As a tribute to her, three DWD bills were introduced in 2009. These bills had been introduced quietly and were intended to fly under the radar of their opponents. The bills were fast tracked and invoked cries of protests from the Hawaii Family Forum. Frantic calls went out seeking testimony. Unfortunately, at the very same time, same sex civil unions legislation was hotly debated and had mobilized the members of the Hawaii Family Forum who marched 2,000 strong to the legislature to oppose the bill. After their show of strength, the same sex civil unions bill as well as the PAS proposal died in committee.

Salience of the Issue

Even though PAS legislation was again defeated, other events in the nation and around the world kept it in the public eye. Perhaps the most dramatic event had occurred earlier, in 2004, in the case of Terri Schiavo, which was discussed previously. Other events developed during this time. In 2006, right to die advocates in California made a strong but failed attempt to persuade the California assembly to pass PAS.

However, two years later, on August 20, 2008, the California Senate passed the Terminal Patients' Right to Know End-of-Life Options Act, AB 2747. The Act was the first in the nation to provide terminally ill patients with a full disclosure of, and counseling about, all available legal and ethical end-of-life care options. The Act also required that health care providers who did not wish to comply with a particular patient's choice must refer or transfer the patient to another provider. The Right to Know End-of-Life Options Act would require physicians and health care providers to provide a full range of information about end-of-life options when patients request it.

A few months later, under the leadership of Stutsman and the former Washington Governor Booth Gardner and other PAS coalition members, on November 4, 2008, Washington became the second state to legalize PAS. Washington voters approved Initiative 1000 which would allow PAS under strict medical guidelines. The new law took effect in March 2009.

On December 8, 2008, Montana legalized PAS. Montana's First Judicial Court issued a landmark decision in a lawsuit brought by a terminally ill Montana man, four Montana physicians and Compassion & Choices. The court decision is currently under appeal.

Negative reports also made the news and kept the issue of PAS in the public's eye. In early 2009, Final Exit members in Georgia were arrested for allegedly helping an undercover state investigator attempt to kill himself. Rumors circulated in Hawaii and among other Final Exit organizations that a "witch hunt" was in progress and that law enforcement officials were closely watching local Final Exit members and waiting to catch them assisting in another person's death.

A movement across the nation in the form of POLST (discussed previously) that seemingly gives doctors more control of patients' end of life care is being put into place. In Hawaii, these initiatives have been adopted through *Kokua Mau*.

Other Tactics

While PAS remains salient, HDWDS' membership and influence have declined. When the members gathered In January 2008, a question posed to them was, "How will HDWDS win?" Those present were the steering committee of HDWDS, a former legislator, supporters of PAS, activists in Kokua Council and a couple of university professors who gave various suggestions. The group looked beyond themselves and sought a *deus ex machina* to rescue their organization and provide a win. The suggestions were dramatic and hopeful but none were enthusiastically endorsed. A few are the following: have a spokesman and advocate like Christopher Reeves, an actor, paralyzed from a riding accident and best known for his role as Superman; use a test case where a doctor volunteers to participate in PAS and is arrested, tried and acquitted; exercise patience and hope that baby boomers who face increasing costs of health care and diminishing services would prefer to hasten death and not want to prolong suffering; advocate for incremental social and legal changes to liberalize and make more accessible do not resuscitate orders; putting the question to the people in a constitutional amendment; wait for a change in the political party; wait for the next state to legalize PAS; and hire a professional lobbyist. Beneath what might seem wishful and wistful thinking, the group knew that to win, they needed money, had to overcome the power and influence of the Catholic Church, the tightly organized Hawaii Family Forum and the objections of the physicians and groups whose members had disabilities. They knew their opponents and felt, justifiably, it would take *a deus ex machine* to win. No action was taken. On December 11, 2009, McElrath died and seemingly with her, the active movement.

Summary:

The PAS movement might have ended with the death of A.Q. McElrath and the failed bills. The HDWDS might have gone into hibernation but for HDWDS' wizard who scripted his own *deus ex machine.* He persuaded Eli Stutsman, founding board member of the Death with Dignity organization to consider Hawaii as the fourth state in which to pass PAS. Stutsman brought a renewed interest in the issue, laid out and provided a strategy. Meanwhile, Foster agreed to the stewardship of HDWDS while it reviewed its mission and goals. Can HDWDS win? Yes, but it would take hard work, executive leadership, deals, buy-ins, and money, lots of it.

Figure 18. The Hawaii Death with Dignity Society Newsletter, Winter 2007

CHOICE MATTERS

THE HAWAI`I DEATH WITH DIGNITY SOCIETY NEWSLETTER

Winter, 2007

SENIOR FAIR BOOTH A GREAT SUCCESS!

OVER 23,000 ATTENDED RECENT 3-DAY EVENT

BY SCOTT FOSTER, EDITOR

Our first public event in over three years took place on Oahu on September 28, 29 & 30 at the Neil Blaisdell Exhibition Center (more photos on page 2). A sincere "mahalo!" to our 16 booth volunteers. Over 23,000 people attended and our new color logo attracted many eyes. As in the past, the reactions from the majority of the fair's attendees to the word "death" in our sign varied from casual glances to looks of stark horror — but over 20 new people signed up as members, and many, many others asked intelligent questions, perused our books on sale, and took away our literature. We came away feeling that we had made a big success.

See "DWDS growing" continued on Page 2

Longtime friend and DwD advocate, Andi van der Voort of the Hawai`i Final Exit Network (formerly Hawai`i Hemlock) dropped by our booth to say hello and lend encouragement.

For your convenience, we now stock a selection of best-selling books & DVDs here in Hawai`i! See page 2 for details.

Former Hawai`i State Representative Lisa Naito joins the Society at our Senior Fair booth.

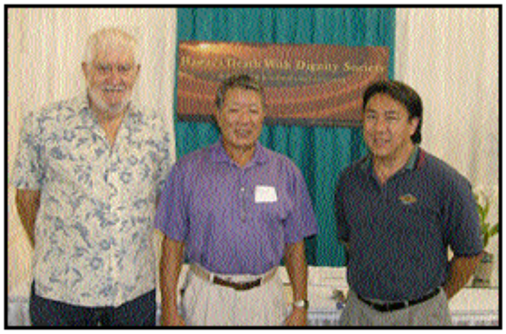
TWO QUESTIONS BEING POSED BY DWDS MEMBERS

There were two reoccurring questions being posed by many long-time members who visited our Senior Fair booth: "Do we intend to introduce a bill again in 2008?" and "Are we planning a membership meeting to discuss our long-range plans?"

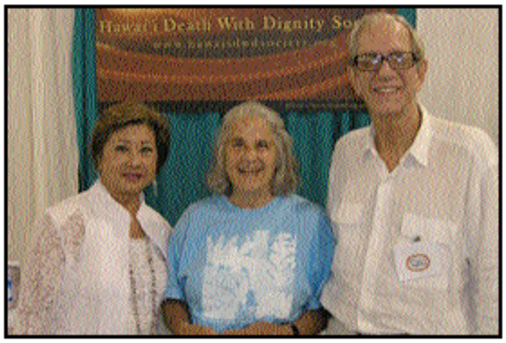
We believe that achieving a hearing for our bill to be important in our public education effort and we will again try to see this happen in 2008, but with one major change. While it's clear that we do not yet have our grassroots organized to the point of being able to pass a bill (much less see this governor sign one), we do intend to try and end the circus-like atmosphere that has prevailed during recent hearings and we want to see many more supportive testimonies presented in 2008. More on this in a later mailing.

We are already planning an Oahu membership meeting, hopefully in late October or early November, 2007. Once we identify a date, time and meeting location, we will notify our Oahu membership via postcard. ☯

Page 1 of 2



(above L) George Fox, our Board President with vol-unteers Takeo Maruyama (C) and Doug Hom (R).



Volunteer Jeanette Ostrow (above L), Steering Committee member Eve Anderson (C), and Scott Foster (R), our Secretary & Communications Director.

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Our Treasurer, Juliet Begley (L), volunteers Lenora Lee and Leona Jona, and Eve Anderson, Steering Committee member (R).

"DWDS growing"...
Clearly we have much work to do in rebuilding our organization back up to full strength statewide.
To this end, we will be moving forward with community meetings, designing and printing a brochure, producing a public access TV production and other outreach activities during the coming months. While our first group membership meeting is being planned for Oahu, we are also beginning to plan meetings on Kauai, Maui and Hawai`i. If you are reading this on one of the neighbor islands, please let us know if and how you can somehow assist us in setting up a meeting in your community. We would need to identify possible meeting places and recruit a few local volunteers to help with the planning and logistics. Please notate the enclosed return form if you can help coordinate such a meeting. ☯

FOR YOUR CONVENIENCE, we are now stocking the following best-selling books and DVDs here in Hawai`i. They may be ordered using the enclosed yellow form (add $2 each for postage).
1. **Patient Directed Dying** by Tom Preston, M.D. outlines and reframes the key issues in the right-to-die debate. A "must" for the serious advocate. **$16.95**
2. **Dying Beautifully** by Dave Karpowicz is an insightful book for anyone facing imminent death and for their loved-ones unsure of what will happen and what should be done. **$24.95**
3. **Final Exit** by Derek Humphry: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying (with the 3rd addendum).
BOOK — **$16.00**
DVD — $20

CHAPTER 7
CONCLUSION

This dissertation has detailed the conflict of morals and values between advocates who seek to change public policy to legalize PAS and opponents who seek to preserve the status quo. In explaining this conflict, this dissertation presented and examined the role of religion, morals, benchmark court cases, laws and bioethical problems. It also pointed out how advocates framed their arguments in terms of values such as independence, choice and control. To frame their stand, opponents evoked morals found in concepts such as the sanctity of life, the slippery slope and obligations proscribed by the Hippocratic Oath. The purpose of such framing was to persuade and win. Having knowledge about the importance of framing the conflict and recognizing that dilemmas in morals and values in end-of-life medical treatment are crucial to understanding this conflict.

This dissertation also examined the politics of PAS in Hawaii by describing the political conduciveness of Hawaii and focusing on key advocates in Hawaii organized under the umbrella of HDWDS. Further, it examined what made their organization, the HDWDS, different from other small interest groups; and why, even after overwhelming defeats, they continue to pursue legislation to legalize PAS. Finally, this dissertation suggested how these advocates might develop a strategy to advance their goals.

It is illuminating to know that the members of HDWDS are individuals with strong personalities that underscore their determination, political savvy and their confidence in their ability to legalize PAS. They believe that the ability to have choice and control in one's death and dying is important to themselves and to society.

I was given the unique opportunity to know the key advocates, participate in planning strategy with them, learn about the need for a hastened way to achieve a good death and hear stories of compassion, sadness and helplessness in caring for a friend or loved one dying badly. It is from these unique experiences that I draw my conclusions about PAS and its politics in Hawaii. I address these conclusions to the individual for whom death is very personal and very profound and to the advocate who accepts the challenge to continue the fight to change public policy.

PAS is Centrist

For the individual, I conclude that PAS has become more centrist and is more intertwined with the law, medicine, ethics and bioethics. Given this situation, the dilemmas posed by end-of-life medical treatment and PAS under the law, seem better resolved by seeking answers within one's personal and private beliefs.

A Good Death

This notion is demonstrated by my interviews and discussions with two very dynamic intellectuals, A.Q. McElrath and Vicar General Marc Alexander. Each adversary posed a rhetorical question, the answer to which was based on his or her position as a leader of PAS or a representative of the Catholic Church. The dilemma appeared in their shared desire for a good death but differing in time, manner and place.

Sitting on a panel discussion with Dr. Brian Issell, a former dissenting member of the Blue Ribbon Panel and an oncologist who favored palliative care in end-of-life treatment, Mc Elrath asked, “What’s the difference between terminal sedation and PAS?” And to make a point, she answered her own question, “Only time and place.”

At a another time and in a another place, Alexander, after ticking off the principle of the double effect, terminal sedation and stewardship of resources and other legal end-of-life options approved by the Catholic Church, rhetorically asked, “Why do we need PAS? We don’t need it.”

If McElrath’s and Alexander’s questions were stripped of framing, their common desire for a good death would be exposed. And, in a way, PAS has become symbolic of the good death for advocates, just as palliative care and hospice have become symbolic of a good death for opponents. For McElrath a hastened death for those in agony is a good death and for Alexander, palliative care that assuages suffering and prolongs life is a good death. This is notion is further examined by Hillyard and Dombrink (2001). They explain that, if we can be simplistic, both advocates and opponents equate a “bad death” as “dying in a hospital, in intractable pain, hooked up to tubes, surrounded by strangers, and at the mercy of events beyond his or her control” (p. 257).

PAS advocates view a “good death” as one that emphasizes “choice, freedom from pain, a greater role for the patient, a greater role for the patient, and acknowledgment that the current legal and medical practice allows for such deliverance, under the acceptance of “double effect” (p.258). This view is very similar to the one held by their opponents, for whom a “good death” is prolonging life through palliative care and hospice care, respecting the dignity of patients and caregivers, application of the “double effect” or terminal sedation, and withholding and withdrawing medications and medical devices.

The difference then, between the advocate’s good death and the opponent’s good death, is time, framed as hastening death or the prolonging of life assuaged of intractable pain; the manner of death, its intention, administered by oneself or the physician; and place, self-administered at most likely at home or by a physician most likely in a healthcare facility.

Intrusion of the Law

Related to the conundrum of time, manner and place, is the Hillyard’s and Dombrink’s notion about the degree of “intrusion” or non-intrusion of the law in medicine. It was observed that those who voluntarily make medical decisions for themselves must follow strict protocols. For example, when making an advance directive for health care, two witnesses unrelated to each other and not a healthcare provider must witness the person’s signature. To be valid, other rules must also be followed according to the law. If the advance directive is not followed, there are legal remedies such as going to court to order that the document’s directions be observed. Other voluntary end-of-life decisions also are regulated. Do not resuscitate orders (DNR), surrogate decision making, and the currently proposed Physician Orders for Life Sustaining Treatment (POLST) which is a program to ensure that end-of-life orders are standardized and followed, have legal guidelines provided by law. The law that would be most intrusive concerns PAS where strict guidelines require physical and mental examinations, a waiting period, witnesses and voluntary self administration of the lethal medication which is prescribed by a licensed pharmacist.

However, the law does not provide the legal protocol for physicians in removing tubes, turning off ventilators, stopping antibiotics and so on. Advocates say the principle of the double effect and terminal sedation are methods applied by a physician and outside the law. The difference, then, between PAS and terminal sedation or the double effect is time, manner, place and the intrusion or non-intrusion of the law. To McElrath and other advocates, they would be spins of PAS where medication applied outside the law "and intended to cure, instead killed" (Hillyard and Dombrink, p. 260). Left unsaid is the perception of society's higher degree of confidence in the physician and less in the individual.

Strategy for Winning

I next shift to a strategy the activist will need to employ when he or she accepts the challenge to win PAS legislation. This strategy was developed and used by Eli Stutsman in the Oregon and Washington wins and presented to the HDWDS advocates at the March event. I conclude that 1) in order to win, HDWDS members must transform themselves from amateurs to professionals whose priority is winning and 2) with the death of McElrath, the opportunity to renew HDWDS' guiding principles, mission and goals can be broadened to include coalitions with competitors and acceptance of financial help from external sources.

HDWDS and Professionalism

In February 2009 Foster announced that Eli Stutsman would come to Hawaii to explore the possibility of the national organization choosing Hawaii as the next state in which to campaign for PAS. Contrary to Foster's original description of these advocates as "old and tired," they were animated and excited about the possibility of a new campaign and a win. They had waited for someone like Stutsman for a long time.

What the author saw was that HWDWS was not moribund but alive and well. These were old friends who had fought many campaigns together; not only on the PAS issue but on issues such as universal healthcare, same sex unions, medical marijuana and amending the Hawaii State Constitution to allow the initiative. Some had sat on McElrath's *Ad Hoc* Committee for Death and Dying and on the Governor's Blue Ribbon Panel for Death and Dying. Among those present were members from the League of Women Voters, former legislators, members of the clergy, retirees, University of Hawaii professors, doctors and publicists. They were intelligent, articulate and still passionate about winning PAS.

Stutsman was direct, honest and savvy. Having worked the almost win campaign in 2002, he knew the landscape of Hawaii's PAS politics. The advocates listened soberly to Stutsman's basic formula for winning: plain old hard work, big donors, executive leadership, buy-in's and making deals. There was no talk about a *deus ex machina* or Superman or Wonder Woman. Before the national Death with Dignity Organization would commit to Hawaii, the advocates would be required to do the groundwork. They would need to commit to meet weekly, recruit executive leadership who can bring other influential people on board, make the deals to that made PAS safe for stakeholders, form coalitions and raise money—lots of money. It meant that HDWDS would need to transform itself from amateurs to professionals as the advocates of the Blue Ribbon Panel had done in 2002. As described earlier, the HDWDS had the power of the governor's office behind them, an infusion of outside money, a professional lobbyist, a public relations person, an opposition researcher and the help of Oregon's Death with Dignity team who hammered the bill into a politically viable instrument.

Stutsman emphasized that grassroots support is not enough. As demonstrated by the campaign in 2002 and in the Oregon and Washington wins, professionalism is important especially in today's brand of politics. The campaign has to be sophisticated, well-organized and well-funded. A professional is a person who is expected to win and who can provide the inducements which the followers require as a condition of their contributing time, effort and money (Wilson, 1966). These inducements could be unrelated to issue but arise from "prestige, sociability and personal loyalties" (p. 9). Thus, HDWDS will need the professional who can make the deals, resolve differences, call in favors and make people want to work for him or her. First and foremost, the professional's priority is winning and not necessarily reforming the law.

It was suggested that the ideal professional for PAS, one with executive leadership, could possibly be ex-Governor Ben Cayetano under whose administration PAS almost passed and who is now retired. Cayetano's leadership would be buttressed by the support of the next governor, who is predicted to be Congressman Neil Abercrombie, a liberal who recently announced his candidacy for governor. If the former

Governor and the future governor could be convinced to provide professional leadership for PAS, HDWDS's power would be tremendously enhanced.

Lobbying

One of the key advantages of having the former Governor and future governor on the side of the advocates are their connections and access to the state legislators. Unlike Oregon and Washington which used the initiative that required persuading the electorate to vote for the initiative ballot, Hawaii must go through the legislative process which requires a different dynamic. Lobbying must be aimed internally, at members of the House and Senate rather externally, toward the voters. Even if the issue may be bi-partisan, the lobbyist must be sensitive to the constituents of each legislator, the risk he or she faces, and how to make PAS safe for the legislator. Internal deals and agreements would need to be made. For example, in 2002, an ethnic group was persuaded to vote as a bloc once the bill crossed over from one house to the other.

Example of Hard Work

As an example of hard work, the national Death with Dignity website details the timeline of activities and money spent in winning Washington's Yes on I-1000. These advocates had begun their campaigning two years prior to the initiative ballot; had formed coalitions with groups from Vancouver and Oregon and hired a professional campaign manger, a polling firm and a media company. They spent $76,000 in in-kind service, over 700 hours of staff time, 360 hours in legal work to modify Oregon's DWDA to fit Washington and to provide wording on the ballot and held over 80 meetings to identify partners and plan strategy. A coalition of the national Death with Dignity organization, Oregon Death with Dignity, Compassion and Choices, Compassion and Choices of Washington, and individuals from many areas in Washington worked closely together. A total of about $5 million was raised, including former Governor Booth Gardner's donation of $750,000. It was the first time that DWD outspent the Catholic Church which spent close to $1 million. More details can be found on the website: http://www.deathwithdignity.org/media/uploads/DDNCCampaignContributions.pdf

Timing

While preparing and executing this strategy may seem daunting for a small group like HDWDS, a proposed timeline provides some leeway. Planning, fundraising, coalition building, getting endorsements and identifying executive leaders could begin right away, but a more favorable time to partner with the future governor would be in 2014 after being re-elected. He or she would be not distracted by running for a second term nor threatened by supporting a controversial issue.

Deals with Doctors

Stutsman was emphatic on making the proposal safe for the stakeholders and giving them a "buy-in." This meant that if the goal is winning, the proposals must be safe for the stakeholders who are the ones involved in implementing the bill; for example, the doctor who prescribes the lethal medication, the attending physician, the mental health doctor, the pharmacist who fills the prescription, the nurse who attends the patient, the person and his or her family. To make the proposal safe and respond to the opposition's attacks on the proposal, each clause of the bill must be carefully and deliberately constructed and made to it fit the needs of the stakeholder.

Building coalitions, getting endorsements, and involving the stakeholders are methods of convincing the public that the proposal is credible and in the public's interest. For example, in Washington the President of the Washington American Medical Association (AMA) and a leading oncologist actively endorsed the bill. In Oregon, meetings were held where doctors debated the proposal and because they were not able to agree, they adopted a neutral position and agreed not to interfere. When Hawaii passed its abortion bill, Hawaii doctors were involved in its drafting and testified in favor of the bill which convinced legislators that the bill was desired, safe and written for the public interest.

Defining the Opposition:

While providing a safe harbor for those closely involved in implementing the proposal, identifying its opponents is crucial to success. HDWDS's most fierce and most powerful opponent is Hawaii Family Forum, a part of the Hawaii Catholic Conference, the political arm of the Church. As was described previously in Chapter 3, it is coalesced with 12 other organizations some of which are also partners with *Kokua Mau*.

Stutsman related that voters' in Oregon tend to abhor interference from outsiders and tend to be independent by nature. These traits are reflected in Oregon's high number of persons not claiming to adhere to a particular religion. As pointed out in Chapter 3, Hawaii's population is the most diverse in the nation and has the most diverse religious adherents. Hawaii’s diversity engenders tolerance and at the same time conundrums that make it difficult to focus on a single strategy.

In Stutsman experience and based on an examination of the amount of campaign money spent, the Catholic Church works behind the scenes and is the main opponent of PAS. This bodes poorly for Hawaii’s advocates. According to the 2008 Pew Forum on Religious Life, 22% of Hawaii’s population is Catholic, 26% Evangelicals, and 5% Mormon. In addition, there are has 66 parishes in the state, 37 schools and its newspaper, the Catholic Herald has a readership of 15,000 people.

The current director of Hawaii Family Forum is the former Hawaii state Senator Dennis Arakaki, who has the reputation of never having lost an election and who chaired the Health Committee when the 2005 PAS bill was killed after a 6 hour hearing. The Hawaii Family Forum had displayed its power in February 2009 when it organized 2,000 people to march against the civil-unions bill. Legislators responded by bottling the civil-unions bill in committee. This display of power plus strong lobbying efforts also appeared to have influenced the Chairman of the House Judiciary committee to kill the 2009 PAS bill.

Stutsman said that to win, HDWDS must match the opposition in organization, finance, publicity, media ads, and in every other way. Thoroughly knowing the opposition and possibly exposing the influence of the church and the amount of money it spends in opposing the bill may be one way to fight church influence. However, Stutsman was quick to explain, exposing the role of the Catholic Church could be problematic for it may lead to claims of Catholic bashing by the Church. Many would fear political reprisal.

To meet this challenge, according to an old hand at politics, the late McElrath, recommended, “Forget about the Catholics. You can’t change their minds. You have to go for the ones in the middle, the ones sitting on the fence.”

Opportunities

With the passing of McElrath and, perhaps, under a different leadership, the opportunity to adapt its goals and missions to reflect a more contemporary time may arise. One of the first strategies HDWDS might consider would be to re-frame PAS to death with dignity. The word “suicide” as Tucker, the attorney for Compassion and Choices, says, is old fashioned and incendiary. It is so undesirable that advocates in the Washington initiative battle went to court to keep the word off the ballot while their opponents used it to repel voters from voting for the initiative. With a new leadership, it might be possible to extend an olive branch to local and mainland competitors to feel out the possibility of partnering. While older members in HDWDS held grudges against mainland competitors, a new leader without the organization’s history may find opportunities in coalition with competitors.

Currently, HDWDS is in need of seed money and a leader to begin planning. Although its current Director of Communications has temporarily accepted the stewardship of HDWDS, it will need a new leader to pick up the challenge posed by Stutsman. However, its present underdog strategy of having a bark bigger than its bite, fits the now five core members. Under this notion, it remains in the public's eye and a thorn in Hawaii Family Forum's side.

However, if HDWDS wants to remain sustainable, it cannot afford to hibernate or merely bark. Already competitors have stepped into its territory, taken and used its data base, sent donation envelopes to its members, made phone calls and solicitations over the web. If HDWDS hibernates, it opens the door for others.

If a leader steps up and begins the groundwork for 2014, it has the opportunity to re-make and sustain itself. Perhaps the first step is mending fences with mainland groups; get executive leadership on board, then adopt the 501c(3) or the 504 tax status that would allow them to seek charitable donations of big money. After that, it can continue with Stutsman's suggested strategy to win.

Conclusion:

Death is very personal and very profound. I believe PAS or the now more acceptable term, death with dignity, will be legalized in Hawaii—eventually. It would be legalized because of the practical things, not the dramatic. Death with dignity will probably not happen because of another Terri Shiavo, or putting a doctor or others on trial for assisting in a terminally ill person's suicide. It will happen because it will be demanded by baby boomers who increasingly are caregivers for their parents and elders and who themselves have experienced caregiver angst, the caregiver burdens and caregiver burnout. They will be the ones who would not want to be a burden to their children or their spouse. They will have experienced the mental or physical decline of the person they are caring for, the financial stresses, and the constant worry of who will provide care for the person they are caring for if they cannot. And as the Vicar General of the Catholic Church predicts, it will be bad deaths, the rising cost of care and fewer resources that will make death with dignity happen.

As written, death with dignity is very narrow and would apply only to terminal illness. But if the illness is chronic, for example, Parkinson's or the late stages of Alzheimer's disease, or if one has brain damage, or suffers a debilitating stroke, death with dignity would not apply and neither would the principle of the double effect or terminal sedation. At that point, perhaps, the notion of a new good death will emerge, one that is hidden away in ancient Hawaiian legends.

Bill Kirtly (2003) writes "that ancient Hawaiians could choose the time of their death and simply will themselves to die. Their phrase for it was, "Na kanaka-oku'u wale aku no i kau uhane" (The people dismissed freely their souls and died). There is evidence that many Hawaiians died in this traditional way."[18] If I could control my destiny and just allow my soul to walk out of my body, death would be personal and profound; I would have conquered death.

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[18] Some Hawaiian scholars have suggested "Nā kānaka-ku'u wale aku no i kana `uhane" as an alternative (Sproat, K., private e-mail, May 5, 2009).

Appendix A. Governor's Blue Ribbon Panel on Living and Dying with Dignity Executive Summary, 1998

June 9, 1998

The Honorable Benjamin J. Cayetano
Governor, State of Hawaii
State Capitol, 5th Floor
Honolulu, Hawaii 96813

Dear Governor Cayetano:

On behalf of the Governor's Blue Ribbon Panel on Living and Dying with Dignity, I am pleased to transmit this report for your review and consideration.

The report is in response your having charged the Panel to "...consider the many issues involved in death and dying and to suggest guidelines for our own public policy." We began our work by mutually sharing the extensive knowledge and experiences in medical, legal and spiritual fields accrued over the years by the distinguished members whom you appointed to serve on the Panel. We then sought advice and counsel of those engaged in patient care, and especially professionals familiar with elderly care. We also listened to the fears and concerns of the physically disadvantaged. Nine public hearings were held throughout the State to provide an opportunity for members of the general public to share their experiences and their personal concerns on the end of life issues. Following these fact finding efforts, including examination of various literature on the subject, we undertook a series of discussions and deliberations which concluded on May 11, 1998 with final adoption of our policy recommendations to you contained in this report.

Among the eight recommendations which the Panel offers for your consideration, six have the unanimous endorsement of the members. The first five recommendations seek improvement in the areas of spiritual counseling, education and training for health care professionals, advance directives, hospice care and pain management. The sixth contains the Panel's unanimous decision that involuntary euthanasia should not be permitted, and that its practice should continue to be a criminal act in our State.

The remaining two issues concern the availability of physician-assisted suicide (PAS) and physician-assisted death (PAD) upon the request of mentally-alert patients who either are terminally ill or suffer intractable and unbearable illness that cannot be cured or successfully palliated. The majority of our panel voted to endorse PAS and PAD. Those in opposition have various reasons. The opposition statements are appended as a part of this report. Implementation of the majority PAS and PAS recommendations to give individuals wider choice in end-of-life decisions will require changes in existing laws, rules and practices, all of which are based on long-standing tradition and deeply-seated beliefs.

The panel therefore recommends extensive public information and education so tha our proposals--including the statutory changes suggested in our report--will be widely discussed, pro and con.

We believe that such an educational effort can be effectively assisted by quasi-public and private organizations willing to step forward. Such groups may find our report useful in generating meaningful discussion and debate. We hope dialogue will address both our six unanimous recommendations and the two on which we are divided.

Respectfully submitted,

Hideto Kono, Chair
Governor's Blue Ribbon Panel on Living and Dying with Dignity

THE FOLLOWING MEMBERS JOIN IN THIS REPORT TO GOVERNOR CAYETANO WITH RESERVATIONS AS STATED

1. Naleen N Andrade
Naleen N. Andrade*

2. Stephan F. Barack

3. Max Botticelli

4. Mary M. Cooke
Mary M. Cooke

5. Jeffrey D. Crabtree

6. Rev. Beth Donaldson with decision to abstain on Section F.
Reverend Beth Donaldson*

7. Sister Roselani Enomoto, csj
Sister Roselani Enomoto, CSJ *

8. Reverend Yoshiaki Fujitani

9. Dr. Norman Goldstein

10. Lawrence L. Heintz
Lawrence L. Heintz

11. Brian Issell*

12. Hideto Kono

13. Patricia A. Lee with Reservations
Patricia Lee*

14. Lawrence Miike
Lawrence Miike

15. Sharyn Stephani Monet
Sharyn Stephani Monet*

16. James H. Pietsch
James H. Pietsch*

17. Alan A. Smyser

18. Betty M. Vitousek
Betty M. Vitousek

We, as appointed members of the Governor's Blue Ribbon Panel on Living and Dying with Dignity, concur with this report in its entirety.

*We, as appointed members of the Governor's Blue Ribbon Panel on Living and Dying with Dignity, concur with the recommendations presented in the report except those that

I. EXECUTIVE SUMMARY

We have been charged by the Governor of the State of Hawaii to explore the issues related to living and dying with dignity. We have spent the last year reading about, listening to, and gathering testimony regarding this issue, both expert and lay. As a result we have concluded that many people unnecessarily face lingering, painful and undignified deaths.

We have taken into consideration many of the medical, legal, financial, ethical, and spiritual dynamics related to living and dying with dignity. What we have learned during this period of inquiry has led to the following unanimous recommendations:

1. **That spiritual counseling be made more available to individuals who are afflicted with life threatening illnesses by integrating those services more fully into the healthcare system.**
2. **That public and healthcare professional education programs be designed and implemented to increase awareness of the choices available to the dying.**
3. **That the content of Advance Directives for Healthcare including living wills be made more specific, their use more widespread and their provisions more binding.**
4. **That hospice care be made more available and offered more expediently to the dying.**
5. **That effective pain management and other symptom control programs be required in all licensed healthcare institutions.**
6. **That involuntary euthanasia should continue to be a crime.**

We recognize and celebrate that we live in a pluralistic society, with many cultural and religious perspectives. We believe that in Hawaii especially, it is important that no one perspective be allowed to impose its beliefs and mores on another.

Beyond our above unanimous recommendations, we have considered the alternatives of physician-assisted suicide or physician-assisted death as a choice for those who hold that it is moral and ethical and who might require the help of their physician to implement that choice.

Therefore we have defined two options for consideration beyond those which were unanimous:

- Physician-Assisted Suicide (PAS): The physician provides the agent by which the patient ends his or her own life.

- Physician-Assisted Death (PAD): The physician actively participates in the administration of a lethal agent with the intent to cause the death of the patient.

These would be available only to mentally alert patients who either are terminally ill or suffer intractable illness that cannot be cured or successfully palliated.

A majority of our members recommend these be legalized by the State Legislature under strict controls so that there will be no reasonable fear of a "slippery slope" down which ailing people might be pushed against their will. We would only recognize requests by mentally alert patients made on repeated occasions to two physicians, a psychiatrist and a social worker pursuant to the recommended policies.

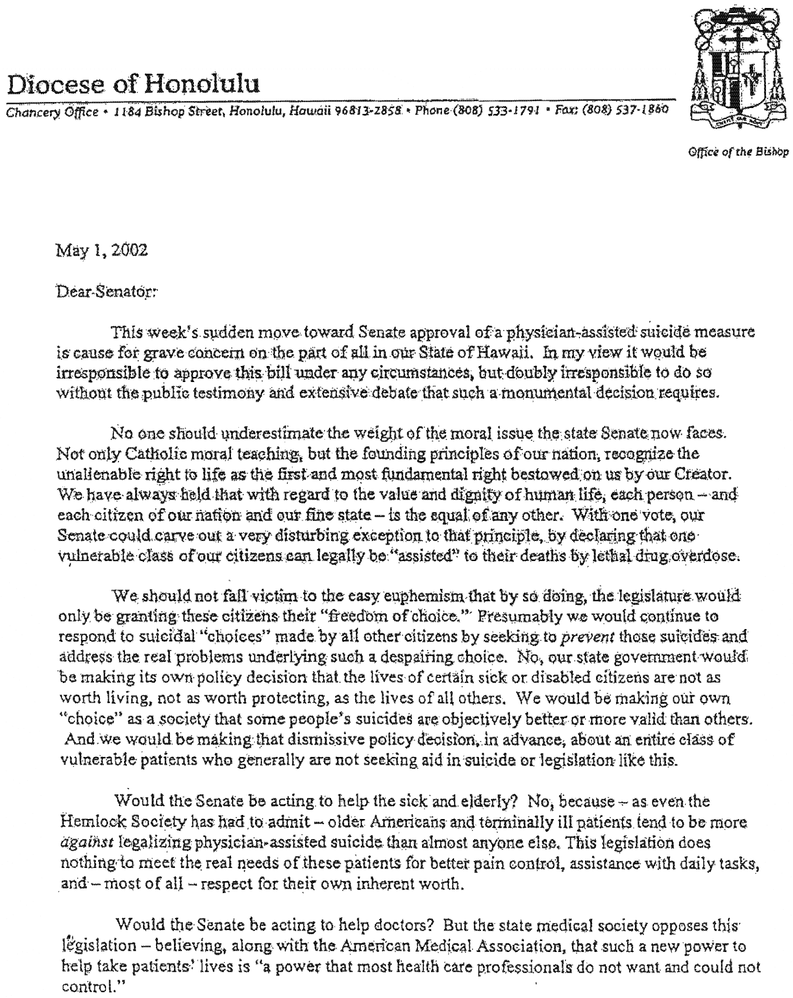
We also present a draft Model Hawaii Law adapted from the recommendation of a national panel that included specialists in law, ethics, philosophy, religion, medicine and economics. It was published in the Harvard Journal on Legislation in January, 1996.

Some of our members strongly oppose this recommendation for a number of reasons. Some have religious objections, others have concerns of abuse, and some believe that improving palliation and offering other alternatives like hospice care can suffice. Several consider themselves ambivalent.

The difference is a moral question to some, a matter of choice to others.

We respectfully present the positions of both sides in this report.

Appendix B. Letter from Bishop



Diocese of Honolulu
Chancery Office • 1184 Bishop Street, Honolulu, Hawaii 96813-2858 • Phone (808) 533-1791 • Fax: (808) 537-1860

Office of the Bishop

May 1, 2002

Dear Senator:

This week's sudden move toward Senate approval of a physician-assisted suicide measure is cause for grave concern on the part of all in our State of Hawaii. In my view it would be irresponsible to approve this bill under any circumstances, but doubly irresponsible to do so without the public testimony and extensive debate that such a monumental decision requires.

No one should underestimate the weight of the moral issue the state Senate now faces. Not only Catholic moral teaching, but the founding principles of our nation, recognize the unalienable right to life as the first and most fundamental right bestowed on us by our Creator. We have always held that with regard to the value and dignity of human life, each person – and each citizen of our nation and our fine state – is the equal of any other. With one vote, our Senate could carve out a very disturbing exception to that principle, by declaring that one vulnerable class of our citizens can legally be "assisted" to their deaths by lethal drug overdose.

We should not fall victim to the easy euphemism that by so doing, the legislature would only be granting these citizens their "freedom of choice." Presumably we would continue to respond to suicidal "choices" made by all other citizens by seeking to *prevent* those suicides and address the real problems underlying such a despairing choice. No, our state government would be making its own policy decision that the lives of certain sick or disabled citizens are not as worth living, not as worth protecting, as the lives of all others. We would be making our own "choice" as a society that some people's suicides are objectively better or more valid than others. And we would be making that dismissive policy decision, in advance, about an entire class of vulnerable patients who generally are not seeking aid in suicide or legislation like this.

Would the Senate be acting to help the sick and elderly? No, because – as even the Hemlock Society has had to admit – older Americans and terminally ill patients tend to be more *against* legalizing physician-assisted suicide than almost anyone else. This legislation does nothing to meet the real needs of these patients for better pain control, assistance with daily tasks, and – most of all – respect for their own inherent worth.

Would the Senate be acting to help doctors? But the state medical society opposes this legislation – believing, along with the American Medical Association, that such a new power to help take patients' lives is "a power that most health care professionals do not want and could not control."

Would this legislation respond to the cries of patients with intractable pain? But as we already know from the Netherlands and Oregon, untreated pain is seldom the chief reason for physician-assisted suicide. In Oregon, disturbingly, the reason increasingly cited by patients is that they have come to feel they are a "burden" on others. Such feelings and attitudes will only be aggravated by the passage of legislation like this.

Finally, is this about saving money? Some will be offended by this question. Yet the founder of the Hemlock Society, Derek Humphry, has written in his 1998 book *Freedom to Die* that assisted suicide will come to be accepted in our society *chiefly* as a matter of "cost containment." Humphry describes elderly patients as "greedy geezers" eating up the nation's health care dollars, who should be gently persuaded by others that assisted suicide can be "the morally correct thing to do" for family and society.

By anyone's standards, this legislation raises too many disturbing questions to be approved now by the Senate. This issue involves life and death, equal protection under law, and the precarious dignity of some of our most vulnerable citizens. I urge you not to take action now that the Senate and the people of our State may bitterly regret in years to come. I urge you to set aside the assisted suicide bill.

With every best wish, I remain,

Sincerely yours in Our Lord,

+Francis X. DiLorenzo

(Most Rev.) Francis X. DiLorenzo
Bishop of Honolulu

Appendix C. HB 806-A Bill for an act Relating to Death with Dignity

Report Title:
Death With Dignity

Description:
Allows a terminally ill, competent adult to get lethal dose of medication to end life. Prohibits mercy killings, lethal injections, and active euthanasia. Requires informed consent. Allows alternate doctor to replace attending doctor if latter declines to prescribe. Requires monitor at time of taking dose.

HOUSE OF REPRESENTATIVES
TWENTY-FIFTH LEGISLATURE, 2009
STATE OF HAWAII

H.B. NO. 806

A BILL FOR AN ACT

RELATING TO DEATH WITH DIGNITY.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

SECTION 1. The Hawaii Revised Statutes is amended by adding a new chapter to be appropriately designated and to read as follows:

"CHAPTER

DEATH WITH DIGNITY

PART I. GENERAL PROVISIONS

§ -1 Definitions. As used in this chapter, unless the context clearly requires otherwise:

"Adult" means an individual who is eighteen years of age or older.

"Alternate physician" means a physician who assumes the responsibilities relinquished by an attending physician who declines or is unable to fulfill the responsibilities of an attending physician as required under section -31(a).

"Attending physician" means the physician who has primary responsibility for the care of a patient and treatment of the patient's terminal disease.

"Capable" means that, in the opinion of:

(1) A court; or

(2) The patient's attending physician or consulting physician, psychiatrist, or psychologist,

a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.

"Consulting physician" means a physician who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's disease.

"Counseling" means one or more consultations as necessary between a state licensed psychiatrist or psychologist and a patient for the purpose of determining that the patient is capable and not suffering from a psychiatric or psychological disorder causing impaired judgment.

"Department" means the department of health.

"Health care facility" means:

(1) A hospital with an organized medical staff, with permanent facilities that include inpatient beds, and with medical services, including physician services and continuous nursing services under the supervision of registered nurses, to provide diagnosis and medical or surgical treatment primarily for acutely ill patients and accident victims, or to provide treatment for the mentally ill or to provide treatment in special inpatient care facilities. For purposes of this definition, a "special inpatient care facility" is a facility with permanent inpatient beds and other facilities designed and used for special health care purposes, including: rehabilitation centers, college infirmaries, chiropractic facilities, facilities for the treatment of alcoholism or drug abuse, or inpatient care

facilities, and any other establishment falling within a classification established by the department, after determination of the need for that classification and the level and kind of health care appropriate for that classification; or

(2) A long-term care facility with permanent facilities that include inpatient beds, providing medical services, including nursing services but excluding surgical procedures except as may be permitted by the rules of the department, to provide treatment for two or more unrelated patients. The term "long-term care facility" includes:

(A) A skilled nursing facility, whether an institution or a distinct part of an institution, that is primarily engaged in providing to inpatients skilled nursing care and related services for patients who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons; or

(B) An intermediate care facility that provides, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment that a hospital or skilled nursing facility is designed to provide, but who, because of their mental or physical condition, require care and services above the level of room and board that can be made available to them only through institutional facilities.

The term shall not be construed to include home health agencies, residential facilities, hospice programs, and homes.

"Health care provider" means a person licensed, certified, or otherwise authorized or permitted by the law of this State to administer health care or dispense medication in the ordinary course of business or practice of a profession and includes a health care facility.

"Informed decision" means a decision that is:

(1) Made by a qualified patient to request and obtain a prescription to end the patient's life in a humane and dignified manner;

(2) Based upon an appreciation of the relevant facts; and

(3) Made after being fully informed by the attending physician of:

    (A) The qualified patient's medical diagnosis;

    (B) The qualified patient's 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 comfort care, hospice care, and pain control.

"Medically confirmed" means the medical opinion of the attending physician has been confirmed by a consulting physician who has examined the patient and the patient's relevant medical records.

"Patient" means a person who is under the care of a physician.

"Physician" means a doctor of medicine or osteopathy licensed to practice medicine by the Hawaii medical board pursuant to chapter 453.

"Qualified patient" means a capable adult who is a resident of Hawaii and has satisfied the requirements of this chapter in order to obtain a prescription for medication to end the patient's life in a humane and dignified manner.

"Terminal disease" means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, result in the patient's death within six months.

§ -2 Severability. Any section of this chapter that is held invalid as to any person or circumstance shall not affect the application of any other section of this chapter that can be given full effect without the invalid section or application.

PART II. WRITTEN REQUEST FOR MEDICATION

§ -21 Who may initiate a written request for medication. (a) An adult who is capable, is a resident of Hawaii, and has been determined by the attending physician or alternate physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed that person's wish to die, may make a written request for medication for the purpose of ending that person's life in a humane and dignified manner in accordance with this chapter.

(b) No person shall qualify under this chapter solely because of age or disability.

§ -22 Form of the written request. (a) A valid request for medication under this chapter shall be in substantially the form described in section -61, signed and dated by the qualified patient and witnessed by at least two individuals who, in the presence of the qualified patient, attest that to the best of their knowledge and belief the qualified patient is capable, acting voluntarily, and is not being coerced to sign the request.

(b) One of the witnesses shall be a person who is not any of the following:

(1) A relative of the qualified patient by blood, marriage, or adoption;

(2) A person who, at the time the request is signed, would be entitled to any portion of the estate of the qualified patient upon death under any will or by operation of law; or

(3) An owner, operator, or employee of a health care facility where the qualified patient is receiving medical treatment or is a resident.

(c) The patient's attending physician or alternate physician at the time the request is signed shall not be a witness.

(d) If the qualified patient is in a long-term care facility at the time the written request is made, a third witness shall be required in addition to the two witnesses described in subsection (a). The third witness shall be an individual designated by the facility and shall have the qualifications specified by the department by rule.

PART III. SAFEGUARDS

§ -31 Attending physician responsibilities; alternate physician. (a) The attending physician shall:

(1) Make the initial determination of whether a patient has a terminal disease, is capable, and has made the request voluntarily;

(2) Request that the patient demonstrate Hawaii residency pursuant to section -40;

(3) To ensure that the patient is making an informed decision, inform the patient of:

  (A) The patient's medical diagnosis;

  (B) The patient's 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 comfort care, hospice care, and pain control;

(4) Refer the patient to a consulting physician for medical confirmation of the diagnosis and determination that the patient is capable and acting voluntarily;

(5) Refer the patient for counseling if appropriate pursuant to section -33;

(6) Recommend that the patient notify next of kin;

(7) Counsel the patient about the importance of having another person present when the patient takes the medication prescribed pursuant to this chapter and of not taking the medication in a public place;

(8) Inform the patient that the patient may rescind the request at any time and in any manner, and shall offer the patient an opportunity, pursuant to section -36, to rescind at the end of the fifteen-day waiting period;

(9) Verify, immediately prior to writing the prescription for medication under this chapter, that the patient is making an informed decision;

(10) Fulfill the medical record documentation requirements of section -39;

(11) Ensure that all appropriate steps are carried out in accordance with this chapter prior to writing a prescription for medication to enable a qualified patient to end the patient's life in a humane and dignified manner; and

(12) (A) Dispense medications directly, including ancillary medications intended to facilitate the desired effect, to minimize the qualified patient's discomfort; provided the attending physician is registered as a dispensing physician with the Hawaii medical board, 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 shall dispense the medications either to the qualified patient, the attending physician, or an expressly identified agent of the patient.

(b) Notwithstanding any other provision of law, the attending physician may sign the qualified patient's death certificate.

(c) If at any time an attending physician declines or is unable to fulfill any of the responsibilities detailed in subsection (a), particularly subsection (a)(12) regarding dispensing medication to a patient, the attending physician shall relinquish the responsibilities to an alternate physician who is willing and able to fulfill the responsibilities detailed in subsection (a). The alternate physician shall confirm with the attending physician or the consulting physician that the diagnosis has not changed and that the patient is capable, is acting voluntarily, has made an informed decision, and remains a qualified patient under this chapter. The alternate physician may not dispense medication to the qualified patient under subsection (a)(12) until at least fifteen days after the alternate physician's initial consultation with the patient.

§ -32 Consulting physician confirmation. Before a patient is deemed qualified under this chapter, the consulting physician shall examine the patient and the patient's relevant medical records and confirm in writing the attending physician's diagnosis that the patient is suffering from a terminal disease and shall verify that the patient is capable, is acting voluntarily, and has made an informed decision. If necessary, the consulting physician shall also confirm with the alternate physician, pursuant to section -31(c), that the diagnosis has not changed and that the patient is capable, is acting voluntarily, has made an informed decision, and remains a qualified patient under this chapter.

§ -33 Counseling referral. If, in the opinion of the attending physician, the alternate physician, or the consulting physician, a patient may be suffering from a psychiatric or psychological disorder causing impaired judgment, any one of the physicians shall refer the patient for counseling. No medication to end a patient's life in a humane and dignified manner shall be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgment.

§ -34 Informed decision. No person shall receive a prescription for medication to end a patient's life in a humane and dignified manner unless the patient has made an informed decision. Immediately prior to writing a prescription for medication under this chapter, the attending or alternate physician shall verify that the qualified patient is making an informed decision.

§ -35 Family notification. The attending or alternate physician shall recommend that the qualified patient notify the next of kin of the qualified patient's request for medication pursuant to this chapter. A qualified patient who declines or is unable to notify next of kin shall not have the qualified patient's request denied for that reason.

§ -36 Written and oral requests. To receive a prescription for medication to end a qualified patient's life in a humane and dignified manner, a qualified patient shall make an oral request and a written request and shall reiterate the oral request to the qualified patient's attending or alternate physician no less than fifteen days after making the initial oral request. At the time the qualified patient makes a second oral request, the attending or alternate physician shall offer the qualified patient an opportunity to rescind the request.

§   -37 Right to rescind request. A qualified patient may rescind a request at any time and in any manner without regard to the qualified patient's mental state. No prescription for medication under this chapter may be written without the attending or alternate physician offering the qualified patient an opportunity to rescind the request.

§   -38 Waiting periods. No less than fifteen days shall elapse between the qualified patient's initial oral request and the writing of a prescription under this chapter. No less than forty-eight hours shall elapse between the patient's written request and the writing of a prescription under this chapter.

§   -39 Medical record documentation requirements. The following shall be documented or filed in a qualified patient's medical record:

(1) All oral requests by the qualified patient for medication to end the qualified patient's life in a humane and dignified manner;

(2) All written requests by a qualified patient for medication to end the qualified patient's life in a humane and dignified manner;

(3) The attending physician's diagnosis, prognosis, and determination that the patient is capable, acting voluntarily, and has made an informed decision and, if necessary, the alternate physician's confirmation that the diagnosis has not changed and that the patient is capable, is acting voluntarily, has made an informed decision, and remains a qualified patient under this chapter;

(4) The consulting physician's diagnosis, prognosis, and verification that the patient is capable, acting voluntarily, and has made an informed decision;

(5) A report of the outcome and determinations made during counseling, if performed;

(6) The attending or alternate physician's offer to the qualified patient to rescind the qualified patient's request at the time of the qualified patient's second oral request pursuant to section -36;

(7) A note by the attending or alternate physician indicating that all requirements under this chapter have been met and indicating the steps taken to carry out the request, including a notation of the medication prescribed; and

(8) A completed form reporting the event to be completed by a monitor who is required to be present at the event pursuant to section -41.

§ -40 Residency requirement. Only requests made by Hawaii residents who have been domiciled or physically present in the State for a continuous period of at least six months prior to the time the initial oral request for medication to end the patient's life is made under this chapter shall be granted. Factors establishing Hawaii residency include:

(1) Possession of a Hawaii driver's license;

(2) Registration to vote in Hawaii;

(3) Evidence that the person owns or leases property in Hawaii;

(4) Filing of a Hawaii tax return for the most recent tax year; or

(5) Any other documentation that establishes legal residency in the State.

§ -41 Monitor required; form. (a) A qualified patient shall designate a competent adult to act as a monitor and who shall be present at the time of actual administration of the medication to the qualified patient and shall witness the event. The monitor shall have the power to act on behalf of the qualified patient to:

(1) Stop the administration of the medication if it has not yet been carried out; or

(2) Enlist medical assistance to attempt to reverse the effect of the medication if the medication has already been delivered,

if the monitor has reason to believe that the qualified patient has had a change of mind and is not able to effectively express or communicate the wish not to proceed taking the medication.

(b) The department of health shall develop a form for a monitor to complete upon witnessing and participating in the event described under this section.

§ -42 Department requirements. (a) The department shall annually review a sample of records maintained pursuant to this chapter and shall require any health care provider upon dispensing medication pursuant to this chapter to file a copy of the dispensing record with the department.

(b) The department shall adopt rules pursuant to chapter 91 to facilitate the collection of information regarding compliance with this chapter. Except as otherwise required by law, the information collected shall not be a government record under chapter 92F and may not be made available for inspection by the public.

(c) The department shall generate and make available to the public an annual statistical report of information collected under subsection (b).

(d) Upon the filing of a death certificate under section 338-9 of any qualified patient under this chapter, the department shall designate the cause of death as the underlying terminal disease or diseases as diagnosed under section -31(a)(1).

§ -43 Effect on construction of wills, contracts, and other agreements. (a) No provision in a contract, will, or other agreement, whether written or oral, to the extent the provision would affect whether a person may make or rescind a request for medication to end the person's life in a humane and dignified manner, shall be valid.

(b) No obligation owing under any currently existing contract shall be conditioned or affected by the making or rescinding of a request, by a person who is a qualified patient, for medication to end the person's life in a humane and dignified manner.

§ -44 Insurance or annuity policies. The sale, procurement, or issuance of any life, health, or accident insurance or annuity policy or the rate charged for any policy in this State shall not be conditioned upon or affected by the making or rescinding of a request, by a person who is a qualified patient, for medication to end the person's life in a humane and dignified manner. A qualified patient's act of ingesting medication to end the patient's life in a humane and dignified manner shall not have an effect upon any life, health, or accident insurance or annuity policy issued in this State, nor be construed as a suicide for purposes of any life, health, or accident insurance or annuity policy issued in this State for purposes of section 431:10D-108(b)(5).

§ -45 Construction of chapter. Nothing in this chapter shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing, or active euthanasia. Actions taken in accordance with this chapter shall not, for any purpose, constitute suicide, assisted suicide, mercy killing, or homicide under the law.

PART IV. IMMUNITIES AND LIABILITIES

§ -51 Immunities; basis for prohibiting health care provider or monitor from participation; notification; permissible sanctions. (a) Except as provided in section -52:

(1) No person shall be subject to civil or criminal liability or professional disciplinary action for participating in actions taken in good faith compliance with this chapter. This includes being present when a qualified patient takes the prescribed medication to end the qualified patient's life in a humane and dignified manner;

(2) No professional organization or association, or health care provider, may subject a person to censure, discipline, suspension, loss of license, loss of privileges, loss of membership, or other penalty for participating or refusing to participate in good faith compliance with this chapter;

(3) No request by a qualified patient for or provision by an attending or alternate physician of medication in good faith compliance with this chapter shall constitute neglect for any purpose of law or provide the sole basis for the appointment of a guardian or conservator; and

(4) No health care provider shall be under any duty, whether by contract, statute, or any other legal requirement, to participate in the provision to a qualified patient of medication to end the qualified patient's life in a humane and dignified manner. If a health care provider is unable or unwilling to carry out a qualified patient's request under this chapter, and the qualified patient transfers the qualified patient's care to a new health care provider, the prior health care provider shall transfer, upon request, a copy of the qualified patient's relevant medical records to the new health care provider.

(b) Except as provided in section -52:

(1) Notwithstanding any other provision of law, a health care provider may prohibit another health

care provider from participating in this chapter on the premises of the prohibiting provider if the prohibiting provider has notified the health care provider of the prohibiting provider's policy regarding participating in this chapter. Nothing in this paragraph shall prevent a health care provider from providing health care services to a qualified patient that does not constitute participation in this chapter;

(2) Notwithstanding subsection (a), a health care provider may subject another health care provider to the sanctions stated in this paragraph if the sanctioning health care provider has notified the sanctioned provider prior to participation in this chapter that it prohibits participation in this chapter:

(A) Loss of privileges, loss of membership, or other sanction provided pursuant to the medical staff bylaws, policies, and procedures of the sanctioning health care provider if the sanctioned provider is a member of the sanctioning provider's medical staff and participates in this chapter while on the health care facility premises of the sanctioning health care provider, but not including the private medical office of a physician or other provider;

(B) Termination of lease or other property contract or other nonmonetary remedies provided by lease contract, not including loss or restriction of medical staff privileges or exclusion from a provider panel, if the sanctioned provider participates in this chapter while on the premises of the sanctioning health care provider or on property that is owned by or under the direct control of the sanctioning health care provider; or

(C) Termination of contract or other nonmonetary remedies provided by contract if the sanctioned provider participates in this chapter while acting in the course and scope of the sanctioned provider's capacity as an employee or independent contractor of the sanctioning health care provider. Nothing in this subparagraph shall be construed to prevent:

(i) A health care provider from participating in this chapter while acting outside the course and scope of the provider's capacity as an employee or independent contractor; or

(ii) A qualified patient from contracting with the qualified patient's attending or alternate physician and consulting physician to act outside the course and scope of the provider's capacity as an employee or independent contractor of the sanctioning health care provider; and

(3) A health care provider that imposes sanctions pursuant to paragraph (2) shall follow all due process and other procedures the sanctioning health care provider may have, including, at a minimum, reasonable notice and an opportunity for a hearing, that are related to the imposition of sanctions on another health care provider.

For the purposes of this subsection:

"Notify" means to make a separate statement in writing to the health care provider specifically informing the health care provider prior to the provider's participation in this chapter of the sanctioning health care provider's policy about participation in activities covered by this chapter.

"Participate in this chapter":

(1) Means to perform the duties of an attending or alternate physician pursuant to section -31, the consulting physician function pursuant to section -32, the counseling function pursuant to section -33, or the monitoring function pursuant to section -41;

(2) Shall not include:

 (A) Making an initial determination that a patient has a terminal disease and informing the patient of the medical prognosis;

 (B) Providing information about this chapter to a patient upon the request of the patient;

 (C) Providing a patient, upon the request of the patient, with a referral to another physician; or

(D) A qualified patient contracting with the patient's attending or alternate physician and consulting physician to act outside of the course and scope of the provider's capacity as an employee or independent contractor of the sanctioning health care provider.

(c) Suspension or termination of staff membership or privileges under subsection (b) is not reportable or otherwise a basis for action under section 453-7.5 or 453-8. Action taken pursuant to section -31, -32, or -33 shall not be the sole basis for a report or complaint of unprofessional or dishonorable conduct under section 453-7.5 or 453-8.

(d) No provision of this chapter shall be construed to allow a lower standard of care for patients in the community where the patient is treated or a similar community.

(e) Actions taken pursuant to this chapter shall not be grounds for revocation, limitation, suspension, or denial of licenses under section 453-8, so long as the health care provider has complied fully with this chapter.

§ -52 Liabilities. (a) A person who, without authorization of the qualified patient, wilfully alters or forges a request for medication, or conceals or destroys a rescission of that request, with the intent or effect of causing the patient's death shall be guilty of a class A felony.

(b) Any person who coerces or exerts undue influence on a patient to request medication for the purpose of ending the patient's life, or to destroy a rescission of a request, shall be guilty of a class A felony.

(c) Nothing in this chapter limits further liability for civil damages resulting from other negligent conduct or intentional misconduct by any person.

(d) The penalties in this chapter shall not preclude criminal penalties applicable under any other law for conduct that is inconsistent with this chapter.

§ -53 Claims by governmental entity for costs incurred. Any governmental entity that incurs costs resulting from a person terminating the person's life pursuant to this chapter in a public place shall have a claim against the estate of the person to recover costs and reasonable attorney fees related to enforcing the claim.

PART V. FORM OF THE REQUEST

§ -61 Form of the request. A request for medication as authorized by this chapter shall be in substantially the following form:

REQUEST FOR MEDICATION

TO END MY LIFE IN A HUMANE AND DIGNIFIED MANNER

I, _________________, am an adult of sound mind. I am suffering from ________________, which my attending or alternate physician has determined is a terminal disease that has been medically confirmed by a consulting physician. I have been fully informed of my diagnosis, prognosis, the nature of medication to be prescribed and potential associated risks, the expected result, and the feasible alternatives, including comfort care, hospice care, and pain control.

I request that my attending or alternate physician prescribe medication that will end my life in a humane and dignified manner.

INITIAL ONE:

_____ I have informed my family of my decision and taken their opinions into consideration.

_____ I have decided not to inform my family of my decision.

_____ I have no family to inform of my decision.

I understand that I have the right to rescind this request at any time.

I understand the full import of this request and I expect to die when I take the medication to be prescribed. I further understand that, although most deaths occur within three hours, my death may take longer and my physician has counseled me about this possibility.

I make this request voluntarily and without reservation, and I accept full moral responsibility for my actions.

Signed: ___________________________

Dated: _____________________________

DECLARATION OF WITNESSES

We declare that the person signing this request:

(1) Is personally known to us or has provided proof of identity;

(2) Signed this request in our presence;

(3) Appears to be of sound mind and not under duress, fraud, or undue influence; and

(4) Is not a patient for whom either of us is the attending or alternate physician.

__________________________ Witness 1/Date

__________________________ Witness 2/Date

__________________________ Witness 3/Date

NOTE: One witness shall not be a relative (by blood, marriage, or adoption) of the person signing this request, shall not be entitled to any portion of the person's estate upon death, and shall not own, operate, or be employed at a health care facility where the person is a patient or resident. If the patient is an inpatient at a health care facility, one of the witnesses shall be an individual designated by the facility. The form shall contain checkboxes to indicate the status of each witness with respect to these qualifications."

SECTION 2. Chapter 461, Hawaii Revised Statutes, is amended by adding a new section to be appropriately designated and to read as follows:

"**§461-   Compliance with death with dignity law.** Notwithstanding any law to the contrary, nothing in this chapter shall be deemed to prohibit a registered pharmacist from dispensing medications to a qualified patient, the qualified patient's attending or alternate physician, or an expressly identified agent of the qualified patient for the purpose of ending the qualified patient's life in a humane and dignified manner, as provided in section -31(a)(12)(B)(ii)."

SECTION 3. Section 327E-13, Hawaii Revised Statutes, is amended by amending subsection (c) to read as follows:

"(c) This chapter shall not authorize mercy killing, assisted suicide, euthanasia, or the provision, withholding, or withdrawal of health care, to the extent prohibited by other statutes of this State[~~.~~]; provided that death with dignity under chapter   shall not be affected by this section."

SECTION 4. Section 431:10D-108, Hawaii Revised Statutes, is amended by amending subsection (b) to read as follows:

"(b) No policy of life insurance shall be delivered or issued for delivery in this State if it contains a provision [~~which~~] that excludes or restricts liability for death caused in a certain specified manner or occurring while the insured has a specified status, except that the policy may contain provisions excluding or restricting coverage as specified therein in event of death under any one or more of the following circumstances:

(1) Death as a result directly or indirectly of war, declared or undeclared, or of any act or hazard of such war;

(2) Death as a result of aviation under conditions specified in the policy;

(3) Death as a result of a specified hazardous occupation or occupations;

(4) Death while the insured is a resident outside of the United States and Canada; or

(5) Death within two years from the date of issue of the policy as a result of suicide, while sane or insane[~~.~~]; provided that death with dignity under chapter   shall not be considered suicide for purposes of this section."

SECTION 5. This Act does not affect rights and duties that matured, penalties that were incurred, and proceedings that were begun, before its effective date.

SECTION 6. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

SECTION 7. This Act shall take effect upon its approval.

INTRODUCED BY: ______________________________

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