DENYING DEATH: THE MANNER OF DEATH AND DYING IN AMERICA 1946-2014

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ABSTRACT

Denying Death: The Manner of Death & Dying in America 1946-2014

DMH Dissertation by

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Death in America has evolved from a communal family setting, in which the dying individual and family members had control over the process of dying, into a completely different way of dealing with death. Twenty-first century death now takes place in a private, hospital/institutional environment, in which doctors and other medical professionals dictate, while the patient and family members have little or no control. The focus has shifted from the dying person's concerns and comfort to those of the standardized medical procedures in which the doctors, nurses, medical and administrative staff rule. The solitary medical death is the prevailing form in America today.

This dissertation begins with a discussion of the cultural, social, and emotional implications of a natural death through a sixty-eight year period in American history. This work analyzes and evaluates death's unfortunate antagonistic relationship with conventional medical treatment. The emphasis is on death choices made by terminally ill patients and families and the healthcare professional's disregard for those choices. The methodology of activity surrounding the cultural, social, and emotional preparation for the patient is explored along with the activity related to the patient's last days among the living and the effect it has on those who remain.

The research suggests the there is a time to accept the inevitability of death and a right time for healthcare professionals to stop the dramatic rescue-treatment-cure strategy, comfort and care for the patient and refer the patient to palliative care, alternative care or a hospice and/or home care.

This work encourages the creation and development of a new branch of American medicine called End-of-Life-Care; a specialization focused on the dying patient and family. Research highlights similar characteristics of a branch of the UK national healthcare system which has shown to be extremely successful in this aspect of medical support and patient centered care for the dying.

CONTENTS

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Chapter 1

INTRODUCTION

"When a person is born we rejoice; when a person gets married
we jubilate; when a person dies we pretend nothing happened."
Margaret Mead, anthropologist

The title is not meant to mislead. This body of work is focused on changing (denying and defeating) the currently tolerated form of dying in America. Everyone dies; except for traumatic unexpected death, greater than eighty percent of all Americans die in hospitals (*Wass, et al, 1988*), removed from their familiar surroundings, separated from their families and at the mercy of the healthcare rescue-treatment-cure culture. Dying patients very often suffer, unnecessarily, through aggressive therapy, *(Berlinger, Jennings, 2013)* focused mostly on postponing death at all costs, even if just for a few days. As a result of the many advanced biotechnical/mechanical measures of healthcare in the 21st century, too many patients die suffering, unable to communicate, without adequate pain medication and without any emotional or spiritual support.

Not everyone who comes into a hospital for treatment wants or even needs to be cured. Many patients need to be comforted, medicated and treated with care and respect, independent of the rescue/treatment/cure approach. The truth is, many do not want to be rescued; they want to be respectfully treated, medicated and supported, and to be free from pain and anxiety. Modern technological medicine has no place for these patients, no place for comforting and supportive care. A modern hospital is a place where people are rescued, treated, cured and discharged, not calmed or comforted. Supportive care and medication are administered only to extend life and rescue the patient from illness. In a hospital death is viewed as a failure, as an unnatural event, one to be avoided at all costs.

This dissertation recommends an evaluation and a realignment of the relationship between conventional medical treatment and the dying patient's needs during the final stages of life. The focus is on the predominance of the physician's, healthcare professionals and hospital's influence, on the treatment choices and selection of medical procedures, terminally ill patients and their families may make during the end of life process.

This document sponsors the creation of an entirely new specialty for the American medical community called "End-of-Life-Care." This new specialty, "EoLC" would focus on an honest and positive attitude towards dying: as the final journey with the proper psychological, emotional, psychosocial, and family counseling and support along with patient palliative care and hospice care: integrated into a new medical aspect of the dying process. The hub of this new process would be the patient and the family. The methodology surrounding the cultural, social and emotional preparation for dying would be the integration point for modern technological medicine and medical humanities, to come together for the benefit of patient and family.

The current medical approach to dying needs to be restructured into a more humane, patient centered supportive, honest and compassionate environment. Death needs to be viewed for what it is, one of life’s major milestones, the final chapter at the end of life.   The disease/battle rescue-treatment-cure culture of modern technological medicine (*Kiernan, 2006)* must be modified and restrained to consider the humanity of the final "moments" of life, whether that means: months, weeks, or days; of dying people. It is essential that we re-educate physicians, nurses, healthcare workers, and hospital administrators to deepen their understanding of medical humanities and of the needs of dying patients and their families. It is essential that the medical profession re-direct its energy to a more empathetic, considerate and respectful focus on dying patients. To provide care, pain medication, support and empathy to the dying patient, whose circumstance of death can be a valuable and precious legacy to care givers, family members and friends as part of a family history and memories.

“*How people die remains in the memory of those who live on!"*
Dame Cicely Saunders, founder of the
modern hospice movement

The ways in which individuals and societies relate to death and dying have real consequences for our everyday lives because how we think about or ignore death influences how we live *(Howarth, 2007*). Conversely, the way we live affects our beliefs about death and the cultural expressions, artifacts and the behaviors we employ in our relationship with death, dying, and the dead. Perceptions of death and dying have changed over time and can even vary across the same geographical areas within America. Even the same or similar behaviors regarding death can take on totally different meanings at different historical moments.

Death in America has evolved from a private family setting, in which the dying person and individual family members had full control over and participated in the process of dying; into a completely different way of dealing with death. Twenty-first century death now takes place in an organized, obscure, medicalized setting, a hospital environment in which doctors and other medical professionals are in control and the individual and family has little or no power. In this context, the focus has shifted from the dying persons concerns and the family's needs, to those of the standardized medical procedures in which the doctors, nurses and medical staff dominate.

The twenty-first century culture hides death from view. In his classic account of the customs associated with dying the social historian Philippe Aries (*1982)* calls this phenomenon the Invisible-Death. He writes:

> "*Dying is ugly and dirty and we do not tolerate anything that is ugly and dirty. Death is therefore to be secluded and to occur in sequestered places."*

Aries goes on to describe his viewpoint on western death:

> *"The hidden death in hospitals began discretely and became widespread after 1950. Our senses can no longer tolerate the sights and smells that in the nineteenth century were part of daily life, along with suffering and illness. The physiological effects have passed from daily life into the aseptic world of hygiene, medicine and morality. The perfect manifestation of this world is the hospital with its compartmentalized discipline. Although it is not always admitted, the hospital has offered society a place where they can hide the sick from view. The hospital has become the place of solitary death (Aries, Weaver, 1988, p 570-571)."*

Isolating the dying is a cultural symbol of how powerful American medicine has become through the use of highly trained medical personnel, improved treatment, potent medications and access to specialized technological facilities. The solitary death is now so well recognized that our society has institutionalized the process into an acceptable end of life routine. This routine is as processed and packaged as doctors "calling" the time of death (*Dix, Graham, 1999*) and using codified and specialized terminology to record the cause of death on a legal document absurdly called the Certificate of Death, as if you cannot die without one! *(Example of the standard certificate of death can be located in Appendix A)* On the death certificate there are forty-four individual data items to be provided and a number of questions that must be answered according to law.

Though tempting, accepting the challenge to overpower death, twenty-first century American medicine, should struggle to restrain its dream at this boundary. In its headlong objective to postpone death, American medicine has reached its first major plateau. Young death is not absent from medicine, a very small percentage of children and young adults still suffer untimely or traumatic death (*National Center for Health Statistics, 2010-2011*), but by far the largest number of deaths now occur among people over the age of sixty-five. In that population, the percentage of deaths goes up past seventy percent for people over the age of eighty (*Statistical Abstract, US Census Bureau, 2010)*. The statistics show that the greater your age the longer you are expected to live.

Medicine needs to suspend its relentless drive to extend the life of the aged and become more humane toward the dying. Medicine needs to turn its attention to the relief of their [aged] suffering and improve the physical, emotional and mental quality of their remaining life *(Kiernan, 2006)*. So great is the American desire for life and the denial of death that this goal, however noble may not be realized at any time within the next few decades of this new century.

Research shows that, in America, approximately eighty-five percent of all lifetime medical expenses and resources are consumed during the last ten percent of a life span (*Statistical Abstract of the United States, Census Bureau, 2010)*. In consideration of this fact; socially and culturally we need both young and old to recognize that it is possible to live out a meaningful and fulfilling old age, in a finite period of time, without requiring a compulsive and heroic effort to make life [just a little bit] longer *(Keirnan, 2006).*

From a cultural point of view we need to create and accept a supportive social context for aging and dying, one that cherishes and respects the elderly. One that at the same time, recognizes that this country's aging population's primary orientation should not be the welfare of their own age group. The focus of dramatic medical intervention should be on the young and to the generations to come. For the aging population to make an unlimited claim upon limited funds and finite medical resources and to want this frontier of death to be constantly pushed back is dangerous and dishonest. According to a CEJA report from 2010, *(Ethical Implications of Age Based Rationing of Health Care)* from the AMA, Society's medical and healthcare resources should and can be better deployed.

This obsession with extending life represents a failure of our own highest vocation to our society and to us as a species. This demand to harbor a desire for life extension will never help individuals to make sense of the full course of their own lives. It will never serve to identify our generation as conservators of the assets needed by our own children and by future generations.

“The hour of departure has arrived, and we go our
separate ways, I to die, and you to live. Which of
these two is better only God knows.”
Socrates

This dissertation starts with an evaluation of death's ever evolving relationship to conventional medical treatment, healthcare administration and local authority. The focus will be on the cultural, social, and emotional implications of a natural death through the sixty-eight year period in American history from nineteen hundred and forty seven (1946) to the present; two thousand and fourteen (2014). Deaths' toll on the loved ones, surviving family members, care-givers and close friends left behind are explored and discussed. This work will also explore the daily effort, stress, and effect of awaiting the end-of-life of a loved one. The death choices made by terminally ill patients and families and the physicians, hospitals and healthcare professional's participation and predominance in those choices, will be explored. The methodology of activity surrounding the cultural, social, and emotional preparation for the patient will also be studied along with the activity related to the patients last days among the living and the effect it has on the family and friends who remain.

The Main Body of This Research Seeks to Prove Three Hypotheses:

One: America has become a death denying society. Medicine [at large] would rather ignore death, as the inevitable end-of-the life cycle, (*Kubler-Ross, 1974*) then deal with it directly, or deal with it at all. This medical and cultural phenomenon needs to change and adjust to incorporate the truth about death in all its humanity and compassion. Our culture almost completely ignores the life experience of people with chronic illnesses that will ultimately end in death. Evening television programs never cover death realistically; TV programs sensationalize death by advancing violence and mayhem for enhanced ratings *(Nimmo, Combs, 1985).* Newspapers and magazines tell peoples life story only up until retirement age and say virtually nothing of the life led in the ensuing years, however long. Even newspaper obituaries leave out the details and substitute euphemistic expressions designed not to offend. Examples like: he passed-away, God called her to heaven, his youthful life ended; even pictures of people (who died in their nineties) show people as they looked in their thirties.

Two: There is a major lack of truth, honesty and support in the medical community, as it relates to death and to the patients and the families of dying patients. The research will show in terms of terminal illnesses that a serious and detrimental paternalistic attitude of concealment and dishonesty prevails in our American medical rescue-treatment-cure healthcare culture. Due to dramatic developments in technology, medical treatments have become more effective at extending life: the physician's age old duty to treat suffering and provide care, compassion and support for dying patients and their families, is set aside and largely forgotten or ignored *(Roter, Hall, 2006*). Physicians even admit that they routinely withhold valuable information from families and patients, independent of reason when dying patients are involved.

Three: An honest and caring relationship and participation with the dying patient [in process] is extremely important to the family members left behind. Modern medicine does not offer, encourage, or seek to provide an engagement opportunity to patients and their families as dying patients approach death (*Rando, 1991*). Extending life, even for just a few days, becomes the primary and single focus of the professional staff in a hospital. The social elements of the relationship between the care-givers and the dying are a crucial component of the grieving process. The importance of actively engaging compassionately with the dying person is vital for handling loss in a healthy accepting way and for dealing with and managing grief. Without this involvement with the dying patient, the loss of a loved one is extremely difficult to accept.

This work advocates for the creation of an End-of-Life-Care specialty in American Medicine, a specialty that, among other things, would provide organized support, compassion, treatment and direction for both the dying patient and family.

Chapter 2

CURRENT MEDICAL TREATMENT FOR THE TERMINALLY ILL

At the beginning of this, the twenty first century, there is a tension between the fact that the vast majority of Americans die in hospitals and institutions (*Callanan, Kelly, 1997)* against the reality that dying patients (social, emotional and family) needs are not taken into consideration as any kind of a priority. Hospitals which are organized as "medical centers" or "health centers" are focused primarily on curing the living and on the extension of life. Death in a hospital, is viewed as an irregularity; something abnormal, an anomaly or as combat to be fought right up to the end. The cost in pain, grief or the emotional toll the process takes on the patient or family members is virtually ignored.

The "rescue-treatment-cure” culture that exists in medicine today is certainly commendable when applied to trauma patients and patients with a good chance of surviving for a minimum of six months to twelve months or more. This sense of survival must include an expectation of a reasonable quality of life. There must be a limit on how a dying patient is treated in the context of how far treatment can be extended *(Callanan, 2009).* When does the focus change from cure to care? Where is the transition from rescue-treatment-cure to comfort, support, pain management and compassion?

In a large clinical study conducted by the Robert Wood Johnson Foundation *(1995-1998, pp. 1 - 4)* the main conclusion was: more than one third of terminally ill patients (in hospitals) died in pain. The study also showed that more than sixty-percent of patients spent their last conscious hours in isolation from their families, their wishes about withdrawing life support (DNR) all but ignored by medical staff. This study also found that patient-doctor-family communication was at best considered "poor" regarding the patient's condition and the options presented to the dying patient. Modern western medicine has a tendency to withdraw treatment (*JAMA, 2008*) and change attention to care when it is too late, if at all; when death is certain, when the patient is dying (in hours/days) with no chance for recovery.

"He/she was a courageous fighter right up to the end", is the current euphemism used to describe the activity related to dying of cancer. The self-serving assumption of modern technological medicine, is that finally dying shows that the patient did not fight hard enough or even gave up! The current healthcare cliché: "He gave it everything he had but in the end he lost the battle" is preposterous, the very arrogance of medical "paternalism" as if somehow it was the patients fault. "Had he not given up he would still be alive today" modern medicine did everything it could but the patient let us down *(Mendelsohn, 1979).*

Respect for the patient and family, the dignity of the individual as a person; the appropriate information and advice to the family, the right to make his/her own choices in dying as well as living is surprisingly absent from this scenario. Comfort, care, support, consideration, and pain management are not a priority in a modern hospital. These comfort/support issues are considered fluff. Hospitals as large, policy driven, medically focused organizations and the medical staff as official members of this organization, follow standard operating procedures. Their goal is to rescue, treat and cure; not to provide comfort, respect, understanding and support. These “soft” requirements are outside the realm of a modern American hospital.

One of the many studies focused on end of life care, published in the *Journal of Clinical Oncology, (2012, pp: 195-204)* measured the amount of aggressive end-of-life (EOL) care received by 1,231 terminally ill patients with stage IV lung or colon cancer. The patients were part of a cohort, a study that follows a large group of people over time, called the Cancer Care Outcomes Research and Surveillance Consortium – “CanCORS”. The researchers defined aggressive EOL care as actions more likely to try to prolong life than to decrease discomfort. Examples include chemotherapy in the last 2 weeks of life, multiple hospitalizations or emergency room visits during the last month of life, being in an acute care hospital for at least 14 days in the last month of life, admission to the intensive care unit in the last month of life, and the use of medical interventions such as defibrillation, cardiopulmonary resuscitation, ventilators, or intubation. These findings were discouraging.

Doctor Jennifer Mack, the leader of the study, said:

> *"One of the downsides of patients' spending their last days in the hospital is that they're giving up that time at home with family or friends. The idea that aggressive care is life-prolonging care is potentially a misconception. I worry about that when I see patients opting for aggressive measures. Measures that may only yield a few more days or weeks. But for some, it's important to feel they did absolutely everything."(Mack, 2012, pp. 195-204)*

PERSPECTIVE

During the period after the American Civil War and extending up to nineteen hundred and fifty, eighty-five percent of all deaths took place in the home and less than ten percent of people died in public institutions. The remaining difference of five percent was made up of people who died destitute or without family or without identification and their bodies remained unclaimed. Subsequent to the turn of this century, over eighty percent of all deaths *(National Center for Health Statistics, 2013)* now take place in public institutions: hospitals, nursing homes, assisted living facilities, mental institutions and long-term care facilities. The hospice movement, (which started in the UK and was then introduced into the USA in the early 1980's) emphasizes "home-style" care for the dying. Hospice now cares for approximately eight percent of all dying patients in the USA.

Hospitals that provide a separate palliative care facility, handle approximately five percent, and only seven percent (the remainder) of patients die at home *(NCHS, 2013).*

Even now American society has not begun to understand the special needs of the dying. Too often people do not get the support they need to face the personal issues that surround death. Although everyone would agree that a peaceful, painless, "comfortable" death is a worthy goal it is nowhere near a patient right nor achievable goal. Many studies (*Tobin, Lindsey, 2011)* verify what people experience over and over; the current medical system lacks the training, perspective, and humanity to offer patients a peaceful, comfortable, pain-free end-of-life. The Institute of Medicine's publication (*Field, Cassel, 1997), Approaching Death: Improving care at the end of life* demonstrates the need to change a healthcare system that allows too many people to suffer pain and other distress that clinicians and medical staff could easily prevent or relieve. Another study of similar nature, published in the *"Journal of the American Medical Association*" (*JAMA, Nov., 1995)* found that over sixty-five percent of patients die in moderate to severe pain and that living wills are frequently ignored by the medical staff while treating the patient.

The problem goes far beyond a simply medical one. Modern medicine has all the tools necessary to make dying physically comfortable and pain free, there are current medications that can alleviate any pain a dying patient might experience. There are other pain medications that are used commonly throughout Western Europe (*that do not depress the central nervous system*) that are forbidden here, because they are “addictive” (*de Ridder, 1996*). The fact that so often these tools go unused speaks to a far deeper problem, denial of death itself by the medical profession at large. The simple truth is when we avoid facing death we cannot do the work necessary to reach any level of preparation for dying. Just because dying is natural and inevitable, however, it does not necessarily follow that it is going to be easy. Having a level of guidance, understanding and support would be a great help. Dying is a natural part of life. It should not be treated as a disease with endless procedures that serve only to create terrible discomfort and perpetuate the illusion that with enough machines and enough medication we can defeat mortality indefinitely.

Sadly much of our culture has come to view a good death as synonymous with a planned and assisted suicide (*Blauner, 2003*). The specifics involved in end-of-life events, can be organized, planned and controlled to make a shift possible from cure based medicine to a care based system. Recognition of the importance of a peaceful and comfortable death will create a demand for programs that help people die with dignity and comfort. A culture that routinely uses methods of "peaceful and comfortable" dying will in time realize that such programs have a strong effect on the entire community. Nowhere is the opportunity for teaching and incorporating this wisdom and compassion into

American medicine, more important than how we treat our dying patients, as human beings.

BRIEF MEDICAL HISTORY OF THE DYING PROCESS

To understand our current medical system and its potential for helping people, specifically in terms of the current treatment toward the dying we need to look at some of the basics of the history of American medicine. Medical history *(Porter, 1999)* shows that there has always been some form of medical practice involving the healing arts but with limited technical resources. Medical practice was originally based on the concept of preventing further illness, helping the body heal by responding to disease and administering to the suffering patient with a great deal of care and compassion. The basic idea was to prompt the body to heal itself and create a quiet and stable mental and emotional state where the patient could "renew" both physically and spiritually.

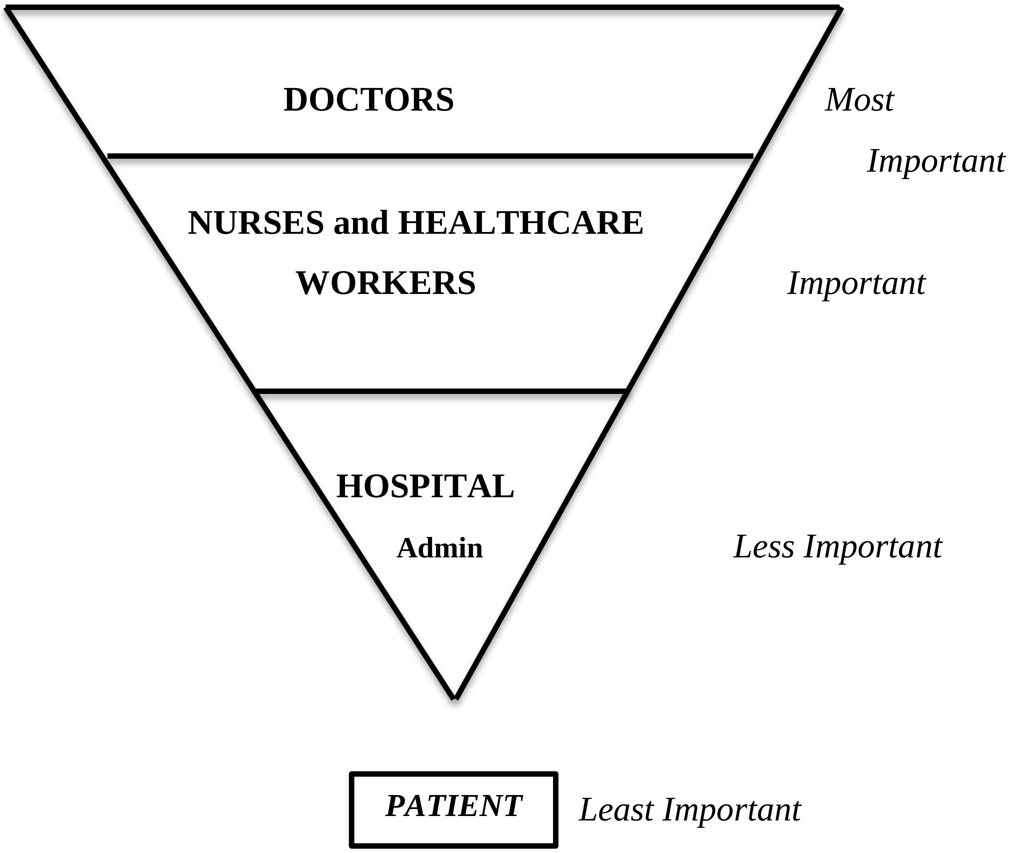
In consideration of the modern Medical Humanities view; a spiritual component to understanding the relationship between illness and healing has always existed throughout the history of medicine. A person's spirituality often leads to various forms of celebration at regular milestones and as a regular part of living. Integration of what we now call mind-body medicine has a certain spiritual component and is seen throughout the evolution of medical philosophy. Here the mind-body connection can be defined as the understanding that emotions can affect disease as well as effecting healing and wellness. Historically, physicians always placed great emphasis on caring for the emotional needs of the dying person *(Miller, 2014*) and understanding that dying "well" meant dying comfortably, surrounded with family whenever possible.

MEDICAL HUMANITIES' A NATURAL APPROACH

Perhaps the greatest limitation of modern western medicine has been its refusal to acknowledge the inevitability and naturalness of death and how important a part of life it is. The passion to enhance and prolong life is wonderful, to a point. This passion is probably (largely) responsible for many of the great advances of modern medicine. But when it does not take into account the simple fact that at some juncture life cannot and should not be prolonged, it creates suffering rather that preventing suffering. If American medicine cannot accept dying as a natural part of living and embrace the dying process, we neglect people when they are at their most vulnerable, most alone, and most desperately in need of love, comfort and a very specific kind of care and understanding. With the best of intentions medicine sometimes inflicts treatments on patients that are extremely painful and neglects the patient's real needs.

Over the past sixty-five years American medicine has grown into a huge business currently surpassing three trillion dollars annually and almost twenty percent of the GDP (*Kaiser Foundation, 2013*). Many significant trends, including the creation of fee-for-service delivery of healthcare services, have caused dramatic changes in the ways nurses, doctors, and healthcare providers relate to their patients. Our American system is also transforming itself even further, into new multiple managed-care models, where people now find themselves at the bottom of an inverted pyramid desperately trying to secure good quality healthcare.

Insert inverted pyramid example here



"Inverted Pyramid" of American Healthcare
Services delivery, showing the patient at the bottom.

Purdue/OWL, 2014

***Note**: In a hospital, Patients are assigned and treated as a series of Numbers,*
IE: Vital signs, test results, patient number, SS number, lab number,
billing numbers, insurance numbers, Medicare claim number, etc.
Another track is to call the patient by his/her medical condition
IE: "give this medication to the tumor in room 338"
Is there any wonder why patients are "faceless?"

Include the new Affordable Health Care Act of 2008 in this mix. All these conflicting pressures result in the doctor patient relationship becoming seriously challenged, worsening the difficulties in the end-of-life care realm. This is a doctor/patient relationship that has historically been based upon intimacy, trust, and the belief that the best medical decisions regarding treatment can and will be made for the benefit of the patient. To continue this trust relationship the public must be able to see a significant change in the way in which doctors manage end-of-life situations and the manner in which they treat dying patients.

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THE "BIRTHING" REVOLUTION

It may be useful here to look at a good example of a dramatic change in our healthcare system in a relatively short period of time: "Birthing." The women's healthcare movement has fought for and won many changes in our western culture's approach to child birth (*Leavitt, 2009*). For generations, doctors dictated the specifics of childbirth and obstetrical care and subsequently women were forced to give birth in a highly specialized and formulaic manner.

Women were confined to a hospital bed, usually anesthetized and kept from participating in the birth effort. Although this is now rare (in some cases) it is no longer the norm. Today, women deliver children in the positions they request, in specially decorated delivery suites, sometimes at home, surrounded by family and friends. A large percentage of women patients now opt out of medication of any kind during childbirth. Fathers who were forced to wait outside the room during the birth of the child are now welcome participants in the process. Sometimes close friends and family members are participants (*Mayo Clinic, 2013).* The number of women who give birth at home has increased dramatically and many are using the original healthcare professional for child birth the "midwife."

Once the initial shift in consciousness developed, economic forces and demand pushed greater changes in the procedure of obstetrical healthcare. Women realizing these changes were taking place began to demand new approaches and techniques which brought greater and speedier transformation, this philosophy resulted in a far superior situation for all: mother, child, father and family. Additionally many fathers wanted and demanded to become a part of the birth process rather than being kept away until the child was born.

We may learn from these efforts and apply them to supporting dying patients and enhancing the dying process. Just as the women's health movement has succeeded in changing the way we treat childbirth restoring it to a more natural approach, so we can create a course of action and participate in shifting the way the current medical system treats the dying patient. The demand for compassionate natural caring and support needs to be implemented as the standard of care in medicine when people are dying.

"You will never change things by fighting the
existing reality. You must build a new model
that makes the existing model obsolete."
Buckminster Fuller, Futurist

The single largest deficit in support of the dying patient is communication. This deficit is not just between the patient and physician, but exists at all levels of communication; administration, nursing, social work, healthcare insurance, family, and support structure. The issue of communication has been identified in the medical literature *(Katz, Capron, 2002)* as the most important area worth addressing in American medical schools. The publication "Medical Clinics of North America" *(Teutsch, 2003)* clearly states that traditionally communication (among doctor, patient and family) is not taught directly in medical schools. It is taught obscurely, through patient rounds and faculty feedback and criticism, but not directly, in a class by itself. Over the course of a physician’s training in medical school gaps develop and the students who graduate as doctors do so with a huge educational void. As a result physician's abilities to comprehend a patient's perspective of illness is diminished, causing distrust of the medical profession in general and a loss of wholeness and values of the patient as a person. Evidence of this attitude is manifest in a small but significant percentage of physicians who will refuse to further treat a patient who seeks a second opinion from another physician *(Klitzman, 2008, p:1-2*). Doctor Robert Klitzman's NY Times article (as a patient) states:

> *"When I went for a second opinion, my internist got mad, a physician with lymphoma recently told me. As if I were his lover and had cheated on him. Historically in medicine, there is a paternalistic approach to deciding what should be done for the patient: the physician knows best and the patient should accept that recommendation without question." (Klitzman, 2008, pp: 1-2*).

Still, in medical school detachment begins with the first gross anatomy laboratory class. Students report being instructed to emotionally detach from the cadaver, *(Thomas, 1978)* as a person and view it as a dead organism or as biological specimen to be used as a leaning tool. This is also accompanied with highly specific medical jargon and "graveyard humor." These mechanisms *(Watson, 2011*) enable students to disengage their emotions at appropriate times. However, these mechanisms become inappropriate when used in other medical situations or carried over into the situation where a patient is concerned. A July

2005 study published in *Academic Medicine* examines student's emotional reactions to their "most memorable" patient death and any support they received. The study included sixty-five graduates of two American medical schools.

> The study *(Rhodes-Kropf, 2005, pp: 634-640)* describes that *"this informal or hidden curriculum may also be a powerful influence on students experience caring for dying patients"*.

According to Dr. Jennifer Rhodes-Kropf, this is how students are expected to react and cope with the difficult emotional situations they face as physicians. This serves as their first opportunity to "act like a doctor" and make the transition from student to doctor. As expected, students experienced strong emotions to their most memorable deaths. Most students report "extremely inadequate" support from supervisors and practically no discussion of death in sixty-three percent of the cases. Dr. Rhodes-Kropf *(2005)* further sites a teaching hospital's study in which thirty percent of students who cried in response to an emotional experience with the death of a patient were ridiculed, viewed with contempt or chastised (by supervision). The study concludes with:

> *"The informal curriculum may thus be teaching students to avoid or deny their emotional reactions to patient's deaths and the resulting consequences." (Rhodes-Kropf, et al, 2005, pp: 634-640).*

Medical students in a University of Pittsburgh study (conducted between 2001 and 2005) showed that they coped with their patient's death experiences in varying ways: engaging in activities aimed at forgetting the event (movies, TV or reading) or focusing on work, on studies or praying. None of the students reported speaking to medical school faculty or pursuing school structured resources (available) for support. Students expressed that their expected reactions to patients deaths must be unemotional, otherwise they would be considered a sign of medical care failure. Discussion of sadness at any level was non-existent. The conclusion was that emotionally diminishing the power of death does not eradicate its essential command of life. The study suggests that engaging in such efforts produce: physician burn-out, emotional depletion, depersonalization, and a sense of low personal accomplishment. The study recommends self- reflection, normalizing physician emotion and discussing its presence as a part of the ever intimate nature of physician's relationship to the dying patient *(Anderson, et al, 2008, 11: pp: 1227-1233).*

Doctor Pauline Chen in her book *Final Exam: A Surgeon's Reflections on Mortality (2006)* writes of her organ harvesting experience as a liver transplant surgeon-in-training, she unexpectedly encounters a profound exhaustion and unbearable grief during her eighty third organ procurement. Why would this now (almost) common experience produce such an uncommon effect? She begins the meticulous surgery, on a "brain-dead" patient who is breathing with the help of a respirator, as an ingrained rote process, completed eighty-two times before, during which she notes:

> *"The undulation of each rib and the gentle fall of breast tissue to her side. Her nipple and areola peeped through; they had the coloring and shape that I had seen on only one other person: myself. It was as if I were standing naked after a shower, looking in a mirror. As we snipped away at the organ attachments about to take her liver, pancreas and kidneys, I tried to ignore the aliveness of her body, to believe that she was only a cadaver, but then, in my sleep deprived state I found I could not bear to think of her - of myself- as dead. I watched her blood fill the canisters on the floor, I felt as if my own life force were draining away." (Chen, 2006, pp: 200-201)*

Clearly, even a highly trained and experienced surgeon cannot detach so completely as to escape such human emotion as viewing her own “corpse”. Doctor Chen is one of the lucky physicians. She wrote about this emotional experience and was neither ridiculed nor ostracized by her peers and supervisors in her hospital. So far she has successfully removed the chains of "detachment" and allowed reality and humanity to penetrate the shield of antiquated medical training. She and many other contemporary physician authors provide a viable solution to a complex yet solvable problem. She helps the medical profession and herself through public exposure to her medical narrative, contributing to the essential storehouse of literature on medical humanities. Doctor Chen's exposure illuminates the deep emotion inherent in medical students and physicians.

Medical Humanities research supports a role for writing personal narratives as a disease reduction process (*Pennebaker, 2004)* and a stress reliever providing an applicable and worthwhile method for relieving this stress. Many psychological studies over these past thirty years show that the simple act of writing about emotionally painful experiences heals. This process has been proven to work for both sick patients and sick doctors. Noted psychologists and leaders in the field of writing for healing James Pennebaker and Sandra Beall *(1986)* reported in their research on undergraduate students asked to write about personally traumatic life events. The study results published in T*he Journal of Abnormal Psychology in 1986,* demonstrated that writing about the emotions and facts surrounding traumatic events may initially raise blood pressure and produce post writing negative moods but then results in fewer health related problems over the subsequent six months.

In another report on a similar subject, a study in the *Journal of the American Medical Association (1999)* on one hundred and seven patients (107) showed clinically significant medical improvement in suffering with chronic life-altering conditions of severe asthma and rheumatoid arthritis. The patient's improvement was achieved through writing about stressful events in their lives, with the positive effects lasting more than six months. These positive outcomes would work if applied to life-altering illnesses affecting doctors and healthcare professionals in the medical community *(Smyth, Stone, 1999).*

FEAR OF FAILURE

In our current healthcare culture the strong personalities of doctors can be psychologically linked to a fear of failure. Evidence of this is available in a study conducted by the American Journal of Medicine in 1994. We see confirmation of a need for situational control which greatly exceeds what most people would find reasonable *(Schniderman, Faber-Langendoen, 1994).* The physician's perception of loss of control can also be manifest in extreme impatience with the patient and family. In a vain attempt to maintain control, a doctor, will "know better" than the patient and even the family. Subsequently, he dispenses only as much information as he sees fit, and manipulates the remainder thereby exerting powerful influence on a patients decision making in ways that are self-serving for the doctor.

This kind of paternalism is precisely the kind that physicians display in today's complex biotechnological and pharmacological culture. For a clear example of "I know better" thinking we quote Dr. Sherwin Nuland *(1995*) in his book *How We Die,* he characterizes this fuzzy thinking perfectly.

> *"Beside me lies the chart of Hazel, a ninety-two year old woman from a convalescing unit of a senior citizens residence complex in New Haven Hospital. Although mentally alert she required nursing care because of such advanced arthritis and arteriosclerotic obstruction in the arteries of her legs that she could no longer walk unassisted At the time her acute illness, she was on the semi-elective list for amputation for one of her toes on her left foot, which had become gangrenous. She was taking anti-inflammatory medication for severe arthritis and was in remission from*

chronic leukemia.

At noon on February 23 she fell to the floor unconscious. An ambulance took her to the emergency room of the Yale-New Haven hospital, where she had no measureable blood pressure; the physical findings were consistent with severe peritonitis. After the rapid intravenous infusion of fluids, she was sufficiently resuscitated to undergo an x-ray examination, which revealed a large amount of air in her abdominal cavity. The diagnosis was clear; she had a perforated digestive tract and the most likely source was an ulcer of the duodenum, just beyond the stomach. By then completely alert and rational she refused an operation. She told me that she had been on this planet quite long enough and didn't wish to go on. There was no one, she said, to live for; the space on the top of her chart for next of kin bode the name of a trust officer at the Connecticut National Bank. To me her decision made no sense. I used every argument I could muster trying to persuade her that the crystal clarity of her brain and the responsiveness of her leukemia treatment meant that she had many good years ahead l was completely frank in telling her that, given the state of her arteriolosclerosis and the peritonitis, her chance of recovery was one in three. But, I said, one in three is a lot better than certain death, which is what will happen if you don't let us operate. She remained adamant and l left her alone to think about it, her chances of survival decreased as the minutes ticked by. I returned later to start on my convincing again. She was upright on the bed, scowling at me as though I were a middle-aged naughty boy. She reached out and took my hand, staring directly into my eyes as though charging me with a grave mission for whose failure she would hold me personally responsible. I'll do it she said but only because I trust you. Suddenly I felt a little less sure that I was doing the right thing. We operated and during the operation I discovered a duodenal perforation so *massive that its repair required much more extensive surgery that we anticipated. The stomach had become almost completely separated from the duodenum; her abdomen was filled with corrosive digestive juices and whole undigested pieces of the lunch she had eaten a few minutes before collapsing. I did what was necessary, closed the abdomen and admitted her to the surgical intensive care unit. She had inadequate respiratory drive to breath so the anesthesiologist tube remained in her windpipe.*

At the end of the week, she was improving, although not mentally alert enough to understand what was happening around her. Finally her mind cleared completely and until the breathing tube could be removed from between her vocal chords she spent every minute of my twice daily visits staring reproachfully at me. When she was able to speak, she lost no time in letting me know what a dirty trick I had pulled by not letting her die as she wished. I indulged her in this, certain that I had done the right thing and with living evidence, I thought to prove it. She had, after all survived. But she saw things differently and didn't hesitate to let me know that I had betrayed her by minimizing the difficulties of the post-operative period. I knew she would have refused the saving surgery, if she had been aware of the kinds of things elderly arteriosclerotic people often endure, in surgical intensive care units. I had, in my description of the postoperative days, seriously played down what she could realistically be expected to experience. She had been through too much, she said, and didn't trust me anymore. She was obviously one of those people to whom survival was not worth the cost and I had not been completely forthcoming in predicting what that cost might be. Although my intentions were only to serve her welfare, I had withheld important information because I was afraid that the patient might use it to make, the wrong decision. Two weeks after her transfer back to the residence unit she suffered a massive stroke and died a

> *day later. In keeping with the instructions she had written in the presence of her trust officer on his first visit after her hospital discharge, no attempt was made to give her anything but nursing care. She wanted no repetition of her recent experience and emphatically said so in her written statement. Although the trauma of her peritonitis and the surgery had obviously strengthened the likely hood of her stroke, I knew that her continuing anger and the stress of loss of control at my well intentioned deception also played a very big role. But perhaps the most important factor in my patient's death may simply have been her wish not to continue living which had been frustrated by my ill-advised operation. I had won over the "riddle" of American healthcare but lost the greater battle of humane and sincere patient care.*
>
> *Had I carefully considered the factors I have described in my books on aging I would have not been so quick to recommend an operation. For Hazel the effort was not justified, no matter what success might have resulted and I was not wise enough to recognize it. After many years of experience I see things differently now. Had I the chance to relive this episode, or another like it in my career I would listen more to the patient and ask her to listen less to me. My objective was to grapple with the healthcare [rescue-treatment-cure] requirement; hers was to use this sudden illness as a gracious way to die. She gave in only to please me." (Nuland, 1995, pp: 250-252).*

Doctor Nuland’s story is first-hand evidence of the "rescue-treatment-cure" culture which exists in most medical facilities today. He continues to say that there is a lie in the last sentences of his story. He implies that he could have acted differently and risk the scorn of his peers and possibly disciplinary action, by the hospital administration. However, he knew he would have done exactly the same thing again.

Ethicists and moralists end up being stranded on the “low ground” in such matters. They cannot see the trenches from their own distant viewpoint when they try to judge the actions of bedside doctors involved with patients. The unwritten but influential code of the surgery profession demands that no patient as salvageable as Hazel be allowed to die. If a straightforward operation can save her, regardless of her own wishes, the attitude is to go ahead and operate!

Dr. Nuland offers a view that this was a strictly clinical decision and ethics should not have been a consideration. Physicians who break this fundamental rule do so at their own peril. Had Dr. Nuland let Hazel have her way he would have had to defend the result at the weekly surgical conference where it would be seen as his decision to make, not hers. His colleagues would certainly view his decision as case of poor judgment if not down-right negligence. Their judgment was that he had a clear duty to save a life regardless of any situation. This is the essence of our paternal American medical philosophy. Her wish [to end her life] would be seen as senseless and irrational to these doctors. They would certainly criticize Dr. Nuland for his failure to overrule such an obviously stupid request from an irrational old woman. Does the mere fact that an old woman wants to die mean you should be a party to it? Would be their question! One way or another the rescue-treatment-cure creed of modern biotechnological medicine wins out, independent of the patient’s wishes. *(Nuland, 1995).*

Dr. Nuland's treatment of Hazel is indicative of similar scenarios played out at hundreds of hospitals across the country. His decision and advice were based upon his goals not hers. In an astonishing admission of truth he confesses that it was also based upon the accepted/unwritten code of his specialty, which was surgery.

He admits that his pursuit was futile, she was deprived of her hope; the hope that she could leave this world without interference and hassle, when the opportunity arose. Even considering her lack of family, the doctors and hospital staff could have seen to it that she did not die alone. Instead she suffered the fate of so many of todays hospitalized dying: separated from reality by the very biotechnological and professional standards that are meant to return people to a meaningful life.

The physician's "age old" duty to treat suffering and provide support for the dying and their families remains largely forgotten, as medical treatments and drugs become more effective at extending life. There is more than ample evidence *(Webb, 1999)* in many studies that modern high-tech medicine does not even do an adequate job of providing palliative care for dying patients. Medical Humanities is sadly lacking in this rescue/cure scenario.

Too many patients still die in acute care hospitals *(Callanan, 2009, pp: 229-230)* where their final days are dominated by futile technological interventions that aggravate rather than alleviate suffering. According to Dr.

Maggie Callanan:

> *"There is a reluctance by medical professionals to accept the inevitable and face the possibility of patient death. Hospice care is then usually offered very late or not at all. Many patients and families are thereby deprived of the opportunity to achieve comfort and a meaningful closure to their lives to say nothing of losing access to adequate pain relief and a multi-disciplinary team of expert support services." (Callanan, 2009, Appendix C*)

Additionally many doctors, regulators, family and even patients *(Webb, 1999)* still have irrational and unrealistic fears about addiction, and insufficient knowledge about the effectiveness and availability of modern pain relief. Although there are small signs that improvements can be made, physicians and healthcare providers are still not adequately trained or encouraged to communicate openly with dying patients and families, nor to provide adequate pain management. Furthermore, the multidisciplinary team support for at-home care hospice programs becomes available only to those with proper insurance and a relatively certain prognosis of three months or less (*Stoddard, 1978*).

Dr. Mildred Solomon of the Education Development Center Inc., in Newton, MA*, (Soloman, 1993, pp:14*) conducted a survey published in the American Journal of Public Health, *(AJPH)* the results:

> "*Doctors and nurses say they frequently violate their own personal beliefs*

> *and ignore requests from patients to withhold life support in cases of terminal illness." (Soloman, 1993, pp:14*)

The doctors and nurses interviewed also admit that they often deliberately fail to provide adequate pain relief for dying patients in hospitals, despite the patients' expressed wishes to be spared severe pain. The study concluded with the statement:

> *"The lack of relief and the unwanted treatment occur even though laws, courts and hospitals support carrying out such requests*." *(Soloman, 1993, pp:14*)

This survey was conducted through a one hundred and twenty-three item questionnaire completed by fourteen-hundred (1400) doctors and nurses at five major hospitals in different parts of the country. The findings of this detailed survey of medical practitioners, *(Soloman, pp: 14, 1993*) point to a wide gulf between rapidly changing societal beliefs about appropriate treatment and the actual practice of medicine in the trenches. Nearly half the attending physicians and nurses and fully seventy percent (70%) of resident physicians reported acting against their conscience in over-treating terminally ill patients, even when there is no chance for recovery and death was considered imminent.

Additionally, four times as many of those surveyed were concerned about burdensome overtreatment as were concerned about under treatment of dying patients. These results suggest that medical personnel are substantially contributing to the uncontrolled escalation of health care costs while ignoring patient' desires and family requests. In the final stages of a terminal illness, hospital care can cost upwards of one hundred thousand dollars per visit or more and divert scarce medical attention and costly resources away from other patients who have a chance to improve or even recover *(Soloman, 1993*).

Along with the report, Nancy Dubler, a lawyer and bioethicist at Montefiore Medical Center in the Bronx, New York, wrote:

> *"The survey indicated that a patient's last days may not be as comfortable and pain-free as good medicine and humane care should demand."* Dubler also added that: "*research shows a huge-chasm continued to separate abstract legal and moral principles from the messy reality of actual patient care."* (*Dubler, 2001, pp: 1512-1517*)

The researchers found that a significant percentage (over 25%) of medical personnel were often unaware of national directives and hospital policies that sanction decisions to withhold or withdraw aids like respirators, kidney machines and other treatments. This included feeding patients by tube or vein, which can prolong life in the terminally ill. In the everyday application of medical care legal milestones and rulings are routinely ignored. Since the landmark court decision in 1976 that allowed the removal of life support from Karen Ann Quinlan, who spent the last years of her life in a coma, there has been a wave of directives defining what is legally and ethically appropriate in caring for dying patients. These rulings and recommendations have come from Presidential commissions, major professional organizations in medicine, law and ethics, and state and federal laws and numerous court decisions *(Kinney, et al, 1994).*

Despite some differences in details, in all cases the directives endorse the obligation of doctors and nurses to respect the expressed wishes of dying patients if they choose to withhold treatments that might prolong their lives and hence their suffering. The directive’s also call for the administration of adequate pain relief, without fear of causing addiction or hastening death, so that patients can die with dignity.

Yet, according to Dr. Solomon (*Educational Development Center)* and her co-authors, in a New York times article *(Brody, 1993, pp: 1)* two-thirds of the health professionals surveyed said they were dissatisfied with the way patients were involved in treatment decisions, and eighty-one percent of respondents agreed that the most common form of narcotic abuse in caring for dying patients is under-treatment of pain not over-treatment. In a 1993 editorial accompanying the EDC report, Dr. Bruce C. Vladeck, president of the United Hospital Fund of New York, noted that actual clinical behavior continues to diverge from the consensus about what is appropriate, but not because clinicians disagree with that consensus, but that changing organizational behavior is far harder than changing individual attitudes. *(Vladeck, 1993).*

As a positive step forward, the Education Development Center, in conjunction with The Hastings Center, a bioethics institute in Briarcliff Manor, N.Y., is attempting to develop a program called Decisions near the End of Life *(Coleman, Drake**,** 2014)* for use at hospitals and nursing homes around the country. The program first assesses prevailing views of the hospital staff, and then provides education and training to improve the care of terminally ill patients. Dr. Solomon said indications from a preliminary analysis of the results of the program in various institutions are very encouraging. This type of program would make a difference in changing institutional policies and in reducing the anxieties of medical personnel and the suffering of patients and their families." (*Educational Development Center, 2009).*

According to a study of the terminally ill by JAMA, doctors are still ignoring patients' last wishes even after thirty-five years of public outcry and milestone legal decisions by the highest courts covering the right to die with dignity. This study, in the Journal of the American Medical Association, *(1995)* found that doctors often misunderstand and then subsequently ignore the patients' requests. The result that large numbers of people still die alone, in pain and tethered to mechanical ventilators in intensive care units.

A generation ago the living will movement began. Living-wills and advanced-directives, which are supposed to give terminally ill patients legal safeguards against unwanted medical treatment, offer virtually no protection, according to the results of this study.

> "*People think advance directives are solving the problem*" said Dr. Joan Teno, one of the directors of the study. *"We have very good information that they aren't, that nothing has changed: the amount of pain at the end of life, the number of people dying alone attached to machines is still the same." (Journal of General Internal Med, 1998, pp: 439-446)*

The study, financed by the Robert Wood Johnson Foundation (*1995*) found large gaps between what the patients wanted and what they got. Thirty-one percent of patients said they did not want cardiopulmonary resuscitation, but close to seventy percent of the doctors either ignored or misunderstood their patients' wishes. Over forty percent of the patients who wanted to avoid cardiopulmonary resuscitation by having their doctors write (DNR) do-not-resuscitate orders did not get their wish. The patients who did, had to wait days, in some cases weeks for the doctors' orders to be posted to their charts.

In the first phase of the study the research showed that depending on their medical specialty, doctors took the unbelievable average of twenty-two to sixty-five days to write the orders after the patients requested them. Additionally, an astonishing forty-six percent of the orders were finally written within two days of the patient's death. Half the patients spent eight or more days in what the researchers defined as an undesirable state, comatose or receiving mechanical ventilation in an intensive-care unit. More than half of all patients were also in moderate to severe pain during their last three days of life.

The second phase of the study tested a system called "SUPPORT", designed to help patients avoid pain and unwanted life-prolonging treatments by fostering better communication between them and their doctors and nurses. Nurses met daily with each patient or the patient's family to discuss the patient's wishes for treatment and then relayed this information to the doctors and the other hospital staff. *(JAMA, 1995).*

After phase two, there was no overall change in the percentage of DNR requests that were written, nor the amount of time it took for doctors to write them, nor the number of days that dying patients spent in undesirable states and the percentage of patients who died in pain. "*The findings were startling to us,"* said Dr. Knaus, *(ACS, 2013)* who was chairman of the department of health evaluation sciences at the University of Virginia in Charlottesville.

> "*Everyone from the American Medical Association to the American Cancer Society said that if you increase communication between patients and doctors and give doctors information on likely outcomes, you would decrease the amount of unwanted medical intervention. But that didn't work" (SUPPORT study results, West Jour. Med, 1995, pp: 250-257).*

Since the doctors were told of the patients' medical status and wishes for or against aggressive treatment, researchers could only conclude that many doctors made the conscious choice to disregard information. Dr. Knaus and several others *(AMA, 1995)* said that

> *"The fault lay not with the individual doctors but with every facet of the medical system, from the way doctors are trained to the way they are paid. Physicians are not trained to have conversations about dying with their patients,* Knaus said. *Doctors feel uncomfortable doing it, so they avoid it." (SUPPORT study, West J. Med, 1995, pp: 250-257).*

Another example of a type of medical neglect of the dying comes from a palliative care physician, Dr. Daniel Matlock, written in an article titled *Among Doctors, a Fierce Reluctance to Let Go.* Dr. Matlock, *(2012)* a geriatrician who specializes in palliative care, was called to consult when a woman in her seventy's arrived at the University of Colorado, Hospital unresponsive after a major stroke. She had done what we are forever chiding people for not doing: she drafted a very specific advance directive and had even taken the trouble to have it notarized. It unambiguously said: no life support, no artificial nutrition or hydration, no nursing home. The ambulance crew had put her on a ventilator, which is standard procedure. After the palliative team removed it, the woman was able to breathe on her own, which is not uncommon. She even opened her eyes, though she could not track or follow objects and remained unresponsive. At that time the prominent surgeon directing her care ordered intravenous fluids.

Dr. Matlock, alarmed at this direct contradiction of her preferences, talked with the patient's sister, who held her medical power of attorney. Dr. Matlock called the surgeon to suggest stopping the intravenous feeding tube. The surgeon said to the patient's sister:

> "*You would have been hung in World War II for doing what you are asking me to do now*." *(Matlock, 2012, pp: 1-2)*

So far all the research and multiple studies (*of this advanced-directives phenomenon*) show that as incredible as this incident may seem this is more the norm than the exception. Within a few days, the woman was transferred to a hospice unit, where the intravenous feed was removed and she was permitted to die. However, Dr. Matlock's anger at his colleague and his sorrow at the woman's treatment, or actually mistreatment, has persisted.

> "*You work so hard to do what's right for the patient* ", he said. *“Administering fluids to a dying patient increases the person's secretions and makes breathing more difficult. Dehydration is a much gentler death, with less agitation. But quite apart from that, the woman had done everything but stencil "no IV" across her forehead.”* A palliative care consultant, however, could not overrule the surgical team whose patient she was. *"I went home that night feeling really bad."* Said Dr. Matlock. *(Matlock, 2012, pp: 1-2)*

His account of this unpleasant exchange, almost a year later prompted a startling study published in *Mayo Clinic Proceedings (2012*). After surveying nearly seven hundred physician-members of a national hospice and palliative medicine organization, the authors report that more than half had at least one experience in the past twenty-four months of another physician or health care professional referring to their treatments as "euthanasia," or "killing" or "murder." This, despite palliative practices being broadly accepted as legal and ethical, as reducing suffering while honoring patients' autonomy, the report concluded that patient autonomy still goes unrecognized or unacknowledged.

The study found that twenty-three percent of the respondents had heard similar accusations from a personal friend or family member. Incredibly, over twenty-five doctors (four percent of the respondents) reported having been formally investigated on the question of whether they had hastened a patient's death.

> *"It was cathartic for me" to read the study*, Dr. Matlock said. "*It was helpful to know I wasn't alone, but it's not exactly reassuring news for the rest of us. We've had frequent discussions here of end-of-life care and why the good-death so many people want proves so elusive. We can, with ample reason, blame physicians who don't want to talk or think about dying patients.”*
>
> *“A favorite joke among hospice workers, who tend toward a dark sense of humor: Question: Why are coffins nailed shut? Answer: To signal oncologists when it’s time to stop administering chemotherapy!"*
>
> *(Matlock, 2012, pp: 2-3).*

Some physicians in the study responded defensively with their own stories of family members who will not accept that further treatment is futile and urge another operation, another drug, another something. There is still an additional part to this dynamic:

> *" Even when the system works as it's supposed to, and palliative care specialists arrive (like the cavalry) to provide comfort care, to stop fruitless and painful interventions and to support what patients want, their own colleagues may brand them murderers. It takes doctors with strong personalities to stand up to that kind of verbal abuse, to calmly explain that courts and ethics committees have approved care that is intended to reduce suffering, to point out that the patient's own wishes are paramount. Perhaps they have to be stronger than we know. The culture needs to change.*" Dr. Matlock commented in an interview after the survey was evaluated: *"But it has not changed yet." (Matlock, pp: 2-3, 2012)*

Clearly, American medicine needs a “working-philosophy” that can help people know what to talk about throughout the process of dying, what issues should be addressed and how to get the right professional help with these issues. We need to create a comprehensive system to help dying people, their families, friends and healthcare providers communicate about the dying process. Most of all we need to recognize that peaceful and pain free dying can be defined by specific criteria and that it is something most of us would want for ourselves and for those we love. To achieve this it is important to start with learning how to talk about dying and how to empower patients to discuss it. *(Street, 2002, J Gen Intern Med, Aug: 18(8):609-16.)*

Physicians are only human and should act with humanity, at all times, despite all of medicine’s uncertainties, weaknesses and shortcomings. Doctors must adjust their vision to focus on the subject of dying. A subject that modern medicine has previously kept locked away, in the dark closet of denial. Opening the door to medical students (*Science Daily, 2013)* and physician's emotional baggage through curriculum changes, support groups and medical narratives offers broad options for professional and emotional growth. These types of changes would greatly improve the patient physician partnership and the healing landscape.

In the next chapter we will cover a historical perspective that spans the cultural, physical and legal changes in America over the past sixty-eight years from the end of World War II through to the current day.

Chapter 3

HISTORICAL PERSPECTIVE

In the United States, from a cultural point of view, World War II changed everything. The culmination of a total national commitment to five long years of total war set the stage for a profound cultural evolution, the magnitude of which we still feel today, almost seventy years later. This new United States would grow at an astonishing pace. As a newly energized industrial giant the USA would shake the foundations of international civilization and serve as a model for individual liberty and equal justice under the law. These individual-liberty and equal-justice concepts would set the stage for a revolution in how citizens relate to their government, how the government would relate to the citizens and how citizens expected to be treated by that government and by local and regional authority.

Over this period, life in America changed dramatically both in the family structure and cultural/social experience. One of the basic alterations of American life, over this period, has been the sacrifice of tradition to the demands of progress. Cultural change through industrial development and growth have been reflected in the increase of government influence on every aspect of life and of death. Death, death related practices, tradition and ritual, has not escaped this influence. In many ways death has radically changed through this process; including how we die, when we die and how those left behind grieve and mourn the loss. Even the location of death, as discussed previously, has changed greatly during the time period under scrutiny. (*Krishnamurti, 1992*).

From a historical perspective the concept of a “private/personal" death in the family, has disappeared. What has evolved in its place is a major expensive cultural-social event that encompasses healthcare professionals, the government, local authority, local businesses, and the participation of family members, social friends, acquaintances, coworkers and even the media. The death of everyday citizens is routinely announced in the news-papers and local publications and very large sums of money are spent on the preparation, presentation and delivery of the death event [*after it has occurred*] as a cultural ritual and a social experience. The body of the recently deceased is routinely displayed (*Haberstein, Lamers, 1974*) in a funeral home: a place created, organized and focused on handling arrangements and caring for the dearly departed. The deceased body is then embalmed and stored in a hermetically sealed concrete sarcophagus, for safekeeping underground. Under these conditions the body will probably remain preserved and identifiable well into the foreseeable future perhaps even into the next century.

In her 2006 book “*Remember me: A lively tour of the new American way of death”,* Lisa Cullen touches on the topic of talking about death. She writes that despite its inevitability discussing the topic of death and dying has become difficult to approach, if not a complete social taboo. The social view of the end of life can be influenced by many factors, such as upbringing, personal experiences, and individual beliefs and values. Perceptions of these experiences are also influenced significantly by the historical and cultural context in which we live. The discourse on death and dying has changed significantly over the last century as the common circumstances of how people die have shifted over time *(Cullen, 2006).*

Changes in the dying process have led to an increased interest and involvement in issues related to end of life, such as end-of-life care, decision making about treatment and professional intervention. Specifically, there has been increased concern regarding the quality of life people experience as they die, as well as the quality of their death. The idea of a good-death has become prevalent in our society. Our ideas of what constitutes a good-death are personal and are likely dependent on social norms/practices and cultural norms and practices.

In an attempt to understand the culturally accepted practices applied to death in America we must view and explore death rituals in the widely diverse mix of religions and cultures that exist in this country today.

OBSERVANCES AND PRACTICES OF DEATH IN VARIOUS CULTURES

1. *Practices of the European-American Culture*: European-Americans follow various cultural, ethnic, and religious traditions regarding post-death ceremonial and bereavement practices. General tendencies include: Friends and

family gather at the home of the deceased or family member to support and share in the common grief. This practice usually occurs following the announcement of the death. High dependence upon a funeral director and/or person of the clergy in preparations for mourning and burial. A visitation and/or viewing at a funeral home are typically followed by a religious and/or graveside/crypt side service. Funeral services tend to be rather subdued. Traditionally, dark clothing tends to be worn during ceremonial services; although this trend has shifted in recent years to a more color-based wardrobe focused on creating an atmosphere of celebration and hope. Interment is followed by a gathering at the home of the deceased, or a family member who prepares food and refreshment (*Fontana, Keene, 2009*).

2. *Practices of the Hispanic-American Culture*: Hispanic/Hispanic-American populations also have diverse cultural backgrounds including individuals from the islands of Cuba, Puerto Rico, and the Dominican Republic, and those who originate from Spain, Mexico, and Central and South America. Most Hispanic populations practice the Roman Catholic faith, but not all follow the religion. Common patterns in the aftermath of death are: Family and friends are part of the commemoration, the priest has a significant involvement in the funeral plans, the rosary is recited by surviving loved ones, and this tradition often takes place at the home of the deceased. Some Hispanic groups recite the rosary each night for nine nights after the death. Some families say the rosary every month for a year after the death and then repeated on each anniversary. Funeral

services often include a full mass. Loved ones and family members express grief during the funeral and many are involved in the procession to the grave. Survivors frequently commemorate the loss of their loved ones with promises or commitments for the future. These promises are taken very seriously and those who fail to honor them are considered sinners. Money gifts to help cover the expense of the funeral and burial are not unusual (*De Spelder, 2009).*

3. *Practices of the African-American Culture*: Black/African-Americans have traditions concerning death that draw from many and varied cultural, ethnic and religious backgrounds. Some common patterns include: High involvement of a funeral director, as the focal point, in preparations for mourning and burial. Friends and family gather at the home of the deceased to offer support and sharing in the common grief. A wake follows, during which music, songs and hymns are played or sung. Some African Americans hold a service known as a "Home-Going" service. It usually reflects the personality of the deceased and celebrates the conviction of going home to Jesus and being reunited with past friends and relatives.   A shared meal among grieving loved ones after the wake and the funeral is prepared and eaten. The traditional funeral service is followed by a burial (cremation is less accepted in the black community) which reflects a deep religious faith and integration of church observances in the process. Memorial services and commemorative gifts are offered to the family by friends. Many in African-American communities mourn by dressing in white as a sign of

resurrection and celebrate with music and hope. However, Native Africans often wear red or black. African-Americans often express grief at death with the physical manifestation of great demonstrative emotion. Some African-Americans may believe in the concept of the "living dead." This concept refers to people who have died but whose spirits live in the memories and thoughts of those still living. These people are the ones who help others who die, move to the next world *(Jamieson, 1995).*

4. *Practices of the Asian-American Culture*: Asian-Americans may follow Buddhist, Confucian, or Taoist practices regarding death, with some elements of Christian traditions mixed in. Common practices include: The full family gathers at the funeral home to make arrangements. The family elders assuming ultimate responsibility for the ceremony. Asians show great respect for the body and warm clothes are used for the burial. Watertight caskets are used to keep the elements at bay. Stoic attitudes are common. Depression may result from the internalization of grief. An open casket allows for respect to elders. Often poems in calligraphy are left for the deceased. Among Chinese Americans, a cooked chicken is usually placed by the casket as a last meal for the deceased spirit. The chicken will be buried with the body. Music is played and a band may wait outside the funeral home to accompany the procession to the cemetery. The funeral route, burial location, and the choice of the monument are important. Incense is usually burned at the grave.

Among some Asian populations, sacrifices are made at the funeral. A gathering of family and friends for a meal after the funeral shows respect for the spirit of the deceased, and gives thanks to those who came to pay their respects. A shrine to the departed with a picture or plaque is usually kept in the home and displayed along with personal items. (*Athan, 2013*).

5. *Practices of the Native American Culture*: Native American traditions and rituals may differ from tribe to tribe, but commonalities exist in Native American death rituals. Modern day Native Americans may incorporate ancient death rituals, handed down from their ancestors, in a modern funeral service. Native American observances vary considerably in their religions but they exhibit a strong commonality among many tribes that center on the natural world, the earth, the animals, the trees, and the natural spirit. Even among those who have been converted to Christianity, an emphasis on the reunion with nature that occurs with death still strongly exists *(Garbarino, 1976).* Common practices include the Medicine Man or spiritual leader usually moderating the funeral or death service. Since each individual is unique the service may not follow a particular order. In some tribes or clans, burial is not traditional. Some tribes call on their ancestors to come to join the deceased and in effect, help in his or her transition. Most Native American cultures are not concerned about preserving the body and so embalming is not common nor is any dismemberment and mutilation of the body permitted, outside of natural deterioration. They believe that the spirit of the person never

dies; therefore, sentimental items and gifts are buried with the deceased as a symbolic gesture that the person still lives. The spirit of the person may be associated with a particular facet of nature - animal, bird, plant, water, and so forth. Symbols of such spirits may be a part of the ritual in the death ceremony. The burial of the person should take place in their native homeland, so that they may join their ancestors, and that they may also inhabit the land to which their loved ones will also return. In some tribal cultures pipes are smoked at the gravesites. Many tribal cultures emphasize a symbolic reference to burial in a circle showing the importance to a cycle of life. In others there is significance in non-burial, but allowing the deceased to pass on to the other world in a natural way *(Athan, 2013*).

6. Practices of the Haitian-American Culture: Although there is diversity in religious practices among the Haitian/Haitian-American population, they tend to share the following common patterns in the aftermath of death: Close family members and relatives make arrangements for the funeral and church services. Then family members and close friends gather at the home of the deceased to pray and to offer support. A wake takes place at the home of the deceased every night from the time of the death to the time of the burial. At the wake, they chat, eat, drink, and share jokes and stories about the deceased. The funeral service and burial then take place shortly thereafter. Close family members mourn by dressing in black or white. The wearing of bright colors such as red is not considered an expression of mourning. Dark colors are preferable such as blue, purple, and brown to attend a funeral. Many Haitians express grief and demonstrate great emotion over the departed. After the burial, family members and friends usually gather at the home of the deceased for a reception. Pastries, black coffee, tea, and other foods are served (*Athan, 2013*).

In an effort to further understand the religious practices applied to death in America we must view and explore the broadly diverse mix of popular religions that coexist in this country today. The role of religion has critical importance for most terminal patients and family. Their answers to religious questions help to form their view of life, death and the meaning of events. Many people do not consider their position on religion as a daily event. They often revisit and reform their religious faith and beliefs only when disaster strikes. Some religions give individuals more power over life than others. Some religions give collections of individual's power over life. Some religions give spirits more power over life than they do the living, some give free will, some give fatalism; all have defined ways of dealing with death. Lisa Athan, a grief recovery specialist and lecturer on traumatic loss, (*Athan, 2013)* covers Observances and Practices of the Three Most Popular Religions in America and Their Various Rites of Death, on her website: Grief Speaks.

RELIGIOUS DIFFERENCES OF THE THREE MAJOR RELIGIONS IN AMERICA

1. Jewish observance: All customs are designed to treat the body with respect; therefore, autopsies and embalming are generally prohibited *(Athan, 2013).* Viewing the corpse is also considered disrespectful. The emotional needs of the survivors are very important. There is variance among Reform, Conservative, and Orthodox Jewish practices. Judaism does not allow funerals on Saturday (the Sabbath) or on any major religious holidays. Music and flowers are not encouraged. Eulogies are given by rabbis, family and friends. As a symbol of high regard for a particular person there are usually several eulogies. Family members and others accompany the casket to the grave and are encouraged to place a shovel of earth on the casket, as a sign of the finality of death. A period of mourning lasts for one year. The mourner's "Kaddish" or declaration of faith is recited at the gravesite: "*Blessed, praised, glorified and exalted; extolled, honored, magnified and lauded is the name of the Holy One. May abundant peace from the heavens descend upon us, and may life be renewed for us and all Israel, and let us say Amen*." "Sitting-Shiva" refers to the seven-day mourning period immediately following burial. The family cooks no food and a burning candle or lamp represents the memory of the deceased. The Kaddish should be said every day during this time. Some people observe a period of three days following the burial during which visitors are not received and the time can be devoted to lamentation.

After the first seven days, survivors are encouraged to rejoin society but still maintain mourning by reciting the Kaddish twice daily for thirty days. Many mourners may wear a black pin with a torn ribbon, or a torn garment during the funeral and for the next week as a symbol of grief. Newborn babies may be named after the deceased. (This is important to remember since many cultures believe it improper to name people after the dead and, in fact, adults may change their names to avoid being named after someone who has died. The first anniversary may be marked by the unveiling of a tombstone at a special ceremony *(Wikipedia, 2013), (Jewish Funeral Traditions, 2014).*

2. *Roman Catholic observances*: *(Wikipedia, 2013), (Catholic Funeral Traditions, 2014)* Since the Second Vatican Council, the terms "last rites" and "extreme unction" are no longer used by the Catholic Church. The Sacraments of the Sick are prayers that are said for the person dying, and involve both confession and communion. If a person dies before the sacraments are given, the priest will anoint the deceased conditionally within three hours of the time of death. At the wake the priest will conduct the service or say the rosary. There are distinct phases to "The Mass of Christian Burial." Prayers are said at the funeral home, and again welcoming the body to the church. Covering the casket with a white cloth, sprinkling the casket with holy water, and celebrating the Eucharist are all accepted ceremoniously. Prayers are often said after the mass with the casket being escorted to back of church. At the cemetery the priest blesses the grave site.

This consecration is a reaffirmation that the person will rise again. Prayers address not only for the dead but the survivors - faith in eternal life is encouraged. The one-month anniversary of the death is often celebrated by a Mass, as are those of other anniversaries, usually again after one year has passed.

3. *Protestant observances*: *(Dignity, 2013)* There are a wide range of Protestant observances, including a family gathering at the family home and usually at the funeral home. Caskets open or closed, are part of the arrangement. Memorial items may be placed in the casket. Cremation is an accepted option for many Protestants. Black dress is a part of mourning and funeral services which include music and testimonials. Music may include traditional hymns and/or songs of praise celebrating the Christian experience and the hope of everlasting life. Those who mourn attend the grave. Gravesite visits may be made for many years some until the mourners are unable to do so or die themselves. Memorial services are common, and sometimes replace funerals and other immediate observances of death. Flowers and donations are preferred ways to express condolences. Church members and friends will usually assist in providing the food needs of the family for a period of time which will vary according to the needs of the family. No formal structure exists to observe the anniversary of the death, month after month or year after year.

Both the cultural and religious aspects of life offer valuable gifts to people as they approach death. When a loved one approaches death there are other aspects of their "journey" besides grief, pain and loss. A dying person can and often does, offer enlightening information to those being left behind. Maggie Callanan in her book "*Final Gifts*" *(Callanan, 1997)* calls this phenomenon "death awareness." Nearing death-awareness she theorizes is a special knowledge of and sometimes even "control" over the death process by the dying individual. According to her theory, death awareness reveals to the dying person, what to expect while dying and what may be needed to allow the individual to die peacefully.

The research conducted by Daniel Tobin *(Tobin, 2011)* from his book *Peaceful Dying,* shows that often times the attempts of the dying to describe what they are experiencing may be misunderstood or even ignored. Communication, in this time of stress and grief can be missed, often by the loved ones and family members who are listening to every word of the dying person. In the final days or hours of life people often make statements or gestures that make no sense or seem childish, silly or even ridiculous. Family members usually explain this as mind-wanderings or hallucinations. Healthcare providers, especially doctors and nurses may label these illogical expressions as confusion or lack of oxygen to the brain or delusions. Family, friends and professionals often respond with frustration or annoyance. They try to humor the patient as if they were dealing with a child. Physicians are often prone to try and stop these "delusions and confusion" with medication. These types of responses serve to distance dying people from those they trust, producing a sense of isolation and bewilderment. At this point the families' attempts to communicate are met with confusion and everyone may stop listening to the dying person. However difficult this may be for both medical professionals and for family members there is another way.

Dr. David Kessler in his book *Visions Trips and Crowded Rooms (2010)* has been studying and recording his own experiences along with the personal experiences of healthcare professionals and clergy and their stories regarding the statements of patients on their deathbed. These hundreds of deathbed accounts suggest that deathbed visions are normal and actually quite common across a broad sample of dying patients. These accounts provide a deeper understanding about what happens in the final moments of life. Dr. Kessler writes:

> “*Working in hospice I realized that doctors and nurses had more time to sit with patients and get to know them. While there I was able to witness so many of my patients experiencing visions before dying and they always seemed to bring peace and reconciliation. I consider these visions to be nothing short of miraculous. We will never be able to prove the existence of visions but we can control how we perceive a person’s experience. It has value simply because it is authentic and meaningful for the individual. Can the medical community be comfortable with a phenomenon that is outside the realm of explanation? After listening to so many doctors and nurses share their stories, I realized that they most often describe their experiences with deathbed visions and conversations as profound. Most say they don’t*

> *think it was a side effect of medication or oxygen deprivation, it was just a profound moment. They weren't talking about the scientific or technical aspects of dying; they were referring to the art of dying. This makes me wonder about how the dying and deathbed visions are portrayed in our culture, books and movies?"(Kessler, 2010, pp: 45 - 46).*

The dying person's requests are sometimes difficult to decipher. Their recognition of the importance of these needs, along with concerns for family and friends can cause the dying to control the time and circumstances of death until those needs are met. Many requests often involve another person, often they may be for meetings or the healing of a relationship.

The research of those working with many hundreds of dying people over many years *(Callahan, 1997)* shows several reoccurring themes of this special type of communication. These messages fall into two broad categories

One: Attempts to describe what someone is experiencing while dying.

Two: A request for something or someone a person needs for a peaceful death.

Nearing death often includes visions of loved ones already dead or visions of spiritual beings, although these do not always signal immediate death. Dying people may also see and speak with religious figures. They may feel warm peaceful and loved and they often express concern for those who will be left behind. Dying people often describe being in two places at once or somewhere in between. However bizarre or unusual their descriptions offer unique opportunities to participate by responding to their needs and wishes and to learn what death is like for them and perhaps what it may be like for others, even us. *(Callahan, 1997).*

A common claim about America is that we are a death-denying society *(Kubler-Ross, 1974)*. This generalization is actually unfair. Mostly Americans are simply unfamiliar with death: at least with the kind of dying that most of us will eventually face. Up until one hundred years ago death came quickly and at almost any age. In nineteen hundred the average age at death was forty six years old (*Web, 1999)* and the majority died of infectious diseases and accidents. Now the average age for adults is seventy eight and climbing. Until the middle of the nineteen hundreds, young people would become familiar with death when siblings or even parents died. A large percentage of young women died in childbirth. Now, most of growing up and well into young adulthood passes without any personal contact with dying. We have very little guidance with death or with a family member who becomes sick and dies slowly. Popular culture greatly ignores the life experience of people with chronic illnesses that will end in death. We have become a nation that desperately needs a narrative about dying, to provide some guidelines for appropriate roles and worthy behavior.

> *"There is a social trend toward death in families to be separated by*

> *large amounts of time. This phenomenon is called Death Delayed Experience: death is generally not experienced in a young family until adult years. Grandparents are usually the first to die when grandchildren are usually into their 20s. Isolation from the death experience has increased discomfort with death and the dying process and as a result many people tend to experience a profound emotional response to the death of a loved one" (Kellehear, 1989, pp: 275 – 292).*

The wide degree of cultural diversity in America makes it unacceptable to try and lump death related attitudes into one category, however broad that category may be. Discussions in chapter one demonstrate that it may be wrong to try and characterize these attitudes as belonging even to a single perspective. From the research we can conclude that the USA may be a death-denying society *(Kubler-Ross, 1969)* however; others contend that America may be even both: a death-denying and a death-ignoring culture *(Canine, 1996*). Unlike most cultures, America exists as a dynamic and changing society and individual Americans focus their death related attitudes on different aspects of the overall subject. There are even strong differences among members of a single family on their attitudes toward any specific topical focus on the subject.

According to Doctor Elizabeth Kubler-Ross Americans go through a cycle of processing when confronted by death. The chart below shows this model as extended slightly from the original 1972 model which does not explicitly include the Shock and Testing stages. These additional stages are included now and are useful to understand and facilitate a dying patient’s cycle to acceptance.

Shock stage: Initial paralysis at hearing the bad news.

Denial stage: Trying to avoid the inevitable.

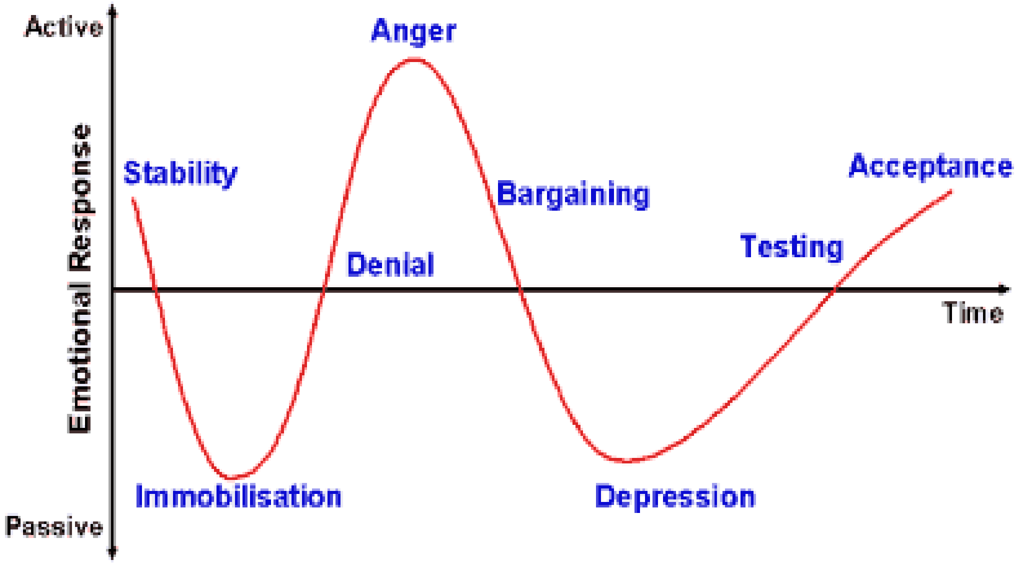
Anger stage: Frustrated outpouring of bottled-up emotion.

Bargaining stage: Seeking in vain for a way out.

Depression stage: Final realization of the inevitable.

Testing stage: Seeking realistic solutions.

Acceptance stage: Finally finding the way forward.



Kubler-Ross 1972

Research *(Kiernan, 2006*) shows that Americans are most concerned about their own dying and about what they believe may be involved in that process. According to Steven Kiernan:

> *“There are those who are concerned about a long, difficult, painful and/or undignified dying process that may take place in an unfamiliar institution under the care of strangers. That these strangers may not respect personal needs or wishes of the dying patient, so that this type of death is a fearful prospect as a last experience. Others may prefer to die quickly (possibly in their sleep) and not to have to prepare for the inevitable. Many report a preference to die quickly without benefit of special life- saving or prolonging activities or drugs used to extend life and indicate this preference in Advanced Directives or in a "living will." (Kiernan, 2010, pp: 7-11).*

By contrast others may be wary of a sudden, unanticipated death and would prefer to have an opportunity to prepare for death and to exchange final messages with loved ones. Similar attitudinal and spiritual differences can be found in individuals who primary focus on what will happen to the “self” at the moment of death and what death will mean for this “self”. Fearing the prospects of nothingness or obliteration verses attitudes of a welcoming release from pain and suffering.

The fate of the “self” after death can be a huge concern for many individuals.

According to David Chidester *(2002)* concerns about the dying of others and bereavement for another's death along with concerns about our ability to help others through terminal illnesses is a social issue. The question of what will happen to loved ones "when I am gone" can be another big concern. Anxiety about the unknown, fear of judgment or punishment for past sins or anticipation of a heavenly reward or passage to a better higher form of existence, are all considered parts of American’s attitude toward death (*Chidester, 2002*).

According to the research there is great diversity in the death related attitudes of Americans (*Field, Kassel, 1997*) and that all such attitudes do not have the same level of concern/anxiety in the culture for how we feel about death. In order to have a clear understanding of our complex and varied attitudes toward death it is important to understand the philosophical basis for these views.

Cultural and historical research by Alan Segal *(2004)* in his book “Life after death: a history of afterlife in western religion” shows that the American view of death has evolved from basic philosophical and mythical approaches from the ancient cultures and civilizations that came before us.

There are four (4) basic ways of looking at death in our American culture. These four approaches serve as the basis for our view and acceptance of death. The Chthonic view, the Pythagorean-Greek view, the General Survival of the species view, and the Extentialist / Personal- Extinction model.

The ***First***: The Chthonic view derived from the "Homeric/Egyptian" cultural view that portrays death as inevitable and unconquerable; a dark presence. However, death is not the end; there is life in a different realm after death. The dead are shadows wandering through the underworld. This "chthonic" form (from under the earth - the spirits of the underworld - rooted in paganism) sees people as full immortal persons, not just their souls, people are spiritless, pale eternal wanderers never to be redeemed; they occupy the netherworld. More than likely this is the genesis for the concept of "hell." (*Segal, 2004)*

Second: The "Pythagorean-Greek" view and many centuries later, the Christian view that sees death as a separation of the soul from the body; the body dies as an empty vessel but the soul lives on in immortality. Plato and Socrates also conceived this philosophy which served as the beginning of our Judeo-Christian faith on immortality. The "Pythagorean-Greek" model views the immortality of the soul as an uninterrupted continuum. The soul freed from the body continues in the form of another existence. Socrates, certain of this in his own mind, drank the hemlock calmly and waited for his soul to be freed from its earthly existence. Most Christians today see death similarly; however, certain Catholics see immortality of the soul slightly differently. Catholic beliefs about death have the body and soul dying and the soul then conditionally resurrected according to strict catholic doctrine. Some conceive the immortality of the soul as a continuous and uninterrupted process. Others believe that the soul is resurrected through God's grace, which may or may not be mediated through our actions here on earth *(Segal, 2004).*

As an adjunct to this data: Hebrew thought follows this Pythagorean-Greek (Christian) model but differs slightly in philosophy by viewing the relationship of man and God as one of a covenant in which each must do his or her part. Life, in the traditional Jewish view point, is sacred to be valued above all else and therefore to be preserved at all costs. The Christian view of heaven and hell do not exist in the same form in the Hebrew faith as acceptable concepts. However, some believe that judgment will be exercised upon those whose actions on earth were not in keeping with appropriate conduct and Hebrew law *(Segal, 2004).*

Third: The "General-Survival of the Species" (scientific) view which Aristotle advanced. This view indicates that we have already attained immortality by living on through our off-spring and other fellow creatures of the same species and that we are all part of the greater human kind and will exist through future generations. This is the non-religious (sometimes called) the positive view *(Segal, 2004).*

Fourth: The Extentialist: "Personal-Extinction model" view of the Stoics and Epicureans that accepted death as the true end of life and all existence. There was nothing before and there is nothing after. Atheists also accept this view that dying is the end of it all, the termination of the earthly life cycle; birth, life, inescapably death *(Segal, 2004).*

Americans social and religious views of death can produce cultural feelings that range from fear and anxiety to enthusiasm and envy. Except for the Homeric/Chthonic view which has gone largely unaccepted in modern times, the Pythagorean, General-Survival, Personal-Extinction models view of death continue to influence us up to the current day. Understanding the function of these different concepts of death and their influence in our everyday lives is of great importance in our culture. The symbolism of these social and religious views and ideas are critical if we are to appreciate people's attitudes about death and the practical problems of dealing with the end of life. These ideas are also very important in our understanding of the cultural view of suicide and euthanasia.

THE GOOD DEATH

Though difficult to accept, there can be little question that some deaths are better than others. People, cross-culturally have always made awkward distinctions between good deaths and bad deaths. Compare, for instance, movie star Bing Crosby's sudden death of a coronary (in the clubhouse in the company of friends) at seventy-four following eighteen rounds of his beloved golf, with the slow motion painful expiration of my eighty-eight year-old diabetic grandmother.

Admitted to the hospital following a severe fecal impaction my grandmother had a heart attack in bed the second day. She was resuscitated and following emergency abdominal surgery for a ruptured colon she eventually began slipping in and out of consciousness. This continued over a period of six weeks, exhausting the emotional, physical and most of the financial resources of our family. She died semi-conscious, during the night, in a strange room attended by strangers, unable to speak because of the airway of a respirator.

The chasm between the worlds of the living and the dead has now shifted culturally, from the period after death to the period immediately preceding it. The essence of a "good death" (*Byock, 1997)* thus involves the needs of the dying (coming at the end of full and completed lives) when death is preferred to continued stressful or even painful existence. This good-death concept also applies to the dying individual’s survivors and to the broader society. The death fears of our modern culture are more focused on the processes of dying, where in ancient cultures the prevalence of unanticipated and premature death led to focus their death fears of individuals' postmortem fates.

Contemporary fears of dying largely focus on the anxieties of dying within institutional settings. Institutional life necessitates a structure for the convenience of staff and where residents unfortunately suffer both physical and psychological pain in their depersonalization *(JAMA, 1995).* There are also fears of being victims of advanced Alzheimer's disease, senile dementia, or being socially dead as in PVS (persistent vegetative state) and yet biologically alive.

Cultural rituals and social coping mechanisms have not kept pace with the dramatic changes in when and how we die. Within a few generations Americans have forgotten how to focus on dying as a human process, how to include the dying in their ongoing family dialogues, and how to learn the lessons of their own existence and demise. Instead, the dying process of institutionalized isolation now too often features silence or diversion or even denial *(O'Gorman, 2002*).

American society has seen dramatic changes during these past generations *(National Affairs, 2014).* Women now work in every aspect and every strata of the workplace. Instant individual communication, affordable by almost everyone to everyone, instantaneous news twenty-four hours a day, social media and internet access has made information into an inexpensive worldwide commodity. These new societal benefits change how people think and act and behave.

The traditional American family has been replaced by a wide variety of house hold structures and relationships. The "transformation" of death has become one of the biggest societal changes of this generation. By far a powerful and dramatic trend because it will touch every person. A dramatic impact because aside from the field of *Medical Humanities,* medical journals, and medical research, it has gone practically unmentioned and unnoticed in the media and comes as tragic surprise for millions of Americans at the end of their lives. There has been a seismic shift in dying in this century and it has altered public policy, law and individual behavior. Dying has now become, for the most part, gradual.

DEFINING DEATH THROUGH LEGISLATION

The American definition of death touches upon many aspects of our lives. Inheritance, taxation, treatment of the corpse, autopsy, mourning, and many other segments of our life are all affected by the way the culture and our society draws the dividing line between life and death. The *Presidents Commission for The Study of Ethical Problems in Medicine, Biomedical and Behavioral Research, (1981*) set the ground work for the legal approach to clarifying many of these death related issues.

In 1968 with the advent of donor organ transplantation, public discussion began to take place about the need to revise the legal definitions of death to more accurately reflect new medical realities. In nineteen hundred and seventy, Kansas became the first state to adopt a law that included brain-based criteria for determining death; a number of other states also adopted similar laws during nineteen seventy and nineteen seventy one (*De Spelder, 2009*). These early laws were confusing because they contained dual definitions for determining death, one based on cessation of vital signs and the other on brain functions. In nineteen seventy-two, Professor Alexander Capron and Doctor Leon Kass (*2005*) offered a proposal that related the two standards. Their work suggested that the law should:

> *One*. Concern the death of a human being, not the death of cells, tissues or organs; and not the death or cessation of a person's role as a fully functioning member of his/her family and community.

Two. Move incrementally, supplementing rather than replacing older cardiopulmonary heartbeat and breathing, standards.

Three. Avoid serving as a special definition for a special function such as organ transplantation.

Four. Apply uniformly to all persons.

Five. Be flexible so that specific criteria can be left to the judgment of physicians.

This proposal was well received and adopted, with various options, by several states. It was criticized however, for not addressing issues related to organ transplantation in that it did not require at least two physicians to participate jointly in determining death. Also, it did not require that the physician who pronounces death not be a member of the medical team seeking organ donation and removal of such. Capron and Kass *(1978)* concluded that transplant considerations should be dealt with separately in a different law which was subsequently called the "Uniform Anatomical Gift Act" originally proposed in nineteen sixty-eight (1968) by the National Conference of Commissions on Uniform State Laws.

In 1975 the American Bar Association, proposed its own version of a law that offered a definition of death "for all legal purposes." Again in nineteen seventy-eight another proposal from the ABA was contained in a suggested law that was part of the Uniform Brain Death Act" (*De Spelder, 2009*). This ABA model was followed the next year by another similar law proposed by the American Medical Association. The legal and medical communities were trying to adjust to new medical technologies and their impact on determination of death. The fact that so many proposals were made during the 1970's is evidence of the complexity and difficulty encountered in determining when and how a person could and should be declared dead *(AMA, 1979*).

In 1983 President Ronald Regan created a presidential commission "*The President's Commission for the Study of Ethical Problems in Medicine*" to study these complex issues. In its report the commission stated that the Uniform Determination of Death Act addresses the matter of defining death at the level of general physiological standards rather than at the level of more abstract concepts or at the level of more precise criteria and tests, because such standards and criteria change over time as knowledge and techniques are refined. The UDOD act acknowledges the fact that in most cases irreversible circulatory and respiratory cessation provides an obvious and sufficient basis for making a determination of death. These cases permit death to be diagnosed on the basis that breathing and blood flow have stopped and cannot be restored. For a patient, not being supported on a respirator, there is no requirement for evaluation of brain function before making a determination of death. *(De Spelder, 2009)*

The commission also stated *(Youngner, 2001)* that a statutory definition of death should be separate and distinct from any provisions concerning organ donation. In contrast to earlier proposals, which stated that a person would be considered dead when their stated criteria were met, the language of the Uniform Determination of Death Act was clearer and more direct. It clearly states that a person who meets the standards set forth in the law is dead.

The Commission further stated that: Confusion about the definition of death had arisen because the same technology not only keeps heart and lungs functioning in some patients who have completely lost all brain functions, but also sustains other less severely injured patients. The result could be a blurring of the important distinction between patients who are dead and those who are alive but are in the process of dying. The conclusion of the commission was: Proof of an irreversible absence of functions in the entire brain, including the brain stem, provides a highly reliable means of declaring death for respirator-maintained bodies. *(Presidents Commission, 1981-B, http://hdl.handle.net/1805/707*)

It was noted that the Harvard Committee's (*Dubois, 1999)* definition of brain-death had been reliable and that: No case has yet been found that met these criteria and regained any brain functions despite continuation of respirator support. The final commission report (*Dubois, 1999)* concluded that death is an absolute and single phenomenon and it would radically change the meaning of death to expand the definition of death to include persons who have lost all cognitive functions but are still able to breathe spontaneously. The Committee’s conclusion was that the patient's condition is not defined as death but is now defined as PVC / persistent vegetative state, when brain stem functions remain and when respiration occurs naturally but there is no cognitive awareness. The lack of higher brain functions results in no awareness of self or the environment but involuntary movements may be observed and unassisted breathing in the patient’s body may continue. Patients in this condition may survive for years without respirator assistance and can be sustained by medical and nursing care including: artificial feeding and antibiotics to fight recurrent infections. *(Youngner, 2001)*

In this new century the "whole-brain" concept is almost fully accepted by the American medical community, the legal community and the general public. Now however, a higher-brain formulation, which would require agreement about the meaning of personhood, does not benefit from such a nation-wide consensus. At the present level of acceptance, understanding and technique the higher-brain exists as a theoretical concept only and not in any medical or legal reality (*Veatch, 1993).*

In summing up the results of the *Presidents Commission for the Study of Ethical Problems in Medicine (1981):* The final report brought conceptual clarity to a confused issue and helped to craft good law. Even up to this time, however, these guidelines for brain death are implemented “piecemeal”, that is not at all consistently, at the state and regional level, by hospitals and institutions. A two thousand and eight study *(Younger, Arnold, 2008)* found a very serious and wide variability in application and practice. There significant differences that might have implications for determination of death and initiation of transplant procedures."

CERTIFICATION OF DEATH

The most important legal procedure immediately following a death has become the official registration of death, the Death Certificate. A Death Certificate is legal proof of death. These certificates are required in all states and jurisdictions in the United States. Certificates do vary somewhat from state to state but most follow the format outlined by the US standard COD *(Appendix A pp: 268*). Death certificates fill both a private and a public function. The document itself serves as a concise summary of the important data regarding the deceased and the mode and place of death. The document does have broader social implications than just recording time, place and cause of death (*Youngner, 1996)*.

According to what Dr. Howard Spiro has written: The death certificate also has significant legal value and purpose as a document that affects disposition of property rights, life insurance benefits, pension payments, and federal and state entitlement payments.

The utility of the certificate can also extend to such matters as: crime detection, genealogy and knowledge of disease and physiological, medical, and psychological heath demographics. The certificate has classifications for four different causes of death: natural, accidental, suicidal and homicidal, but the cause of death is not the same as the mode of death. If a death is caused by asphyxiation due to drowning it can be classified as an accident, suicide or homicide; any of these modes may apply (*Spiro, McCrea, 1996*).

According to Stuart Youngner *(1999)* in his book on Certificates of Death, the distinction of the mode of death is a more complicated issue than cause of death. Mode of death looks to reason in the subconscious factors and the state of mind and actions of the deceased. As an example: if a person has had too much to alcohol to drink and then jumps into a swimming pool with no one else present and drowns, should that death be considered accidental or suicidal? Does it make a difference if the alcohol abuse was related to emotional distress or despondency? You can see that the intentions and subconscious factors of the deceased can be more than is covered by elementary distinctions in a single document. In some cases the resultant death may have been caused by the deceased own actions prior to death. Considering the possibility that the deceased had lethal intentions against him/her-self, all these complex issues may not be covered in a simple legal form (*Youngner, 1999*).

In nineteen seventy-seven Dr. Robert Kastenbaum *(2004)* introduced the concept of a "death system" in America. The death-system is a helpful model for considering how death shapes the social order and the culture and in turn our life in this country. A network of people, places, times, objects and symbols that make up the death system and how it affects our collective, individual and personal relationship to mortality.

In his published work Doctor Robert Kastenbaum *(2004, 28, no. 4: 375-392)* wrote that everything that goes to a collection of individuals and into a society and keeps that society going has implications for our relationship with death.

The manner in which this death system functions varies among different societies and at different times in the same society. The functions of a common Kastenbaum death-system may include all of the following.

- Warnings and predictions about potentially life-threatening events. Storms, tornados, hurricanes, and other natural disasters as well as advise to specific individuals such as doctors' reports of laboratory results or even a mechanics warnings about faulty brakes.

- Preventing death: for example emergency and acute medical care, public health initiatives like anti-smoking campaigns.

- Caring for the dying: doctors, nurses, trauma workers, family care-givers, and hospice staff

- Disposing of the dead: mortuaries, cemetery plots, memorialization processes, identification of bodies in disasters.

- Social consolidation after death: coping with grief, maintaining community bonds, settling estates.
- Making sense of death: religious or scientific explanations, funeral services, support groups, consolidation literature, and last rites.
- Killing: capital punishment, war, hunting, raising and marketing of animals for food.

In actual practice there are numerous interconnections and mutual influences among these functions. The elements composing a death system touch on virtually every aspect of social and individual life.

> *" Everything that makes a collection of individuals into a society and keeps that society going has implications for our relationship with death" (Kastenbaum, 2001, pp: 62).*

Physicians, nurses and all levels of health care professionals are profoundly influenced by this complex mix of multiple ethnicities, individual people, cultural assumptions and complicated laws. Religious or not, the ideology of our culture also plays a significant role in forming and shaping our individual beliefs *(Kleinman, Benson, 2006).* Such views profoundly influence the way physicians and nurses deal with their critically ill and dying patients.

Even a physician's own personal philosophy of such things can become a stumbling block when it runs across the patient's equally unexamined and often different philosophy. Misunderstandings between health care professionals and patients can flourish under these circumstances *(Kastenbaum, 2004)*.

As an example, in the next chapter will cover how American medicine has come to view death as a failure; a failure of technique, a failure of treatment, and a failure of patient attitude. We will see how physicians and healthcare administrators routinely ignore the wishes and rights of the dying patient.

Chapter 4

ISSUES IN AMERICAN MEDICINE

Pain is a more terrible lord of mankind than even death itself
Albert Schweitzer

In our current healthcare culture the strong personalities of physicians and specialists can be psychologically linked to a fear of failure (*Salwitz, 2012)*. According to Dr. Ira Byock, in his book *The Best Care Possible (2012)* we also see confirmation of a need to control most people would find unreasonable. When that control is lost, the doctor is also a bit lost and so deals poorly even badly with the consequences of that loss. This loss of control can also be manifest in extreme impatience with the patient and family. In a futile attempt to maintain control, a doctor will often without being aware of it, convince himself that his course of action is better than the course selected by the patient and even the family. His influence on what decisions are to be made is crucial and he will dispense only as much information as he sees fit. He will then manipulate the remainder by exerting a powerful influence on a patient's decision making in ways that are self-serving for the doctor. This kind of paternalism is precisely the kind that physicians abide by in today's complex technological- biological and pharmacological culture. (*Byock, 1997).*

The following case history is a focused example of these types of “control” problems in American medicine today. According to State of California civil court records established in *Bartling v. Glendale Adventist Medical Center 1987, (Hastings, 1984),* William Bartling was admitted to the Glendale Adventist Medical Center in California on April 8, 1984 with an abdominal aneurism and additional admitting diagnosis of pulmonary emphysema, arteriosclerotic cardiovascular disease, coronary arteriosclerosis, and advanced lung cancer. After a brief period of observation he was also diagnosed with alcoholism, severe chronic depression, and chronic acute anxiety. Mr. Bartling underwent a needle biopsy on his left lung five days after admission, on April 14. The biopsy caused his lung to collapse. His chronic lung disease prevented the doctors from re-inflating his lung. The doctors performed a tracheotomy and he was placed on a mechanical ventilator. During Mr. Bartling's hospitalization he would often attempt to disconnect the ventilator. The hospital staff applied commercial hospital wrist restraints to prevent him from either accidentally or purposefully disconnecting the tubing. This situation (being confined and restrained in his hospital bed) continued unchanged until his death, in the hospital seven months later on November 6, 1984.

During his time in the hospital, Bartling realized that while his condition would certainly decline it was not immediately terminal. He was alert and responsive but did not want to continue under these conditions. Being aware of his living will he wanted his life support removed. Mr. Bartling was not comatose; he was fully conscious, responsive to stimuli and indicated often that he was afflicted with severe physical pain as well as emotional suffering. After being in his hospital bed, for seven weeks, he wrote the following living will:

> "*While I have no wish to die, I find intolerable the living conditions forced upon me by my deteriorating lungs, heart and blood vessel systems and find intolerable my being connected to this ventilator, which sustains my every breath and my life for the past six and one half weeks. Therefore I wish the court to recognize, honor and protect my constitutional right to liberty, privacy, self-dignity and the control over my own body. I wish this court to order that the sustaining of my respiration by this mechanical device violates my constitutional right, is contrary to my every wish and constitutes a battery upon my person. I fully understand that this request... which I have frequently made to my wife and to my doctors will likely cause respiratory failure and ultimately lead to my death I am willing to accept that risk rather than to continue the burden of this artificial existence which I find unbearable, degrading and dehumanizing. I also suffer a great deal of pain and discomfort because of being confined to bed, being on this ventilator and from other problems which are occurring? " (Civ. No. B007907. Court of Appeals of California, Second Appellate District, Division Five.12/27/1984) Mr. Bartling further requested in other areas of his living will that he not be kept alive by artificial means or saved through heroic measures (DNR). The court record of Bartling v. Superior Court 17*

> *reveals that William Bartling's advanced directives, formalized in May 1984, also included a "Durable Power of Attorney for Healthcare" naming his wife as his representative. The written directions given to Mrs. Bartling were extremely clear. He did not want to be supported on a respirator if he could not care for himself, had continuous pain, and had to have his every need met by another person. He requested that the respirator be removed if the conditions specified were occurring and stated he accepted that the outcome would be his death. He did not want any impairment, incapacity or unconsciousness that he would experience during the dying process to be treated. (Civ. No. B007907. Court of Appeals of California, Second Appellate District, Division Five.12/27/1984)*

Mr. Bartling, his wife, and his daughter requested in writing that the respirator be disconnected and Mr. Bartling be allowed to die. Mrs. Bartling and her daughters each wrote separate papers to the hospital relieving the institution and the physicians caring for Mr. Bartling from all claim of civil liability if the institution honored their request. Even with a guarantee of exemption from liability the physicians refused to remove the respirator or the restraints that prevented Mr. Bartling from removing the respirator himself. He and his wife initiated a court case by filing against the hospital to allow independent removal of the restraints and the respirator. However, Mr. Bartling died before the case could be presented at trial. Despite the fact that Mr. Bartling died, the court decided that the trial would be held regardless because the basis for this case was significant to many individuals.

Glendale Adventist Hospital was a well-established Christian hospital and their ethical position was the preservation of life. This "ethical" position and the lack of any established policy regarding alert, competent patients being able to refuse life sustaining treatment led to their decision to maintain Mr. Bartling on the respirator. The hospital and the physicians were also concerned that removal of the ventilator and his subsequent death would lead to charges of homicide and civil liability (more than likely the real reason for their refusal to comply with the wishes of a dying patient, independent of any "ethical" concerns). The court determined that Mr. Bartling was an alert, legally competent adult and had the right to refuse life-sustaining treatment if he so desired. That he had an incurable condition that required extensive, invasive treatment, which limited the state's interest and affirmed his right to determine his own treatment. Mr. Bartling's right to decide his own care took precedent over an institution's concern for its own mission. This constitutional right to self-determination has also been decided in subsequent court cases which affirmed that a person's right to refuse treatment is guaranteed and may not be revoked secondary to the benefits of any hospital or institutional policy. (*Hastings et al, 1984*)

According to a JAMA study (*2008*) *The Role of Chemotherapy at the End of Life: When is enough, enough, clinicians* often struggle with initiating discussions about shifting treatment goals and in particular transitioning to palliative care or hospice. The study was focused upon chemo-therapy treatment goals for terminally ill patients at the end of life and when is it time to start cutting back on therapy. For many clinicians this shifting of treatment goals is a sign of “giving up the fight” and admitting defeat in the rescue-treatment-cure disease battle. The fact that many patients often respond with denial, anger or sadness should not sway clinicians from telling the truth to patients with advanced cancer. However, devastating news most often does sway judgment. These are normal human responses to the associated loss of control, a fear of the immediate future or even the underlying fear of death. In these cases clinicians need to respond with honesty and patience emphasizing support and assurances of aggressive symptom management. That is not always the case however; the JAMA study shows that thirty-five percent of the patients reported learning more about treatment options for their prognosis from their own research and from other patients in the waiting room then from their own treatment doctors. Physicians are loath to pronounce a "death sentence" and they feel that patients do not always want to hear it as a certainty.

This same study also showed that physicians prescribing high-dose chemotherapy almost always overestimated survival rates to the patient, especially for patients with poor prognosis who might need to balance toxicity against outcomes. The results showed that optimistic patients had no better survival rates than those who were more realistic about their condition. (*JAMA, 2008)*

Modern American medicine practioners are trained to focus on the living. The principle objective is "rescue, treatment and cure" that is to prolong or extend life with all the resources at its disposal. Medicine does not account for the fact that as a patient's physical condition deteriorates his needs do not. American healthcare tends to equate the loss of physical capability with a loss or lack thereof of mental and emotional capabilities and then medicine treats the dying as "less" than the living or less than those who have a higher rate of survival *(Reader, Gullispie, 2013, 1472-6963/13/156).*

Being unable to speak anymore does not and never did mean that you are unable to think. Dignity is somehow lost during the act of dying; it's even lost to the healthy patient who comes to the hospital for a minor surgical procedure (naked under a hospital gown), no money, no watches, no rings, and no underwear (no identity)! How do you like being called by the name of your affliction? The kidney tumor in room A-23. (*Vitez, 1998*)

Treating a patient with dignity also means including them in conversations about the imminent death and the decision making process. How often does a doctor try to "protect" the dying from unnecessary excitement by excluding them from major/serious conversations? Doctors often leave the room with family members to discuss a patient's condition. We discuss grandpa's condition, in private, as if somehow we are protecting him by not allowing him to know about or participate in the discussions about his own life care. Interestingly enough the conversation (we are having in private) is about what happens to him. In truth, our efforts to shield grandpa may actually harm him by denying him the right to make his own decisions, by acting as if he's too fragile or incompetent to participate in his own life and death. We disregard his dignity and his needs as a human being when we leave him out of this process. Being treated with dignity means being fully included in all aspects of life, regardless of the level at which one can participate (*Novack, 1979*).

As social animals we sometimes have trouble expressing our feelings, even in the best of circumstances. We have even greater difficulty accepting the feelings and emotions of others. These feelings are even more difficult to express in times of crisis, when our fears are realized and our emotions are exposed. Humans have an elemental need to express their feelings. The need to speak and share our feelings grows as the death of a loved one approaches. Just as we are comforted in life by those around us, we also need to give and receive that comfort to the dying person. Sharing emotions while grieving together is not surrendering to death, quite the contrary, grieving in each other’s arms can raise us to new heights of intimacy and love (*Kessler, 2007*).

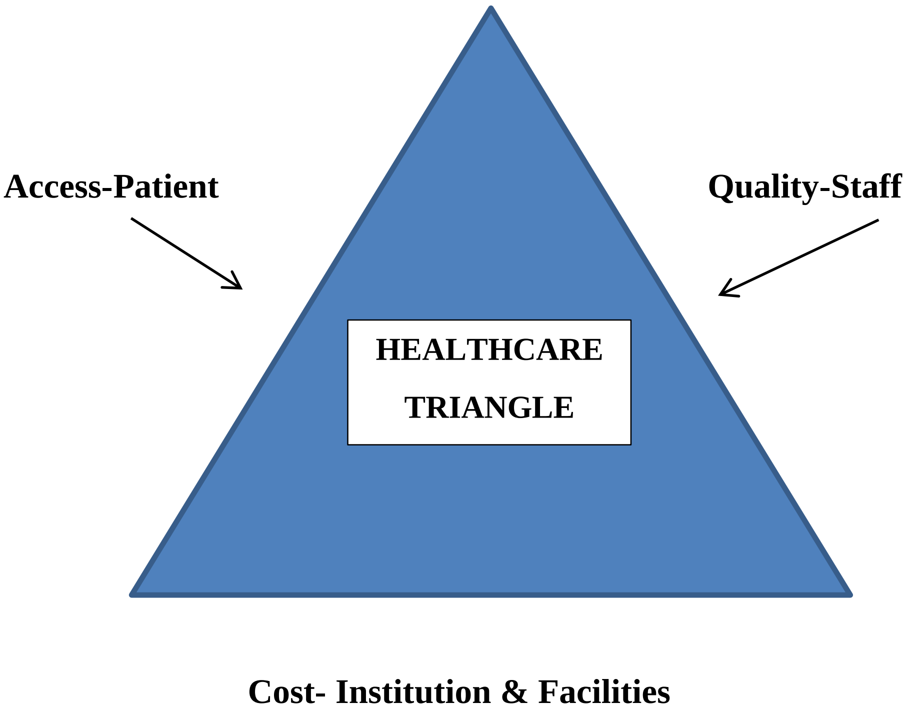
Our extreme social discomfort with death can make it difficult, almost impossible, to talk with a dying person about what's happening to them. This social discomfort also applies to physicians and healthcare professionals. Being nervous about talking to a patient facing a life threatening illness is certainly understandable. We can find harmony and fulfillment in relationships that are current, at every stage of life. A current relationship is one in which both members feel they have said everything they need to say to each other, either supportive or challenging. Relationships are current when we no longer harbor unexpressed feelings (*Thomas, 1978).* When there is an obstacle in the relationship, or when things have been left unsaid we are bound to be uncomfortable and unhappy. Our discomfort is even more pronounced when issues have been held back for years, from someone and now that someone is gravely ill. Sadly, we are less likely to make an effort to make a relationship current when one member is gravely ill. We may fear doing harm or we may fear rejection but if unspoken thoughts are not expressed, they will probably never be.

According to Doctor Elizabeth Kubler-Ross (*1974),* however counterintuitive or uncomfortable the urgency of a serious or terminal illness may be it is a golden opportunity to push through old blockages and talk openly and honestly. Dr. Kubler-Ross writes the story of a woman she interviewed who reminisces about her husband. The wife remembers a time when she was young and immature; she dropped a blueberry pie on the upholstery of his beloved car. She thought he would be furious but he was not. Another time she dragged him to a dance he did not want to attend and she forgot to tell him it was formal attire. Again she thought he would be angry, but he was not. She remembers the time she danced and flirted with an old boyfriend to make her husband jealous. She thought he would leave her but he did not. She wanted to tell him that she loved how he always accepted her, but she did not. She thought she would tell him how much she loved him, when he returned from his military tour in Vietnam but he did not come home, he was killed in combat. Because she was unable to give herself permission to be open and honest with him, she never acknowledged those moments of love and respect for him. Their business was never finished and she admitted that she would carry that burden with her for the rest of her life. We tend to look for comfort outside the sick room and away from the terminal patient. But we shouldn't deprive them of any chance to be a loving person, however brief *(Kubler-Ross, 1974).*

AMERICAN HEALTHCARE

A patient admitted to a hospital expects to receive medical and nursing care appropriate to his or her particular medical problem. The relationships among the patient, staff and institution influence the quality of care provided. Each side of this healthcare triangle *(Carroll, 2012)* access-patient, staff-quality and institution-cost, contributes to the overall quality and nature of the care delivered.

Insert Healthcare triangle about here



(Carroll, 2012)

With the aim being efficient use of two sides of the triangle (quality-staff and cost-facilities): procedures must become standardized policy and a matter of routine. Additionally many of these policies and procedures are set by federal and state law. Because of this policy driven treatment of attempting to treat everyone equally, the ability to meet the highly specialized needs of any individual (particular) patient is inherently limited.

One trade off that is made for sophisticated / technological health care is the loss of personal attention and less individual time allocated to individual patients by doctors, nurses and hospital staff:

> *"We expect a great deal of our hospitals: alleviation of pain, the most current treatments, extension of life, and management of death - and the awkward and painful circumstances surrounding the approach of death."*
>
> Charles Rosenberg *(Rosenberg, 1995, pp: 11).*

Patient's experiences are shaped by rules, regulations, law, convention and policy both written and unwritten. Unwritten rules (not documented as policy) though equally enforced, may contribute to an even greater sense of confusion and alienation because one has to discover them by chance. The family of a dying patient may even be relegated to maintaining a death watch in the corridor or the waiting room down the hall, with one person at a time squeezing into the patient's room to keep a bedside vigil. In many cases there is no private space (even though mandated by HIPA) where relatives can meet to discuss concerns with doctors or nurses. In public spaces grieving relatives may feel obliged to contain or repress their emotions. *(Attig, 1989,13:361-370).*

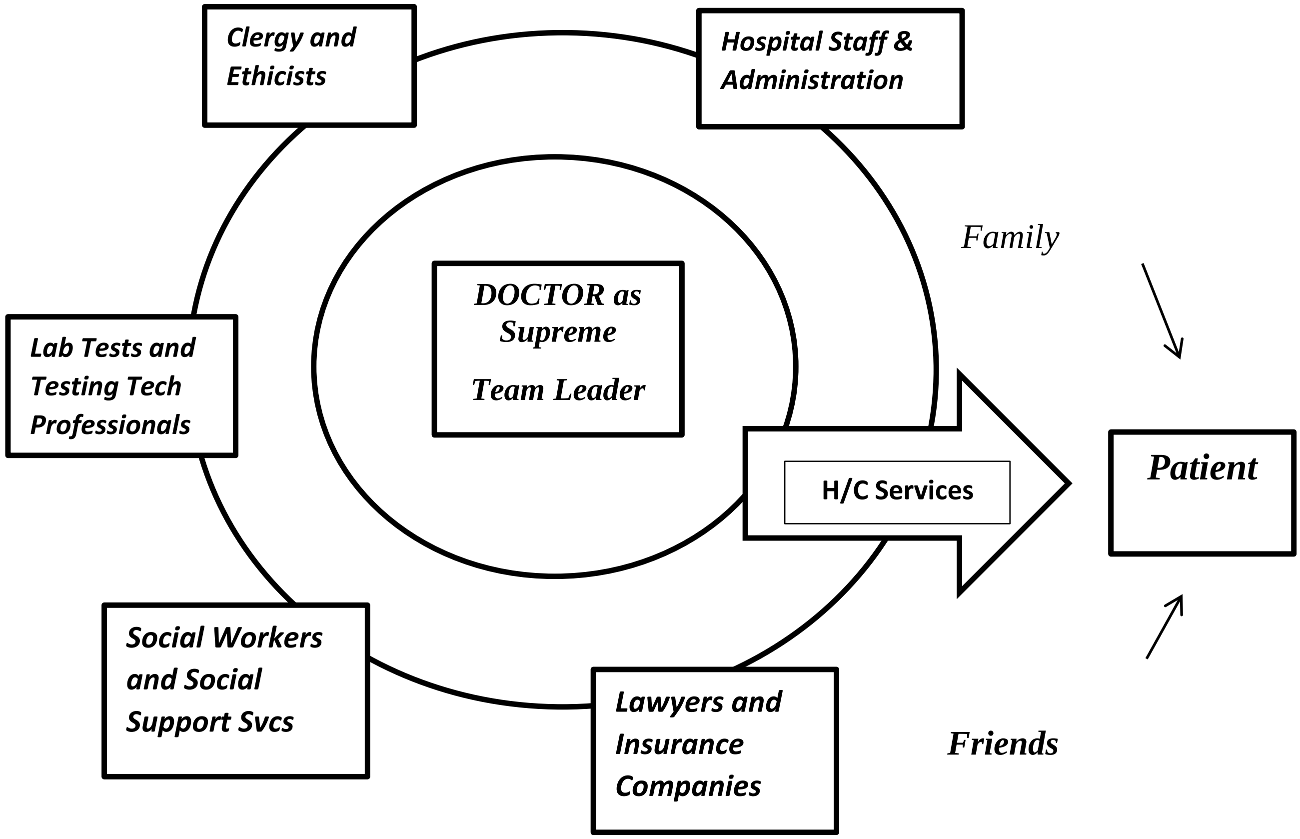
In the conventional medical model, patient and staff are central, while family members are less important. For dying patients however, the goal is not to simply provide expert medical care to an individual patient but to help give voice, connection and meaning to the patient and the whole family during this process.

The two charts below represent distinct types of healthcare situations. The first is a graphic representation of the existing situation where the physician is the centerpiece of American medical care and the patient / family is on the receiving end of the doctor/administration determination of what is to be done for the patient. The second graphic represents the "ideal" caring situation where the patient and family are at the centerpiece of the activities directing (with advice and options from the experts) what needs to be done now and in the immediate future. Humanity, caring and support are the hallmarks of this situation. Though this "ideal" model may exist in only a few healthcare organizations it is a worthy goal to focus upon (*Barton, 1977*).

Insert charts here

Classic (A) and Ideal (B) Barton’s Healthcare Service Delivery Models

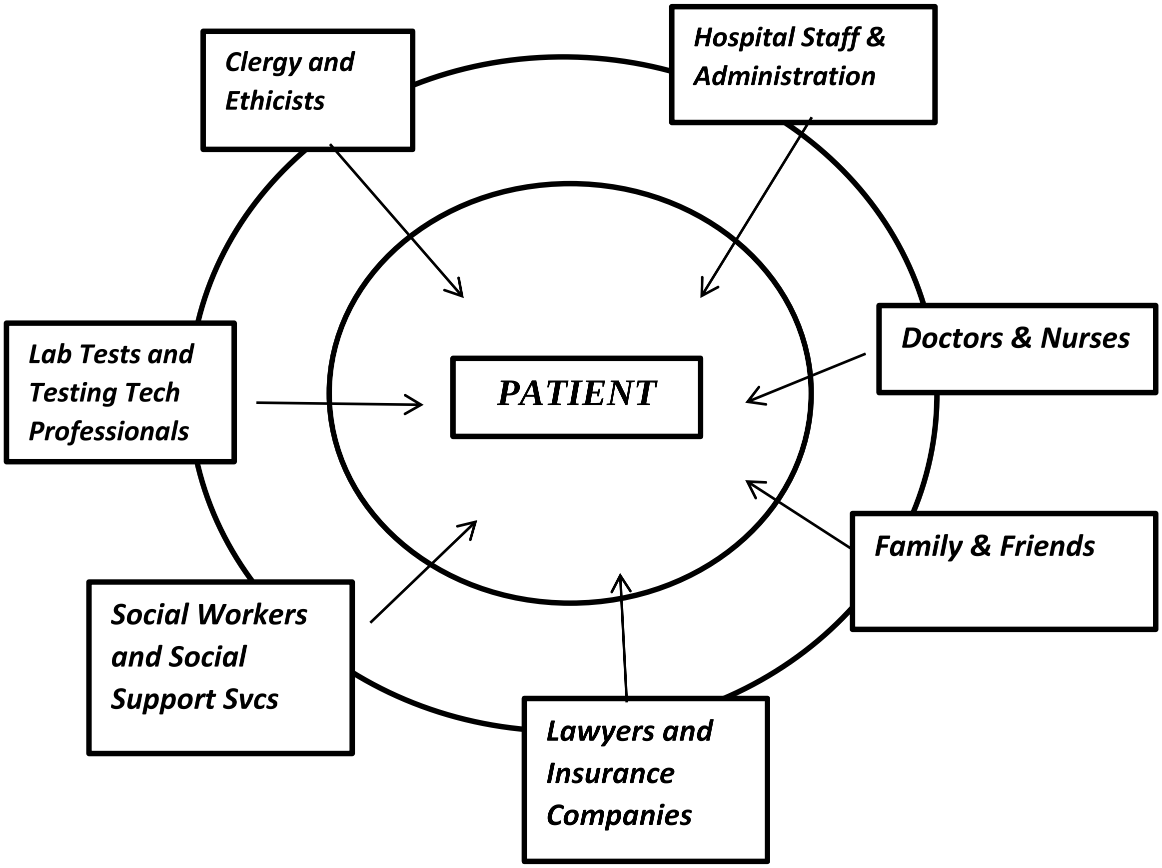
A: Classic Model



(Barton, 1977)

Classic (A) and Ideal (B) Healthcare Services Delivery Models

B: Ideal Model



(Barton, 1977)

Depersonalization, regularization and standardization are all aspects of the "scientific" method for the application of medical treatment. The scientific method probably serves as the basis for a great many of the life-saving medical advances we have today. However, the application of these wonderful advances does not have to be applied to patients in this same less than humane scientific methodology. When these technological and pharmaceutical advances are not managed and applied properly, in a caring and supportive environment, this less than humane treatment is the unwelcome result. It also occurs when physicians show a greater interest in the disease than in the patient,

Depersonalization also takes place when dying patients are given less attention because doctors and nurses believe "nothing more can be done" to save this life. Doctors tend to avoid personal contact, with the patient due to fears of their own mortality. Studies by the Educational Development Center *(Brody, 1993, NY Times,* 1993/01/14) and The Journal of Clinical Psychiatry *(Sekeres, 2002, 4(5): pp: 178–183)* have indicated that doctors and nurses actually admit to treating terminally ill patients differently. The research shows that they take longer to respond to bedside calls of dying patients then to answer the calls of less severely ill patients. Doctors also admitted to withholding pain medication under the guise of heading off addiction. Although this finding may not be representative of the norm, it is a horrific finding when applied to a professional group like doctors. In reality there is always something more that can be done, to help, support and care for a dying patient.

THE SUPPORT STUDY: DYING AT YOUR OWN RISK

In a four-year experiment called SUPPORT, involving nine thousand one hundred and five (9105) terminally ill patients in five teaching hospitals, the study produced definitive conclusions related to treatment of terminally ill patients. Conducted by the Journal of the American Medical Association *(JAMA, 1995)* Titled: *A controlled trial to improve care for seriously ill hospitalized patients, the study to understand prognoses and preferences for outcomes and risks of treatments*. These results provide a searing indictment of the way Americans die in our nation's hospitals. The report also encouraged a call for changes in how doctors and nurses treat patients in their final days of life. The “SUPPORT” principal investigators published at the completion of this twenty eight million dollar experiment *(SUPPORT, 1995, Journal of Medicine, pp: 250-257)* concluded that:

> *“Patients' wishes are often ignored, their pain is often unrelieved and their physicians too often persist in ordering the most extreme measures to keep them alive. Even though the researchers recruited and specially trained nurses to help improve care nothing improved. The report also concluded: A common hallmark*

> *of hospital deaths in America remains a mechanically- supported, painful and prolonged process of dying."*

During the study and according to the process, researchers followed more than 9,100 patients, their families, and the physicians and hospital staffers who cared for them, at five major teaching hospitals. The study was the largest ever undertaken to examine the entire process of dying in America. A subsequent nationwide survey in addition to the original study, established that the study's findings were equally valid for virtually all community hospitals across the country.

In the first two years of the study, the researchers examined more than 4,000 dying patients and found:

- Half of those who were able to communicate said they were suffering moderate or severe pain that was not relieved by their medications.

- Nearly forty percent spent at least ten days in a coma, attached to a mechanical ventilator or in an intensive care unit where they were isolated from their families most of the time.

- Nearly a third of the patients and their families spent all or most of their savings during the vain and unsought effort to postpone inevitable death.

- When dying patients did not want to be resuscitated artificially, if they became unconscious, doctors did not know or were not informed about their wishes nearly half the time (forty-seven percent) because of woefully inadequate or misdirected communication.

This is not the picture of the end of life that most of us would want to face *(Lynn, J. 1996).*

In the second two-year phase of the study, (*JAMA, 1997*) involving nearly 5,000 patients, the researchers examined the effectiveness of aggressive intervention by the specially trained "nurse- advocates" who were assigned to encourage doctors to communicate with their terminally ill patients and families. To discuss and determine patient/family wishes about intensive care, and to avoid futile and unwanted high-technology efforts when death was near. The "intervention" efforts were focused on half of the patients. The other half (in the control group) were cared for according to the normal standards of the hospitals

The researchers had expected that the nurse-advocates could change the picture significantly for patients in the intervention group by making doctor-patient communication easier and the knowledge of death far more bearable. However; the advocates had no such effect, the study team found. The patients in this part of the experiment spent the same amount of time in intensive care units;

> "*Almost as many suffered unrelieved pain during their last days, and almost as many were kept alive artificially on mechanical ventilators* -- *often against their wishes." "There is a tragic mismatch between the health care many seriously ill and dying people want and what they get,*" *(JAMA, 1996, 275 (16) 1232).*

Dr. William Knauss of the University of Virginia, *(1996)* a critical care specialist and one of the co-directors of the study.

> "*We need to change the entire culture of hospitals and doctors, and instead develop a new culture (in its place) with an affirmative vision that it is possible to live well even in the process of dying. We need to spend less on high-tech intervention for the dying and divert more resources to them for support, home care and hospice care." (JAMA, 1996, 275 (16) 1232).*

Hospices, numbers of which are slowly increasing in U.S. communities, provide a dramatically different way, for many people, to die. The facilities focus on palliative care for terminally ill patients and on establishing honest communication about death between physicians and nurses on one hand and patients and families on the other.

At the Hospice Caring Project in Santa Cruz, California, for example, terminally ill patients move out from hospitals into their homes. Their families as well as hospice nurses care for them, working under the direction of physicians. Other hospice facilities offer in-patient care, but the philosophy is basically the same. If a patient has to return to the hospital, they can without readmission. An agreement is reached by both the hospital and the patient’s doctor that hospice patients will be: kept pain-free, won't be isolated and won't be subjected to needless tests or futile high-tech machinery *(Hospice of Santa Cruz, 2014).* The same is true among many other hospices.

In a number of editorial articles published as a result of this study, Dr. Bernard Lo, *(2009)* director of medical ethics at the University of California at San Francisco, calls for *"changing the organization and the culture*" of both hospitals and doctors. Lo stated in an interview related to the study results, that:

> *"While doctors are skilled at determining when death is near for critically ill patients, few have any training in how to communicate with patients and their families about what death involves and what their rights are.*" *(Lo, 2009, 08-6002-OD-OER).*

Most of the public does not know that they can execute legally-binding instructions about just how much last-ditch efforts they will want.

Ironically, some of the pain and futile high-tech intensive care that dying patients face today may be limited more and more by the spread of managed care programs, both doctors Lo and Siemsen noted.

> *“While critics of managed care plans complain that necessary care is often too limited, controlling the use of intensive care units when death is*

> *inevitable may also serve as a strong financial incentive to reform the system",* according to Lo. *"Although medical students and hospital interns at UCSF receive some training on these issues",* Lo said *"such education is far from universal*." *(Lo, 2009, 08-6002-OD-OER).*

As a result of this JAMA study, discussed above, Dr. Steven A. Schroeder, (2013) president of the Robert Wood Johnson Foundation, announced that the foundation is planning on financing a multi-million dollar campaign to begin changing the attitudes of the public, doctors and healthcare professionals toward a more humane approach to patients with terminal illness.

When Dr. Elizabeth Kubler-Ross (*2003*) educated interns, in an urban hospital, about the dying, her goal was to let terminally ill patients make their own case in interviews. She planned to do this by having these patients tell their "story" to groups of interns and residents in their own style and on their own terms. Informing staff members and administrators of her plan she was told by resident after resident that no one was dying on their wards; there were only some patients who were very critically ill. She realized that the social and administrative pressure to not categorize patients as dying was ingrained even down to the level of medical student.

"Dying is a natural event often-times better witnessed than managed."

Balfour Mount (2005).

Healthcare professionals are often called upon to put aside their own beliefs in order to discover what's appropriate for a particular patient in a particular situation.

> "*Care of the dying"* Mount writes "*involves both the heart and the mind, the dying need the friendship of the heart with its caring, acceptance, vulnerability, and reciprocity. The dying also need the skills of the mind embodied in competent medical care. Neither alone is sufficient." (DeSpelder, Strickland, 2009, p: 125-132).*

Considering that the course of any serious disease may be highly unpredictable, forcing a patient to choose between spending last days or weeks at home or having access to the sophisticated medical technologies available only in a hospital, is a cruel dilemma. Would a patient prefer one choice over the other? This forced choice often leads to confusion and frustration in choosing the place where he/she will die or the exact nature and focus of the medical care needed. Even so, it is always wise and prudent to consider as many options as possible. When doctors and patients finally admit that death is foreseen and expected, as the final chapter of a long illness, there are usually many choices about where death will occur.

Doctors and healthcare administrators must consider the possibility that the end of a patient’s life may involve a combination of home care, hospital stays, and hospice or palliative care both at the hospital and at home. Helping patients and their families to learn about the options for end of life care empowers all of us to make informed choices and meaningful decisions

Doctors are entrusted with the health of society. The Charter on Medical Professionalism, drafted in 2002 by the *American College of Physicians,* declares that professionalism is the basis of medicine's contract with society. According to the ACP this "contract" is the articulation of something essential to medicine: physicians become what they are because of their individual capacity and sacrifice but also because society permits their education and practice in the first place. Any physician can discuss or brag about skill level and credentials but in the end, every doctor learns to suture a wound only because of the selflessness of a volunteer patient who understands that medical proficiency must start somewhere. How many patients have volunteered to serve as a training example for a new doctor or a trainee nurse? This "*contract*" is sealed with the studious efforts of one, the trainee doctor and the pain and patience of the other, the volunteer patient, (*ACP, 2002*).

Consequently, all physicians have a social obligation, requiring that the interests of patients are upheld above those of all other individuals, including the physicians themselves, setting professional standards of integrity, and "providing expert advice to society on matters of health." (*American College of Physicians, 2002*)

According to the ACP policy the fundamental principles of this charter/contract advocate the primacy of patient welfare. Altruism is the catalyst of the physician-patient relationship, and market forces, societal pressures, and administrative policies must not compromise this principle. Contemplating this contract / charter, physicians must empower their patients, help them to understand their options and to make informed health decisions, and acknowledge their (patient) autonomy. Finally, the charter advocates social justice*:*

> *Physicians must promote justice in the health care system, including the fair distribution of health care resources, working to eliminate discrimination in health care, whether based on race, gender, socioeconomic status, ethnicity, religion, or any other social category. (ACP, 2002, ln: 474090)*

In the next chapter we will reflect on issues impacting the current situation in American healthcare and the cultural components that have contributed to our dying patient dilemma in American medicine.

Chapter 5

THE DYING DILEMMA IN AMERICAN MEDICINE

"Without death, life would be meaningless."
William James

Why do we die? What is the point? Viewing the phenomenon of death from a purely scientific interpretation, we can see that death promotes variety through evolution of the species *(De Spelder, 2009*). The normal human life span is long enough to allow for reproduction of new members of the species and to ensure that the lineage of human kind continues. The length of a human lifetime, however long, is also short enough to allow for new genetic combinations that provide a means of adaptation to changing conditions in the environment. From the perspective of species survival and evolution, death makes perfect sense; clearing out the old to making way for the new. The species is constantly renewed by always creating new DNA combinations from successful previous combinations, to form a virtually infinite variety. However, this purely objective scientific explanation offers little comfort when death personally touches us. At the core of this philosophical conversation is the idea that death is both a blessing and a curse *(Tolken, 1956)*.

In Greek Mythology, the god Thanatos was the personification of death, the twin brother of Hypnos, the god of sleep. Over time the Greeks came to use thanatos as a generic word for death. Even though the definition of the modern discipline of “thanatology” is well documented in the English language, by the early twentieth century the word thanatos became closely associated with Freudian psychoanalytic theory *(Mitchell, 1996*). Freud postulated that “the death instinct” (thanatos) was the source of all unconscious destructive urges and behaviors. This he held in contrast to Eros which he felt was the source of all constructive instincts and behaviors “the life instinct.” Freud theorized that every variation of human behavior was a result of the interaction between Eros and Thanatos, the dual instincts for life and death. Freud’s genius always represents an interesting and thoughtful perspective on life and death, one to be considered in pursuit of any meaningful philosophy or discussion that includes death in our culture *(Freud, 1968).*

Our relationship with death has a significant power to shape our thinking and behavior at all points in our life span. The way in which we anticipate death, according to Herman Feifel, governs our perception of “now” in a very influential manner. This construct applies not only to the terminally ill, combatants in war or to people who fit other categories we associate with an increased risk of death (the very old, suicidal people, risk-takers, stunt-daredevils), but applies to all people everywhere. This philosophy applies to the medical profession, in particular, because members of the medical and healthcare professions have a significant ongoing relationship with every aspect of sickness and death. *(Feifel, 1992).*

SOCIAL FAMILIARITY WITH DEATH

The past one hundred years have seen dramatic changes in the demographics of the American population in its size, shape, and distribution. These changes are significant for all of us and affect our expectations about death because they provide for increased life expectancy and lower mortality rates (*Crissman, 1994).* In the America of the past a typical household would include not only parents but uncles, aunts, and aged grandparents as well as a host of children of various ages. Such extended families, with several generations living under the same roof are rare today. One consequence of this change is that most of us have fewer opportunities to experience our relative's deaths first hand. Additionally, the greater geographic mobility in America makes it less likely that we will be present when older relatives die.

Consider how our experiences with death and dying have changed over this time period. In the nineteenth century people typically died at home surrounded by an extended family that often spanned several generations. When death grew near relatives and friends gathered to maintain a vigil at the bedside. After the death occurred they washed and prepared the body for burial. A hand-built coffin was constructed and placed in the parlor of the house where friends and relatives participated in a wake and shared in mourning the deceased. Death was a common domestic family experience. Children were included in the activities surrounding the death, staying with adults and often sleeping in the same room as the corpse. Later in a family plot at the home site or in a church yard cemetery the coffin was lowered into the grave by those closest to the deceased who would then shovel the soil over the coffin to fill in the grave. Throughout this process, from caring for the dying to preparing the body for burial, to the coffin, to the actual grave and burial, death was within the realm of the family. Now in the twenty-first century all these tasks are carried out by trained, certified and impartial professionals.

In this new millennia, our familiarity with death, has also been powerfully influenced by sophisticated medical technologies, standardized healthcare policy and laws governing verification, certification and pronouncement of death. These social circumstances now govern and affect the place where death occurs and most often the manner in which people die. In contrast to earlier generations *(Farrell, 1980)*, where family members played a large role in the care of their dying relatives, we now rely on professionals such as the cardiologist, the insurance agent, the funeral director, to act as our surrogates in the death event. The net result is that the vast majority of us are completely unfamiliar with death as a phenomenon of life.

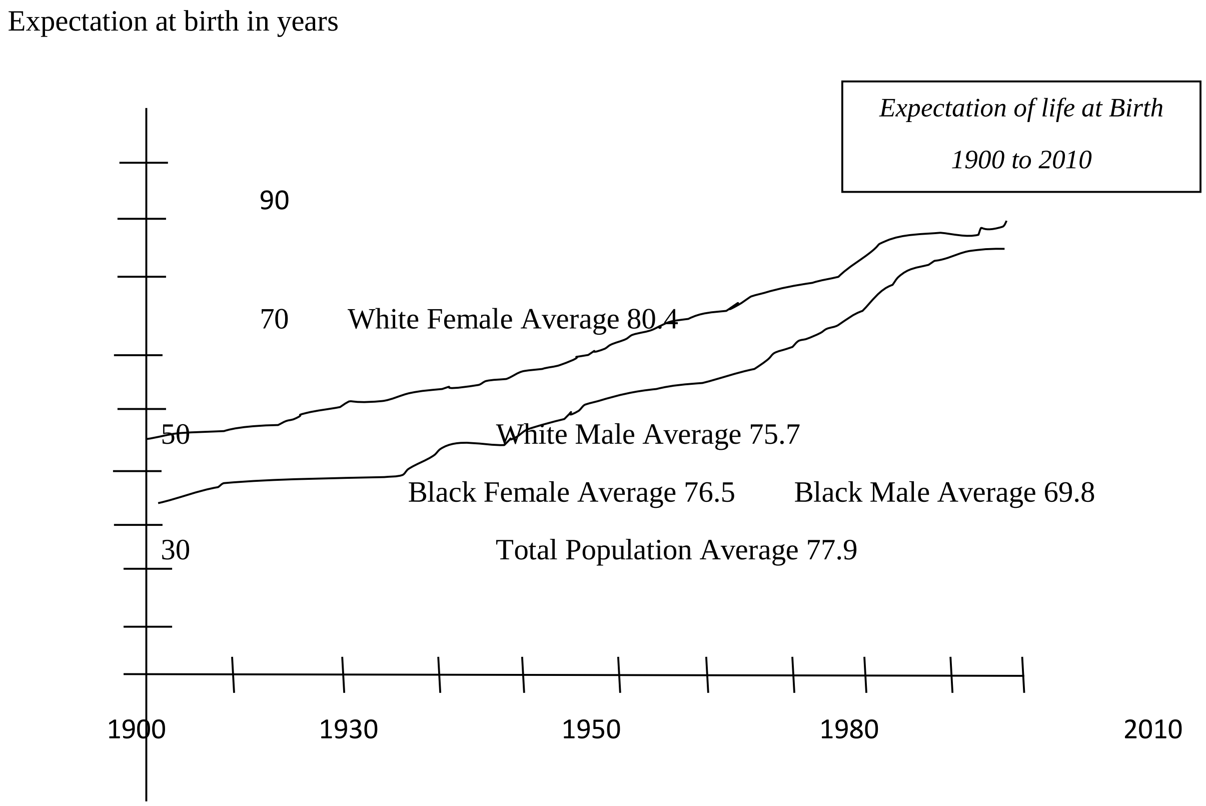
Since the turn of the century in the year nineteen hundred, life expectancy in America has increased from an average of forty-seven years to an average of seventy-eight years. These figures reflect a “cohort life expectancy” of approximately eighty years which means that this is the average number of years a specified group of infants would live if they were to experience the age-specific death rates prevailing in their birth year.

In 2010 the life expectancy at birth for the US population as a whole (average of women, men, blacks and whites) is seventy-seven point nine years (77.9). This overall cohort can be broken out into four segments: white females at eighty point four years (80.4), white males at seventy-five point seven years (75.7), black females at seventy-six point five years (76.5) and finally black males at sixty-nine point eight years (69.8). Today we can assume that a newborn child will live well into his or her eighth decade or perhaps even longer (*US Census Bureau*, *2010*).

This was not the case in the year nineteen-hundred. Over ninety-nine percent of infants born in the America now survive the first year of life. In the year nineteen-hundred less than eighty-eight percent of new born children survived beyond their first year of life.

The following graphs provide a visual illustration of the dramatic changes in the life expectancy of the average American during this time period. All graphs are reprinted from the 2010 U.S. Census Bureau.

Insert chart about here



Data from: Crase, D., 1987,
Chart from US Census Bureau 2010

More illustrative of these changes is the fact that over half of the deaths of the total population, in nineteen hundred, occurred among children age fourteen and younger. Now, in two thousand and twelve -2012 slightly more than one percent of deaths occur in this age group. In his book Save the Babies: American Public Health Reform 1850-1929 Richard A. Meckel *(Meckel, 1998)* indicates that these figures also have a powerful influence on how we as a society think about and live with death. He points out that today we can only imagine an environment where death at an early age is common, how different experiences of dying and death would be in a time when the high percentage of infant deaths were thought of as a matter of "fate" that could not be changed. In those days mothers died in childbirth, babies were still born, one or both parents might die before their children had grown to adolescence. Surviving siblings often had a private memorial to a dead sibling as a personal memory of a lost loved one. Both young and old would be extremely familiar with death as a natural part of the human condition. Living with such a common awareness of mortality our predecessors had to accept death as a familiar event in their lives.

Changes in life expectancy and mortality rates are due largely to changes in the common causes of death. In the year nineteen hundred the leading causes of death were infectious diseases, IE: typhoid fever, tuberculosis, diphtheria, syphilis, pneumonia and streptococcal infection (IE: staff, septicemia). These diseases came on suddenly and death was almost always the immediate result within weeks or even days (*US Census Bureau, 2010*).

The majority of the population, today, die from chronic illnesses like heart disease or cancer where death follows a slow progressive course that may go on from months or even years.

Insert chart about here

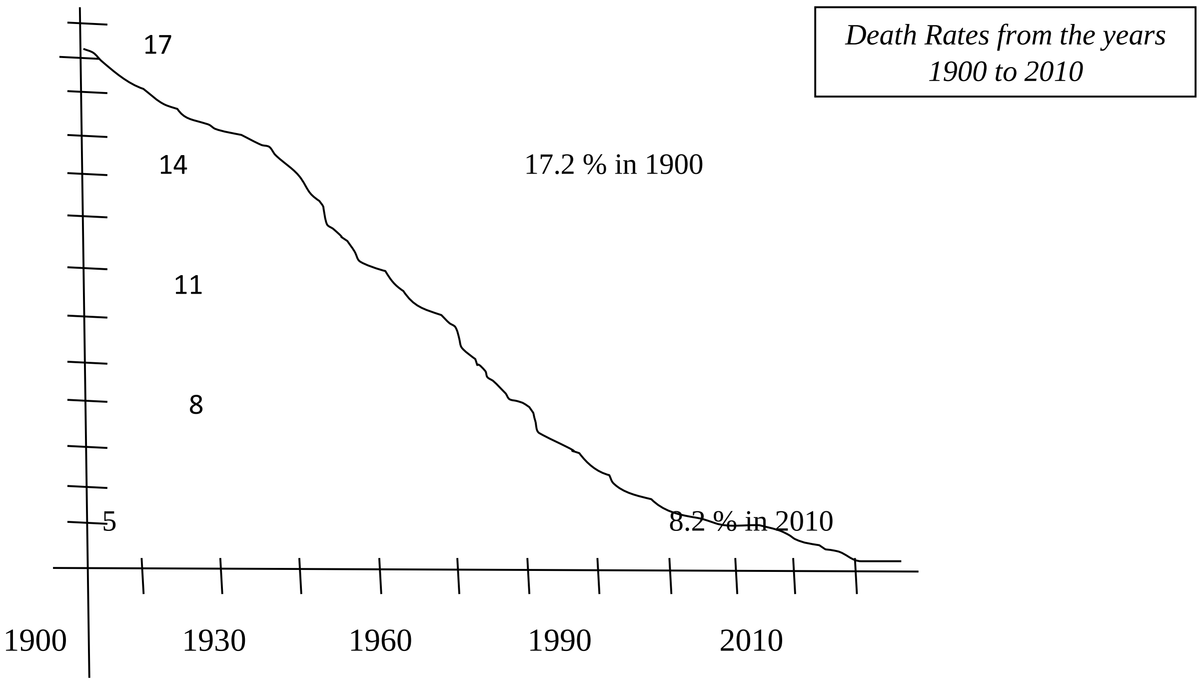


Chart from US Census Bureau 2010

Death Rates from US Census Bureau figures and statistics: 2010

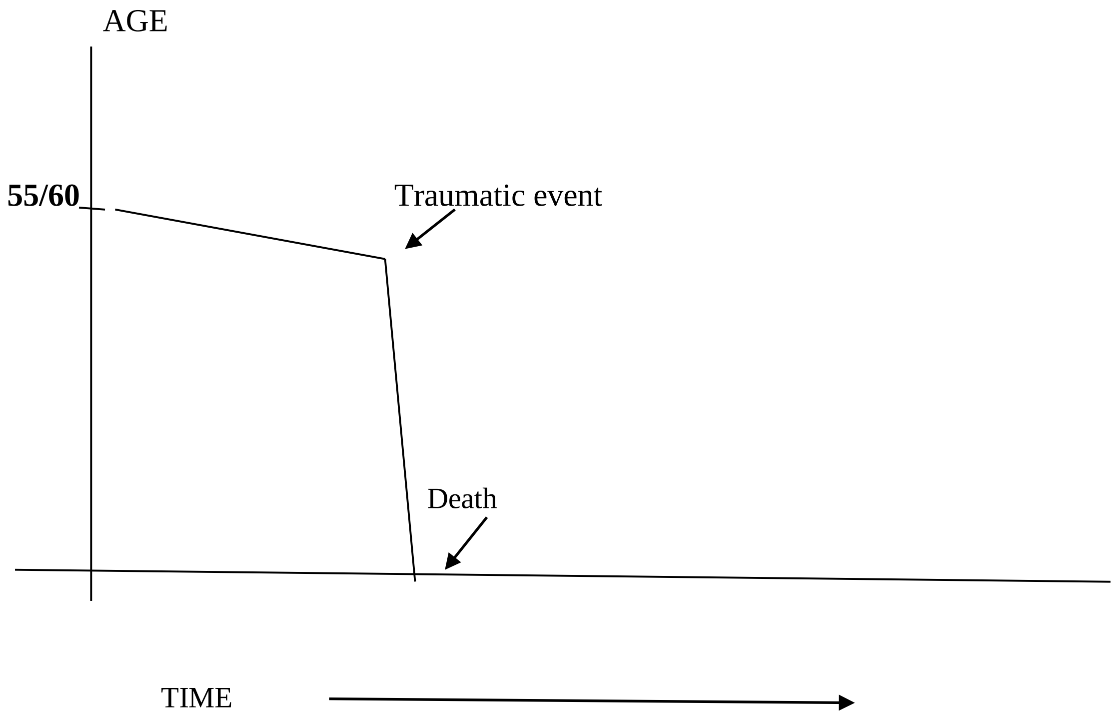
DYING TRAJECTORIES

Expectations about dying among the general population, may be significantly different from what most people actually experience. Research shows that young adults tend to imagine themselves living into old age and then quickly dying at home, surrounded by loved ones, pain free, alert and lucid until the end (*Butler, 2013).* The realities of pain, discomfort, confusion and indecision, tend to be absent from these deathbed scenarios. Fantasies from the movies and images and scenes of dying on TV seem to be more influential in the culture, than what is likely to actually occur in reality.

The concept of a "*Dying Trajectory*" *(Glasser, Strauss, 2012)* is extremely useful for research into categories of dying and for a greater understanding of patient's experiences as they approach death. The importance of using these death trajectory scenarios for research cannot be over emphasized in the study of human death experience in both the patients experience and the family's experience. Sudden death from an unexpected cause like massive heart attack, stroke or tragic accident is a type of dying trajectory (see chart 4.1) but for research into the majority of deaths the focus is on those deaths that occur with a specific lead time as in the following scenarios displayed in charts (4.2), (4.3), (4.4) and (4.5). *(Kiernan, 2006, pp: 55 -64).*

Insert chart about here

4.1 Trajectory for Sudden Unexpected Death *(heart attack/accident, stroke)*



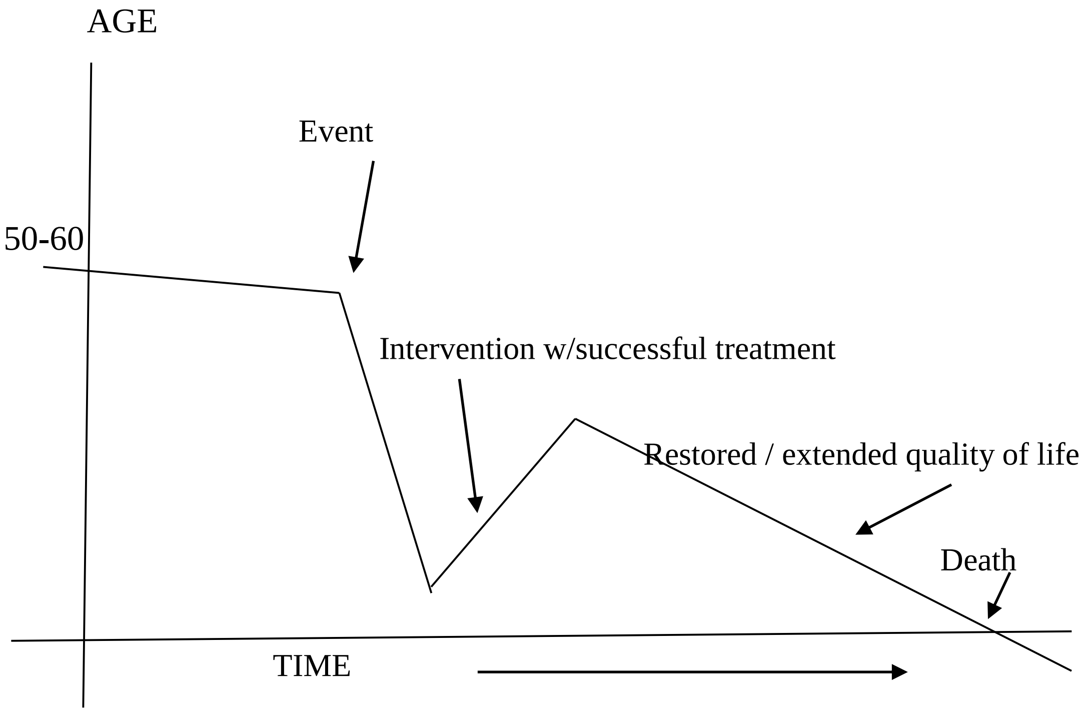
Glasser & Strauss 2012

Among types of deaths (see chart 4-2 below) are those that involve an immediate life threating event, subsequent life-saving treatment and a partial recovery. Then treatment / remission and a fairly predictable remaining life span, albeit with slow gradual decline. An example would be a coronary event and a subsequent dramatic intervention and treatment regimen like multiple coronary bypass surgery and lifestyle change.

Insert chart about here

4.2 Dying Trajectory for life threatening event with successful treatment

(Heart attack, stroke with dramatic successful intervention and appropriate treatment)

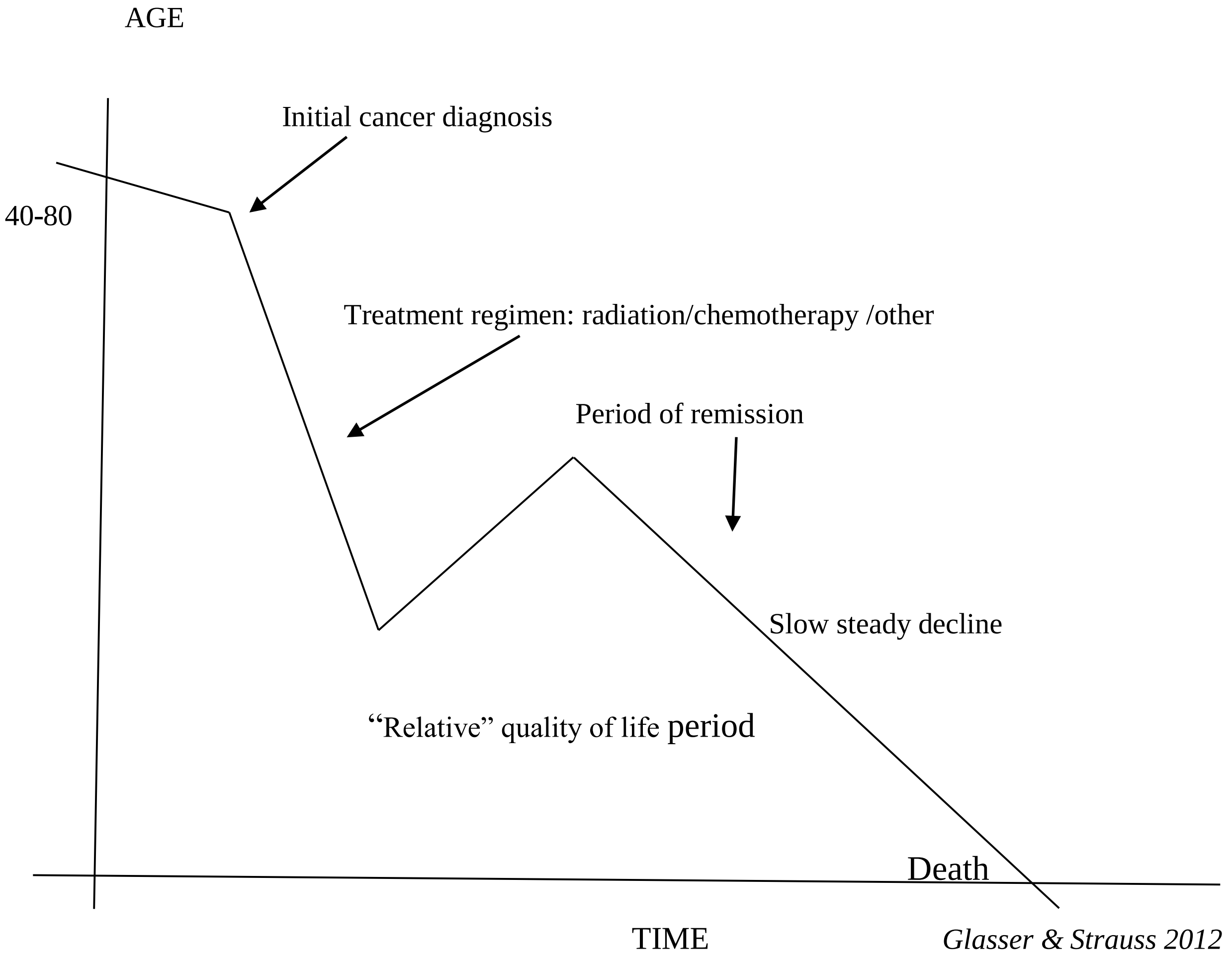


Glasser & Strauss 2012

Amid these trajectories are those that involve critical diagnosis and subsequent treatment with possible remission and /or a slow steady decline but no real depreciable immediate loss of quality of life for a prolonged period (see chart 4-3). This is the case with many cancers and progressive heart disease. In the majority of these the patient receives dramatic life-saving treatment with the appropriate therapy and recovers (remission) to live an extended period after the treatment.

Insert chart about here

4.3 Dying Trajectory: Diagnosis, Treatment, Remission

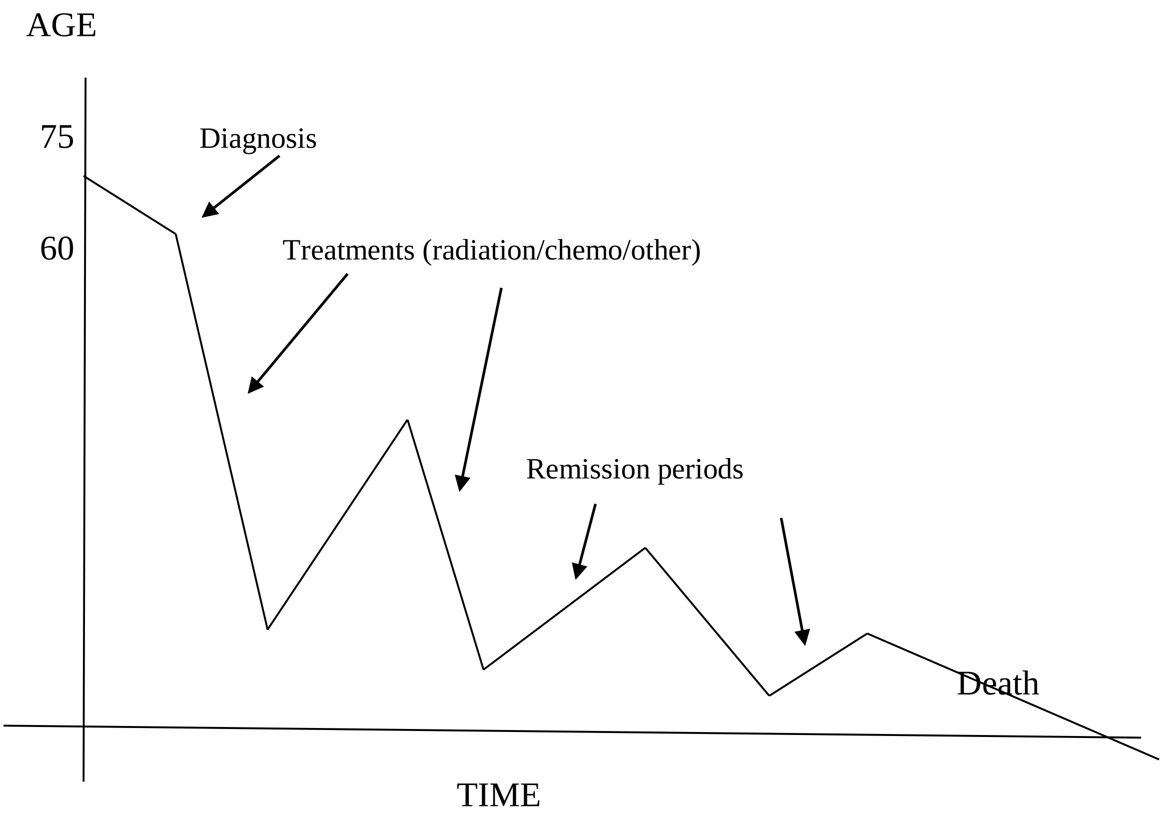


Glasser & Strauss 2012

There are those trajectories that involve a diagnosis of advanced chronic illness and a long period of steady decline marked by episodes of crisis/treatment and remission, the last of which proves to be suddenly fatal (see chart 4-4).

Insert chart about here

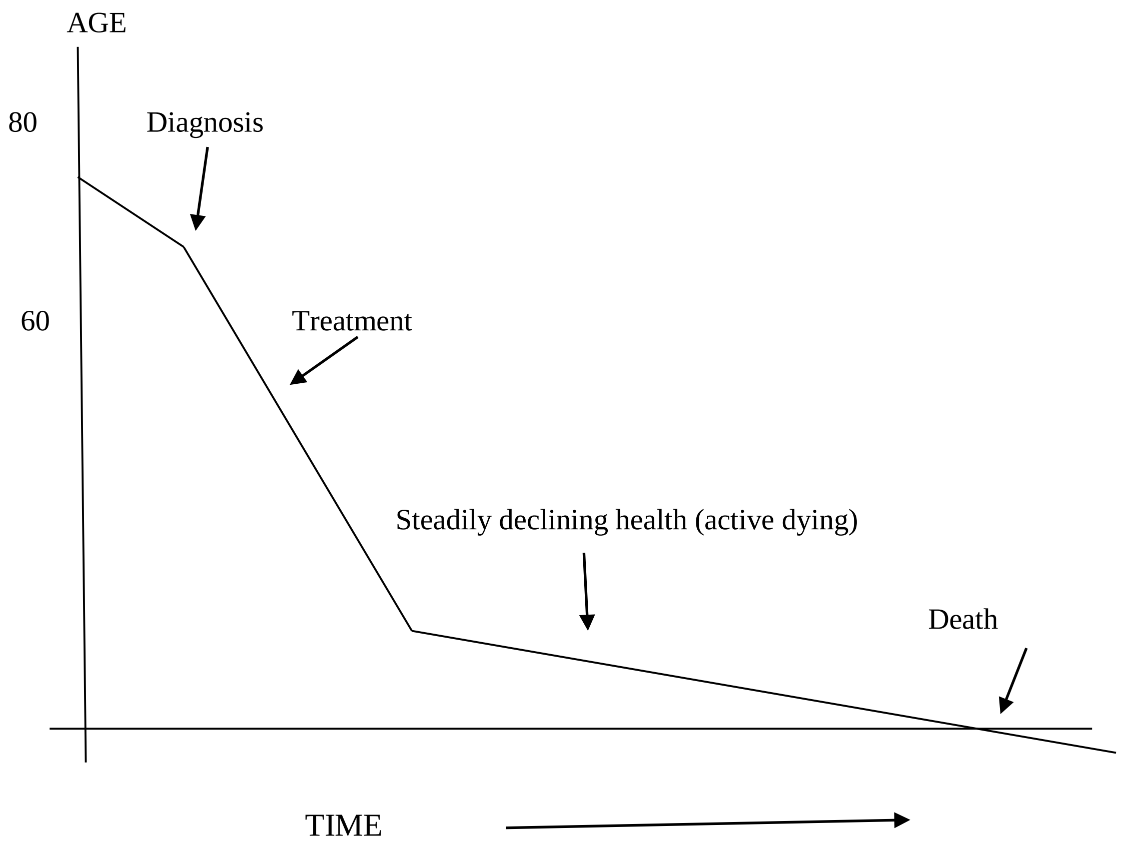
4.4 Dying Trajectory: Diagnosis-Treatment/Remission Cycle



Finally, there are those trajectories where a patient is known to be terminally ill but is living with a finite life expectancy of perhaps months that evolves into a condition that can be termed as actively dying (see chart 4-5).

Insert chart about here

4.5 Dying Trajectory: Actively Dying



The way in which these trajectories are estimated, their duration and expected course, affects patients, doctors, and family actions. Specific patterns of dying trajectories are important for research to show very graphically the “lingering-trajectory” when a patient’s life fades away slowly and inevitably.

Organized around locations and settings American medicine focuses upon localities where people die most often: hospitals, nursing homes, long term care facilities, and hospice. Treatment and therapy is organized by specific disease categories: one method for one disease and another method for a different disease. These processes are currently accepted in our healthcare system. However, either kind of organizational scenario (treatment or therapy) creates a system in which many patients do not get the care they need when they most need it or not in an environment that makes sense for the patient *(Lynn, Schuster, et al, 2008).*

Organized healthcare *(AMA, 2012)* maintains conventional divisions by disease and setting of care that do not make logical sense for a large percentage of those patients who have multiple diseases and require multiple care settings. Health care administrators and providers as well as policy makers, public officials and legislators should be encouraged to consider modifications to a system that would be based upon these “trajectories” that patients follow when living with and coping with, a fatal illness.

The most important three trajectories are those patients with: a short period of evident decline as is typical with virulent cancer (chart 4.3); patients with long term limitations with intermittent serious episodes (chart 4.4) and patients with prolonged decreasing quality of life due to their disease and including frailty and dementia (chart 4.5). Each of these three trajectories or pathways through dying presents its own unique challenges and requirements. Cancer patients, for example, benefit from intense but relatively brief hospital care, where patients with organ system failure require long-term support to live comfortably with their uncertain prognosis.

According to Karen Steinhauser *(2001)* in her article: *Preparing for the end of life*, patients in this stage of life want to live as well and a pain free as they can for as long as possible. They and their families have many of the following goals:

- Relief from symptoms
- Help with family burdens
- Reasonable costs for care
- Good quality of life with whatever is left
- Sense of being in control and maintaining dignity
- Opportunity to come to peace with spiritual issues & relationships

These goals should be balanced against the desire to prolong life and prevent further illness when their pursuit requires invasive or aggressive treatment. Pursuing all of these goals simultaneously makes sense but contrasts with the conventional wisdom that people near death need comfort and closure but not treatment. Instead of the clear cut transition from cure to care we must start to view patients living with fatal illnesses as having many complex goals and priorities *(Steinhauser, Christakis, et al, 2000).*

By applying the study of these “trajectories” to a predetermined healthcare response we can anticipate and react to the patient and family needs during the “dying” process. The appropriate trajectory would serve as a general model of what should be expected for this patient. The social impact, for the family, and the management impact of patients care, can be greatly enriched by the study of the effects of these “dying” concepts. The impact and expectations (*Kastenbaum, 2004*) that doctors, the healthcare community of providers, family members and others have about a patient’s course of treatment toward death are very likely to be critical in determining the nature and kind of care received by the dying patient.

Healthcare professionals and administrative treatment strategies, for the most part, do not take into account the impact a serious diagnosis or “terminal” declaration has on patient and family. If we study these dying trajectories we should be able to quantify treatment focus and adjust it for the “actively dying” in hopes of making their death more comfortable and pain-free and more acceptable of the inevitable. When the naturalness of biological death is removed or unacknowledged the cessation of physical functions can be preceded by the phenomenon known as social death.

> Eric Cassell, (*2008*) writes: “*There are two distinct things happening to the terminally ill: the death of the body and the passing of the person. The death of the body is a physical event where the passing of the person is a non-physical (social, historical, emotional, spiritual even psychological) one.”(De Spelder,*

Strickland, 2009, pp: 269).

A terminally ill patient does not readily fit into the Parsons *(1977)* model of the "sick-roll" in society because terminal illness is not a temporary condition followed by a return to society when wellness is achieved. The social roll for the dying person is not plainly defined, if at all. Even when circumstances and diagnosis are clearly to the contrary, many medical professionals will still urge the dying patient and family to hope. This "false hope" in turn denies the dying patient the reality of his experience and may result in actions and decisions that are inconsistent with real life.

A SOCIAL ROLE FOR THE DYING

What does society "owe" a dying person? Does a dying person even have a social role and what is that social role? Certainly the dying person would not be presumed to maintain an appearance of expecting to live forever or of getting well again or of sustaining false hope of dramatic recovery. In medicine, nursing and the allied health professions, end-of-life care refers to health care, not only of patients in the final hours or days of life, but more broadly the care of all those with a terminal illness or a terminal condition that has become advanced, progressive and incurable. According to the National Cancer Institute *(2009), "Last days of life: PDQ",* when a patient's healthcare team determines that cancer can no longer be controlled, medical testing and cancer treatment should stop, but the patient's care needs will continue. The care then should focus on making the patient comfortable. The patient should receive medications and treatments to control pain and other symptoms, such as constipation, nausea, and shortness of breath. The NCI says that some patients can remain at home during this time, while others may need to enter a hospital or other facility. Services should be available to help patients and their families with the medical, psychological, and spiritual issues surrounding dying. This time at the end of life is different for each person, however Hospice often provides such services. Each individual has unique needs for information and support. Ideally the patient's and family's questions and concerns about the end of life should be discussed with the health care team as they arise.

According to Eric Cassell in his book *“Dying in a Technological Society”* (*1974)* patients and their family members often want to know how long a person is expected to live. This is a hard question to answer, factors such as where cancer is located and whether the patient has other illnesses, can affect what will happen. Although doctors may be able to make an estimate based on what they know about the patient, they are usually hesitant to do so. *“Doctors may be concerned about over or underestimating the patient's life span and they may also be fearful of instilling false hope or destroying a person's hope. End-of-life care requires a range of decisions, including questions of palliative care, patients' right to self-determination and types of treatment.” (Cassell, 1974, pp: 43-48,).*

There is also the question of medical experimentation for untried treatments. When a patient is terminal, the ethics and efficacy of extraordinary or hazardous medical interventions for new medications, along with the ethics even of continued routine medical interventions become important. In addition, end-of-life treatment often touches upon rationing and the allocation of resources in hospitals and the national medical system. Such decisions are informed by technical and medical considerations and economic factors as well as bioethics. In addition, end-of-life treatments are also subject to considerations of patient autonomy. Ultimately, it is still up to patient and family to determine when to pursue aggressive treatment or to withdraw life support.

Dr. Lauren Jodi Van Scoy, *(2012)* a board-certified internist who has spent hundreds of hours in the intensive care unit, where she has witnessed the manner in which many critically ill patients choose to die, writes how sometimes such a decision is mired in upheaval when family members are forced to confront the inevitable. She believes, people think DNR means give up. They think DNR and hospice means you are quitting. This is untrue, it’s more about accepting and embracing the next phase of life, even if it’s death. DNR does not mean do not treat and it does not mean do not care. It just means do not resuscitate by giving CPR, electric shocks or medications to restart the heart. If things go badly, there is a role in certain situations for letting the natural breakdown of the body occur.

The patient and family should be encouraged to mobilize the necessary resources and attitude for attending to and accepting the prospect of death. One huge advantage of an appropriate social role (regarding death) is the allowance of family and friends to accept the perspective of death as a natural and inevitable event at the end of life, not a medical failure or a willpower failure. The “blame” is focused away from the medical community and removes the false “responsibility” for death from the patient. Most importantly the patient can be free to set his own agenda around activities and relationships as the end of life is acknowledged and comes closer *(Baugher, 1990).*

In a study titled “Farewells by the Dying” by Allan Kellehear and Terry Lewin, *(1989)* discovered that:

> *“The majority of the dying patients interviewed wanted to express their farewells to those closest to them. To spend time with and be in close physical proximity with those they love. This “expression” could also take the form of conversations, gifts of personal possessions and even written letters and notes to their loved ones and family.” (Kellehear, #19, 1989, pp: 275-292).*

Discussed previously, the social role for the dying person should also embrace the spiritual needs of the dying. In a study published in the Oncology Nurse Forum, *(Hermann, 2001, 28(1): 67-72)* conducted in 2001 titled: Spiritual needs of dying patients: a qualitative study to identify dying patients' definitions of spirituality and their spiritual needs. Participants initially defined spiritual as relating to God or religion; however, as the study interviews progressed, it became apparent that spirituality was a part of their total existence. During the study twenty-nine unique spiritual needs were identified and subsequently grouped into these six themes:

1. Need for religion
2. Need for companionship
3. Need for involvement and control
4. Need to finish unfinished business
5. Need to experience nature
6. Need for a positive outlook.

The study conclusion was that spiritual care of dying patients is within the scope of healthcare/nursing practice. Spiritual needs are quite varied and encompass more than just religion. If nurses are to enhance the quality of life of dying patients, the patient's spiritual needs must be addressed. *(Hermann, 2001, 28(1): 67-72).*

According to Alfred Killilea, *(2003)* in his book, "The Politics of Being Mortal" *w*e can be encouraged by what the cultural research shows as the beginnings of an increased openness about death in American society. Killilea suggests that there are some positive signs that many of the circumstances surrounding dying as an event are being brought back to the personal control of the dying individual and family. Many traditional customs and practices are being revived in new ways however; he warns that we must be cautious that this new openness is not misleading us into an informal or easy relationship with death. When death becomes just another topic of casual discussion it can reflect a trivializing or devaluing of the death event. *(Killilea, 2003).*

According to Dr. Marjorie Kagawa-Singer, M. *(1998)* in her article: *The cultural context of death rituals and mourning practices,* we do not want to put forth a great effort to change and then find ourselves confronted with only the image of death and not death itself. Death is not a solitary event. It is a social event that ripples outward to touch the lives not only of family and friends but also the lives of casual acquaintances and even to relative strangers in ways that we really do not understand *(Kagawa-Singer, 1998, 25, 1752-1756).*

Lars Sandman postulates in his book Facing-Death, *(2005). The value of death and dying*, that there is no single characterization of what constitutes a good-death. In ancient Greece to die young, in the fullness of one’s creative energies, was considered exceptional luck. Now in modern society to die young is considered a horrible misfortune. The untimely death of one just starting out on life’s journey or the death of someone in the prime of life seems like a great tragedy and a terrible loss. Relating to the good-death, there is a contemporary widespread fantasy that we may reach eighty or ninety years old in relative good health and then die in our sleep. The actual reality (research shows) is quite different from this popular illusion.

Robert Kastenbaum in his book On Our Way: The Final Passage through Life and Death *(2004, (4), pp: 96 - 98)* has advanced the following components of what might constitute a good-death:

- Patient should be spared extreme physical, mental and spiritual suffering at the end of life.
- A good death should enact the highest values held by society. Communal values are affirmed when people end their lives in a congruent manner.
- The good death affirms our most significant personal relationships.
- The good death should be transfiguring. One experiences an epiphany- a profound sense of beauty, love, understanding… The moment of death can become a peak experience of life.
- The good death is simply the final phase of a good life. People should die as they have lived.
- The good death is coherent. It is a story or narrative, a drama that makes sense, one that satisfies our need for closure.

A second attempt to define a good death comes from the Annals of Internal Medicine in a 2002 essay titled: *Reforming Care for Persons at The End of Life: The Promise of Quality Improvement (2002, 137(2):pp:117-122).* The essay indicates six basic components of a good death:

- *Pain and symptom management:* Minimizing the likelihood of dying in pain or suffering "breakthrough" pain by administering adequate analgesia and other forms of pain relief.

- *Clear Decision Making:* Empowering the dying patient by striving for clear communication between the patient, his family and the medical team. Discuss vital end-of-life decisions before crisis occurs and emotional reserves are low.

- *Preparation for Death:* Knowing what to expect at the end stage of an illness relative to the physical and psychosocial changes likely to occur as death approaches. Planning for actions taken after death.

- *Completion:* Acknowledging the importance of spirituality and other avenues of meaning, including life review, resolving conflicts, spending time with family and friends, enacting specific cultural rituals, and saying goodbye.

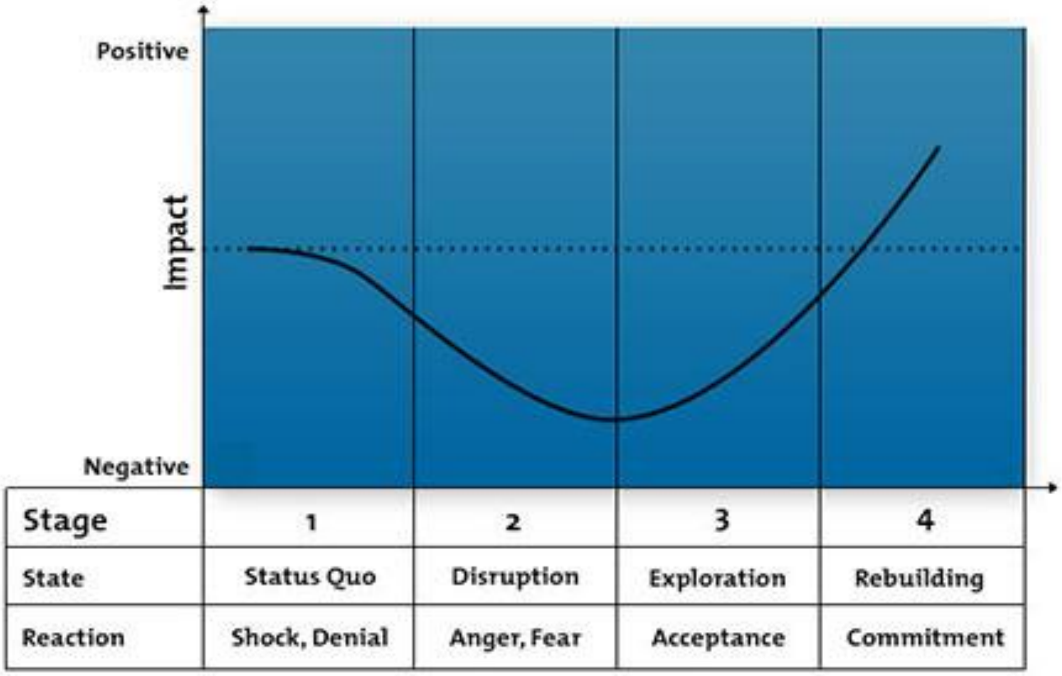
- *Contributing to others:* Sharing meaningful aspects of one's self through tangible or intangible gifts, such as time, concern for others, personal reflection and understanding.

- *Affirmation of the whole person:* Seeing the dying person not as a "disease", but in the context of his life and values and preferences.

Social change is a difficult and often slow process. Industrial psychologists *(Aamodt, 2010)* postulate that resistance to change is directly proportional to the extent of that change. But social change can happen and it is possible for American society to change dramatically over time.

The Change Curve model (below) describes the four stages that people go through as they adjust to change. You can see this in the chart *(Mind Tools, 2012)* when a change is first introduced, people's initial reaction will be shock or denial, as they react to the challenge to their status quo. This is Stage One of the Change Curve. Once the reality of the change starts to hit, people tend to react negatively and move to Stage Two of the Change Curve: They may fear the impact; feel angry; and actively resist or protest against the changes. *(Aamodt, 2010, (14), pp: 516-519).* Some will wrongly fear the negative consequences of change. Others will correctly identify real threats to their position. As a result, there will be disruption which, if not carefully managed, can quickly become chaotic.

The Change Curve



Stage	1	2	3	4
State	Status Quo	Disruption	Exploration	Rebuilding
Reaction	Shock, Denial	Anger, Fear	Acceptance	Commitment

Mind Tools 2012

For as long as people resist the change and remain at Stage Two of the Change Curve, the change will be unsuccessful, at least for the people who react in this way. This is a stressful and unpleasant stage. In the overall, it is much healthier to move to Stage Three of the Change Curve, where pessimism and resistance give way to optimism and acceptance.

Consider smoking, still one of the leading causes of death in the United States. The CDC *(Center for Disease Control, 2011*) indicates that approximately four hundred and forty-five thousand (445,000) Americans die each year from smoking related illnesses. The research shows that approximately fifty-five thousand (55,000) of those deaths can be attributed to exposure to “second-hand smoke” the study of which was once dismissed as quackery/junk-science. The CDC *(2011)* also estimates that smoking related illnesses add ninety-six billion ($96,000,000,000) dollars to the nation’s healthcare bill each year. Yet things could be worse; if we had not participated in and forced social change regarding the social acceptability of smoking. *(Egan, 2013, 6/25).*

Less than thirty (30) years ago the Surgeon General’s office (*2010)* officially verified the link between smoking and fatal illnesses (cancer, heart and lung diseases). Since that time the percentage of adult Americans who smoke has dropped by more than half, fifty (50) percent, from approximately forty-three (43) percent of the total population to approximately nineteen (19) percent of the total population. The rate of high school smokers went from a spike of approximately forty (40) percent, in the nineteen eighties, down to approximately eighteen (18) percent during this same time period. The current goal for 2020 is to achieve an adult smoking rate of sixteen (16) percent and a youth rate of twelve (12) percent across the total population.

This astonishing progress and rate of change resulted from a cultural/social shift in our attitude and significant efforts by NGOs (Non-Governmental Organizations), public services efforts, healthcare organizations and the general population.

Remember when cigarette smoking was everywhere in every restaurant and public venue and was socially accepted everywhere? Now cigarette smoking is not permitted in any public venue in the US. As a society we decided to make a change and the result was worth the effort.

Similar attention has been paid to commercial air travel. Recent reports and studies *(NTSB, 2012, SS-01/01, NTIS No. PB2001-917004)* show air travel in America has never been safer. This is the fourth full year (forty-eight months) with no significant American commercial aviation mishaps or fatalities. The main reason is a change in policy that rendered commercial aviation crashes socially and culturally unacceptable. In nineteen hundred and seventy-four congress mandated the creation of the National Transportation Safety Board reporting to the Transportation Secretary (for budgetary purposes) but as an independent and autonomous federal agency. This cemented the agencies mission and allowed the NTSB to pursue its goal of increasing safety standards while avoiding compromising safety principles for any political reasons. When there are any fatalities or any commercial aviation accidents the NTSB investigates and issues reports on the accident and the cause. These reports also contain uncompromising recommendations for safety or engineering improvements to prevent these types of accident in the future. *(FAA, 2013).*

In the past forty years, because of the NTSB's influence, commercial aviation accidents have steadily declined every year until 2008 when it can be said that we now have had no commercial aviation accidents, in the United States, for over four years. Again, an incredible achievement involving the efforts and labors of many thousands of people, and a great deal of time; that shows any change is possible however large and complicated it may be as long as there is enough effort and focus. *(NTSB, 2012, SS-01/01, NTIS No. PB2001-917004).*

If you prefer driving to flying, traffic safety has also hit record high levels and accidents are steadily decreasing. *(Cronin, 2000, Vol III, pp: 34-35).* After a twenty year effort and campaigns against drunk-driving, DUI, driving while distracted, emphasis on seat belts and improved roads, driving a vehicle is now safer than ever before by any standard or comparative measure. Auto makers, which resisted safety regulations in the nineteen sixties, now use safety as a selling point and as a sales promotion. As a society and a culture we decided to change and change we did. This past year according to the NHTSA *(2012)* traffic fatalities reached a new national low over the past five years and are at their lowest point in fifty years. Where we have specific goals and a major effort to achieve those goals, change is very possible, even dramatic change can be achieved.

"In the final analysis human societies are merely men
and women banded together in the face of death."
David Clark, Sociologist

In our complex relationship with death we are both survivors and experiencers. *(Samuel, 2013, 6/23).* Research across a wide variety of cultures shows that there are numerous different and varying attitudes toward death and dying. Death can be seen as a threat or as a catalyst provoking greater awareness and creativity in life, it may be seen as an ignominious end to even the best of human accomplishments or it may seem a welcome relief from life's sufferings. For many, death is seen as reward for following the rules and requirements of a particular religion. *(Thrane, 2010, 12(6), pp: 337 – 342).* For many religions death is a promotion/elevation to a better existence. One thing is certain: death holds many meanings. For some, confronting death puts them in greater touch with life. For others the idea of death is frightening. Death is inseparable from the "human" experience and of life in general.

The study of death and dying touches on the past, the present, and the future. The very concept of death takes into account individual acts as well as the customs of entire societies and cultures. Death education is important in social relationships but is crucial in medicine and in the delivery and offerings of healthcare services. *(Samuel, 2013, 6/23).*

There are current efforts underway to bridge the gap between death research; social, psychological, and physiological, and its practical application to medical practice and healthcare services among terminal patients (*Kastenbaum, 2004,28, no. 4: pp: 375-392*). This research attempts to narrow the gap between the theoretical and the practical so that findings and conclusions are more fully integrated into actual practice. For this to take place we must clarify the goals of death education on a broader perspective.

According to Robert Kastenbaum (*2004*), counselors, therapists and other medical/healthcare professionals; currently do not make much use of the knowledge and insights derived from any thanatological research. It seems that there is a cultural split/divide between researchers and the clinicians in the medical and healthcare services organizations.

In examining critical issues in thanatology Kastenbaum remarks

> "*That there are few current signs that practioners have made much use of either theory or research in their work with patients or with the bereaved*." Kastenbaum goes on to say:
>
> "*Most practioners in the area of terminal care and bereavement counseling have neither a current mastery of thanatological research nor a secure grasp of the historical and theoretical dimensions." (Kastenbaum, 2004, 28, no. 4: pp: 375-392).*

Along similar lines Myra Bluebond-Lagner *(1988,*) notes that:

> "*While the quality of research has increased what more do we actually know? Has progress in thanatology kept pace with publication and application? What differences have our efforts made in the care of dying patients and their families and in our own responses to death and dying?" (Bluebond-Langner, 1988, #18, pp: 257-263).*

The study of death and dying should include elements of information and data but it should also embrace the Medical Humanities approach and the wisdom that arises out of the human-condition and its encounter with death. Each person dies only once so the study of that event is crucial to enhancing and expanding our knowledge of death and saving that knowledge for future patients *(Bluebond-Langner, 2000).*

According to Schoenoff *(1993)* death education should include the practical aspects of the individual experience but also the psychosocial components of the patient's encounter with death. It should offer and include more than that, it should bring an added dimension to the moment-to-moment experience of living.

The discipline of death-education is still in its infancy. Albert Strickland (*2009)* calls death education a work in progress, an endeavor that welcomes ideas and visions of new contributors.

> Wass *(2004)* observes: "*The study of death and dying has the potential to help individuals and societies make the leap from a parochial to a global view, transcending self-interest in favor of concern for others, the ultimate rationale for death studies is about love, care and compassion, about helping and healing." (Wass, 2004, 28, pp: 289-290).*

Dr. Warren Holleman writes that appropriate and focused death education as a key part of medical education could bring us into the present and serve as a living reminder of the preciousness and fragility of life. Extensive death education as a required part of the medical curriculum would help doctors appreciate the complexities of the human experience with death and develop a finer appreciation for their part and their sensitivity in this final human journey. Both patients and families would benefit from a more aware and refined healthcare system and more sensitive and caring healthcare providers *(Holleman, 1991, Vol 12, No. 1, Spring issue*).

Chapter 6

MENDING AMERICAN HEALTHCARE

Mending American healthcare and changing its imbedded attitude is a formidable task, but it is not an impossible one. Time to accomplish this however, may be running out, and as bad as the treatment of the dying seems now, in the near future, we may feel melancholy for these times *(Cardarelli, 2009).*

For the year 2011 the CDC tracked two million four hundred sixty-eight thousand, four hundred and thirty five (2,468,435) deaths in America *(CDC Mortality Data).* Of this number subtract out approximately forty-five thousand (45,000) that are killed in transportation related accidents including DUI and DWI. Also subtract: the number of homicides, poisonings, and accidental fatalities that are approximately seventeen thousand (17,000) and surprisingly the one hundred seventy-eight thousand (178,000) Americans that die from hospital errors, medical errors, inappropriate drug dosages, and the administration of the wrong prescription medication every year.

Subtract SCD (sudden cardiac death) which claims approximately three hundred and twenty-five thousand (325,000) annually. The remainder: one million, nine hundred and three thousand, four hundred and thirty-five (1,903,435) are classified as “normal medical” deaths that can be tracked and that follow a calculated death trajectory (see Chapter 4 / death trajectories).

Current research and multiple medical studies (*Harrington, 2008*) discussed previously in this document, show that approximately thirty five (35) percent of these (one point nine million) trajectory deaths or almost six hundred and sixty-seven thousand (666,202) involve unnecessary pain and prolonged suffering at the hands of the medical establishment who are focused on dramatic treatment strategies and prolonging life at all costs.

According to The Center for Health Enhancement Systems Studies *(CHESS, 2013),* at “*The Active Aging Research Center*”, these thirty-five percent are what can be characterized as “bad” deaths. Morally this number is unconscionable. That this “torture-death-phenomenon” is allowed to happen to our most frail and vulnerable population is a national disgrace. The main reason that these tens of thousands of patients are forced to die “badly” is that as a society, we permit it to happen.

No one individual will ever admit to allowing this to happen and no one will ever say that a terminally ill patient should be left to suffer for any reason. However, as a culture and as a society we generally ignore and tolerate this extensive and unnecessary suffering in the hope that it will “go-away” *(Gustafson, 2007).* Knowledge of this suffering and “torture” is easily available through research into the well documented deficiencies in our medical healthcare and social-care systems. The data and facts about these deficiencies are not secret, they are available to anyone who wants to look and this information has existed for more than fifty years.

Americans are a caring, charitable and supportive people but when it comes to discussing or even approaching a discussion on end-of-life care and dying the atmosphere becomes politically charged and even poisonous. Inaction on this public health crisis is unlike our character, unlike our culture and unlike our society. Meaningful discussion and debate are muted by political correctness and a desire to avoid conflict on such a sensitive issue. The media participates in this charade, in fact the media may help to perpetuate it by constantly leveling charges of healthcare death-panels and doctor mandated euthanasia during any discussion. The conditions for discussion are derailed and then reduced to a negative sound bite on the evening news.

Like the inevitable 100 year flood the demographics of the aging baby-boomer generation and its advancing cohorts of seniors are already starting to burden our current healthcare system. All indicators show that we may be on the verge of a national crisis in healthcare for the aged and dying that will make our current situation seem tame by comparison *(Kelton, 2007)* .Similar to a slow-motion rising tide, the immediate future will see mounting frailty and physical illness not just nationally but locally and in our own communities. Even today there are a large number of ill and dying elderly that cannot cope within the healthcare system, nor can they afford to be cared for properly outside the system.

According to Doctor Ira Byock *(2012):*

> *"Mortality should be the one thing that brings all together. In science fiction novels when a planet-killing asteroid is headed toward earth, people set petty differences aside. Historically in the face of natural disasters even bitter enemies suddenly look pretty small. Cultural differences aside, death is the natural disaster that awaits us all. Instead of bringing people together in a common purpose, how we die has become a polarizing subject, rife with acrimony and righteous indignation. The irony would be funny if the social paralysis were not so damaging. Unfortunately in many people's minds and specifically in the media the question of people's right to die, how they choose, and when they choose, has been reduced to a representation of physician assisted suicide and euthanasia. This is the matter most audibly debated in the courts and legislatures. Both settings tend to dichotomize each matter considered and impose an adversarial framework to any discussion. Legislators can vote for or against a bill. The court can decide for or against a plaintive. Creative solutions are all but foreclosed." (Byock, 2001, #7, no. 12, pp: 1123-1132).*

With these words Doctor Ira Byock *(2012)* characterizes the essence of opposition to any current discussion of death and why the subject is reduced to a single element with no room for compromise or even any reasonable discussion.

"We need first to define the problem and
understand it before we can deal with it"
Albert Einstein

Current healthcare delivery systems and community services simply are not organized to meet the needs of the large and growing number of senior patients facing a long period of progressive illness and disability before death *(Hogan, et. al. 2000)*. The research discussed previously, in this document, shows a large percentage of older Americans now facing chronic illness and disability, in the final years of life. These final years can prove painful and difficult for sick and disabled elderly people, who may have difficulty finding care to meet their needs. This period is also stressful and expensive for families and loved ones

The good news is that it does not have to be this way: older people, for the most part, can live reasonably well with serious chronic illness. America's health care system can be flexible and has adapted to demographic changes before. It is more than capable of adapting again. But adapting for a good-death will require seeing end-of-life care in new ways and reforming the health care system to recognize, finance and provide the necessary support services.

Previous chapters in this dissertation covered how Americans live and die and how that has changed dramatically in the past century. In nineteen hundred (1900), an American's life expectancy was much shorter: an average of forty seven (47) years. Illness and disability were more common at every age. Death, when it arrived, came abruptly. Very few people lingered for many months with worsening disabilities arising from an eventually fatal chronic illness. The time from onset of a serious disability to death was measured in hours or days, possibly weeks, definitely not anywhere near months or years. Families bore the bulk of medical expenses, and the main caregivers were family members, especially women (mothers, wives, sisters and daughters). Dying people generally lived their final days at home among family members.

Now, Americans are healthier in every phase of life and live in relative good health well into old age. In the year two thousand (2000), the average life expectancy for Americans is about 75 years (77 for women and 73 for men). Improved public health and medical treatments have translated into far fewer deaths from acute causes.

Dramatic and remarkable improvements in life expectancy and relative freedom from disease and injury pay tribute to America's approach to public health and healthcare over the past sixty years. Indeed, the fatal conditions of 1900 are precisely those that cleaner and healthier living conditions and better health care have been most effective at alleviating. A much larger percentage of Americans survive into old age than at any time in our history. However, the health care system has been slow to adapt to the chronic illness and disability *(Crimmins, 1997)* that elderly Americans are likely to face at the end of their longer lives.

According to a Rand Corporation study on the elderly, dementia and multi-factorial frailty shape the last few years of life for a large portion of the population *(RAND, 2003).* Medicare, for citizens sixty-five years of age or over, currently pays for most physician and hospital expenses at the end of life. However, many Americans live out the end of their lives in special care facilities rather than at home. Additionally, paid professionals will provide most of their visible support and costly health care. Elderly Americans now spend a significant portion of their final months disabled enough by chronic illness to need someone to help with the routine activities of daily living.

Changes in the way Americans die are mirrored in health care cost patterns. There are signs of wasteful use of healthcare resources everywhere we look *(Berwick, Hackbarth, 2012).* CTs are ordered for minor head bumps, stress tests are ordered for routine exams. Tests of questionable benefit are publicized as the latest and greatest until evidence comes to light that shows the contrary. Then these tests are quickly replaced by the next batch of the latest and greatest advances. According to Dr. Donald Berwick, unnecessary testing alone is estimated to cost close to fifty (50) billion dollars each year.

According to research conducted by the Medicare News Group *(2013)* the overwhelming preponderance of U.S. health care costs are incurred in the final few years of life. Estimating these costs across a life span along with the shape of the expenditures at the end of life, reflects new and challenging health and demographic circumstances. The final phase of life, (averaging eighteen to twenty-four months) when patients are living with eventually fatal chronic illnesses, has the most intense costs and treatments. This *(MNG, 2013)* research also shows that neither clinical services delivery nor Medicare has kept pace with these changes in the pattern of needs that underlie these additional costs. Increasingly, fragile health and complicated care needs are now a requirement during the extended period before death.

According to the US Department of Health and Human Services Data *(2012)* in the next thirty years the number of older Americans will continue to grow at an accelerating rate. In the year two thousand (2000) four point two (4.2) million Americans were eighty-five years of age or older. By the year two thousand and thirty (2030), the baby-boom cohort of the nineteen fifties (1950) will begin to hit age eighty-five and face the prospect of substantial disability. At that time, nearly nine million Americans will be over the age of eighty-five, more than twice the number that we have now. The rising number of people who will be facing old age by two thousand and thirty (2030) makes it likely that supporting elderly persons with serious chronic illness will be a monumental challenge for health care and related services in this new millennia.

The looming financial consequences of this aging tide are extremely worrisome. In fiscal year two thousand (2000), Medicaid paid for forty-five percent *(Breaux, 2002)* of the one hundred and thirty-seven (137) billion dollar annual cost of "formal long-term care". Note here that paid-care, covered by Medicaid does not include volunteer services by family members or local NGOs and charities.

The U.S. government *(National Health Information Center, 2012)* forecasts that the cost of long-term care will reach three hundred seventy-nine (379) billion, in current dollar values, by two thousand thirty (2030), an almost three fold increase over current expenditures in less than thirty years. Medicaid spending has now become the second largest expenditure for states, behind education, and is projected to continue growing rapidly.

At the same time, caregivers for the elderly are becoming scarce *(Atchley, 1996)*. Para-professional workers provide more than three-quarters of care in nursing homes and more than ninety percent of care at home. By two thousand and twenty (2020), when the baby boomers start to actively retire, the pool of middle-aged women who staff most of these positions will be substantially smaller than it is now. Likewise, family caregiving - long the backbone of long-term care - will be heavily burdened. Smaller family sizes and demographically changed family structures (discussed in Chapter Three) are leaving a smaller potential group of family caregivers. Longer durations of illness and greater numbers of women working full-time and part-time outside the home also place greater burdens on the pool of potential caregivers. Meeting the need for caregivers may prove even more difficult than the financial strain imposed by the aging baby boomers *(Atchley, 1996).*

A significant percentage of elderly people experience some chronic conditions. *(Cutler, 2001, Vol 20, No. 6, pp.11-27).* In planning for health care, we may usefully split these conditions into three categories:

1. <u>Nonfatal chronic illness</u>: Common nonfatal chronic conditions include arthritis, joint difficulties, and hearing or vision problems. Most elderly people live for many years with these conditions, which gradually worsen but seldom pose a threat to their life. These chronic conditions contribute substantially to disability and health care costs. An important subset of these chronic conditions tends to worsen and eventually cause death. *(Lynn, 2001*)
2. <u>Serious and eventually fatal chronic illness</u>: The common fatal chronic conditions are cancers, organ system failures (including those affecting the heart, liver, kidney, or respiratory system), dementia, and strokes. Nine out of ten elderly who die while covered by Medicare have one or more of

> these conditions in their final year of life. While most of the elderly eventually have to live with one of these conditions, probably only about one-quarter of the elderly are actually seriously ill or disabled by their (eventually) fatal chronic conditions at any given time.

Frailty (some form of disability): While no research yet has directly estimated this exact rate of disability, the numbers show that forty percent of people who live past age sixty-five experience some permanent or reoccurring disability. Additional recent studies on Medicare claims shows that most elderly patients were already sick with their eventually fatal conditions as early as three years before their death. With a projected life expectancy of about fifteen years past age sixty-five, many elderly people who are relatively healthy can expect to be chronically ill for some extended period at the end of their lives. *(Cutler, 2001, Vol 20, No. 6, pp.11-27).*

ADAPTING TO CHANGE

The America medical community is still having difficulty learning how to think about and respond to these changes in living at the end of life *(Kane, et al, 2001)*. Shaped largely in the decade after World War II, the U.S. health care system is designed mainly to prevent illness and to engineer dramatic rescues from injury, trauma or illness - mostly with surgery and medication. This concept works very well for younger, basically healthy people. Indeed, its success has contributed to the dramatic improvements in American life expectancy.

At its best, medicine has been agonizingly slow to adapt to the new challenge of chronic illness in old age. Commonplace experience, buttressed by studies of current care arrangements for the chronically ill elderly, suggests that these patients must navigate a fragmented care system, offering them a patchwork of uncoordinated services that do not meet their needs. In the Kane, Priester *(2001)* study the conclusion was that between the health care we have and the health care we could have lies not just a gap but a huge chasm. The experience of an increasing number of families confirms the point that health care arrangements for persons with chronic illness often do not work smoothly, reliably, or even well if they are available at all. *(Kane, 2001, M-HB05-1_VI.pdf)*

ORGANIZATION

According to a Brookings Institution study *(2009)* America’s current health care delivery system is organized by location: hospital, doctor's office, nursing home, patient’s home, testing lab, etc. This setup determines how insurance companies pay bills, how providers meet patients, and how regulations are applied. Each care provider generally works in only one setting, with a separation between settings. Like a series of vertical elevator shafts that have no provision for movement between them, only movement up and down the shafts from top to bottom. Patients needing care for a chronic condition, change settings often and may do so over a period of several months or even years. These chronic-care patients could benefit greatly from continuity of care which does not exist across these settings (IE: across the shafts). The challenges of a worsening illness causes many patients, with multiple conditions to have some of these conditions go unattended. *(Brookings, 2009, Bipartisan Policy Ctr, report, Aug 21).*

Research conducted by Drs. Jessie Pines and Zach Meisel, *Why doctors order too many tests, (Pines, Meisel, 2011*), describes how doctors and nurses approach diagnosis and treatment. Their efforts are organized around eliminating or ruling out possible causes (pathways). Doctors schedule as many tests as possible to help with diagnosis and to cover the possibility of future liability; this technique drives up the course of care and treatment. Our current system of healthcare is ‘morbidly obese”; there are too many tests done too often without valid medical justification. There is a belief that getting the best care means getting the most care but often more is not necessarily better. Chronically ill people coming to the end of life ordinarily have multiple diagnoses, none of which may be particularly revealing about the severity of their illness. Additionally, a single diagnosis may not highlight their needs. For example: a person may have greater need for help in daily functioning - grocery shopping or in-home supervision - than for a particular course of medical treatment for a condition they have had for many months or even years.

The situation for elderly people living with chronic conditions is like walking a tight-rope. The slightest shock to their “balance” - such as a cold, flu or a fall will stress their already fragile systems and might push them off the “tight-rope” into a serious condition. Very often, the health care system will label this final blow the cause of death, when the cause was more accurately the cumulative effect of multiple illnesses or frailty *(Haskell, 2013)*. However, predicting the timing of the "big fall" is difficult. Those with serious chronic illness may live reasonably well for many years or succumb quickly to early complications.

Steven Haskell a lawyer specializing in healthcare law *(2013)*, has written that one of the fundamental challenges patients with chronic illness pose for our current system is the way in which treatment distorts traditionally distinct concepts of health care. Diagnosis and cause of death, in the chronically ill elderly, has become ambiguous because most elderly people experience some overall decline in general health and many have multiple conditions. The value of preventing or curing any one illness diminishes greatly when patients have multiple conditions or face the onset of new symptoms as part of a broader deterioration.

We can conclude from the research *(Haskell, 2013)* that the whole concept of dying is becoming less clear. At one time, a person was healthy, then sick, and either recovered reasonably quickly or died suddenly. Only mental illness and tuberculosis were exceptions to this pattern. The recognition in the late nineteen sixties and early nineteen seventies that elderly patients were dying and thus not appropriately treated with aggressive interventions was a radical one in American health care. This recognition went on to spawn the hospice movement, carried over from the UK in the 1970s. Even today this aggressive/treatment model does not apply well to most chronically ill elderly.

According to Doctors Leana Wen and Joshua Kosowsky in their book "When Doctors don't listen" (2012):

> *"What America needs is the right medical care, care that is leaner and more patient-centered, starting with the right diagnosis and leading to the right treatment" Currently American healthcare isn't the best but it sure is the fattest." (Wen, Kosowsky, 2012, pp: 254-255).*

Doctors Wen and Kosowsky go on to characterize how this sixties/seventies healthcare model that does not fit the current needs of a different type of care from those patients who might recover or remain stable. This is in sharp contrast to the treatment of many chronically ill elderly patients who have ambiguous medical diagnosis. They may be medically evaluated as sick enough to die but could also go on to live for many years. A more useful way to think about this condition may be to focus on fragility rather than time to death. People living with serious illness, at the end of life, can then be identified as suffering long periods of illness, disability, diminished functioning, and additional symptoms, any of which may prove fatal. These patients may keep living like this for some years, or die in a week. Under our current system these conditions are difficult for healthcare to quantify with one word or phrase or one Medicare diagnosis code.

Healthcare policymakers lack the terms to define the types of care that individuals, facing eventually chronic illness, may need most. Many in the health care services talk of end of life care as palliative or comfort-oriented care, but there is still no widely accepted medical/administrative definition of the term. The language typically associated with palliative care is often misleading. Many medical care providers assume that it means a turning away from conventional care. This is not true and can be misleading, since treatment of chronically ill elderly patients routinely blur this distinction by needing a mix of different kinds of care. Early in the course of their illness, many need both curative treatment as well as "palliative" care aimed at treating symptoms; and late in life, some treatments may still stall the progression of illness, even while most needs are for relieving symptoms and providing support. *(Wen, Kosowsky, 2012*).

A more quantifiable way of envisioning care for elderly people who are sick enough to die follows from classifying them into separate groups, using the trajectory of decline over time (refer: Ch. 4). That is, each trajectory corresponds to a different situation and a different set of priorities in how a patient is cared for. Hospice should (must) also be included as an important part in these trajectories.

Patients with long-term limitations who experience intermittent health difficulties and then sudden death, typical of organ system failure, often live for a relatively long period of time prior to organ failure *(Lynn, Adamson, 2001)* and may have only minor limitations in everyday life. Occasionally some physiological stress overwhelms the body's reserves and then leads to a worsening of serious symptoms. Patients who survive a few such episodes and then die from a complication often do so rather suddenly. Ongoing disease management, advance-care planning, and mobilizing services to the home are key to optimal care in these cases.

Work by Field and Cassel *(Division of Healthcare Services, Institute of Medicine, 1997)* shows that those patients who escape cancer and organ system failure are likely to die at older ages of either neurological failure (IE: Alzheimer's or Dementia) or generalized frailty of multiple body systems.

> *"Frailty while not a true medical diagnosis, is the fragility of multiple body systems as their customary reserves diminish with age and disease. Frailty may already be a major path through the end of life, but the standard medical classifications of illness often fail to recognize it." (Field, Cassel, 1997, pp: 37).*

Patients in a general state of decline are often misleadingly labeled with "heart failure" or some other specific manifestation of their more general decline. Fatal chronic conditions are those that occur when the body's systems have no real substantial reserves. From a general medical view-point frailty is a fatal chronic condition in which all of the body's systems have little reserves left and even small upsets can cause cascading health problems that result in death *(Field, Cassel, 1997)*. Supportive services at home, like Meals on Wheels and home health aides and visiting nurses, then institutional long-term care facilities are central to good care for this path.

Analysis of Medicare claims *(CDC, 2002)*, matched against dying-trajectories show that about one-fifth of those patients tracked who die have a course consistent with the (Ch. 4) 4.2 trajectory (mostly cancer patients); another fifth share the course of the 4.3 trajectory (mostly organ system failure patients); and two-fifths follow the 4.5 trajectory course (frailty/dementia). The last one-fifth of decedents are split between those who die suddenly (4.1 trajectory) and others who have no real classification *(Lunney, 2002).*

The key point for care across all of these groups is that diagnosis, which drives medical care needs, does not generate all service needs. Other needs arise as disabilities and symptoms emerge during the course of a life. The range of available healthcare services needs to address these emerging practical needs of patients as well as matching with patient diagnosis. Tailoring services to match the needs of the last phase of life requires defining that phase in the most relevant ways. The phenomenon of a long, healthy life, followed by chronic illness and disability in the last phase, is relatively new in American history. American medicine and healthcare are just beginning to understand its dynamics. *(Day, 2014, NCPC).*

According to Marilyn Field *(Wash., DC, Institute of Medicine, Committee on care at the end of life, 1997)* the following are some key points that physicians and administrators should use in support of an end of life care program:

- It is possible to live comfortably, even with serious chronic illness. Living with such illness requires planning for the ongoing course of the illness so that services match the course of that illness.
- Serious chronic illnesses require continuity and comprehensiveness of care. Care needs generated by symptoms or disabilities are urgent priorities. Flexibility is important in adjusting care to family and patient resources and to patient and family preferences.
- The prediction of the time of death remains difficult until late in the course of a serious chronic illness. In consideration of this, special arrangements for care near the end of life must be triggered by the severity of symptoms, rather than waiting for a reliable prediction that

death is near, which is the current method used in healthcare administration and allocation of resources.

- The major causes of death are all progressive, degenerative illnesses that leave people in fragile health for an extended period of time before death. New programs and policies to improve care for chronic conditions need to acknowledge and accommodate these facts and that death is the eventual result/outcome.
- Designing reliable End of Life care systems should be built upon the course and nature of the service needs of populations, differentiated by trajectory of disability and symptoms over time. The conventional differentiation by care setting and location which is the current method must change.

Some health care innovators have launched successful pioneering programs by building on insights into the special needs of chronically ill elderly patients. However, the majority of these programs are small-scale funded and operated with limited funds.

Several programs have developed ways of improving connections among home health care, disease management, hospice and palliative care. At Kaiser-Bellflower in Southern California *(Kaiser Permanente, 2013)* the hospice and palliative care teams work closely with staff members from disease management programs to improve end-of-life care. Teaching hospitals have also begun to develop palliative care consultation teams, both to teach health care professionals about end-of-life issues and to improve care delivery.

The Program of All-Inclusive Care of the Elderly – PACE (*PACE, 2013)* under Medicaid, offers a comprehensive set of services to persons eligible for nursing home care: housing, personal, and health-care services. PACE patients are almost all seriously ill with fatal conditions, mostly in the frailty trajectory. PACE/Medicaid care is not characterized as an end-of-life service, most PACE patients are not discharged but are considered outpatients and thus may die while covered by the program. The PACE discipline provides a comprehensive range of services whenever needed. These services include adult day care, nursing, meals, social support, primary medical care by a PACE/Medicaid certified physician, medical specialists, dentists, podiatry, optometrists, eyeglasses, prescriptions, and hospital / nursing home care. PACE serves less than 7,000 patients at 24 sites, and another 1,100 at nine pre-PACE sites. Formal evaluation of PACE is ongoing, but early reports show good rates of satisfaction but uncertain effects on costs of care.

Authors Joanne Lynn and Janice Schuster, *(2008)* in their book *"Improving care for the end of life"* make the point that additionally a small number of (non-PACE) type provider programs have been recognized for success in improving end-of-life care.

> *"An important outcome of these programs has been the gradual circulation of new approaches to pain management, advance-care planning, palliative-care consultation, and family support. Continuous quality improvement has shown that energetic and well-informed efforts, starting small in scale, can make a difference in elder healthcare."(Lynn, Schuster, 2008, pp: 248-250)*

In this newly recognized complex area, the need for rapid improvement is becoming critical. The medical establishment needs to be able to differentiate reforms that deserve strong support from those that are counterproductive or irrelevant. For patients with fatal chronic illness, conventional education for physicians and nurses could make a difference but there should be concern that these are only low-level changes. Accomplishing many of these recommended changes would improve end-of-life care but not enough as is needed. Teaching practitioners about good elder care may be a worthwhile goal but it does not actually implement good elder care. Additionally, better tracking of payment for current providers would probably not significantly alter the incentives nor remove many of the dysfunctions.

According to Dr. Robert Stall *(2012)* of the National Care Planning Council:

> *"To make meaningful changes the system must address the looming imbalance between the number of chronically ill elderly and the number of available caregivers. If sick elderly people cannot receive*

> *competent and caring day-to-day assistance, other health care reforms are unlikely to have much impact. Caregivers for this population, whether paid attendants or family "volunteers," generally face poor working conditions, low wages, isolation, and few opportunities for advancement or professional development. Under these conditions it is not surprising that this important occupation is not attracting a large pool of candidates." (Stall, 2014, medical-care-issues.htm#american-perspective,* Vol 58, No.17*)*

Specific reforms to improve the availability and working conditions of caregivers could offer health, disability, and retirement benefits for caregivers. Increased wages for professional caregivers and some sort of career ladder or recognition for experience and skills would also be helpful. Pay for family caregivers, at least those with low incomes would also help as would encouragement of family caregiving through graduated tax credit incentives. Additionally specific training should be available and at-home support should be provided. Finally, linkages of family caregivers together via newsletters, online conversations, chat-rooms, political agendas, and organizations would be a big help toward improvement.

FINANCE

Federal money *(US Senate Committee on Aging, 2001)* currently pays for the majority of health care costs for those 65 years or over. Unfortunately, current federal payments are not designed to promote continuity of care over any long term. Medicare and Medicaid are both simple billing-pay-out systems. Federal payments also do not cover supportive home health care, many prescription medications, symptom control, family and caregiver support, or even professional services meant to reduce the rate of decline in patient function. Neither Medicare nor Medicaid cover nursing home care for those who are impoverished and disabled.

According to the Medicare Payment Advisory Commission –MedPAC *(2014)* Medicare is now the main financing mechanism for medical services in the last phase of life. Medicare covers over eighty percent of all who die in the United States. Under the usual fee-for-service program, doctors, hospitals, and other service providers are paid for each billed service. Hospitalization services are mostly packaged and paid with one fee for the entire hospitalization. This arrangement encourages bundling billable services, but does not encourage continuity of care.

There is no current insurance coverage available for caregiver training, classroom education of patients, on-call advice, bereavement support, or spiritual counseling, so they are generally unavailable as well. Medicare managed care does generally not pay enough to cover the high costs of the seriously ill; thus most managed care programs cannot capitalize on their potential to provide good care *(Hogan, 2000)*.

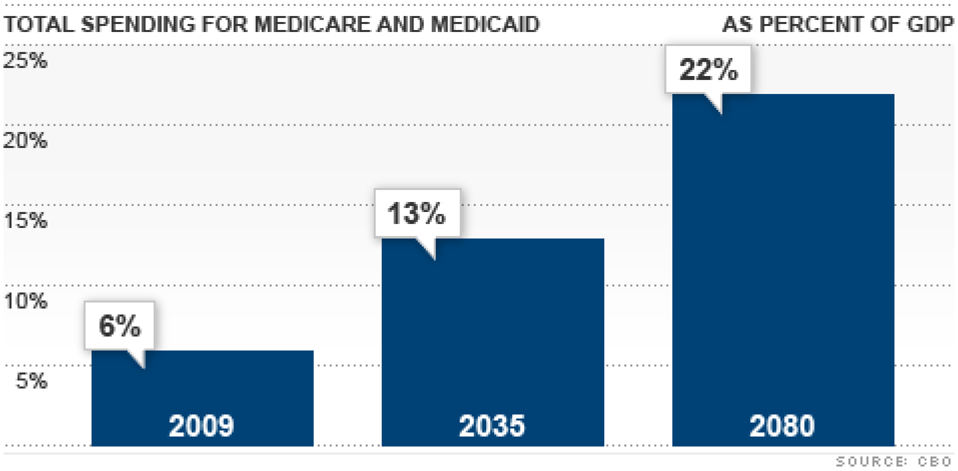
A RAND Corporation study *(2003)* conducted on “Healthcare for the Elderly” included suggestions for incentives that could help to align Medicare coverage more closely with needed care. The Rand study recommended:

1. Medicare payouts could require specific performance criteria for key elements of care such as continuity, symptom relief, and advance-care planning.
2. Payments for Medicare's managed care benefit could be higher for those who are more seriously ill, in addition to the current adjustments for age, gender, region, and diagnosis.
3. Hospitals could be paid much less for second admissions for the same serious chronic condition in a patient who had no advance-care planning during the first hospitalization. This would provide an incentive for hospitals to cover extended care during the first admission.

The Rand study concluded that the escalating cost of treating illness at the end of life raises a difficult and sensitive issue that few Americans have been willing to confront the value of giving expensive new treatments to people whose life expectancy is drastically limited, even with treatment.

The UK and some Scandinavian countries have begun to base coverage decisions, in part, on how many years of life a treatment is expected to produce *(National Institute for Clinical Excellence, 2003)*. Problematically, even raising the subject of monitoring or restricting access to life-extending treatment on anything (costs, effects on life span, or effects upon quality of life) in the United States would provoke way too much political controversy. However, it is an option that should be considered and explored.

The charts below show total spending across the United States for Medicare and Medicaid as a percentage of GDP projected to 2080.



Source: Jeanne Sahadi, CNN December 24, 2009:

Another alternative may be to cut back on other services that are hard to track or whose benefit may not be so clear. The challenge is to establish a method by which the federal budget (for care of those with fatal chronic illnesses) can match the major problems and concerns of the chronically ill elderly and their families. An approach with these goals should be considered even if this means that very costly treatments are sometimes not readily available to a few chronically ill elderly who possibly may benefit *(Evans, Funkenstein, 1989)*.

Using available research, consumer focus groups, analysis and computer modeling, services could be tailored to deliver what the covered population needs and values. Chronic-illness and shortened life-expectancy must be a factor to consider in decisions about treatment of individuals. In any decision consideration of life span should also be required. Quality of life matched against treatment guidelines for Medicare coverage should also be a factor. Finally, Medicare and Medicaid could be funded and authorized to develop methods for weighing and evaluating merits against beneficial treatments and services. Treatment decisions, which are now based almost entirely on political considerations, must be made using data from scientific analysis and research.

COGNITIVE DEFICIENCY IN THE ELDERLY

Serious cognitive deficiency will affect as many as one third of those over age eighty-five before they die *(Freedman, 2002).* With any level of dementia, a patient cannot serve his or her usual role of decision making. Each adult person makes his or her own choices about what is important for them and how to balance trade-offs among alternatives throughout life. However, such choices eventually become impossible for those who cannot remember their own past, or apply their own values, or envision possible alternatives for the future. For this highly vulnerable group, society needs to develop a shared understanding of how to proceed in evaluating the merits of prolonging life of those patients with progressive dementia. We need to build a broader scope of choices into any advance planning activities that involves elderly patients.

According to a JAMA study conducted by Danniele Laurin and her colleagues, (*Laurin, 2008)* some possible approaches to this extremely sensitive issue include:

1. Reworking our language toward accurate descriptions of trade-offs among fatal illnesses and frailty as dominant causes of death.
2. Building a public discourse about the nature and value of lives with severe dementia.

3. Testing strategies to limit use of high-cost but somewhat effective treatments.
4. Develop regulation, legislation and financing to allow for trials of warranted reforms. Support follow-up on those suggestions.

The JAMA study concludes: That efficient and worthwhile reform depends on creating, designing and pursuing high-leverage strategies and avoiding low-leverage ones.

Some possibilities that are a result of these study activities that could improve on the current uncoordinated efforts toward these goals:

1. Include convening stakeholders and others experienced in reform efforts to consider options and identify a short list of priority agendas for all to endorse.
2. Conducting local, regional and statewide trials of major innovations that have already shown results and simulating the effects of innovations in computer modeling systems.

According to research conducted by the Agency for Healthcare Research and Quality *(AHRQ, 1999):* a reliable care system that helps the chronically ill elderly live well at the end of life, would make seven basic promises:

1. Correct medical treatment.
2. Reliable symptom relief.
3. No gaps in care.
4. No surprises in the course of care.
5. Customized care for individuals and groups
6. Consideration for family situation.
7. Help as needed to make the best of every day.

Additionally the AHRQ report stated:

> *“A consistent healthcare system that would honor these promises to provide support and compassion to the chronically ill elderly would also have to include advance-care planning for early treatment, adapting the plan as the disease progresses. It would have to provide for managing symptoms and rehabilitation for disabilities throughout the course of illness. Where appropriate, it could provide some costly "aggressive" treatments even very late in the illness, if there is a chance that they may still work to enhance a life. It would have to provide a smooth transition across settings - from hospital or office to home care (and hospice) as the patient becomes progressively more ill. Finally it should attend to family needs and spiritual/emotional issues throughout the disease span. The key*

> *providers would probably be oncologists, cancer centers, and hospice programs, with additional support from nursing homes, home care providers, and assisted living facilities."(AHRQ, MEPS, 1999, Research Findings No. 9 AHCPR Publication No. 99-0042)*

Additionally the AHRQ report indicated that worthwhile healthcare for advanced organ failure, prevention and early treatment of multiple complications should:

1. Avoid suffering
2. Reduce costs
3. Prolong life, where possible.

The AHRQ report results also suggests that major service providers should be specially trained advanced-care nurses who are familiar with the medications and physiology of the elderly. These service staffers would be able to call on other professionals from an interdisciplinary team when necessary. Medical specialists, social workers, counselors, and occupational therapists could also be called in as needed when a patient decides to forgo or stop aggressive life extending treatment *(AHRQ, 1999).*

The AHRQ research report also stipulated that:

> *“For elderly persons who are suffering from dementia, services need to focus on supporting family caregivers and meeting concrete, realistic everyday needs. Day care centers, home health aides, Meals-on-Wheels, legal aid, family relief, behavioral management, and nursing homes would form the core of the service array. While cancer patients might be very sick for a year, and organ system failure patients sick, off and on, for a few years, dementia and frailty patients can often live for a decade with increasing symptoms and increasing disability. Thus, the care system must be structured to accommodate very long durations of progressive illness and to adapt to changing family situations, slow decline in the patient's capabilities, and either a sudden or lingering death.” (MEPS Research Findings, 1999, No. 9 AHCPR Publication No. 99-0042)*

According to Joanne Lynn and David Adamson in their article *“Living well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age”* authored by the Rand corporation in 2001 *(Lynn, Adamson, 2001)* chronically ill elderly people and their families, living through the end of life of a family member deserve a better system than the one currently available in American medicine.

> *“They depend on the current health care system to serve their needs and at the very least, do not expect the system to add to the burden of their or a loved one's final days.”(Lynn, Adamson, 2001, WW137.html)*

Meeting these types of patient and family needs will require a clear vision of good care and tackle any barriers to putting that vision in place. One of the essential components in any solid improvement is sustainability, which is being able to maintain what has been changed. Achieving and holding these sustainable results will require focus, and the very reluctant cooperation of a firmly-established medical culture that is resistant and reluctant to change.

Where we have extraordinary challenges we also have extraordinary opportunities. *(Byock, 2012).*

We urgently need to get started. We must aim higher than just working to correct problems in our healthcare and support systems. Only when we agree on what an appropriate end of life looks like can we express our goals and deliver the best possible care.

Chapter 7

CHANGING THE CULTURE OF MEDICAL DEATH

The GOAL: a positive beginning, directed toward the creation of an End-of-Life-Care specialty in American medicine, a specialty similar to: pediatrics, oncology, cardiology, etc. To start a fundamental and sincere change that would take hold, endure and be recognized, as a new and worthwhile segment of modern American Medicine, by:

I. The healthcare establishment
II. The educational establishment
III. The government
IV. The general population

> *"There is nothing more difficult to plan, more doubtful of success,*
> *more dangerous to manage, than a change to something new.*
> *For the initiator has the enmity of all who would profit by the*
> *preservation of the old institution and merely lukewarm*
> *defenders in those who stand to gain by the*
> *implementation of a new institution. "*
>
> *Machiavelli, (The Prince, 1965, pp: 91)*

Those words were written by Niccolo Machiavelli *(Machiavelli, 2005),* to characterize a fact of political life in fifteenth century Florentine Italy. Machiavelli wrote those words in frustration regarding his efforts to get the ruling Medici royalty to change their corrupt and nepotistic political ways and practices. The comment stands as an enduring testament to a basic human reluctance to accept any kind of organizational change even as far back as the fifteenth century.

One of the biggest issues we face in American medicine today is the dramatization of healthcare, especially end of life issues (*Chopra, 2007*). Deepak Chopra writes:

> *"We dramatize end of life issues as death-squads or death-panels when In fact the end of life is where most of the suffering happens and most of the expense goes. The patients suffer, the family and relatives suffer, and everybody suffers, except the hospital which makes money, even the insurance company, in the end, suffers because they lose money from that point. We hardly have anyone dying at home. They all have to die in a hospital hooked up to the machines around them. It's a system that is totally divorced from the essence of human beings who are spiritual beings, who want to find meaning even in death and want to find some kind of nurturing, even in the last stages of life, that's what's wrong." (Chopra, 2007, http:// curiosity.discovery.com/question/biggest-challenges-in-medicine)*

Doctor Ira Byock *(2012)*, writes in his book: Best Care Possible: A Physician's Quest: To Transform Care through the End of Life:

> *"Americans are scared to death of dying, and with good reason. While rarely easy under any circumstances we make dying a lot harder than it has to be. Few of us could ever imagine how things could be different. Therein lies the crux of the problem. American society and main stream American culture have never grappled with the fundamental fact of mortality. Therefore we do not know what to expect or what is even possible.*
>
> *When someone we love is faced with a life threatening illness the worst thing we can imagine is that they die. The sobering fact is, that there are worse things than having someone you love die. Most basic is having someone you love die badly, suffering fight up to the end. Worse still is realizing later on that much of his/her suffering was unnecessary" (Byock, 2012, pp: 1)*

With these carefully chosen words Doctor Ira Byock verbalizes the core of one of the single most important issues of this new century, care at the end of life! Doctor Byock's contention is precise; if we do not "grapple" with mortality then we will never know what is possible or what to expect or what is suitable and what is proper.

END OF LIFE CARE

The “*Committee on Transforming End of Life Care*” of the Institute of Medicine, released a report (*1997)* that made important and wide sweeping procedural recommendations, to be applied in hospitals for treatment of dying patients. During the past sixteen years, progress in implementing these recommendations, has been agonizingly slow. Now in 2014, not only have these recommendations gone unrealized, we must also consider them against a backdrop of the rapidly developing and changing technological environment in healthcare services delivery. Additionally, the landmark passage of the Affordable Care Act *(2009)* mandates an obligation to improve the quality of health care while controlling costs. Now is the time for a new examination of how individual values and preferences can be aligned to improve End-of-Life Care. In doing this we must also insure that compassionate care, focused on the needs of individuals approaching death, can be sustained in an affordable and cost-effective manner. These issues are made even more relevant as life-expectancy increases and as our population ages. This matter of death and dying has become a political as well as an ethical, moral and social cause.

According to the National Hospice and Palliative Care Organization position paper *(2013):*

> *"Good end-of-life-care is based upon the understanding that death is inevitable and should be viewed as a natural part of life. The final stages in a person's life are a uniquely important time for the dying person* and *for the family and for close friends."*
>
> (NHPCO, 2013, *http://www.nhpco.org/publications-press-room/nhpco-position-statements,PDF, pp: 6-7)*

The specific goals proposed by this NHPCO proposal for end of life care are:

I. To maintain the comfort, choices and quality of life of the dying patient
II. To support the patients individuality and to care for the psychosocial and spiritual needs of the patient and family
III. Provide support counseling for families when needed even after the patient's death (as bereavement/mourning counseling)
IV. Reduce inappropriate and burdensome healthcare interventions and support the choice of a place of care where possible.

NHPCO research conducted over a ten year period *(1991-2011)* also suggests that the factors most important to patients and families at the end of life are:

I. Pain and symptom management
II. Preparation of the patient for the end of life

III. Relationships between patients, family members and healthcare providers

IV. Achieving a sense of completion and closure

SPIRITUAL CARE

Spiritual care is regarded as very important by many patients and families at the end of life. Cultural differences *(Leavitt, 1999)* also need to be identified and appropriately addressed. The concept of satisfaction with end-of-life care has also been studied by the *National Institute of Health* in a recent systematic review *(Heyland, 2009).* A number of aspects of patient and family satisfaction with care are identified in the literature; they are:

I. Accessibility, co-ordination, and competence of health care services.

II. Quality of communication and relationships with health care providers.

III. Personal focus on type of care by patient.

IV. Administrative support for family and patient decision-making.

The meta-analysis conducted by the National Institute of Health on end-of-life care studies *(2009)* showed that the use of palliative care services definitively improved satisfaction levels with end-of-life care.

This NIH meta-analysis concluded that:

> "*Shared decision-making between clinicians and patients and their families is only possible when all have an awareness of the patient's approaching death. This awareness increases the likelihood of a good death - one in which the patient's needs, wishes and preferences can be addressed. Reluctance by either clinicians or family to disclose information about a patient's changing condition can sidetrack support efforts and increase patient and family distress." (NHI, Journal of Palliative Care., 2009, 25(4):245-56)*

Supporting patients' and families' acceptance of the inevitability of death is acknowledged as a central component of end-of-life care. Discussing changing goals of care is an important part of this process. The most common goals of care *(NIH, 2009)* identified by patients as they approach the end of life are:

I. To be cured and if at all possible to live longer
II. If the (above) is not possible then to improve or maintain functionality
III. To maintain quality of life and independence for as long as possible.

IV. To be comfortable, free from pain and be supported by family and caregivers.

Note: These life-goals may shift as patients become increasingly aware that their death is imminent *(Heyland, 2009)*.

All persons have spiritual needs. Some persons have religious needs. The Pastoral Care Services of a hospital or hospice usually works to help patients, family members and staff address both spiritual and religious needs. What is meant by "spiritual needs"? According to the University of Maryland Medical Center *(2013)* website, spiritual needs and concerns usually relate to what we call the "big" questions of life. These are questions that include:

1. Why is this happening? Why is it happening to me?
2. What does it all mean?
3. How do I make sense of everything?
4. How do I feel about changes in my life?
5. What gives me comfort and hope?
6. What do I call "good" in my life? What do I call "bad"?
7. What am I grateful for?
8. What do I trust? Who do I trust?
9. Who is my "beloved community" -- who loves me and is loved by me, no matter what?

10. What or who -- beyond myself -- do I believe is important in my life?

All of these questions relate to spiritual needs, concerns and resources. All people ask these questions during their lives, especially when they or someone they love are sick or in crisis. In support of this, Doctor Harvey Chochinov writes in his *(2005)* paper on End-of-Life Care about spirituality in an end-of-life scenario:

> *"It is certain that the distinction between somatic distress and psychological or spiritual disquietude becomes less clear and increasingly entangled as a patient's death draws near. Yet, there is an inclination for care providers to parse out support, focusing on those things that seem within our grasp to attenuate, while neglecting those we sense are beyond reach. There is, however, growing awareness in palliative care that patients must not only be made to feel more comfortable, but more broadly, provided with comfort. Although the distinction may appear subtle or merely semantic, it is in fact the difference between technically competent symptom management versus a holistic approach to end-of-life care—an approach that encompasses the psychosocial, existential, and spiritual aspects of the patient's experience."(Journal of Palliative Medicine. 2005; 8 Sup, 1:S103-15)*

Acute care medical facilities, in the United States, do not acknowledge spiritual care as a component of healing or comfort. For dying patients spiritual care may be a key element in their journey. Lessons in spiritual care are there for us, all we have to do is look to the past. Richard Groves and Henriette Klauser in their work "*The American Book of Living and Dying*" *(2009)* write:

> *"For the past three thousand years our ancestors have left an impressive legacy on the art-of-dying. Their collective insights about the relationship between physical pain and spiritual suffering are timeless, as true today as then. It is this wisdom that appears to be the missing link in our modern care of the dying. Our ancestors knew that at the end of life answers to these universal questions are accessible. We may only have to step out of the way and allow the dying to be our teachers"(Groves, 2009, pp: 3)*

Some people find meaning, comfort, hope, and community through their religious practice, beliefs and/or community of faith. Some people do not. Regardless of whether religious faith is a part of a person's life, spiritual concerns, resources and needs can still be very important, especially during hospitalization and should be addressed and included accordingly as a major component in critical care.

Advance care planning aims to encourage people to discuss, consider, and document their future wishes for care, even spiritual care; well in advance if possible. The impact of advance care planning is mixed, and acceptance of any advanced end-of-life care planning processes has not been widespread. There is also evidence from NHPCO studies that a percentage of seriously ill patients wished to discuss their treatment preferences with medical staff and family together and did not have, nor were they given, the opportunity to do so. *(NHPCO, 2013)*

> The most effective end-of-life care is provided when there is skillful and honest communication with patients and families about realistic goals of care. Attention to understanding the patient's and family's concerns as well as competent symptom management add to this effectiveness. In order to achieve the goals which are important to patients and families, and to provide good end-of-life care, it is essential to identify that a patient is imminently dying. This truth, however uncomfortable, should be given the highest priority. Only when the medical community, patient, and the family come to terms with the truth and reality of the actual situation can they then make appropriate and meaningful decisions. *(NHPCO, 2013)*
>
> It is often difficult to identify when a person is close to the terminal phase with a prognosis of days to weeks but, where it is possible, this knowledge can be of great value to patients. It helps them reorient their priorities. At this juncture, honesty and the truth are the most critical components in the evaluative, diagnostic and treatment process. It may be stated, without exaggeration that truth and honesty are the keys to a good-death.

“Progress is impossible without change and those who

can’t change their own minds can’t change anything”

George Bernard Shaw

HOW END-OF-LIFE-CARE IS ACCOMPLISHED OUTSIDE OF AMERICAN MEDICINE:

“Modeling the UK in End-Of-Life-Care”

United Kingdom (all of Great Britain) can serve as an excellent model for American medicine in their “End of Life Care” specialty and treatment context.

In England all medical and healthcare services are organized, controlled and delivered by the National Health Service (NHS). The NHS is an independent agency created by law and funded by the government with government auditing and controlled oversight. The NHS purpose is to provide all UK citizens with the best possible care available at no charge to the individual.

The British NHS was founded in 1948. Its creation was the culmination of an ambitious government plan to bring good healthcare to all citizens regardless of wealth or social background. For the first time in England hospitals, doctors, nurses, pharmacists, opticians, and dentists are brought together under one unified organization to provide medical and healthcare services at the point of delivery, free of charge.

UK END-OF-LIFE-CARE IN HISTORICAL PERSPECTIVE

In early 2000 End of Life Care was identified by the UK Department of Health and the British NHS as an area that was lacking in attention, where quality of care had previously been neglected and which had not had a high profile in the NHS organization. End-of-Life Care was not considered a part of social healthcare. Various UK funded Department of Health studies and government committees were created to address these problems.

In 2004 a national "End of Life Care" program was established to identify and propagate "best-practices" *(QS13, 2011*) for the treatment and care of terminally ill patients. To address this, the national End-of-Life Care program was established in two thousand and five *(2005).* A national strategy document (A*ppendix-B*) was published to cover new EoLC procedures and practices.

In two thousand and six (*2006)* the annual death rate (in the UK) showed just over half a million people died in England. Approximately 99% of them were adults over the age of 18, and almost two-thirds (66 percent) were adults over the age of seventy-five (75). The research showed that approximately three-quarters (seventy five percent) of deaths were be considered “predictable” and followed a clear trajectory (*see chapter four: death trajectories*) of a period of chronic illness – for example heart disease, cancer, stroke with dementia – and then death, at various points along a projected time line.   At this time, 58% of UK deaths occurred in an NHS hospital, 18% at home, 17% in residential care and extended care homes (most commonly people over the age of 85), and about 4% died in hospices.

A majority of people surveyed by the National Health Service (in early 2000) said they would prefer to die at home or in a hospice. According to one survey less than five percent (5%) would rather die in hospital. A key aim of the NHS “End of Life Care” strategy therefore was to reduce the need for dying patients to have to go to a hospital and/or to have to stay there; and to improve provision for support and palliative care in the community to make this possible. An additional follow-up study conducted by the Department of Health estimated that 40% of the patients who had actually died in a hospital had no genuine medical needs which required them to be there.

In 2010 a survey by the Economist Magazine: Intelligence Unit commissioned by the Lien Foundation *(EIU, Lien, 2010)* ranked the UK top out of forty countries globally for End of Life Care quality and best-practices.

In two thousand and thirteen, (2013) in the UK; administrative medicine, nursing and the allied health professions include End-of-Life Care as part of overall health care, not only of patients in the final hours or days of their lives, but more broadly to include care of all those with a terminal illness or a terminal condition that has become advanced, progressive and incurable.

At the diagnosis juncture an NHS representative will recommend the creation of an EoLC health care team for the patients benefit. The team will include the patient’s regular physician a social worker and any number of support personal to include additional doctors and End-of-Life Care physicians and hospice staff. The team members must meet with the patient’s approval.

When a patient’s NHS health care team determines that a terminal disease (cancer, heart disease, stroke, etc.) can no longer be controlled, progressive interventions like medical testing and cancer treatment (both chemo and radiation) are stopped, but the patient’s care continues. The care then focuses on making the patient comfortable, pain free and attending to his/her needs and the family’s requirements. The patient receives whatever medications and treatments necessary to control pain and other symptoms, not only pain but conditions like constipation, nausea, shortness of breath, dry mouth. Some patients remain at home during this time, while others enter a hospital (temporarily) or other medical facility. Either way, all services are available (across venues) and encouraged to help patients and their families with the medical, psychological, and spiritual issues surrounding dying. Hospice may often provide such services and they are also available across a number of venues. NHS acknowledges, by policy and procedure, that the time at the end of life is an important time but is different for each person. Each individual has unique needs for information and support. The patient's and family's questions and concerns about the end of life are thoroughly discussed and sincerely covered with the health care team as they arise...

Standard NHS policy for End of Life Care covers family counseling, recommendations for the creation of an advanced directives (living-will) document, additional appointments and choices for an End of Life Care treatment team and discussions with the patient and family members on what to expect and what is in store, also help with what legal requirements and documentation is needed. A member or members of the team will meet with the patient and family members frequently and advise them of progress and requirements. The treatment team (within practical limits) will remain together and work with the patient and family through the death of the patient and even thereafter for the families' sake. The treatment team has several goals but the most important are: familiarity, consistency of treatment and care for the patient along with continuity of care for the patient and family.

CONCLUSION

This dissertation illustrates that a significant social change has taken place in modern America from 1946 through to 2014. This transformation has altered life dramatically both in the family structure and in the cultural and social experience of living and dying in this country. Considering the social / cultural change that has taken place, the analysis and evaluation in this dissertation assesses death’s ever-evolving relationship to conventional medical treatment. Attention is focused on death choices that should be made by terminally ill patients and their families replacing the healthcare professional’s predominance in those choices.

Research and studies referenced in this dissertation have focused on that change, and clearly indicate a serious trend in the unfortunate way dying patients are treated and cared for by the American medical establishment. Reports and study conclusions reveal an alarming lack of empathy and attention by medical staffers to terminal patients and particularly to DNR patients. Even though there is over thirty five years of legislation, court decisions and established procedures for patient desired end-of-life treatment, (including advanced-directives and living-wills) doctors and nurses routinely ignore or override DNR orders. A significant percentage of doctors and nurses are particularly lax in following through on recording DNR on the patient’s chart, even when patients insist that it be recorded. It was not always this way.

Modern American medicine seems compelled to encroach on the hallowed ground of the dying and engage the rescue-treatment-cure strategy at all costs, regardless of the patient’s or families’ expressed wishes. The American medical rescue-treatment-cure culture has spilled over into the sacred territory of the terminally ill patient. This is the patient who needs understanding, support, pain-relief, and comfort, not rescue-treatment-cure. Medical paternalism is alive and well in modern America.

In twenty-first century America death now takes place in a private hospital / institutional environment in which doctors and other medical professionals prevail, while the patient and family members have little control. The American focus on death has shifted away from the dying persons concerns and comfort. The focus is now on the standardized medical procedures in which the doctors, nurses, medical and administrative staff dominate. Death in America has evolved from a communal, loving, family setting, in which the dying individual, and family members had control over the process, into something completely different. The current method of dealing with death is systematic: procedure, method, and process. It is a system that ignores individual wishes, a system in which the patient and family are practically bystanders in the process.

No self-respecting doctor, nurse, nor healthcare worker ever admits to treating a dying patient. The presumption here is that no one dies, everyone can be saved. It doesn't matter that these patients may not want to be saved nor can be. They may need to be properly medicated, cared for, comforted, respected and appreciated. These patients may not need nor want the dramatic rescue-treatment-cure options involving ventilators, respirators, heart bypass machines, defribulators, IV feeds, intubation, etc. Many of these terminal patients have already accepted their circumstance and just want to die a comfortable and timely death, unencumbered by pain and in the company of family and friends. Considering that a good-death perhaps, coming as a full circle release and closure to the end of worthwhile life, may be a sensible and humane goal in and of itself. The current manner of death that is predominant and ubiquitous in America at the beginning of this 21st century must be defeated and changed.

Expectations about dying among the general population are significantly different from what most people actually experience in real life. Young to middle aged adults tend to imagine themselves living to an old age and then quickly dying at home, surrounded by loved ones, pain free, alert and aware until the end. The realities of pain, discomfort, confusion and indecision, tend to be absent from these death bed scenarios. Fantasies from film and images and scenes of dying on TV and in popular novels, seem to be more influential in the culture then what is likely to actually occur in reality.

Most people would consider the worst thing that can happen to a family, is the death of a seriously ill loved one. Perhaps that is not really the worse-case, death may not be the worst thing that can happen. Consider that this loved one dies a suffering, painful, and prolonged death. Bear in mind, finding out later on that the suffering and lingering pain was actually unnecessary and could have been circumvented. With proper care and hospice support this patient could have had a pain free and meaningful death, preferably at home and surrounded by a loving and supportive family. Finding this out would be worse still, if you were the individual tasked with making those decisions. Learning later that with different advice, and knowledge of other options, things could have been handled differently. Perhaps, in hindsight, you would have made different decisions. Type of death and the decisions and events leading up to that death are some of the key elements that remain in the memory of those who go on living.

In the course of an actual life, many family members are called upon to make crucial decisions for patients who may not be capable of fully understanding the consequences of current treatment options. These decisions, whether good or bad, will have a profound effect on the lasting memory of family members and, in particular, the memories and attitudes of the actual decision makers. The concept of a good-death memory living on, is significant in that it characterizes one of the major components of this research and conclusions.

The belief in a good-death is often associated with hospice. Dame Cicely Saunders is widely credited with being the founder of the modern hospice movement. This movement started in the UK in the early nineteen seventies and eventually migrated to America in the middle nineteen eighties. Saunders is particularly noted for her philosophy and attitude on the way dying patients are treated. From a medical humanities point of view, she felt that the way people die and how terminally ill patients are treated, right up to the end, will remain in the memory of those who live on.

One of the basic alterations of American life, has been the sacrifice of tradition to the demands of progress. Change through cultural evolution and industrial development and growth have been reflected in the increase of government influence on every aspect of life and of death. Death and death related practices, tradition and ritual, have not escaped this influence. In many ways death has been radically changed through this process, including how we die, when we die and how those left behind grieve and mourn the loss. Even the location of death, as discussed previously, has changed greatly during the time period under scrutiny. Prior to World War II, over eighty percent of all deaths took place at home. Now in 2014, over eighty percent of all deaths take place in hospitals, nursing homes, assisted living facilities and state institutions; quite a radical departure during this time period.

This dissertation shows that in modern medicine, dramatic technological treatments and powerful drugs have become more effective at extending life and more procedurized in their use. However, the application of this technological phenomenon to the terminally ill is often misdirected. Trying to extend a few more weeks of life for a dying patient, just because it is possible, is inappropriate and insensitive. It is also a waste of finite resources that may be more appropriately applied in other situations. Reflection on the abuse of the rescue-treatment-cure effort shows that the physician's age old duty, to alleviate suffering and provide support for the dying and their families, remains largely in the background. For those patients subjected to this dramatic endeavor, there is more than ample evidence, in many studies, to show that modern high-tech medicine does not do an adequate job of providing care, respect and support for dying patients.

To become more humane toward the dying, American medicine needs to suspend its relentless drive to extend the life of terminally ill patients. At this frontier, medicine must restrain itself and turn its attention to the relief of the suffering of the terminally ill. There is a genuine need to improve the physical, emotional, and mental quality of life remaining. The Medical Humanities component, emphasizing the person and the concept of treating people as individuals, is sadly lacking in this rescue-treatment-cure scenario.

One of the basic issues that hamper the advancement of coordinated humane treatment for the dying is the implementation and use of advanced pain management techniques. Since America’s culture is rife with taboos and fears of drug addiction and drug abuse, addressing the concerns regarding over-medication of patients, the medical community seems to have responded in the wrong direction. Many doctors, regulators, family members and patients still have irrational and unrealistic fears about addiction in the terminally ill. Aligned with a lack of knowledge about the availability and effectiveness of modern pain relief management, these fears result in all too frequent under-medication for pain. Although there are small signs that improvements can be made, physicians, nurses, and healthcare providers, in general, are still not adequately trained or encouraged to communicate openly with dying patients or families. Additionally, they are often unfamiliar with the latest techniques and equipment for modern pain relief management. Moreover, the patient-centered, multi-disciplinary-team support for at-home care / hospice programs, becomes available only to those with proper insurance and a relatively certain prognosis of minimum life remaining. Independent of the financial issues, isolating, pinpointing and/or forecasting time of death is a tough call for any medical professional.

Forecasting the time remaining in the life of a terminal patient is part science, part experience, and part deduction. This forecasting process can be supported by the application of a dying-trajectory. The idea of estimating a dying-trajectory first came into use in the mid nineteen sixties and refers to tracking the change in health status over time as a patient approaches death. These trajectories are used to identify different patterns of dying, [i.e.] sudden death, lingering death, certain to die rapidly, and a vacillating pattern. The use of a dying-trajectory is helpful in calculating and identifying paths relative to the expected time until death. Formally, plotting and documenting dying-trajectories for many patients over a long period is helpful in many ways, particularly for tracking and documenting trends and determining how finite healthcare resources can be allocated to support those trends. A trajectory graph is usually plotted, retrospectively for an individual, with time on the X axis and health status on the Y axis. The X and Y axis of the trajectory focuses on expectations about when a patient would die and how that could help communication among hospital staff, patients, and families regarding such expectations. This concept of a dying-trajectory is useful in understanding a patient's experiences as they approach death. It is also valuable when considering the systemic studies of dying categories for medical research. The importance of using these trajectory scenarios for research cannot be over emphasized in the study of human death in both the patient's and the family's experience. Sudden death from an unexpected cause (SUD) like massive heart attack, stroke, or tragic accident is also a type of dying trajectory. However, for research into the majority of deaths, we exclude SUD and focus on those deaths that occur with a specific lead time as in the scenarios displayed in chapter four.

Americans are a caring, charitable and supportive people, but when it comes to approaching a discussion on end-of-life care and dying, the atmosphere becomes politically charged and even poisonous. Inaction on this public health crisis is unlike our character, unlike our culture, and unlike our society. Meaningful discussions and debate are muted by political correctness and a desire to avoid conflict on such a sensitive issue. The media then participates in this charade. In fact, the media may help to perpetuate it by constantly leveling charges of healthcare “death-panels” and doctor mandated “euthanasia” during any attempt to have an open discussion. The 24-hour news spectacle is immersed in creating dramatic conflict for any event to maintain and increase viewer volume numbers. Under these circumstances the conditions for discussion are derailed and then reduced to a level of simplicity that is almost silliness. The end result is as far from meaningful discussion as is possible. Attempting a vital dialogue ends up as a negative sound bite in the healthcare segment on any of the evening news programs.

All indicators show that we may be on the verge of a national crisis in healthcare, which for the aged and dying will make our current situation seem subdued by comparison. Similar to a slow-motion flood, the immediate future will see mounting numbers of frailty and physical illness nationally and locally. The demographics of the aging baby-boomer generation, and its advancing cohorts of seniors, are already starting to burden our current healthcare system. Today, there are a large number of ill and dying elderly that cannot be cared for sufficiently nor can they cope within the healthcare system. They are not treated adequately by the healthcare system, nor can most of them afford to be cared for properly outside the system.   Since there is no representative treatment or appropriate care for this group it is truly a catch-22 dilemma for the chronically ill who are elderly.

Too many patients still die alone in an acute care hospital room with their final days dominated by futile technological interventions that aggravate rather than alleviate suffering. There is a reluctance by a significant percentage of medical professionals, at all levels, to accept the inevitable and face the possibility of patient death. This reluctance also includes the lack of recognition that death is certain and is a part of the human life-cycle which must be accepted and acknowledged as the truth. There is a time to accept the inevitability of death and a right-time for healthcare professionals to stop the dramatic rescue-treatment-cure strategy and refer a patient to palliative care, alternative care, hospice, or home care. Unfortunately, the conventional medical wisdom has hospice care referral coming at the very end of an unnecessarily prolonged treatment cycle. In many cases the primary care physician waits until there is virtually no time remaining in the patient's life before referring a patient to hospice or suggesting hospice to the family.

In point of fact, many doctors and nurses think hospice means giving up, but that has never been the case. Calling in hospice means managing the situation to make the most of it. Helping the patient to be more comfortable, more at ease, pain free and appreciated. Hospice is a special healthcare option for patients and families who are faced with a terminal illness. Under ideal circumstances a multi-disciplinary team of physician(s), nurses, hospice aides, social workers, bereavement counselors and volunteers work together to address the physical, social, emotional and spiritual needs of each patient and family. The hospice team provides care to patients in their own home or in a home-like setting including symptom management, emotional support, spiritual support and psychosocial intervention. Hospice care is dedicated to addressing issues most important to the patient’s needs and desires at the end of life, focusing on improving the individual’s quality of life within the time remaining.

This dissertation encourages the creation and development of a new branch / specialty of American medicine called End-of-Life-Care. This aspect of medicine would be specifically targeted toward the dying patient and family. Physicians, nurses and healthcare workers would receive specific training, preparation and credentials in working with the terminally ill and their families. Segments of American healthcare can be restructured and redirected to provide more comprehensive social, psychological, and spiritual support to dying patients and families without huge expenditures and drastic upheavals in the overall process. Shifting the colossal American healthcare establishment to accommodate compassion for the dying may seem like an intimidating task however, healthcare consumers will be a powerful influence for change as the need for care increases in the ever growing elderly population. A good beginning would start with the creation of an organized (non-emergency 911-type) response for initializing and summoning End-of-Life-Care for a patient.

There are two reassuring factors that aid in the support of the creation of an End-of-Life-Care specialty in the US. First, unlike most of America's technological, pharmaceutical, and emergency medicine; decent compassionate treatment for the dying is relatively inexpensive. Rather than revolving around high-priced machinery and specialty credentials, good treatment for the dying relies on nurses, volunteers, ministerial councilors and in large part on family members, to provide most of the care. The most important pharmaceutical component is delivery and management of pain medication. After a proper pain management procedure and delivery system is set up, compassionate care by design, minimizes costly surgeries and/or heroic technologies. Also, most hospice care is conducted in the patient's home and/or in his own bed rather than in an expensive acute care hospital trauma bed. Second, acute care medicine is complex, requiring diagnostic tools and experts with specialty training and must be conducted in a highly organized administrative setting. Treating a dying patient in an acute care "rescue-treatment-cure" hospital is wasteful and counter-productive. Proper End-of-Life-Care is actually simpler from a medical and technological standpoint, the paramount job qualifications are empathy and compassion.

American medicine could do well to begin the creation of an End of Life Care specialty in American medicine by carefully evaluating the documented results achieved by the UK in their End-of-Life-Care program and build on that success. They have devoted decades of effort and spending to achieve this goal.

This research highlights the features of a branch of the UK National Health Care system which has proven to be extremely successful in this aspect of medical support and patient centered care. It is widely acknowledged that the UK is leading the way in its treatment of dying patients. They have firmly established policies, training, qualifications, credentials and certifications for healthcare service providers that work with the terminally ill and the families of the terminally ill. Documentation on the successes, failures, and achievements in the UK, in End of Life care, as well as policy and procedures are readily available for us in America to study and use at no charge.

CHART INDEX

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Osiris (/oʊˈsaɪərɨs/; also Usiris), (*Wilkinson, 2003*) is an Egyptian god, usually identified as the god of the afterlife, the underworld and the dead. As ruler of the dead, Osiris was also sometimes called "*king of the living*", since the Ancient Egyptians considered the blessed dead "*the living ones*". Osiris was considered not only a merciful judge of the dead in the afterlife, but also the underworld agency that granted all life, including sprouting vegetation. The Kings of Egypt were associated with Osiris in death — as Osiris rose from the dead they would, in union with him, inherit eternal life. All people, not just pharaohs, were eventually believed to be associated with Osiris at death.

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APPENDIX A

U.S. STANDARD CERTIFICATE OF DEATH (GENERIC)

MEDICAL CERTIFIER INSTRUCTIONS for selected items on U.S. Standard Certificate of Death

(See Physicians' Handbook or Medical Examiner/Coroner Handbook on Death Registration for instructions on all items)

ITEMS ON WHEN DEATH OCCURRED

Items 24-25 and 29-31 should always be completed. If the facility uses a separate pronouncer or other person to indicate that death has taken place with another person more familiar with the case completing the remainder of the medical portion of the death certificate, the pronouncer completes Items 24-28. If a certifier completes Items 24-25 as well as items 29-49, Items 26-28 may be left blank.

ITEMS 24-25, 29-30 – DATE AND TIME OF DEATH

Spell out the name of the month. If the exact date of death is unknown, enter the **approximate** date. If the date cannot be approximated, enter the date the body is found and identify as **date found**. Date pronounced and actual date may be the same. Enter the exact hour and minutes according to a 24-hour clock; estimates may be provided with "Approx." placed before the time.

ITEM 32 – CAUSE OF DEATH (See attached examples)

Take care to make the entry legible. Use a computer printer with high resolution, typewriter with good black ribbon and clean keys, or print legibly using permanent **black** ink in completing the CAUSE OF DEATH Section. **Do not abbreviate** conditions entered in section.

Part I (Chain of events leading directly to death)

•Only **one** cause should be entered on each line. Line (a) **MUST ALWAYS** have an entry. **DO NOT** leave blank. Additional lines may be added if necessary.

•If the condition on Line (a) resulted from an underlying condition, put the underlying condition on Line (b), and so on, until the full sequence is reported. **ALWAYS** enter the **underlying cause of death** on the lowest used line in Part I.

•For each cause indicate the best estimate of the interval between the presumed onset and the date of death. The terms "unknown" or "approximately" may be used. General terms, such as minutes, hours, or days, are acceptable, if necessary. **DO NOT** leave blank.

•The terminal event (for example, cardiac arrest or respiratory arrest) should not be used. If a mechanism of death seems most appropriate to you for line (a), then you must always list its cause(s) on the line(s) below it (for example, cardiac arrest **due to** coronary artery atherosclerosis *or* cardiac arrest **due to** blunt impact to chest).

• If an organ system failure such as congestive heart failure, hepatic failure, renal failure, or respiratory failure is listed as a cause of death, always report its etiology on the line(s) beneath it (for example, renal failure **due to** Type I diabetes mellitus).

•When indicating neoplasms as a cause of death, include the following: 1) primary site *or* that the primary site is unknown, 2) benign or malignant, 3) cell type *or* that the cell type is unknown, 4) grade of neoplasm, and 5) part or lobe of organ affected. (For example, a primary well- differentiated squamous cell carcinoma, lung, left upper lobe.)

•Always report the fatal injury (for example, stab wound of chest), the trauma (for example, transection of subclavian vein), and impairment of function (for example, air embolism).

PART II (Other significant conditions)

•Enter all diseases or conditions contributing to death that were not reported in the chain of events in Part I and that did not result in the **underlying cause of death**. See attached examples. •If two or more possible sequences resulted in death, or if two conditions seem to have added together, report in Part I the one that, in your opinion, most directly caused death. Report in Part II the other conditions or diseases.

CHANGES TO CAUSE OF DEATH

Should additional medical information or autopsy findings become available that would change the cause of death originally reported, the original death certificate should be amended by the certifying physician by **immediately** reporting the revised cause of death to the State Vital Records Office.

ITEMS 33-34 - AUTOPSY

•33 - Enter "Yes" if either a partial or full autopsy was performed. Otherwise enter "No."
•34 - Enter "Yes" if autopsy findings were available to complete the cause of death; otherwise enter "No".
Leave item blank if no autopsy was performed.

ITEM 35 - DID TOBACCO USE CONTRIBUTE TO DEATH?

Check "yes" if, in your opinion, the use of tobacco contributed to death. Tobacco use may contribute to deaths due to a wide variety of diseases; for example, tobacco use contributes to many deaths due to emphysema or lung cancer and some heart disease and cancers of the head and neck. Check "no" if, in your clinical judgment, tobacco use did not contribute to this particular death.

ITEM 36 - IF FEMALE, WAS DECEDENT PREGNANT AT TIME OF DEATH OR WITHIN PAST YEAR?

This information is important in determining pregnancy-related mortality.

ITEM 37 - MANNER OF DEATH

•Always check Manner of Death, which is important: 1) in determining accurate causes of death; 2) in processing insurance claims; and 3) in statistical studies of injuries and death. •Indicate "Pending investigation" if the manner of death cannot be determined whether due to an accident, suicide, or homicide within the statutory time limit for filing the death certificate. This should be changed later to one of the other terms.
•Indicate "Could not be Determined" **ONLY** when it is impossible to determine the manner of death.

ITEMS 38-44 - ACCIDENT OR INJURY – to be filled out in all cases of deaths due to injury or poisoning.

•38 - Enter the exact month, day, and year of injury. Spell out the name of the month. **DO NOT** use a number for the month. (Remember, the
date of injury may differ from the date of death.) Estimates may be provided with "Approx." placed before the date.
•39 **-** Enter the exact hour and minutes of injury or use your best estimate. Use a 24-hour clock.
•40 - Enter the general place (such as restaurant, vacant lot, or home) where the injury occurred. **DO NOT** enter firm or organization names.
(For example, enter "factory", **not** "Standard Manufacturing, Inc.")
•41 - Complete if anything other than natural disease is mentioned in Part I or Part II of the medical certification, including homicides, suicides, and accidents. This includes all motor vehicle deaths. The item **<u>must</u>** be completed for decedents ages 14 years or over and may be completed for those less than 14 years of age if warranted. Enter "Yes" if the injury occurred at work. Otherwise enter "No". An injury may occur at work regardless of whether the injury occurred in the course of the decedent's "usual" occupation. Examples of injury at work and injury not at work follow:

Injury at work
Injury not at work

Injury while working or in vocational training on job premises Injury while engaged in personal recreational activity on job premises Injury while on break or at lunch or in parking lot on job premises Injury while a visitor (not on official work business) to job premises Injury while working for pay or compensation, including at home Homemaker working at homemaking activities Injury while working as a volunteer law enforcement official etc. Student in school injury while traveling on business, including to/from business contacts Working for self for no profit (mowing yard, repairing own roof, hobby) Commuting to or from work

•42 - Enter the complete address where the injury occurred including zip code.
•43 - Enter a brief but specific and clear description of how the injury occurred. Explain the circumstances or cause of the injury. Specify
type of gun or **type of vehicle** (e.g., car, bulldozer, train, etc.) when relevant to circumstances. Indicate if more than one vehicle involved;
specify type of vehicle decedent was in.

•44 -Specify role of decedent (e.g. driver, passenger). Driver/operator and passenger should be designated for modes other than motor vehicles such as bicycles. Other applies to watercraft, aircraft, animal, or people attached to outside of vehicles (e.g. surfers).

Rationale: Motor vehicle accidents are a major cause of unintentional deaths; details will help determine effectiveness of current safety features and laws.

REFERENCES

For more information on how to complete the medical certification section of the death certificate, refer to tutorial at http://www.TheNAME.org and resources including instructions and handbooks available by request from NCHS, Room 7318, 3311 Toledo Road, Hyattsville, Maryland 20782•
2003 or at www.cdc.gov/nchs/about/major/dvs/handbk.htm

REV. 11/2003

Cause-of-death – Background, Examples, and Common Problems

Accurate cause of death information is important
•to the public health community in evaluating and improving the health of all citizens, and
•often to the family, now and in the future, and to the person settling the decedent's estate.

The cause-of-death section consists of two parts. **Part I** is for reporting a chain of events leading directly to death, with the **immediate cause** of death (the final disease, injury, or complication directly causing death) on line a and the **underlying cause** of death (the disease or injury that initiated the chain of events that led directly and inevitably to death) on the lowest used line. **Part II** is for reporting all other significant diseases, conditions, or injuries that contributed to death but which did not result in the underlying cause of death given in **Part I**. **The cause-of-death information should be YOUR best medical OPINION.** A condition can be listed as "probable" even if it has not been definitively diagnosed.

CAUSE OF DEATH (See instructions and examples)

Approximate interval:
Onset to death

32. **PART I.** Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

IMMEDIATE CAUSE (Final disease or condition **--------->** resulting in death)
a. Rupture of myocardium — Minutes
Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**

b. Acute myocardial infarction — 6 days
Due to (or as a consequence of):
c. Coronary artery thrombosis — 5 years
Due to (or as a consequence of):
d. Atherosclerotic coronary artery disease — 7 years

PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I

Diabetes, Chronic obstructive pulmonary disease, smoking

33. WAS AN AUTOPSY PERFORMED?
■ Yes
No

34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ■ Yes No

35. DID TOBACCO USE CONTRIBUTE TO DEATH?
■ Yes
Probably
No
Unknown

36. IF FEMALE:
■ Not pregnant within past year
Pregnant at time of death
Not pregnant, but pregnant within 42 days of death
Not pregnant, but pregnant 43 days to 1 year before death
Unknown if pregnant within the past year

37. MANNER OF DEATH
■ Natural
Accident
Suicide
Homicide
Pending Investigation
Could not be determined

Examples of properly completed medical certifications

CAUSE OF DEATH (See instructions and examples)

Approximate inter
Onset to death

32. **PART I.** Enter the <u>chain of events</u>--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

IMMEDIATE CAUSE (Final disease or condition **--------->** resulting in death)
a. Aspiration pneumonia — <u>2 Days</u>
Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**

b. Complications of coma — <u>7 weeks</u>
Due to (or as a consequence of):
c. Blunt force injuries — <u>7 weeks</u>
Due to (or as a consequence of):
d. Motor vehicle accident — <u>7 weeks</u>

PART II. Enter other <u>significant conditions contributing to death</u> but not resulting in the underlying cause given in PART I

33. WAS AN AUTOPSY PERFORMED?
■ Yes
No

34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ■ Yes No

35. DID TOBACCO USE CONTRIBUTE TO DEATH?
Yes
Probably
■ No
Unknown

36. IF FEMALE:
Not pregnant within past year
Pregnant at time of death
Not pregnant, but pregnant within 42 days of death
Not pregnant, but pregnant 43 days to 1 year before death
Unknown if pregnant within the past year

37. MANNER OF DEATH
Natural
Homicide
■ Accident
Pending Investigation
Suicide
Could not be determined

38. DATE OF INJURY (Mo/Day/Yr) (Spell Month): August 15, 2003

39. TIME OF INJURY: Approx. 2320

40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area): road side near state highway

41. INJURY AT WORK? Yes ■ No

42. LOCATION OF INJURY: State: Missouri City or Town: near Alexandria
Street & Number: mile marker 17 on state route 46a Apartment No.: Zip Code:

43. DESCRIBE HOW INJURY OCCURRED:
Decedent driver of van, ran off road into tree

44. IF TRANSPORTATION INJURY, SPECIFY:
■
Driver/Operator
Passenger
Pedestrian
Other (Specify)

Common problems in death certification

The **elderly decedent** should have a clear and distinct etiological sequence for cause of death, if possible. Terms such as senescence, infirmity, old age, and advanced age have little value for public health or medical research. Age is recorded elsewhere on the certificate. When a number of conditions resulted in death, the physician should choose the single sequence that, in his or her opinion, best describes the process leading to death, and place any other pertinent conditions in Part II. If after careful consideration the physician cannot determine a sequence that ends in death, then the medical examiner or coroner should be consulted about conducting an investigation or providing assistance in completing the cause of death.

The **infant decedent** should have a clear and distinct etiological sequence for cause of death, if possible. "Prematurity" should not be entered without explaining the etiology of prematurity. Maternal conditions may have initiated or affected the sequence that resulted in infant death, and such maternal causes should be reported in addition to the infant causes on the infant's death certificate (e.g., Hyaline membrane disease **due to** prematurity, 28 weeks **due to** placental abruption **due to** blunt trauma to mother's abdomen).

When **SIDS** is suspected, a complete investigation should be conducted, typically by a medical examiner or coroner. If the infant is under 1 year of age, no cause of death is determined after scene investigation, clinical history is reviewed, and a complete autopsy is performed, then the death can be reported as Sudden Infant Death Syndrome.

When processes such as the following are reported, additional information about the etiology should be reported:

Abscess	Carcinomatosis	Disseminated intra vascular	Hyponatremia	Pulmonary arrest
Abdominal hemorrhage	Cardiac arrest	coagulopathy	Hypotension	Pulmonary edema
Adhesions	Cardiac dysrhythmia	Dysrhythmia	Immunosuppression	Pulmonary embolism
Adult respiratory distress syndrome	Cardiomyopathy	End-stage liver disease	Increased intra cranial pressure	Pulmonary insufficie
Acute myocardial infarction	Cardiopulmonary arrest	End-stage renal disease	Intra cranial hemorrhage	Renal failure
Altered mental status	Cellulitis	Epidural hematoma	Malnutrition	Respiratory arrest
Anemia	Cerebral edema	Exsanguination	Metabolic encephalopathy	Seizures
Anoxia	Cerebrovascular accident	Failure to thrive	Multi-organ failure	Sepsis
Anoxic encephalopathy	Cerebellar tonsillar herniation	Fracture	Multi-system organ failure	Septic shock
Arrhythmia	Chronic bedridden state	Gangrene	Myocardial infarction	Shock
Ascites	Cirrhosis	Gastrointestinal hemorrhage	Necrotizing soft-tissue infection	Starvation
Aspiration	Coagulopathy	Heart failure	Old age	Subdural hematoma
Atrial fibrillation	Compression fracture	Hemothorax	Open (or closed) head injury	Subarachnoid hemor
Bacteremia	Congestive heart failure	Hepatic failure	Paralysis	Sudden death
Bedridden	Convulsions	Hepatitis	Pancytopenia	Thrombocytopenia
Biliary obstruction	Decubiti	Hepatorenal syndrome	Perforated gallbladder	Uncal herniation
Bowel obstruction	Dehydration	Hyperglycemia	Peritonitis	Urinary tract infectio
Brain injury	Dementia (when not	Hyperkalemia	Pleural effusions	Ventricular fibrillatio
Brain stem herniation	otherwise specified)	Hypovolemic shock	Pneumonia	Ventricular tachycar

Carcinogenesis	Diarrhea			Volume depletion

If the certifier is unable to determine the etiology of a process such as those shown above, the process must be qualified as being of an unknown, undetermined, probable, presumed, or unspecified etiology so it is clear that a distinct etiology was not inadvertently or carelessly omitted.

The following conditions and types of death might seem to be specific or natural but when the medical history is examined further may be found to be complications of an injury or poisoning (possibly occurring long ago). Such cases should be reported to the medical examiner/coroner.
Asphyxia Bolus Choking
Drug or alcohol overdose/drug or alcohol abuse

1. DECEDENT'S LEGAL NAME (Include AKA's if any) (First, Middle, Last)
2. SEX
3. SOCIAL SECURITY NUMBER

4a. AGE-Last Birthday (Years)
4b. UNDER 1 YEAR — Months — Days
4c. UNDER 1 DAY — Hours — Minutes
5. DATE OF BIRTH (Mo/Day/Yr)
6. BIRTHPLACE (City and State or Foreign Country)

7a. RESIDENCE-STATE
7b. COUNTY
7c. CITY OR TOWN

7d. STREET AND NUMBER
7e. APT. NO.
7f. ZIP CODE
7g. INSIDE CITY LIMITS? ☐ Yes ☐ No

8. EVER IN US ARMED FORCES? ☐ Yes ☐ No
9. MARITAL STATUS AT TIME OF DEATH ☐ Married ☐ Married, but separated ☐ Widowed ☐ Divorced ☐ Never Married ☐ Unknown
10. SURVIVING SPOUSE'S NAME (If wife, give name prior to first marriage)

11. FATHER'S NAME (First, Middle, Last)
12. MOTHER'S NAME PRIOR TO FIRST MARRIAGE (First, Middle, Last)

13a. INFORMANT'S NAME
13b. RELATIONSHIP TO DECEDENT
13c. MAILING ADDRESS (Street and Number, City, State, Zip Code)

14. PLACE OF DEATH (Check only one: see instructions)
IF DEATH OCCURRED IN A HOSPITAL: ☐ Inpatient ☐ Emergency Room/Outpatient ☐ Dead on Arrival
IF DEATH OCCURRED SOMEWHERE OTHER THAN A HOSPITAL: ☐ Hospice facility ☐ Nursing home/Long term care facility ☐ Decedent's home ☐ Other (Specify):

15. FACILITY NAME (If not institution, give street & number)
16. CITY OR TOWN , STATE, AND ZIP CODE
17. COUNTY OF DEATH

18. METHOD OF DISPOSITION: ☐ Burial ☐ Cremation ☐ Donation ☐ Entombment ☐ Removal from State ☐ Other (Specify):___________________________
19. PLACE OF DISPOSITION (Name of cemetery, crematory, other place)

20. LOCATION-CITY, TOWN, AND STATE
21. NAME AND COMPLETE ADDRESS OF FUNERAL FACILITY

22. SIGNATURE OF FUNERAL SERVICE LICENSEE OR OTHER AGENT
23. LICENSE NUMBER (Of Licensee)

ITEMS 24-28 MUST BE COMPLETED BY PERSON WHO PRONOUNCES OR CERTIFIES DEATH
24. DATE PRONOUNCED DEAD (Mo/Day/Yr)
25. TIME PRONOUNCED DE

26. SIGNATURE OF PERSON PRONOUNCING DEATH (Only when applicable)	27. LICENSE NUMBER	28. DATE SIGNED (Mo/Day/Yr)

29. ACTUAL OR PRESUMED DATE OF DEATH (Mo/Day/Yr) (Spell Month)	30. ACTUAL OR PRESUMED TIME OF DEATH	31. WAS MEDICAL EXAMINER OR CORONER CONTACTED? ☐ Yes ☐ No

CAUSE OF DEATH (See instructions and examples)

Approximate interval: Onset to death

32. **PART I.** Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

IMMEDIATE CAUSE (Final disease or condition **--------->** resulting in death) a.______________________________

Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**

b.______________________________

Due to (or as a consequence of):

c.______________________________

Due to (or as a consequence of):

d.______________________________

PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I

33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No

34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? ☐ Yes ☐ No

35. DID TOBACCO USE CONTRIBUTE TO DEATH?

☐ Yes ☐ Probably

☐ No ☐ Unknown

36. IF FEMALE:

☐ Not pregnant within past year

☐ Pregnant at time of death

☐ Not pregnant, but pregnant within 42 days of death

☐ Not pregnant, but pregnant 43 days to 1 year before death

☐ Unknown if pregnant within the past year

37. MANNER OF DEATH

☐ Natural ☐ Homicide

☐ Accident ☐ Pending Investigation

☐ Suicide ☐ Could not be determined

38. DATE OF INJURY (Mo/Day/Yr) (Spell Month)	39. TIME OF INJURY	40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area)	41. INJURY AT WORK? ☐ Yes ☐ No

42. LOCATION OF INJURY: State: City or Town:

Street & Number: Apartment No.:

Zip Code:

43. DESCRIBE HOW INJURY OCCURRED:

44. IF TRANSPORTATION INJURY, SPECIFY:

☐ Driver/Operator

☐ Passenger

☐ Pedestrian

☐ Other (Specify)

45. CERTIFIER (Check only one):

☐ Certifying physician-To the best of my knowledge, death occurred due to the cause(s) and manner stated.

☐ Pronouncing & Certifying physician-To the best of my knowledge, death occurred at the time, date, and place, and due to the cause(s) and manner stated.

☐ Medical Examiner/Coroner-On the basis of examination, and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner stated.

Signature of certifier:______________________________

46. NAME, ADDRESS, AND ZIP CODE OF PERSON COMPLETING CAUSE OF DEATH (Item 32)

47. TITLE OF CERTIFIER	48. LICENSE NUMBER	49. DATE CERTIFIED (Mo/Day/Yr)	50. **FOR REGISTRAR ONLY**- DATE FILED (Mo/Day/Yr)

51. DECEDENT'S EDUCATION-Check the box that best describes the highest degree or level of school completed at the time of death.

☐ 8th grade or less
☐ 9th - 12th grade; no diploma
☐ High school graduate or GED completed
☐ Some college credit, but no degree
☐ Associate degree (e.g., AA, AS)
☐ Bachelor's degree (e.g., BA, AB, BS)
☐ Master's degree (e.g., MA, MS, MEng, MEd, MSW, MBA)
☐ Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD)

52. DECEDENT OF HISPANIC ORIGIN? Check the box that best describes whether the decedent is Spanish/Hispanic/Latino. Check the "No" box if decedent is not Spanish/Hispanic/Latino.

☐ No, not Spanish/Hispanic/Latino
☐ Yes, Mexican, Mexican American, Chicano
☐ Yes, Puerto Rican
☐ Yes, Cuban
☐ Yes, other Spanish/Hispanic/Latino (Specify) ______________________

53. DECEDENT'S RACE (Check one or more races to indicate what the decedent considered himself or herself to be)

☐ White
☐ Black or African American
☐ American Indian or Alaska Native (Name of the enrolled or principal tribe)
☐ Asian Indian
☐ Chinese
☐ Filipino
☐ Japanese
☐ Korean
☐ Vietnamese
☐ Other Asian (Specify)______________________
☐ Native Hawaiian
☐ Guamanian or Chamorro
☐ Samoan
☐ Other Pacific Islander (Specify)______________________
☐ Other (Specify)______________________

54. DECEDENT'S USUAL OCCUPATION (Indicate type of work done during most of working life. DO NOT USE RETIRED).

55. KIND OF BUSINESS/INDUSTRY

NAME OF DECEDENT ____ **For use by physician or institution**
LOCAL FILE NO.
STATE FILE NO.

APPENDEX B

THE AFFORDABLE HEALTHN CARE ACT - PATIENTS BILL OF RIGHTS AND OTHER PROTECTIONS:

The Patient Protection and Affordable Care Act
Detailed Summary

The Patient Protection and Affordable Care Act will ensure that all Americans have access to quality, affordable health care and will create the transformation within the health care system necessary to contain costs. The Congressional Budget Office (CBO) has determined that the Patient Protection and Affordable Care Act is fully paid for, will provide coverage to more than 94% of Americans while staying under the $900 billion limit that President Obama established, bending the health care cost curve, and reducing the deficit over the next ten years and beyond.

The Patient Protection and Affordable Care Act contains nine titles, each addressing an essential component of reform:

- Quality, affordable health care for all Americans
- The role of public programs
- Improving the quality and efficiency of health care
- Prevention of chronic disease and improving public health
- Health care workforce
- Transparency and program integrity
- Improving access to innovative medical therapies
- Community living assistance services and supports
- Revenue provisions

Title I. Quality, Affordable Health Care for All Americans

The Patient Protection and Affordable Care Act will accomplish a fundamental transformation of

health insurance in the United States through shared responsibility. Systemic insurance market reform will eliminate discriminatory practices such as pre-existing condition exclusions. Achieving these reforms without increasing health insurance premiums will mean that all Americans must be part of the system and must have coverage. Tax credits for individuals and families will ensure that insurance is affordable for everyone. These three elements are the essential links to achieve reform.

Immediate Improvements: Achieving health insurance reform will take some time to implement. In the immediate reforms will be implemented in 2010. The Patient Protection and Affordable Care Act will:

- Eliminate lifetime and unreasonable annual limits on benefits
- Prohibit rescissions of health insurance policies

- Provide assistance for those who are uninsured because of a pre-existing condition
- Require coverage of preventive services and immunizations
- Extend dependant coverage up to age 26
- Develop uniform coverage documents so consumers can make apples-to-apples comparisons when shopping for health insurance
- Cap insurance company non-medical, administrative expenditures
- Ensure consumers have access to an effective appeals process and provide consumer a place to turn for assistance navigating the appeals process and accessing their coverage
- Create a temporary re-insurance program to support coverage for early retirees
- Establish an internet portal to assist Americans in identifying coverage options
- Facilitate administrative simplification to lower health system costs

Health Insurance Market Reform: Beginning in 2014, more significant insurance reforms will be implemented. Across individual and small group health insurance markets in all states, new rules will end medical underwriting and pre-existing condition exclusions. Insurers will be prohibited from denying coverage or setting rates based on health status, medical condition, claims experience, genetic information, evidence of domestic violence, or other health-related factors. Premiums will vary only by family structure, geography, actuarial value, tobacco use, participation in a health promotion program, and age (by not more than three to one).

Available Coverage: A qualified health plan, to be offered through the new American Health Benefit Exchange, must provide essential health benefits which include cost sharing limits. No out-of-pocket requirements can exceed those in Health Savings Accounts, and deductibles in the small group market cannot exceed $2,000 for an individual and $4,000 for a family. Coverage will be offered at four levels with actuarial values defining how much the insurer pays: Platinum – 90 percent; Gold – 80 percent; Silver – 70 percent; and Bronze – 60 percent. A lower-benefit catastrophic plan will be offered to individuals under age 30 and to others who are exempt from the individual responsibility requirement.

American Health Benefit Exchanges: By 2014, each state will establish an Exchange to help individuals and small employers obtain coverage. Plans participating in the Exchanges will be accredited for quality, will present their benefit options in a standardized manner for easy comparison, and will use one, simple enrollment form. Individuals qualified to receive tax credits for Exchange coverage must be ineligible for affordable, employer-sponsored insurance any form of public insurance coverage. Undocumented immigrants are ineligible for premium tax credits. The Secretary of Health and Human Services (HHS) will establish a national public option – the Community Health Insurance Option – and permit states to opt-out. Federal support will also be available for new non-profit, member run insurance cooperatives. States will have flexibility to establish basic health plans for non- Medicaid, lower-income individuals; states may also seek waivers to explore other reform options; and states may form compacts with other states to permit cross-state sale of health insurance. No federal dollars may be used to pay for abortion services.

Making Coverage Affordable: New, refundable tax credits will be available for Americans with incomes between 100 and 400 percent of the federal poverty line (FPL) (about $88,000 for a family of four). The credit is calculated on a sliding scale beginning at two percent of income for those at 100 percent FPL and phasing out at 9.8 percent of income at 300-400 percent FPL. If an employer offer of coverage exceeds 9.8 percent of a worker‟s family income, or the employer pays less than 60 percent of the premium, the worker may enroll in the Exchange and receive credits. Out of pocket maximums ($5,950 for individuals and $11,900 for families) are reduced to one third for those with income between 100-200 percent FPL, one half for those with incomes between 200-300 percent FPL, and two thirds for those with income between 300-400 percent FPL. Credits are available for eligible citizens and legally-residing aliens. A new credit will assist small businesses with fewer than 25 workers for up to 50 percent of the total premium cost.

Shared Responsibility: Beginning in 2014, most individuals will be required to maintain minimum essential coverage or pay a penalty of $95 in 2014, $350 in 2015, $750 in 2016 and indexed thereafter; for those under 18, the penalty will be one-half the amount for adults. Exceptions to this requirement are made for religious objectors, those who cannot afford coverage, taxpayers with incomes less than 100 percent FPL, Indian tribe members, those who receive a hardship waiver, individuals not lawfully present, incarcerated individuals, and those not covered for less than three months.

Any individual or family who currently has coverage and would like to retain that coverage can do so under a „grandfather‟ provision. This coverage is deemed to meet the requirement to have health coverage. Similarly, employers that currently offer coverage are permitted to continue offering such coverage under the „grandfather‟ policy.

Employers with more than 200 employees must automatically enroll new full-time employees in coverage. Any employer with more than 50 full-time employees that does not offer coverage and has at least one full-time employee receiving the premium assistance tax credit will make a payment of $750 per full-time employee. An employer with more than 50 employees that offers coverage that is deemed unaffordable or does not meet the standard for minimum essential coverage and but has at least one full-time employee receiving the premium assistance tax credit because the coverage is either unaffordable or does not cover 60 percent of total costs, will pay the lesser of $3,000 for each of those employees receiving a credit or $750 for each of their full-time employees total.

Title II. The Role of Public Programs

The Patient Protection and Affordable Care Act expands eligibility for Medicaid to lower income persons and assumes federal responsibility for much of the cost of this expansion. It provides enhanced federal support for the Childrens Health Insurance Program, simplifies Medicaid and CHIP enrollment, improves Medicaid services, provides new options for long-term services and supports, improves coordination for dual-eligibles, and improves Medicaid quality for patients and providers.

Medicaid Expansion: States may expand Medicaid eligibility as early as January 1, 2011. Beginning on January 1, 2014, all children, parents and childless adults who are not entitled to

Medicare and who have family incomes up to 133 percent FPL will become eligible for Medicaid. Between 2014 and 2016, the federal government will pay 100 percent of the cost of covering newly-eligible individuals. In 2017 and 2018, states that initially covered less of the newly-eligible population (“Other States”) will receive more assistance than states that covered at least some non-elderly, non-pregnant adults (“Expansion States”). States will be required to maintain the same income eligibility levels through December 31, 2013 for all adults, and this requirement would be extended through September 30, 2019 for children currently in Medicaid.

Children’s Health Insurance Program: States will be required to maintain income eligibility levels for CHIP through September 30, 2019. Between fiscal years 2014 and 2019, states would receive a 23 percentage point increase in the CHIP federal match rate, subject to a 100 percent cap.

Simplifying Enrollment: Individuals will be able to apply for and enroll in Medicaid, CHIP and the Exchange through state-run websites. Medicaid and CHIP programs and the Exchange will coordinate enrollment procedures to provide seamless enrollment for all programs. Hospitals will be permitted to provide Medicaid services during a period of presumptive eligibility to members of all Medicaid eligibility categories.

Community First Choice Option: A new optional Medicaid benefit is created through which states may offer community-based attendant services and supports to Medicaid beneficiaries with disabilities who would otherwise require care in a hospital, nursing facility, or intermediate care facility for the mentally retarded.

Disproportionate Share Hospital Allotments: States‟ disproportionate share hospital (DSH) allotments are reduced by 50 percent once a state‟s uninsurance rate decreases by 45 percent (low DSH states would receive a 25 percent reduction). As the rate continues to decline, states‟ DSH allotments would be reduced by a corresponding amount. At no time could a state‟s allotment be reduced by more than 65 percent compared to its FY2012 allotment.

Dual Eligible Coverage and Payment Coordination: The Secretary of Health and Human Services (HHS) will establish a Federal Coordinated Health Care Office by March 1, 2010 to integrate care under Medicare and Medicaid, and improve coordination among the federal and state governments for individuals enrolled in both programs (dual eligibles).

Title III. Improving the Quality and Efficiency of Health Care

The Patient Protection and Affordable Care Act will improve the quality and efficiency of U.S. medical care services for everyone, and especially for those enrolled in Medicare and Medicaid. Payment for services will be linked to better quality outcomes. The Patient Protection and Affordable Care Act will make substantial investments to improve the quality and delivery of care and support research to inform consumers about patient outcomes resulting from different approaches to treatment and care delivery. New patient care models will be created and disseminated. Rural patients and providers will see meaningful improvements. Payment accuracy will improve. The Medicare Part D prescription drug benefit will be enhanced and the coverage gap, or donut hole, will be reduced. An

Independent Medicare Advisory Board will develop recommendations to ensure long-term fiscal stability.

Linking Payment to Quality Outcomes in Medicare: A value-based purchasing program for hospitals will launch in FY2013 will link Medicare payments to quality performance on common, high-cost conditions such as cardiac, surgical and pneumonia care. The Physician Quality Reporting Initiative (PQRI) is extended through 2014, with incentives for physicians to report Medicare quality data – physicians will receive feedback reports beginning in 2012. Long-term care hospitals, inpatient rehabilitation facilities and hospice providers will participate in value-based purchasing with quality measure reporting starting in FY2014, with penalties for non-participating providers.

Strengthening the Quality Infrastructure: The HHS Secretary will establish a national strategy to improve health care service delivery, patient outcomes, and population health. The President will convene an Interagency Working Group on Health Care Quality to collaborate on the development and dissemination of quality initiatives consistent with the national strategy.

Encouraging Development of New Patient Care Models: A new Center for Medicare & Medicaid Innovation will be established within the Centers for Medicare and Medicaid Services to research, develop, test, and expand innovative payment and delivery arrangements. Accountable Care Organizations (ACOs) that take responsibility for cost and quality received by patients will receive a share of savings they achieve for Medicare. The HHS Secretary will develop a national, voluntary pilot program encouraging hospitals, doctors, and post-acute providers to improve patient care and achieve savings through bundled payments. A new demonstration program for chronically ill Medicare beneficiaries will test payment incentives and service delivery using physician and nurse practitioner-directed home-based primary care teams. Beginning in 2012, hospital payments will be adjusted based on the dollar value of each hospitals percentage of potentially preventable Medicare readmissions.

Ensuring Beneficiary Access to Physician Care and Other Services: The Act extends a floor on geographic adjustments to the Medicare fee schedule to increase provider fees in rural areas and gives immediate relief to areas harmed by geographic adjustment for practice expenses. The Act extends bonus payments by Medicare for ground and air ambulance services in rural and other areas. The Act creates a 12 month enrollment period for military retirees, spouses (and widows/widowers) and dependent children, who are eligible for TRICARE and entitled to Medicare Part A based on disability or ESRD, who have declined Part B.

Rural Protections: The Act extends the outpatient hold harmless provision, allowing small rural hospitals and Sole Community Hospitals to receive this adjustment through FY2010 and reinstates cost reimbursement for lab services provided by small rural hospitals from July 1, 2010 to July 1, 2011. The Patient Protection and Affordable Care Act extends the Rural Community Hospital Demonstration Program for two years and expands eligible sites to additional states and hospitals.

Improving Payment Accuracy: The HHS Secretary will rebase home health payments starting in 2013 based on the current mix of services and intensity of care provided to patients. The Secretary will update Medicare hospice claims forms and cost reports to improve payment accuracy. The Secretary will update Disproportionate Share (DSH) payments to better account for hospital uncompensated care costs; Medicare DSH payments will reflect lower uncompensated care costs tied to decreases in the number of uninsured. The bill also makes changes to improve payment accuracy for imaging services and power-driven wheelchairs. The Secretary will study and report to Congress on reforming the Medicare hospital wage index system and will establish a demonstration program to allow hospice eligible patients to receive all other Medicare covered services during the same period.

Medicare Advantage (Part C): Medicare Advantage payments will be based on the average of the bids submitted by insurance plans in each market. Bonus payments will be available to improve the quality of care and will be based on an insurer‟s level of care coordination and care management, as well as achievement on quality rankings. New payments will be implemented over a four-year transition period. MA plans will be prohibited from charging beneficiaries cost sharing for covered services greater than what is charged under fee-for-service. Plans providing extra benefits must give priority to cost sharing reductions, wellness and preventive care prior to covering benefits not currently covered by Medicare.

Medicare Prescription Drug Plan Improvements (Part D): In order to have their drugs covered under the Medicare Part D program, drug manufacturers will provide a 50 percent discount to Part D beneficiaries for brand-name drugs and biologics purchased during the coverage gap beginning July 1, 2010. The initial coverage limit in the standard Part D benefit will be expanded by $500 for 2010.

Ensuring Medicare Sustainability: A productivity adjustment will be added to the market basket update for inpatient hospitals, home health providers, nursing homes, hospice providers, inpatient psychiatric facilities, long-term care hospitals and inpatient rehabilitation facilities. The Act creates an independent, 15-member Medicare Advisory Board to present Congress with proposals to reduce costs and improve quality for beneficiaries. When Medicare costs are projected to exceed certain targets, the Board‟s proposals will take effect unless Congress passes an alternative measure to achieve the same level of savings. The Board will not make proposals that ration care, raise taxes or beneficiary premiums, or change Medicare benefit, eligibility, or cost-sharing standards.

Health Care Quality Improvements: The Patient Protection and Affordable Care Act will create a new program to develop community health teams supporting medical homes to increase access to community-based, coordinated care. It supports a health delivery system research center to conduct research on health delivery system improvement and best practices that improve the quality, safety, and efficiency of health care delivery. And, it support medication management services by local health providers to help patients better manage chronic disease.

Title IV: Prevention of Chronic Disease and Improving Public Health

To better orient the nation‟s health care system toward health promotion and disease prevention, a set of initiatives will provide the impetus and the infrastructure. A new interagency prevention council will be supported by a new Prevention and Public Health Investment Fund. Barriers to accessing clinical preventive services will be removed. Developing healthy communities will be a priority, and a 21st century public health infrastructure will support this goal.

Modernizing Disease Prevention and Public Health Systems: A new interagency council is created to promote healthy policies and to establish a national prevention and health promotion strategy. A Prevention and Public Health Investment Fund is established to provide an expanded and sustained national investment in prevention and public health. The HHS Secretary will convene a national public/private partnership to conduct a national prevention and health promotion outreach and education campaign to raise awareness of activities to promote health and prevent disease across the lifespan.

Increasing Access to Clinical Preventive Services: The Act authorizes important new programs and benefits related to preventive care and services:

- For the operation and development of School-Based Health Clinics.
- For an oral healthcare prevention education campaign.
- To provide Medicare coverage – with no co-payments or deductibles – for an annual wellness visit and development of a personalized prevention plan.
- To waive coinsurance requirements and deductibles for most preventive services, so That Medicare will cover 100 percent of the costs.
- To authorize the HHS Secretary to modify coverage of any Medicare-covered preventive service to be consistent with U.S. Preventive Services Task Force recommendations.
- To provide States with an enhanced match if the State Medicaid program covers: (1) any clinical preventive service recommended with a grade of A or B by the U.S. Preventive Services Task Force and (2) adult immunizations recommended by the Advisory Committee on Immunization Practices without cost sharing.
- To require Medicaid coverage for counseling and pharmacotherapy to pregnant women for cessation of tobacco use.
- To award grants to states to provide incentives for Medicaid beneficiaries to participate in programs providing incentives for healthy lifestyles.

Creating Healthier Communities: The Secretary will award grants to eligible entities to promote individual and community health and to prevent chronic disease. The CDC will provide grants to states and large local health departments to conduct pilot programs in the 55-to-64 year old population to evaluate chronic disease risk factors, conduct evidence-based public health interventions, and ensure that individuals identified with chronic disease or at-risk for chronic disease receive clinical treatment to reduce risk. The Act authorizes all states to purchase adult vaccines under CDC contracts. Restaurants which are part of a chain with 20 or more locations doing business under the same name must disclose calories on the menu board and in written form.

Support for Prevention and Public Health Innovation: The HHS Secretary will provide funding for research in public health services and systems to examine best prevention practices. Federal health programs will collect and report data by race, ethnicity, primary language and any other indicator of disparity. The CDC will evaluate best employer wellness practices and provide an educational campaign and technical assistance to promote the benefits of worksite health promotion. A new CDC program will help state, local, and tribal public health agencies to improve surveillance for and responses to infectious diseases and other important conditions. An Institute of Medicine Conference on Pain Care will evaluate the adequacy of pain assessment, treatment, and management; identify and address barriers to appropriate pain care; increase awareness; and report to Congress on findings and recommendations.

Title V — Health Care Workforce

To ensure a vibrant, diverse and competent workforce, the Patient Protection and Affordable Care Act will encourage innovations in health workforce training, recruitment, and retention, and will establish a new workforce commission. Provisions will help to increase the supply of health care workers. These workers will be supported by a new workforce training and education infrastructure.

Innovations in the Health Care Workforce: The Patient Protection and Affordable Care Act establishes a national commission to review health care workforce and projected workforce needs and to provide comprehensive information to Congress and the Administration to align workforce resources with national needs. It will also establish competitive grants to enable state partnerships to complete comprehensive workforce planning and to create health care workforce development strategies.

Increasing the Supply of the Health Care Workers: The federal student loan program will be modified to ease criteria for schools and students, shorten payback periods, and to make the primary care student loan program more attractive. The Nursing Student Loan Program will be increased and the years for nursing schools to establish and maintain student loan funds are updated. A loan repayment program is established for pediatric subspecialists and providers of mental and behavioral health services to children and adolescents who work in a Health Professional Shortage Area, a Medically Underserved Area, or with a Medically Underserved Population. Loan repayment will be offered to public health students and workers in exchange for working at least three years at a federal, state, local, or tribal public health agency. Loan repayment will be offered to allied health professionals employed at public health agencies or in settings providing health care to patients, including acute care facilities, ambulatory care facilities, residences, and other settings located in Health Professional Shortage Areas, Medically Underserved Areas, or with Medically Underserved Populations. Authorization of appropriations for the National Health Service Corps scholarship and loan repayment program will be extended 2010-2015. A $50 million grant program will support nurse-managed health clinics. A Ready Reserve Corps within the Commissioned Corps is established for service in times of national emergency. Ready Reserve Corps members may be called to active duty to respond to national emergencies and public health crises and to fill critical public health positions left vacant by members of the Regular Corps who have been called to duty elsewhere.

Enhancing Health Care Workforce Education and Training: New support for workforce training programs is established in these areas:

- Family medicine, general internal medicine, general pediatrics, and physician assistantship.
- Direct care workers providing long-term care services and supports.
- General, pediatric, and public health dentistry.
- Alternative dental health care provider.
- Geriatric education and training for faculty in health professions schools and family caregivers.
- Mental and behavioral health education and training grants to schools for the development, expansion, or enhancement of training programs in social work, graduate psychology, professional training in child and adolescent mental health, and pre-service or in-service training to paraprofessionals in child and adolescent mental health.
- Cultural competency, prevention and public health and individuals with disabilities training.
- Advanced nursing education grants for accredited Nurse Midwifery programs.
- Nurse education, practice, and retention grants to nursing schools to strengthen nurse education and training programs and to improve nurse retention.
- Nurse faculty loan program for nurses who pursue careers in nurse education.
- Grants to promote the community health workforce to promote positive health behaviors and outcomes in medically underserved areas through use of community health workers.
- Fellowship training in public health to address workforce shortages in state and local health departments in applied public health epidemiology and public health laboratory science and informatics.
- A U.S. Public Health Sciences Track to train physicians, dentists, nurses, physician assistants, mental and behavior health specialists, and public health professionals emphasizing team-based service, public health, epidemiology, and emergency preparedness and response in affiliated institutions.

Supporting the Existing Health Care Workforce: The Patient Protection and Affordable Care Act reauthorizes the Centers of Excellence program for minority applicants for health professions, expands scholarships for disadvantaged students who commit to work in medically underserved areas, and authorizes funding for Area Health Education Centers (AHECs) and Programs. A Primary Care Extension Program is established to educate and provide technical assistance to primary care providers about evidence-based therapies, preventive medicine, health promotion, chronic disease management, and mental health.

Strengthening Primary Care and Other Workforce Improvements: Beginning in 2011, the HHS Secretary may redistribute unfilled residency positions, redirecting those slots for training of primary care physicians. A demonstration grant program is established to serve low-income persons including recipients of assistance under Temporary Assistance for Needy Families (TANF) programs to develop core training competencies and certification programs for personal and home care aides.

Improving Access to Health Care Services: The Patient Protection and Affordable Care Act authorizes new and expanded funding for federally qualified health centers and reauthorizes a program to award grants to states and medical schools to support the improvement and expansion of emergency medical services for children needing trauma or critical care treatment. Also supported are grants for coordinated and integrated services through the co-location of primary and specialty care in community-based mental and behavioral health settings. A Commission on Key National Indicators is established.

Title VI—Transparency and Program Integrity

To ensure the integrity of federally financed and sponsored health programs, this Title creates new requirements to provide information to the public on the health system and promotes a newly invigorated set of requirements to combat fraud and abuse in public and private programs.

Physician Ownership and Other Transparency: Physician-owned hospitals that do not have a provider agreement prior to February 2010 will not be able to participate in Medicare. Drug, device, biological and medical supply manufacturers must report gifts and other transfers of value made to a physician, physician medical practice, a physician group practice, and/or a teaching hospital. Referring physicians for imaging services must inform patients in writing that the individual may obtain such service from a person other than the referring physician, a physician who is a member of the same group practice, or an individual who is supervised by the physician or by another physician in the group. Prescription drug makers and distributors must report to the HHS Secretary information pertaining to drug samples currently being collected internally. Pharmacy benefit managers (PBM) or health benefits plans that provide pharmacy benefit management services that contract with health plans under Medicare or the Exchange must report information regarding the generic dispensing rate; rebates, discounts, or price concessions negotiated by the PBM.

Nursing Home Transparency and Improvement: The Act requires that skilled nursing facilities (SNFs) under Medicare and nursing facilities (NFs) under Medicaid make available information on ownership. SNFs and NFs will be required to implement a compliance and ethics program. The Secretary of Health and Human Services will publish new information on the Nursing Home Compare

Medicare website: standardized staffing data, links to state internet websites regarding state survey and certification programs, a model standardized complaint form, a summary of complaints, and the number of instances of criminal violations by a facility or its employee.

The Secretary also will develop a standardized complaint form for use by residents in filing complaints with a state survey and certification agency or a state long-term care ombudsman.

Targeting Enforcement: The Secretary may reduce civil monetary penalties for facilities that self- report and correct deficiencies. The Secretary will establish a demonstration project to test and implement a national independent monitoring program to oversee interstate and large intrastate chains. The administrator of a facility preparing to close must provide written notice to residents, legal representatives of residents, the state, the Secretary and the long-term care ombudsman program in advance of the closure.

Improving Staff Training: Facilities must include dementia management and abuse prevention training as part of pre-employment training for staff.

Nationwide Program for Background Checks on Direct Patient Access Employees of Long Term Care Facilities and Providers: The Secretary will establish a nationwide program for national and state background checks of direct patient access employees of certain long-term supports and services facilities or providers.

Patient-Centered Outcomes Research: The Patient Protection and Affordable Care Act establishes a private, nonprofit entity (the Patient-Centered Outcomes Research Institute) governed by a public- private board appointed by the Comptroller General to provide for the conduct of comparative clinical outcomes research. No findings may be construed as mandates on practice guidelines or coverage decisions and important patient safeguards will protect against discriminatory coverage decisions by HHS based on age, disability, terminal illness, or an individual‟s quality of life preference.

Medicare, Medicaid, and CHIP Program Integrity Provisions: The Secretary will establish procedures to screen providers and suppliers participating in Medicare, Medicaid, and CHIP. Providers and suppliers enrolling or re-enrolling will be subject to new requirements including a fee, disclosure of current or previous affiliations with any provider or supplier that has uncollected debt, has had their payments suspended, has been excluded from participating in a Federal health care program, or has had their billing privileges revoked. The Secretary is authorized to deny enrollment in these programs if these affiliations pose an undue risk.

Enhanced Medicare and Medicaid Program Integrity Provisions: CMS will include in the integrated data repository (IDR) claims and payment data from Medicare (Parts A, B, C, and D), Medicaid, CHIP, health-related programs administered by the Departments of Veterans Affairs (VA) and Defense (DOD), the Social Security Administration, and the Indian Health Service (IHS). New penalties will exclude individuals who order or prescribe an item or service, make false statements on applications or contracts to participate in a Federal health care program, or who know of an overpayment and do not return the overpayment. Each violation would be subject to a fine of up to $50,000. The Secretary will take into account the volume of billing for a DME supplier or home health agency when determining the size of a surety bond. The Secretary may suspend payments to a provider or supplier pending a fraud investigation. Health Care Fraud and Abuse Control (HCFAC) funding will be increased by $10 million each year for fiscal years 2011 through 2020. The Secretary will establish a national health care fraud and abuse data collection program for reporting adverse actions taken against health care providers, suppliers, and practitioners, and submit information on the actions to the National Practitioner Data Bank (NPDB). The Secretary will have the authority to disenroll a Medicare enrolled physician or supplier who fails to maintain and provide access to written orders or requests for payment for durable medical equipment (DME), certification for home health services, or referrals for other items and services. The HHS Secretary will expand the number of areas to be included in round two of the DME competitive bidding program from 79 of the largest metropolitan statistical areas (MSAs) to 100 of the largest MSAs, and to use competitively bid prices in all areas by 2016.

Additional Medicaid Program Integrity Provisions: States must terminate individuals or entities from their Medicaid programs if the individuals or entities were terminated from Medicare or another state‟s Medicaid program. Medicaid agencies must exclude individuals or entities from participating in Medicaid for a specified period of time if the entity or individual owns, controls, or manages an entity that: (1) has failed to repay overpayments; (2) is suspended, excluded, or terminated from participation in any Medicaid program; or (3) is affiliated with an individual or entity that has been suspended, excluded, or terminated from Medicaid participation. Agents, clearinghouses, or other payees that submit claims on behalf of health care providers must register with the state and the Secretary. States and Medicaid managed care entities must submit data elements for program integrity, oversight, and administration. States must not make any payments for items or services to any financial institution or entity located outside of the United States.

Additional Program Integrity Provisions: Employees and agents of multiple employer welfare arrangements (MEWAs) will be subject to criminal penalties if they provide false statements in marketing materials regarding a plan‟s financial solvency, benefits, or regulatory status. A model uniform reporting form will be developed by the National Association of Insurance Commissioners, under the direction of the HHS Secretary. The Department of Labor will adopt regulatory standards and/or issue orders to prevent fraudulent MEWAs from escaping liability for their actions under state law by claiming that state law enforcement is preempted by federal law. The Department of Labor is authorized to issue "cease and desist" orders to temporarily shut down operations of plans conducting fraudulent activities or posing a serious threat to the public, until hearings can be completed. MEWAs will be required to file their federal registration forms, and thereby be subject to government verification of their legitimacy, before enrolling anyone.

Elder Justice Act: The Elder Justice Act will help prevent and eliminate elder abuse, neglect, and exploitation. The HHS Secretary will award grants and carry out activities to protect individuals seeking care in facilities that provide long-term services and supports and provide greater incentives for individuals to train and seek employment at such facilities. Owners, operators, and employees would be required to report suspected crimes committed at a facility. Owners or operators of such facilities would be required to submit to the Secretary and to the state written notification of an impending closure of a facility within 60 days prior to the closure.

Sense of the Senate Regarding Medical Malpractice: The Act expresses the sense of the Senate that health reform presents an opportunity to address issues related to medical malpractice and medical liability insurance, states should be encouraged to develop and test alternative models to the existing civil litigation system, and Congress should consider state demonstration projects to evaluate such alternatives.

Title VII – Improving Access to Innovative Medical Therapies

Biologics Price Competition and Innovation: The Patient Protection and Affordable Care Act establishes a process under which FDA will license a biological product that is shown to be biosimilar or interchangeable with a licensed biological product, commonly referred to as a reference product. No approval of an application as either biosimilar or interchangeable is allowed until 12 years from the date on which the reference product is first approved. If FDA approves a biological product on the grounds that it is interchangeable to a reference product, HHS cannot make a determination that a second or subsequent biological product is interchangeable to that same reference product until one year after the first commercial marketing of the first interchangeable product.

More Affordable Medicines for Children and Underserved Communities: Drug discounts through the 340B program are extended to inpatient drugs and also to certain children"s hospitals, cancer hospitals, critical access and sole community hospitals, and rural referral centers.

Title VIII – Community Living Assistance Services and Supports

Establishment of national voluntary insurance program for purchasing community living assistance services and support (CLASS program). The Patient Protection and Affordable Care Act establishes a new, voluntary, self-funded long-term care insurance program, the CLASS Independence Benefit Plan, for the purchase of community living assistance services and supports by individuals with functional limitations. The HHS Secretary will develop an actuarially sound benefit plan that ensures solvency for 75 years; allows for a five-year vesting period for eligibility of benefits; creates benefit triggers that allow for the determination of functional limitation; and provides a cash benefit that is not less than an average of $50 per day. No taxpayer funds will be used to pay benefits under this provision.

TITLE IX – Revenue Provisions

Excise Tax on High Cost Employer-Sponsored Health Coverage: The Patient Protection and Affordable Care Act levies a new excise tax of 40 percent on insurance companies and plan administrators for any health coverage plan with an annual premium that is above the threshold of $8,500 for single coverage and $23,000 for family coverage. The tax applies to self-insured plans and plans sold in the group market, and not to plans sold in the individual market (except for coverage eligible for the deduction for self-employed individuals). The tax applies to the amount of the premium in excess of the threshold. A transition rule increases the threshold for the 17 highest cost states for the first three years. An additional threshold amount of $1,350 for singles and $3,000 for families is available for retired individuals age 55 and older and for plans that cover employees engaged in high risk professions.

Increasing Transparency in Employer W-2 Reporting of Value of Health Benefits: This provision requires employers to disclose the value of the benefit provided by the employer for each employee's health insurance coverage on the employee's annual Form W-2.

Distributions for Medicine Qualified Only if for Prescribed Drug or Insulin: Conforms the definition of qualified medical expenses for HSAs, FSAs, and HRAs to the definition used for the medical expense itemized deduction. Over-the-counter medicine obtained with a prescription continues to qualify as qualified medical expenses.

Increase in Additional Tax on Distributions from HSAs and Archer MSAs Not Used for Qualified Medical Expenses: Increases the additional tax for HSA withdrawals prior to age 65 that are used for purposes other than qualified medical expenses from 10 percent to 20 percent and increases the additional tax for Archer MSA withdrawals from 15 percent to 20 percent.

Limiting Health FSA Contributions: This provision limits the amount of contributions to health FSAs to $2,500 per year.

Corporate Information Reporting: This provision requires businesses that pay any amount greater than $600 during the year to corporate providers of property and services to file an information report with each provider and with the IRS.

Pharmaceutical Manufacturers Fee: This provision imposes an annual flat fee of $2.3 billion on the pharmaceutical manufacturing sector beginning in 2010 allocated across the industry according to market share. The fee does not apply to companies with sales of branded pharmaceuticals of $5 million or less.

Medical Device Manufacturers Fee: This provision imposes an annual flat fee of $2 billion on the medical device manufacturing sector beginning in 2010 allocated across the industry according to market share. The fee does not apply to companies with sales of medical devices in the U.S. of $5 million or less. The fee also does not apply to any sale of a Class I product or any sale of a Class II product that is primarily sold to consumers at retail for not more than $100 per unit (under the FDA product classification system).

Health Insurance Provider Fee: This provision imposes an annual flat fee of $6.7 billion on the health insurance sector beginning in 2010 allocated across the industry according to market share. The fee does not apply to companies whose net premiums written are $25 million or less and whose fees from administration of employer self-insured plans are $5 million or less.

Eliminating the Deduction for Employer Part D Subsidy: This provision eliminates the deduction for the subsidy for employers who maintain prescription drug plans for their Medicare Part D eligible retirees.

Modification of the Threshold for Claiming the Itemized Deduction for Medical Expenses: This provision increases the adjusted gross income threshold for claiming the itemized deduction for medical expenses from 7.5 percent to 10 percent. Individuals age 65 and older would be able to claim the itemized deduction for medical expenses at 7.5 percent of adjusted gross income through 2016.

Tax on Elective Cosmetic Surgery. This provision imposes a five percent excise tax on voluntary cosmetic surgical and medical procedures performed by a licensed medical professional. The tax would be collected by the medical professional at the point of service. The definition of voluntary cosmetic procedures generally would be the same as the definition of cosmetic surgery or similar procedures that are not treated as included in medical care under the current Section 213(d)(9) definition. The excise tax would be effective for procedures performed on or after January 1, 2010.

Executive Compensation Limitations. This provision limits the deductibility of executive compensation for insurance providers if at least 25 percent of the insurance provider‟s gross premium income is derived from health insurance plans that meet the minimum essential coverage requirements in the bill (“covered health insurance provider”). The deduction is limited to $500,000 per taxable year and applies to all officers, employees, directors, and other workers or service providers performing services for or on behalf of a covered health insurance provider.

Additional Hospital Insurance Tax for High Wage Workers. The provision increases the hospital insurance tax rate by 0.5 percentage points on an individual taxpayer earning over $200,000 ($250,000 for married couples filing jointly).

Special Deduction for Blue Cross Blue Shield (BCBS): Requires that non-profit BCBS organizations have a medical loss ratio of 85 percent or higher in order to take advantage of the special tax benefits provided to them, including the deduction for 25 percent of claims and expenses and the 100 percent deduction for unearned premium reserves.

Simple Cafeteria Plans for Small Businesses. This provision would establish a new employee benefit cafeteria plan to be known as a Simple Cafeteria Plan. This eases the participation restrictions so that small businesses can provide tax-free benefits to their employees and it includes self-employed individuals as qualified employees.

IMPORVING END-OF-LIFE CARE: PROFESSIONAL DEVELOPMENT FOR PHYSICIANS.

March 2012

The Royal College of Physicians

The Royal College of Physicians is a registered charity that aims to ensure high-quality care for patients by promoting the highest standards of medical practice. It provides and sets standards in clinical practice and education and training, conducts assessments and examinations, quality assures external audit programs, supports doctors in their practice of medicine, and advises the government, public and the profession on healthcare issues.

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INDEX

Well over a quarter of a million people die in hospitals in England each year. This is more than the combined total for deaths at home, in care homes and in hospices. In an average-sized NHS trust, four or five patients are likely to die every day, and the number dying can be twice this in a large trust. However, we know that
End-of-life care in hospitals often falls short of the standard we would wish for ourselves, our relatives and our friends.

We welcome the practical recommendations set out in this report. They are based on the results of a survey of more than 1,800 physicians and in-depth interviews and focus groups. Although clinicians rated their confidence in discussing end-of-life care with those approaching the end of their lives highly, two thirds reported that they had not attended any professional development event on end-of-life care in the last five years. Ratings of support for education on end-of-life care from trusts and organizations were also generally low. In contrast, experiential learning from working alongside palliative care teams was identified as an important source of learning.

Improving the quality of end-of-life care in hospitals is a very high priority in the End of Life Care Strategy published by the Department of Health. Implementation of the recommendations from this working party will do a great deal to make this a reality.

This document rightly highlights that most physicians will be involved in the provision of end-of-life care during their careers and that they need particular skills to meet the challenges that this can present.

As the report notes, these skills should not be the sole preserve of end-of-life care or palliative care specialists. In setting out proposals, there is a clear call for improving pre- and post-registration training and education in end-of-life care for physicians. This report recognizes the importance of issues such as patient choice, closer working between primary and secondary care, and multidisciplinary working. We strongly endorse that approach and the recognition of the place of e-learning, for example the free e-learning resource, e- ELCA (www.e-elca.org.uk), which offers around 150 learning sessions on end-of-life care.

The working party has laid out a clear path for helping consultants and their teams to improve end-of-life care. We urge the relevant training and regulatory bodies and employers to start down that path with
little delay.

Claire Henry
Director, National End of Life Care Program

There is broad recognition that the delivery of good care at the end of life cannot be left to specialists in palliative care but is an important part of the role of most physicians.

As the population of the UK ages, the death rate will rise steadily from 2012, mostly among the very old. The oldest old are likely to die after a period of increasing frailty and many will also suffer from dementia.

Recognition that someone is entering the last phase of their life is pivotal to establishing patient priorities for treatment and care and to balancing therapeutic burdens and benefits. Doctors may fear charges of therapeutic nihilism or futile overtreatment.

End-of-life care marks the last phase of life, which may span many months or even years. Late recognition of deteriorating health, and a prevailing culture where this is not openly discussed with patients until the last days of life, leads to most people dying in the acute hospital environment. When asked, most people would prefer both to spend more time, and to die, at home.

The first national End of Life Care Strategy for England, published in 2008,[A1] and its counterparts in Scotland and Wales encouraged early recognition of people entering the last phase of their lives with open, sensitive discussion of their preferences for type and place of care. It emphasized that this must be underpinned by training and professional development for a range of staff who deliver care at the end of life.

Many people will continue to die in the acute hospital environment, either by choice or because of the circumstances of their illness. Delivering high-quality care to the dying remains a key part of hospital practice.
Effective education should start at undergraduate level and continue through postgraduate training. Hospital trusts and their commissioners have a responsibility to see the delivery of high-quality end-of-life care as part of their core work and to support a learning culture, encouraging professional development for staff at all levels. This should be underpinned by their clinical governance systems.

In recent years a wealth of resources has been developed to support the delivery of high-quality care within and across care settings. Although some, such as the Liverpool Care Pathway for the Dying Patient (LCP),[A2] have been widely adopted, most have not yet become part of routine practice at a personal or organizational level.

In developing this report, the working party conducted an online survey of nearly 2,000 physicians, which was followed by focus groups and telephone interviews. Most physicians recognized the importance of delivering good end-of-life care in their practice. The majority reported that they were confident and competent in most aspects of such care, although less so when dealing with advance care planning and people with dementia. Surprisingly, only a third had attended any learning event on end-of-life care in the last five years and many of the events were about communication skills.

Data from complaints and audits would suggest that the self-reported confidence of physicians is sometimes misplaced or that physicians are not putting their skills into practice. The earlier identification of patients entering their last phase of life and planning with them for their preferences for care is an area that is particularly lacking. Patients and their carers have an important role in helping staff to consider their practice more carefully. Patient stories provide a powerful resource, although, in this context, they may be told by bereaved carers. Physicians should seek ways to incorporate patients' feedback into their day-to-day care.

Continuing professional development is best integrated into routine clinical practice. This delivers the most powerful learning and reduces the need for staff to leave practice to attend more formal learning events. E-learning is a useful way of supporting learning in practice; it is widely available and its use should be encouraged.

Hospital palliative care teams have a key role in setting the culture for end-of-life care, as well as in delivering high-quality care to those with the highest level of need. Physicians reported having learnt most from spending time with good palliative care teams and services in joint clinics, ward rounds or placements.

Specialists in palliative care should look to deliver more local teaching and be open to staff requesting joint working. They should be prepared to work with physicians in all relevant specialties and learn from them about the issues faced by different patient groups, as well as sharing their own knowledge and expertise. This type of work-based learning is time intensive and palliative care teams should be resourced to make this possible.

The use of an integrated care pathway for the dying, such as the LCP,[A2] has helped physicians to deliver high- quality care in the last hours and days of life, when it has been underpinned by an extensive program of education and support. The introduction of tools without such support may lead to a 'tick-box' approach, which is counterproductive and should be discouraged.

Tools to help physicians recognize the last phase of life earlier in patients' illnesses and to begin to talk with them about their preferences, such as the AMBER care bundle,[A3] should be developed and evaluated. Such tools should be introduced with due regard for the training and support needed to use them appropriately and sensitively.

End-of-life care should be incorporated into established learning events as part of study days run by colleges, specialist societies and networks on long-term conditions, extending the reach to those who would not self- select for end-of-life professional development. Physicians would value more local events, although they are unlikely to attend full-day events just about end-of-life care. Joint learning with GP colleagues can help to bridge the gap between primary and secondary care.

To support the earlier identification of patients nearing the end of their lives and to encourage sensitive discussions about their preferences, we have developed prompt sheets that can be incorporated into day-to- day hospital practice.

Recommendations

These recommendations have been grouped under subheadings to highlight where the main responsibility for their implementation lies. The chapter from which each recommendation derives has been included in brackets for ease of reference.

Recommendations for trust boards

Trust boards should make the delivery of high-quality care at the end of life a priority for their organizations. End-of-life care metrics should be developed, based on the End of Life Care Strategy[A1] quality markers for acute hospitals, and should be included on their management dashboards and risk registers (Chapter 1).

Senior management support is critical to enable professional development in end-of-life care. This must include:

- Provision of time for learning
- Appropriate appraisal systems that encourage continuing professional development in end-of-life care
- An organizational culture that values quality of care at the end of life (Chapter 3).

Hospital trusts should review the provision of learning opportunities for their consultant, trainee and non-training grade workforce and, where necessary, increase the availability of local end-of-life care training and education (Chapter 6).

Tools such as care pathways for end-of-life care must be properly implemented and should receive continuing support to sustain the learning that is required, otherwise such tools can be counterproductive by encouraging a ‘tick-box’ approach rather than promoting high-quality care (Chapter 6).

The introduction of systems of care that help to highlight patients who may be at risk of dying during a hospital admission, such as the AMBER care bundle[A3] or equivalent, should be considered as a tool to help professional development within teams and to guide day-to-day practice

Recommendations for commissioners

Commissioners and hospital trusts should consider how they can support the uptake of training in end-of-life care – for example, by using the Commissioning for Quality and Innovation (CQUIN) framework.[A4] Example standards should be based on the End of Life Care Strategy quality markers and might include specifying a proportion of physicians conducting a patient/carer survey of experience under their care, team-based learning events around death reviews and a percentage for educational uptake in a target proportion of medical staff (Chapter 1).

The role of hospices and specialist palliative care units/teams in providing experiential placements for physicians should be recognized and resourced (Chapter 6).

Training in advanced communication skills for physicians who care for those with long-term conditions should have equal priority and resources as the training required for those involved in caring for patients with cancer (Chapter 5).

Hospital palliative care teams should be available in each hospital and should be resourced to lead the delivery of professional development in end-of-life care. As experiential learning is most valued, this should include time to work with colleagues in clinical practice and to provide clinical placements and mentorship (Chapter 6).

Recommendations for physicians

Physicians whose practice includes patients in the last phase of their lives should consider using the 'Top ten tips' and 'Prompts forward rounds and mortality and morbidity meetings' provided in this report during their routine practice (Chapter 6).

Medical consultants should provide leadership in establishing opportunities for professional development in end-of-life care in their own settings, including agreeing how best to implement this as a department/directorate and across the trust (Chapter 3).

Teams involved in end-of-life care should actively plan for cultural change in the delivery of care at the end of life by identifying medical leaders, engaging colleagues and supporting the development of expertise among colleagues (Chapter 4).

In order to influence their practice and ensure that patients have time to adjust, physicians must recognize that end-of-life care is not just care in the last few hours and days but that it marks the last phase of life, which may be many months or sometimes years (Chapter 3).

Professional development for end-of-life care should:

- strengthen multiprofessional teams and promote collaboration between team members
- support the development of effective communication skills through interactive approaches such as simulation, observation and practice with feedback
- use opportunities in routine practice to draw on clinical experiences with a direct relevance to patient care, developing problem-solving and reflective skills
- Actively seek engagement with, and feedback from, patients and caregivers to improve understanding of the patient experience
- be embedded into a wide range of educational events such as conferences, workshops and study days, not just those that focus specifically on end-of-life care (Chapter 4).

Reflection and learning on end-of-life care should be integrated with daily clinical practice. This may be done through directorate meetings; structured multidisciplinary meetings; mortality and morbidity meetings; joint ward rounds and outpatient clinics with palliative care colleagues; grand rounds; mentoring; and placements (Chapter 6).

Consultants who provide care at the end of life should incorporate this into their continuing professional development (CPD) and undertake at least one learning event in end-of-life care within a five-year CPD cycle. This should be reviewed at their annual consultant appraisal (Chapter 6).

Hospital and primary care teams should acquaint themselves with the range of general and disease-specific tools to identify patients with advanced illness, or who may be approaching the end of life, and consider their applicability and use within their routine practice (Chapter 6).

Joint learning with GPs should be encouraged to further the understanding of each other's roles and services and to improve coordination of care across traditional boundaries (Chapter 6).

The use of e-learning, such as End of Life Care for All (e-ELCA), to support work-based learning should be included where relevant (Chapter 6).

Recommendations for palliative care teams

Specialist palliative care clinicians should develop wide-ranging educational skills in supporting colleagues through formal and non-formal learning by:

- using structured interactive events
- facilitating effective bedside teaching
- conducting joint ward rounds and mentoring colleagues
- facilitating mortality and morbidity meetings (Chapter 4).

Hospital palliative care teams should include leading professional development in end-of-life care as an integral part of their role. This should include providing support as well as working with staff from other disciplines and professions to learn with, and from, them (Chapter 6).

Local palliative care providers should work with the palliative and end-of-life care networks to deliver more extensive and targeted CPD for physicians (Chapter 5).

Recommendations for medical schools and foundation program

All medical schools in the UK should review their undergraduate curricula to ensure that they provide an adequate grounding in end-of-life care, as outlined in *Tomorrow's doctors*[A6] (Chapter 1).

All foundation schools should review their delivery of the foundation curriculum in relation to end-of- life care (Chapter 1).

Recommendations for the Royal Colleges of Physicians

The chairs of each specialty advisory committee should review their training curricula in regard to end-of-life care in the light of this report (Chapter 1).

The Royal College of Physicians and specialist societies should promote the inclusion of end-of-life care within study days and conferences related to long-term conditions (Chapter 5).

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'Knowing is not enough: we must apply. Being willing is not enough, we must do.' Leonardo Da Vinci

Since the publication in 2007 of the Royal College of Physicians (RCP)'s working party report, *Palliative care services: meeting the needs of patients,*[1] there has been a growing impetus for palliative care and end-of-life care to be accessible to all those in need, whatever their underlying disease. In 2008, the NHS bodies in England, Scotland and Wales published strategies for end-of-life care,[2–4] which provided frameworks for improving end-of-life care across all settings. Each put a strong emphasis on the need for education, training and continuing professional development (CPD) at all levels. The National Audit Office (NAO)'s report, published later the same year, supported the strategies.[5] In particular, the NAO's report noted that there were 'significant gaps in the education and training curricula' for health professionals and recommended that the General Medical Council (GMC) address the issue of raising awareness of and improving skills involved in identifying and delivering end-of-life care. In addition, end-of-life care is one of the eight national Quality, Innovation, Productivity and Prevention (QIPP) work streams set up as a result of the *NHS next stage review* led by Lord Darzi, which was also published in 2008 (Department of Health).

Around 1% of the population dies each year, which amounts to about 500,000 people in England. Of those, 58% die in hospital, largely under the care of physicians,[6] and up to 75% of deaths are considered to be 'expected'.[7] The death rate in the UK has been falling, but it will start to increase from 2012 as the population ages.[8] Death largely occurs in old age, with two-thirds of deaths in 2008 occurring in people aged over 75. Overall, the largest number of deaths was in people aged 80–89, who accounted for more than one third of deaths. In 2008, 17.1% of all deaths were of people aged 90 and over. As the population has aged, the prevalence of dementia has increased, and this is now one of the 10 most common causes of death in women aged 70–79. The proportion of deaths from pneumonia is also higher with increasing age, representing 3.6% of deaths in men and 4.3% in women aged 75–79 years, and 12.1% in men and 11.7% in women aged 90 years and over.[9] These changes illustrate the importance of ensuring that physicians are well trained and supported to deliver high-quality end-of-life care, particularly to older patients with non-cancer diagnoses, often in the context of underlying dementia.

The importance of professional development in end-of-life care has been highlighted in a number of recent publications:

- In 2009, the Department of Health published a set of quality markers to support the End of Life Care Strategy.[10] One of its top 10 markers relates specifically to the accessibility of training opportunities in end-of-life care.
- The GMC's guidance on treatment and care towards the end of life came into effect in July 2010.[11] This included specific expectations that doctors participate in 'educational activities that maintain and develop your competence and performance' in the care of patients towards the end of life.
- The RCP has made end-of-life care a priority, reviewing specific competencies embedded in training curricula for core medical and specialty training and including it as one of the five key themes in the publication *Leading for quality: the foundation for healthcare over the next decade*.[12]

Since 2008 there has been a step change in the education and training opportunities offered to a wide range of doctors. At the undergraduate level, the Association for Palliative Medicine of Great Britain and Ireland (APM) has endorsed a consensus syllabus for undergraduate palliative medicine[13] that builds on the GMC's syllabus in *Tomorrow's doctors*.[14] The National End of Life Care Programme has published a wealth of documents for qualified doctors, including the 'Routes to success' series, which highlights how end-of-life care can be improved in a variety of settings.[15] In recognition that skilled communication underpins much of the delivery of good end-of-life care, the Department of Health (DH) funded a series of pilot trials of different approaches to training in communication skills, which has resulted in the publication of recommendations and resources to support practice. In addition, the DH has funded eight pilot trials across England to develop and use electronic palliative care coordination systems (EPCCS) in order to encourage staff to identify patients nearing the end of their lives and to improve communication between services about their care.[17]

Several documents have been produced to highlight and encourage good practice in certain specialties and disease groups.

In addition to traditional methods of classroom and bedside learning, there have been considerable developments using online media. e-Learning for Healthcare has supported the development of more than 150 e-learning sessions in end-of-life care in conjunction with the APM,[21] and a module in palliative care within the e-GP program in conjunction with the Royal College of General Practitioners.

Support for professional development in end-of-life care has also come from the 10 strategic health authorities (SHAs) in England, which have used funding from their multiprofessional education and training (MPET) budgets to target this specific area of practice. The nature and extent of this has varied between SHAs, and different systems apply in the other countries of the UK. However, our own survey suggests that nearly 30% of training accessed by physicians was on communication skills.

In November 2011, the National Institute for Health and Clinical Excellence (NICE) published a quality standard on end-of-life care which included a specific quality statement relating to the competence of health professionals to deliver safe and effective end-of-life care (www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp).

Recommendations

All medical schools in the UK should review their undergraduate curricula to ensure that they provide an adequate grounding in end-of-life care, as outlined in *Tomorrow's doctors*.

All foundation schools should review their delivery of the foundation curriculum in relation to end-of-life care.

The chairs of each specialty advisory committee should review their training curricula in regard to end-of-life care in the light of this report.

Trust boards should make the delivery of high-quality care at the end of life a priority for their organisations. End-of-life care metrics should be developed, based on the End of Life Care Strategy quality markers for acute hospitals, and should be included on their management dashboards and risk registers.

Commissioners and hospital trusts should consider how they can support the uptake of training in end-of-life care – for example, by using the Commissioning for Quality and Innovation (CQUIN) framework. Example standards should be based on the End of Life Care Strategy quality markers and might include specifying a proportion of physicians conducting a patient/carer survey of experience under their care, team-based learning events around death **reviews and** a percentage for educational uptake in a target proportion of medical staff.

Following the publication of the first national end-of life care strategies for England, Scotland and Wales in 2008,[2–4] many consultants in palliative medicine and other medical specialties found themselves in the position of leading the implementation in their organisations. The scale of the changes needed to implement the strategies in full are considerable and cannot, and should not, be confined to those who specialise in this area of practice. This was highlighted in the RCP's working party report of 2007, *Palliative care services: meeting the needs of patients*,[1] which also noted the variations in practice according to patients' diagnoses and marked geographical differences in access to services.

The RCP's Joint Specialty Committee for Palliative Medicine approached the Medical Specialties Board to discuss how all relevant physician groups could engage with this work. It was decided to set up a working party to:

- Review the progress that has been made since 2007 and identify areas for further action
- Highlight the education and professional development required for doctors to support service changes and earlier identification of the end-of-life care needs of their patients
- Identify and recommend approaches to address education, training and development needs, primarily of consultant physicians and medical non-training grade doctors, including identifying strategies for providing and enhancing uptake of educational opportunities in end-of-life care
- Improve the quality of end-of-life care for all patients.

Experts were selected from the membership of the original working party in 2007, supplemented by representatives from the APM, National End of Life Care Programme Board, Joint Specialty Committee in Palliative Medicine and British Geriatrics Society, as well as a consultant in learning and teaching.

The remit of this working party built on the work done in 2007, which had a much larger authorship and included many relevant specialties. This working party's membership was kept small but set out to ensure that as many physicians as possible had the opportunity to contribute to the findings. A representative from the British Geriatrics Society was included because elderly medicine has such a major contribution to make both to care delivery and education and to training in end-of-life care.

The working party identified some evidence that would be useful in developing recommendations about professional development. This included:

- Literature relating to educational theory and changing culture in large organisations
- A survey from 2008 commissioned by the NAO to report on doctors' skills and training in end-of-life care.[5] Although this was a helpful resource, most respondents were GPs or emergency/intensive care physicians and the working party wanted to access the views of a wider range of senior hospital physicians.

Evidence was gathered from as broad a range of physicians as possible. The following methods were used:

- A new electronic survey was undertaken. This was aimed at hospital consultants, staff and associate specialists, and registrars within one year of obtaining their certificate of completion of specialty training (CCT) in the UK. The survey explored how confident and competent clinicians felt in various areas of end-of-life care, what training they had accessed and how they would prefer to receive professional development in the future. It also covered perceived barriers to training about end-of-life care and examples of good practice. The survey was designed by the working party in conjunction with the RCP's Medical Workforce Unit and was released through Survey Monkey, with requests to members of all medical royal colleges and a reminder after one month. The survey results are reported in chapter 6.
- Telephone interviews were conducted with 15 physicians who responded to the electronic survey and volunteered to be contacted for further information. The telephone interviews were designed to generate more in-depth responses to areas highlighted in the survey. Working party members acted as interviewers, using a series of semi-structured questions emailed to the respondents in advance, along with a consent form.
- Two focus groups were run to test some of the earlier findings and elicit more detail in the responses. One was conducted with geriatricians following an afternoon symposium on 'Working together – partnerships in end of life care for the older people'. In response to an invitation, eight people attended, comprising consultant geriatricians and old-age psychiatrists and one general practitioner with a special interest in older people. The second group followed an RCP 'Regional update in medicine' and included seven consultants and two registrars from a wide variety of specialties across Yorkshire and the Humber. For both groups, verbal consent was obtained and a list of questions and prompts was used.
- Themes were drawn from the qualitative evidence, which was recorded in free text in the electronic survey and in detailed contemporaneous notes from the telephone interviews and focus groups. This was done by the consultant in learning and teaching, who has significant training and experience in the field. The emergent themes were tested in subsequent interviews and groups. Where conflicting opinions were expressed, both have been included.
- Early drafts of the report were shared with the director of the National End of Life Care Programme, care givvers and palliative care nursing colleagues, and their comments were incorporated in the text.
- Current provision of CPD was reviewed by searching the RCP's database of approved courses and seeking examples of good practice. Results are reported in chapter 5.

As robust evidence from published literature was not available, this report is based on consensus using the evidence listed above.

The working party met three times for 2 hours each and had three conference calls during the preparation of this work. The work was completed over a 9-month period. The draft report was sent for consultation to the leads of medical specialties at the RCP, the Professional Development Committee and the Executive Committee of the APM, the curriculum lead of the UK Foundation Programme, the GMC, the patient and public involvement group at the RCP, and the National End of Life Care Programme.

The impact of this report will be assessed in 2013–14 by a survey of hospital-based palliative care teams about the uptake of the recommendations in their trusts, the use of prompt tools in clinical practice, and a review of courses approved for CPD by the RCP. Examples of effective change that are identified will be disseminated back through hospital-based palliative care services and the Medical Specialties Board in order to trigger wider uptake.

Working party remit

This working party was set up to review what professional development is available to support physicians in this area of practice, what physicians see as their priorities, and the types and styles of learning that are most valued, and then to recommend how these can be enhanced in practice. The report describes the current workload for consultant physicians and final-year registrars in end-of-life care, where this is not their main specialty focus. It considers the importance attached to this area of work, uptake of development opportunities, and areas where physicians feel confident or in need of further support. It provides practical recommendations on how to prioritise and address the issues raised that should be taken up by individuals and organisations to improve this area of care.

3 Issues clinicians face in delivering high-quality end-of-life care

Defining end-of-life care and deciding when the focus of care should change is fraught with difficulties. For some people there will be a clear transition point in their illness – days, weeks or months before they die; some may face a general deterioration over months or years; while others die suddenly and unexpectedly.

The recognition that someone is entering the last phase of their life is pivotal to eliciting patient priorities for treatment and care and balancing therapeutic burdens and benefits. Doctors may fear charges both of therapeutic nihilism or futile overtreatment. For the purposes of this report, end-of-life care is taken to start from the time when a condition (or combination of conditions) is no longer curable, when there is irreversible deterioration over a period of time and when there is a clear risk of death in the following months to a year or so.

Timely open discussions with patients and care givers about the aims and limitations of treatment can enable people to consider their priorities for care. When given this opportunity, more patients and carers would choose care at home and more would achieve their wish to die in their usual place of residence when the time comes.[22,23] However, many people will continue to die in acute hospitals for clinical and practical reasons or because of changes in patient or carer choice. There is evidence of the need to improve care during the last days in hospital in addition to avoiding hospital admission or facilitating discharge for patients who choose to die at home.[24] The National Confidential Enquiry into Patient Outcome and Death (NCEPOD)'s report *Caring to the end?*, which was published in 2009, reviewed the notes of more than 3,000 patients who died within four days of admission to hospital.[25] It highlighted differences in groups of patients admitted for terminal care (largely those with cancer) and those whose doctors expected them to die but who were not admitted for terminal care (largely with non-cancer diagnoses). Involvement of palliative care was less frequent in those not admitted for terminal care, and these patients were also much less likely to have discussions about withdrawal of treatment. This suggests that physicians find it particularly difficult to initiate discussions about end-of-life care with patients with non-malignant disease.

Trust boards are in a position to emphasise, through their clinical governance structures, that high-quality end-of-life care is part of the core business of the organisation. Creation of a supportive culture is essential to help doctors in this area of practice, which many find particularly challenging.

The use of tools to support end-of-life care has increased in recent years, becoming routine in many areas. The document *The route to success in end of life care – achieving quality in acute hospitals* emphasises the need to introduce tools systematically and to invest in training staff on their proper use.[15] The most widely used tool at present is the Liverpool Care Pathway for the Dying Patient (or equivalent), which provides guidance for the care of people in the last hours or days of life (Marie Curie Palliative Care Institute: www.mcpcil.org.uk/ liverpool-care-pathway). Use of the Liverpool care pathway has been the subject of three national audits between 2006 and 2011, with 115 trusts submitting data in 2009 out of a possible 159 that provided relevant services. Participating trusts can benchmark the quality of the different aspects of terminal care they deliver, which enables staff to direct their professional development to areas highlighted as needing improvement.[26]

Specialist palliative care services support patients with complex needs from any diagnosis and at any appropriate stage of their illness, but most medical care in the last year of life is delivered by physicians from a range of specialties and by GPs. As such, end-of-life care is part of most doctors' core business and should be supported by relevant training and CPD.[11]

Access to training and education varies across specialties and by region. By developing the knowledge and skills of senior doctors, improvements can be made to support effective decision-making about treatment and care options. The need to address this issue explicitly and formally was highlighted in the End of Life Care Strategy in 2008.[2]

Recommendations

Senior management support is critical to enable professional development in end-of-life care. This must include:

- **provision of time for learning**
- **appropriate appraisal systems that encourage continuing professional development in end- of-life care**
- **an organizational culture which values quality of care at the end of life.**

Medical consultants should provide leadership in establishing opportunities for professional development in end-of-life care in their own settings, including agreeing how best to implement this as a department/directorate and across the trust.

In order to influence their practice and ensure that patients have time to adjust, physicians must recognise that end-of-life care is not just care in the last few hours and days but that it marks the last phase of life, which may be many months or sometimes years.

4 Educational approaches to professional development in end-of-life care

High quality end-of-life care is a multiprofessional process that requires not only clinical knowledge but appropriate attitudes, sensitive behaviors and excellent communication skills. Professional development and training programs should therefore incorporate educational approaches that have been demonstrated to deliver effective learning in these areas.

Strengthening multidisciplinary and multiprofessional teams

Active encouragement of multiprofessional collaboration can be used successfully to ‘modify negative attitudes and perceptions’ and ‘remedy failures in trust and communication’ between professions and disciplines,[27] both of which can result in improved patient care. Where the primary purpose is to improve awareness of different roles and communication within teams, the most effective approaches would involve real patient scenarios – for example, in mortality and morbidity meetings. However, the Health Professions Council cautions that the ‘profession specific skills and knowledge must also be adequately addressed’.[28]

Developing communication skills

‘Communication skills are not an optional extra; without appropriate communication skills our knowledge and intellectual efforts are easily wasted.’[29] Effective end-of-life care requires highly developed communication skills, which are best developed through experience supported by flexible and interactive approaches to learning – for example, observation, simulation, practice, feedback and reflection on experience.[30]

Learning from clinical practice

End-of-life care is covered in undergraduate and postgraduate programs to varying degrees depending on the specialty. However, most professional development in end-of-life care is gained through interactions in clinical practice. Supportive educational approaches such as bedside teaching, ward rounds, and mortality and morbidity meetings can build on existing knowledge, providing new insights and helping to develop problem-solving and reflective skills.[30,31]

Learning from patients and care givers

Feedback from patients is recognized as a valuable means of understanding patient perspectives; however, involving users in end-of-life care can be complex and challenging.[32] Structured interactions with selected caregivers have proved a powerful approach to challenging misconceptions about end-of-life care, as well as to understanding the practical and psychological support needs of patients and carers.[33] Postal surveys such as the VOICES questionnaire,[34] which has been validated for use with bereaved relatives, can provide important feedback on services from a wide range of people.

Developing competence and confidence

Physicians tend to self-select to participate in professional development in end-of-life care. However, studies have found evidence to suggest that competence in personal performance does not always link directly with confidence, with those who are unskilled at a task being more likely to overestimate their ability.[35–37] Opportunities for professional development in end-of-life care should be embedded in courses, conferences, seminars and other professional development events in order to extend the reach to those who would not self-select for such training.

Disseminating innovations and effective practice

Professionals face the challenge of needing to continually update their knowledge and embrace new approaches. Specialist palliative care clinicians need to be skilful educators who are able to support colleagues in developing their knowledge and skills in end-of-life care, using a range of flexible and creative approaches.[31]

Promoting cultural change in organisations

Cultural change in relation to end-of-life care is needed in the UK. Organisational change has been shown to be more likely to succeed when the change is clearly identified, when criteria for success (both short and long term) are identified, when there is leadership at all levels, when the message is clearly communicated, when there is positive gain for all stakeholders, and when the change is supported by respected champions.

Recommendations

Professional development for end-of-life care should:

- Strengthen multiprofessional teams and promote collaboration between team members
- Support the development of effective communication skills through interactive approaches such as simulation, observation and practice with feedback
- Use opportunities in routine practice to draw on clinical experiences with a direct relevance to patient care, developing problem-solving and reflective skills
- Actively seek engagement with, and feedback from, patients and caregivers to improve understanding of the patient experience
- Be embedded into a wide range of educational events such as conferences, workshops and study days, not just those that specifically focus on end-of-life care.

Teams involved in end-of-life care should actively plan for cultural change in the delivery of care at the end of life by identifying medical leaders, engaging colleagues, and supporting the development of expertise among colleagues.

Specialist palliative care clinicians should develop wide-ranging educational skills in supporting colleagues through formal and non-formal learning by:

- using structured interactive events
- facilitating effective bedside teaching
- conducting joint ward rounds
- mentoring colleagues
- facilitating mortality and morbidity meetings.

5 The need for and provision of CPD across the UK

The End of Life Care Strategy identifies three groups of staff with regard to professional development needs in end-of-life care:[2]

- Group A – staff who work in specialist palliative care and hospices

- Group B – staff who frequently deal with end-of-life care as part of their role, eg secondary care staff who work in accident and emergency, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, intensive care, and those who work with patients with long-term neurological conditions
- Group C – staff who work within other services and who infrequently have to deal with end-of-life care.

Four areas were identified as common core requirements for the workforce:

- Training in communication skills
- Assessment of a person's needs and preferences
- Advance care planning
- Symptom control.

The professionals in Group B should be given a high priority in terms of CPD, with particular emphasis on training in advanced communication skills for staff who may initiate discussions with patients about end-of- life care issues.

To assess the number and type of CPD opportunities open to physicians, an analysis of approved CPD events for palliative and end-of-life care between 1 April 2006 and 1 October 2011 was undertaken using the RCP database for approved CPD. Local events and those aimed primarily at junior doctors are likely to have been missed, as the organisers of such events would not usually apply for CPD approval. The analysis of activities over the 4.5-year period identified 1,298 activities, 1,233 of which were eligible (those provided by commercial organisations were excluded). Country of origin, type of provider organisation, type of educational event and the medical specialties that events were approved for were ascertained (Tables 1–3).

Table 1 Approved CPD activities in end-of-life care by country of origin

Country of origin	Number of approved CPD activities
Scotland	82
Wales	52
Northern Ireland	17
England	1,082

For palliative medicine physicians, there were 120 events, most of which were regional training or physician meetings. Most CPD events also open to other physicians were on advanced communication skills training (28%). Eight per cent of these events could be linked to pain and symptom management, which may also have been embedded in the 79 palliative care conferences (6.5%).

Table 2 Approved CPD activities in end-of-life care by type of organization

Type of organization		Approved CPD activities
	Number (%)	Notes
NHS trust or equivalent	438 (35)	

Cancer network	332 (27)	Most (n=309) were for advanced communication skills training
Hospice	278 (23)	80% were from the voluntary sector
Specialist society	94 (9)	Wide spectrum of societies, most of which were linked to non-cancer diagnoses (see Table 4), with 29 specific to the APM
Academic institution	60 (5)	
Deanery	15 (1)	Educational supervision, appraisal and teaching skills
Not specified	16	

Table 3 Approved CPD activities by type of educational event

Type of educational event		**Approved CPD activities**
	Number (%)	**Notes**
Communication skills training	340 (28)	Most initiated via cancer networks
Pain and symptom management	102 (8)	
Palliative care conferences	79 (6.5)	Open to multiprofessionals
Research	88 (7)	
Cancer	56 (4.5)	
Ethics	21 (2)	
Psychological	24 (2)	
Teaching and training	25 (2)	
Events organised by non-palliative care societies	65 (5)	
Clinical updates for doctors in palliative medicine	120 (10)	
Not specified	313	

During the survey period, no approved events in palliative care were aimed specifically at physicians who were not palliative medicine specialists, although two joint study days on breathlessness and fatigue were run at the Royal College of Physicians in London. It was difficult to identify CPD entries linked to advance care planning. Only 5% of events were linked specifically to long-term conditions despite the high associated mortality (Table 4).

Table 4 Non-cancer CPD events with palliative care content

Type of educational event	**Approved CPD activities**
Diagnosis	**Number n=47 (5%)**

Renal	5
Cardiac	5
Neurological disorders	17
Respiratory	4
Dementia	1
Elderly care	1
Stroke	3
HIV	2
Learning disability	1
Nutritional medicine	8

Recommendations

i**The Royal College of Physicians and specialist societies should promote the inclusion of end-of-life care within study days and conferences related to long-term conditions.**

i**Training in advanced communication skills for physicians who care for those with long-term conditions should have equal priority and resources as the training required for those involved in caring for patients with cancer.**

i**Local palliative care providers should work with the palliative and end-of-life care networks to deliver more extensive and targeted CPD for physicians.**

6 Evidence gathered from physicians

Survey*

The online survey received 1,846 responses;[38] this compares favorably with the NAO's survey from 2008, which reported 901 completed replies.[5] Despite the large number of responses, it must be acknowledged that the survey reflects the views of a self-selected group of clinicians. However, the demographics suggest that they are representative of the geographical areas and gender differences (2:1 male to female) that would be expected in the whole population of consultants, doctors in non-training grades, and registrars within one year of obtaining their CCT. As would be expected, the split between male and female respondents was more even in the group of registrars. The distribution by SHA was similar to that in the NAO's survey[5] and in data from the RCP's census of consultants in 2010 (RCP: www.rcplondon.ac.uk/resources/2010-census-summary), with SHAs in London best represented and those in the South East Coast least well represented.

The survey seemed to reach the target audience in terms of grade of doctor and specialty. Consultants made up 61.1% of respondents, registrars 34.3%, and specialty and associate specialist (SAS) doctors 4.8%. We analysed data separately for consultants and registrars to see whether there was a discernable difference between these groups. By and large the results were similar; where they differed we have made a comment. There was a good spread of medical specialties; although there was some dissemination outside our target population, this only amounted to around 2% of the total. The vast majority of doctors identified themselves as being in acute hospital medical specialties; geriatricians made up the majority (Fig 1). The proportion of patients eligible for end-of-life care in our survey was similar to that in the NAO's survey, with about half of doctors identifying less than 10% of their patient population as in this group (Fig 2).

Fig 2. 'Please estimate the proportion of patients whose care you were involved with in the last 12 months who would have been eligible for end-of-life care.' *Source:* RCP End-of-life care survey 2011.[38]

Self-rating of confidence and competence in providing end-of-life care

Respondents were asked to rate their confidence and competence on a scale of 1–10 for a number of items (Table 5 and Fig 3). They reported high levels of confidence in the provision of end-of-life care, including recognising when a patient entered this phase and discussing it with the patient and their family. Doctors felt highly competent in breaking bad news, pain control, and withholding and withdrawing treatment. Areas with the lowest reported competence included end-of-life care in dementia, other symptom control, and advance care planning. For most of the questions, there was a trend towards greater confidence/ competence for consultants than for registrars. Similarly, consultants were more likely to identify that their

training had prepared them well to provide end-of-life care (Fig 4). The survey was not set up to test skills in providing end-of-life care, and, as already discussed, high levels of confidence do not necessarily indicate high levels of competence.

Table 5. Competence/confidence in providing different aspects of end-of-life care (1 = not competent/confident at all, 10 = extremely competent/confident).

Item	**Competence/confidence**
Breaking bad news	9
Dealing with distressed families	8
Pain control	8
Other symptom control	7
Arranging discharge at the end of life	8
Withdrawing/withholding treatment at the end of life	8
Advance care planning	7/8
End-of-life care in dementia	7
Source: RCP End-of-life care survey.[38]	

300 325 350

Total number of responses

Fig 3. 'How would you rate your confidence in discussing end-of-life care with those who are approaching the end of their lives?' (1 = not confident at all; 10 = extremely confident). *Source:* RCP End-of-life care survey 2011.[38]

RESPONSES

Fig 4. 'How poorly or well do you feel your training so far has prepared you to deliver end-of-life care to patients and families?' (Grade: consultants; 1 = not at all well prepared; 10 = extremely well prepared). *Source:* RCP End-of-life care survey 2011.[38]

Opportunities for professional development in end-of-life care

Two thirds of respondents reported that they had not attended any professional development event on end-of-life care in the last 5 years. This is surprising given the recent focus on end-of-life care, the development of tools for managing the last days of life in acute trusts, advance care planning,[39] and new guidance from the GMC published in 2010.[11] However, this may reflect how respondents define end-of-life care: whether they only consider end of life as the last days and weeks and whether they consider end-of-life care as separate from palliative care.

Seminars were the most usual/popular event identified and conferences the least popular. The majority providers were NHS trusts, and most events attended were up to 3 hours in duration. The most common topics were the use of end-of-life care tools and ethical issues, followed by pain and symptom management. Interestingly, advance care planning was less commonly the topic of attended events. 'Other' topics identified revealed a pattern of disease-specific professional development events that included end-of-life care as part of the day. Most common among these were renal medicine courses, but there were also courses with the main topics of cardiology, elderly medicine, dementia and Parkinson's disease. Psychological support and spiritual support were identified as the focus of a number of events, as was strategic planning.

Complaints and critical incidents featuring end-of-life care were reported as relatively low, although there was a broad spread. This is in contrast to the Healthcare Commission's finding that 50% of unresolved complaints in acute trusts are related to care at the end of life.[40] However, these data have been challenged by more recent research reported by the National End of Life Care Program, which put the figure at 4% of all complaints in four trusts over a 6-month period.[41] Specialist registrars associated end-of-life care with critical incidents or complaints to a greater degree than consultants. The results suggest that critical incident reporting and complaint reviews could be used to raise awareness of issues relating to end-of-life care. Morbidity and mortality meetings, notes reviews and complaint reviews are all possible means of learning.

Respondents rated the importance of professional development in end-of-life care highly in terms of their overall CPD (Fig 5). However, the support received from their trust or local organization to provide training for themselves and other staff and to embed it into routine practice was rated less highly (Fig 6):

> *'These courses are too few. My specialty is liver cancer, so I deal with palliative care related issues on a daily basis, having never had any "formal training". My own trust has arranged one event in the last 5 years, but it was oversubscribed and I could not get a place. More frequent shorter sessions would be helpful, or regional half or one-day meetings rather than having the expense of trips to London, especially if [an] overnight stay was involved.'*

Fig 6. 'How much do you think your trust/ organization has done to support end-of-life education for you?' (1 = nothing at all; 10 = fully supportive). *Source:* RCP End-of-life care survey 2011.[38]

When respondents were offered a choice of professionals as their educators, consultants in palliative medicine were preferred. Registrars were more open to being taught by registrars in palliative medicine than consultants. The next most- favored educators for both groups were palliative care clinical nurse specialists. There was less enthusiasm about receiving training from general physicians or GPs with a special interest.

Future professional development

When asked how they would prefer to access professional development in the future, less than 10% of respondents wanted to attend events that lasted longer than a day. Trust-run courses were identified as the most popular source for day-long courses. For periods of time less than 3 hours, respondents ranked in descending order: e-learning, morbidity and mortality meetings, educational literature such as the *Clinical Medicine* journal, and clinical governance events.

Other suggested opportunities for learning were specialty-specific meetings that include end-of-life care as a part of the course or conference, departmental meetings that include joint meetings with the palliative care team, on-the-job training from palliative care professionals and placements with the palliative care team. Several comments suggested that mandatory training in end-of-life care would not be welcome.

> *'There is limited need to devolve this from good standard care provision. Updates should be around changes in law, new symptom control medications/evidence. Short targeted workshops and seminars/presentations occasionally is all that is needed. It is not necessary to have yearly mandatory CPD requirements in this specifically.'*

Barriers to end-of-life care training

Of the potential barriers we had identified, limited time for training was acknowledged by 70% of respondents. Availability of courses and teaching was identified as a barrier by 45%, with accessibility and cost also rating highly. Only 1.7% of respondents felt that you cannot teach this type of care and only 3.1% that teaching in end-of-life care would not help their practice. Our respondents did seem to recognize that developing themselves in this area is important.

Examples of good practice and other comments

The presence of a supportive palliative care team was identified as an important source of professional development, as well as being important for provision of good end-of-life care. Placements with a palliative care team were highly rated; most comments reflected an opportunity taken during training. However, doctors also stated that good end-of-life care was part of their role and that they learnt from experience (including the death of relatives) supplemented by private study and common sense.

> *'Availability and contact with the palliative care team has proved the most effective agent for change.'*
>
> *'Our palliative care [team] is very proactive and has regular slots at our hospital teaching sessions in medicine; they also do a lot of ad-hoc/opportunistic teaching on the ward.'*
> *'I believe our end-of-life care has been improved by the integrated care provided by the palliative care team with joint ward rounds. This has been far better than any training course.'*
> *'I strongly believe that [end-of-life care] is best taught clinically – by observation and mentoring. I think a short stint in a palliative care ward/hospice is almost compulsory for any clinician who would be dealing with patients approaching their end of life. My 8 weeks as a locum palliative care SpR threw me in the deep end but provided me with a breadth of experience that no taught course or e-learning module will ever be able to.' 'I worked as a palliative care registrar in Australia, which was very valuable. I think all medical registrars in the UK should have similar [experience].'*

There were some comments from clinicians who found palliative care teams either unavailable or unhelpful.

> *The reality is that the specialists in palliative care are a) not very available when needed [and] b) often not very helpful.*

A number of respondents commented that they found discussion of cases at departmental meetings a useful way of continued improvement in end-of-life care.

> *'At our 3-monthly morbidity and mortality meetings, all deaths are reviewed and stratified for risk. This includes highlighting when aspects of an expected death were not perfect.'*
>
> *'Departmental reflection on end-of-life care in mortality [is] part of clinical governance meeting[s].'*

The Liverpool Care Pathway for the Dying Patient (LCP) was identified as a driver for improved recognition of patients at the end of life in several settings.

> *'Our unit recently implemented the Liverpool care pathway and this has greatly improved the recognition of the dying patient and improved the patient's and family's care.'*

However, there were also a number of negative comments about the LCP and other pathways, which suggests that careful implementation of such tools is as important as the documentation itself in ensuring that staff have a good understanding of their use.

The value of multidisciplinary and multiprofessional collaboration was highlighted by some respondents.

> *'Keep it multidisciplinary – everyone shines a different light on the problem.'*

Telephone interviews

Fifteen telephone interviews were conducted with senior physicians (12 consultants, two registrars and one clinical fellow). Seven of the interviewees were geriatricians; the remaining participants were spread between internal medicine, respiratory medicine, cardiology, neurology, gastroenterology, medical oncology and intensive care medicine. Results are presented together with themes from the two focus groups.

Interviewees had a wide range of definitions and understanding of end-of-life care, identifying the last days of life and an indeterminate period of time before that. In addition, interviewees recognized that a feeling of professional failure can be associated with a diagnosis of dying, which may overshadow the appreciation that this can lead to greater involvement of patients and families in choices about their priorities for care in the face of the inevitable.

> *'[There is a] barrier to making [a] diagnosis of end-of-life care as [I am concerned that] it becomes a self-fulfilling prophecy.'*

We asked about competence and confidence in areas related to end-of-life care. There was some discussion about the relationship between the two: 'Confidence and competence don't always go together – you can have one without the other!' Areas of least confidence identified by this group included advance care planning, managing adults who lack capacity, and holding discussions about withholding cardiopulmonary resuscitation.

Participants identified informal learning, including departmental audit and clinical or personal experience, as good sources of development. Next to that, the most frequently mentioned source of learning was role models, including palliative care teams. As in the online survey, there were also comments from telephone interviews and the focus groups about palliative care teams not being sufficiently available or amenable to assist with end-of-life care.

> *'I am very lucky to have support from [a] great palliative care team.'*

> *'In my experience palliative care specialists do not have much interest in providing end-of-life care for the majority of people that die. I am afraid they prefer to remain in the ivory tower and just look after the small proportion of people who die in hospice settings.'*

Most respondents identified that courses purely aimed at end-of-life care may not be the best way to learn or the most attractive to general physicians, although communication skills and breaking bad news were identified as areas that require specific training.

> *'Most of my colleagues would not go to a separate palliative care conference'…'opportunity is to integrate [end-of-life care] learning into the major conferences…they would all go to the plenary lectures'*
>
> *'The thing is how you get palliative and end-of-life care into mainstream care.'*

Another theme that emerged was the difficulty in identifying what is happening in primary care and the need for joint working between the acute sector and community services – both to facilitate good care and for professional development. One respondent had a joint conference with community professionals on end-of- life care and had been encouraged by the attendance and enthusiasm of GPs.

> *'Having meetings with primary and secondary care representatives…this would also be an opportunity for two-way education through this meeting'*
>
> *'Working in hospital…less aware of what GPs can do, and updates about this would be useful'*
>
> *'[It is] sometimes a bit of a gamble when you send people home to die.'*

Many interviewees stressed that it was difficult to develop these skills in other people. Working with junior staff to embed this into the culture of care was likely to be more productive than trying to change the way consultants approach things. Modelling 'good' behaviour and encouraging junior staff to reflect on what they had seen was regarded as important. Mentoring and the 'apprenticeship' approach were mentioned as the most powerful methods of learning.

Focus group discussions

Additional themes that came out strongly from the focus groups were:

- Active treatment and palliative care can coexist but it takes courage and experience to manage patients in this way and explain the approach to patients and their families.
- Disjointed care with multiple handovers is not conducive to 'standing back and looking at the patient, rather than treating the pathology'. Routine use of general and disease-specific prognostic indicator tools may help with this.[42,43]
- There is a tendency to treat the presenting complaint and discharge the patient quickly rather than to see them as someone likely to be in the last weeks or months of life and then open a conversation about their preferences for care.
- Approaching conversations about end-of-life care is more difficult in patients with non-malignant diagnoses, as both patients and their doctors see cancer as a terminal illness but this is not always the case with other conditions, such as severe heart failure.
- There are 'always good reasons not to initiate difficult conversations' and it is easier to 'break bad news than to discuss uncertainty'.

- Routine questions as part of the post-take ward round may be useful in prompting further discussion. Such questions may include: ‘Is this patient at risk of dying during this admission? If so, have you discussed this with the patient and asked about their preferences for care in the event of their deterioration?’
- There was broad agreement that many out-of-hours calls from junior staff to consultants were about ‘the focus of care and how active to be’; consultants welcomed this and saw it as an opportunity for teaching.

There was recognition that good end-of-life care should not be seen as ‘giving up’ but rather as ‘giving alternatives’. A structured approach to the management of such patients – akin to the Liverpool Care Pathway for the Dying Patient but earlier in the course of an illness – would be very helpful. The AMBER care bundle (Assessment, Management, Best Practice, Engagement of patients and carers, for patients whose Recovery is uncertain), devised and introduced initially by Guy’s and St Thomas’ Foundation Trust, provides such a structure for patients in hospital for whom recovery is uncertain.[44] This involves a four-part process:

Within 4 hours of identifying a patient whose recovery is ncertain:
(1) a clear medical plan should be recorded in the hospital notes
(2) a clear escalation plan should be recorded in the hospital
notes (3) nursing staff should have understood and agreed the
plans
(4) within 12 hours, a patient/carer meeting or discussion should have been organised, conducted and documented.

The plan should be reviewed daily.

Themes that came out from those working with older people were that dementia is particularly challenging because this condition does not start at one particular time and patients often cannot be involved directly in decision making. Geriatricians may be reluctant to refer to palliative care as it is seen as associated with cancer and with withdrawal of treatment. Some participants assumed that active treatment cannot coexist with symptomatic treatment or palliative care. These issues and the difficulty in judging prognosis for these patients meant that dying was often diagnosed too late. Participants agreed that patients would find the term end-of-life care more acceptable and that specialist palliative care is not always required. They were also of the opinion that there is inequity of care and clear age discrimination in all sectors. They recommended that end-of-life care should be delivered on the basis of need rather than diagnosis; dementia must be given special attention, communication around the dying process is fundamental, and advance care planning should not be compartmentalised. Leadership and follow-through were regarded as essential.

Although participants felt largely competent and confident in carrying out end-of-life care, they would appreciate further training in all areas of palliative care, especially:

- recognition of delirium
- behavioural and psychological aspects of dementia
- end-of-life care in dementia
- dealing with unpredictability and uncertainty
- communication skills to hold early discussions
- learning to implement the ‘surprise question’; ie Would you be surprised if this patient died in the next 12 months? [42]
- recognition of the dying process

- understanding capacity and consent and managing the legal framework
- identifying when advance care planning in dementia should start.

Although e-learning was said to be excellent, participants personally had learnt through shadowing palliative care physicians and nurses, hospice attachments, and attending courses on advanced communication skills.

Participants recommended that more training be delivered at the undergraduate and postgraduate levels using e-learning, observation, reflective practice and problem- or case-based discussions. Trainees and consultants should be encouraged to listen to patients' stories and learn about both good and bad experiences. Multidisciplinary meetings should be promoted to provide a venue where discussion about challenging cases could take place. For example, the Schwartz round, a multidisciplinary format that originated in the USA, has been evaluated by the King's Fund and found to be an effective way of reflecting on and changing practice.[45]

Advanced communication skills courses and compulsory courses using the GMC's guidelines were thought to be helpful. Sponsorship from the RCP could ensure take-up and peer respectability.

Recommendations

iReflection and learning on end-of-life care should be integrated with daily clinical practice. This may be done through directorate meetings; structured multidisciplinary meetings; morbidity and mortality meetings; joint ward rounds and outpatient clinics with palliative care colleagues; grand rounds; mentoring; and placements.

iHospital palliative care teams should be available in each hospital and should be resourced to lead the delivery of professional development in end-of-life care. As experiential learning is most valued, this should include time to work with colleagues in clinical practice and to provide clinical placements and mentorship.

iHospital palliative care teams should include leading professional development in end-of-life care as an integral part of their role. This should include providing support as well as working with staff from other disciplines and professions to learn with, and from, them.

iThe role of hospices and specialist palliative care units/teams in providing experiential placements for physicians should be recognized and resourced.

iThe use of e-learning, such as End of Life Care for all (e-ELCA), to support work-based learning should be included where relevant.

iConsultants who provide care at the end of life should incorporate this into their continuing professional development (CPD) and undertake at least one learning event in end-of-life care within a 5-year CPD cycle. This should be reviewed at their annual consultant appraisal.

iHospital trusts should review their provision of learning opportunities for their consultant, trainee and non-training grade workforce and, where necessary, increase the availability of local end-of-life care training and education.

iTools such as care pathways for end-of-life care must be properly implemented and should receive continuing support to sustain the learning that is required, otherwise such tools can be counterproductive by encouraging a ‘tick box’ approach rather than promoting high- quality care.

- The introduction of systems of care that help to highlight patients who may be at risk of dying during a hospital admission, such as the AMBER care bundle or equivalent, should be considered as a tool to help professional development within teams and to guide day-to-day practice.
- Hospital and primary care teams should acquaint themselves with the range of general and disease-specific tools to identify patients with advanced illness, or who may be approaching the end of life, and consider their applicability and use within their routine practice.

- Physicians whose practice includes patients in the last phase of their lives should consider using the ‘Top ten tips’, ‘Post-take ward round prompts’ and ‘Mortality and morbidity meeting prompts’ provided in this report during their routine practice.

- Joint learning with GPs should be encouraged to further the understanding of each other’s roles and services and to improve coordination of care across traditional boundaries.

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1 Integrate palliative care into your daily practice – ask a member of your palliative care team to attend clinics, ward rounds and multidisciplinary team meetings, especially in areas with a high proportion of patients who require palliative care.

2 Adopt the 'prompting tool' during the post-take ward round to help identify patients who require supportive care (see Appendix 2).

3 Adopt the 'prompting tool' during mortality and morbidity meetings to see whether patients' choices for type and place of care were ascertained in a timely way and acted upon (see Appendix 3).

4 Actively incorporate feedback from patients and carers to guide your professional development.

5 Refer to your local palliative care guidelines for quick reference and a stepwise management guide to common palliative care problems.

6 Include at least one learning event on 'end-of-life care' within a 5-year continuing professional development (CPD) cycle.

7 Find an up-to-date list of useful courses on palliative and end-of-life care locally and nationally at www.apmonline.org.

8 Approach your hospital palliative care team to find out about professional development opportunities in your trust or unit.

9 Find advice and guidance on prescribing in palliative care by registering free at www.palliativedrugs.com.

10 Try out the free e-learning resource on end-of-life care at www.e-elca.org.uk.

Appendix 2 Prompt tool for post-take ward rounds / general ward rounds

- Does the patient have an advance care plan?
- Does the patient have a valid and applicable advance decision to refuse treatment (ADRT)?
- Does the patient fall into one of the following categories?
  - advanced, progressive, incurable conditions(s)
  - general frailty and coexisting conditions that mean they may be expected to die within the next 12 months
  - existing condition(s) as a result of which they are at risk of dying from a sudden acute crisis
  - life-threatening acute condition caused by sudden catastrophic event(s).

If so, discuss preferences of treatment and place of care with the patient and their family.

Appendix 3 Prompt tool for mortality and morbidity meetings

- Was this death expected?
- Were the patient’s priorities for end-of-life care (eg place of care/death) known?
  - If yes, were they adhered to?
  - If no, were there opportunities for advance care planning?
- Was the patient’s terminal care supported by the integrated care pathway for the dying patient?
  - If not, should it have been?

APPENDEX D

ENGLANDS APPROACH TO IMPROVING END-OF-LIFE CARE A STRATEGY FOR HONORING PATIENTS CHOICES JULY 2011

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ABSTRACT: In the U.S. health care system, and in those of many other countries, the care of dying patients is generally not performed well, with pain and other distress frequently undertreated and patients' preferences not respected. England's evidence-based End of Life Care Strategy could prove instructive. This issue brief discusses the origins, content, and implementation of the Strategy, as well as its potential impact. Both England and the United States struggle with similar challenges, including looking beyond the province of hospice and palliative-care specialists and initiating palliative services before the patient's final days. Aspects of the English approach that may be useful in the United States include strategies to help physicians recognize when patients are entering a trajectory that may end in death, the use of "death at home" as a metric for measuring progress, improving the skills of clinical and caregiving personnel through Web-based training, and developing a national improvement pathway.

OVERVIEW

Ideally, the care of patients at the end of life would be humane, respectful of their dignity and wishes, and helpful in coping with the accompanying physical and psychological insults. But the reality is too often quite different. What happens to us at the end of life depends very much on the health care system of a country. And in the American system, and those of many other nations, the care of dying patients is generally not performed well.

In the only available international comparison of care at the end of life, the *Economist* magazine's Economist Intelligence Unit (EIU) developed and applied a "quality of death" index made up of some 24 indicators pertaining to the basic end- of-life care environment as well as to the availability, cost, and quality of end-of-life care. In the 2010 report, *The Quality of Death: Ranking End-of-Life Care Across the World*, the EIU made comparisons among 40 countries. The United Kingdom and Australia were ranked as having the best quality of death. The United States tied with Canada for 9th place.

This does not necessarily mean that end-of-life care in any country approaches the ideal. In fact, the United States is ahead of the U.K. in some respects—for example, a higher percentage of patients receive hospice and palliative care in the U.S. at the end of life. An important difference between the two countries, however, is that the U.K. made a governmental decision in 2008 to adopt a systematic strategy to improve end-of-life care.

This issue brief addresses England's End of Life Care Strategy—a 10-year plan that was adopted in 2008 by the country's Department of Health and National Health Service. England's adoption of the Strategy provides an opportunity to see how improvements in end-of-life care are being pursued in a health system that was already, in international terms, doing relatively well. The author discusses why the strategy came about, what it consists of, how it is being implemented, and what is known about its impact.[5] This account is based both on published sources and on some 15 interviews in London in early 2010 with individuals who have been deeply involved either with the Strategy and its implementation or with end-of-life and palliative care.

A CHALLENGE FOR THE UNITED STATES Though most Americans (71 percent in a recent survey[7]) say that their home is their preferred place of death, only 15 percent of U.S. deaths occur at home.[8] Most of the 2.5 million deaths each year in the United States occur in institutional settings (45 percent in hospitals and 22 percent in nursing homes) and over 25 percent of Medicare expenditures go to beneficiaries' final year of life. Moreover, researchers have found that the pain and other kinds of distress that commonly occur among dying patients are frequently undertreated in the U.S. Medicare's hospice benefit, though intended to facilitate palliative care (relief or prevention of pain and suffering) at the end of life, is limited to patients who forgo other treatment for their terminal illness; the benefit is used by fewer than 40 percent of dying patients, often only in the last few days of life. (The median length of stay in a hospice is about 20 days, and about one-third of patients live less than a week after admission.) In general, communication about end-of-life care between patients (or their families) and the patient-care team is inadequate, sometimes resulting in unwanted interventions that only prolong the dying process.[13] Clearly there are discrepancies between the care that people envision for themselves and the care they typically receive.

The challenge of improving end-of-life care in the United States was tackled in 1997 in the Institute of Medicine report *Approaching Death.* Although its authors recognized positive developments in hospice care, palliative care, and patient autonomy, they found major problems in the quality of end-of-life care and recommended many ways to make improvements. However, none of these recommendations was directed at any specific entities—governmental or nongovernmental—that could be held accountable for implementing them. How might the challenge be handled in a different health care system?

WHY AN END-OF-LIFE CARE STRATEGY IN THE U.K.?

As defined by British policymakers, "end-of-life care" should help people with advanced, progressive, and incurable illnesses to live as well as possible until they die.[15] But there was considerable evidence in the mid-2000s that end-of-life care was inadequate in England, despite the excellent models that existed there—particularly in the hospices that had been introduced as charitable organizations several decades earlier. The majority of deaths in England occurred in hospitals, even though surveys indicated that few people stated a preference for hospitals as the places where they would wish to die
(50%–70% said they would prefer to die at home).

About half of the 16,000 complaints within the National Health Service (NHS) from July 2004 to July 2006 pertained to care given in acute hospitals, and within that fraction 54 percent related to end-of-life care.[17] The primary criticisms involved communication problems, lack of basic comfort, inadequate symptom control, unmet psychological needs, and late referral to specialist palliative care. Care within hospitals thus came to be flagged
by the NHS as a critical problem.

Health care in England, including hospital and physician services and prescription drugs, is provided to all residents through the National Health Service (NHS). The NHS is financed primarily through general taxation and requires very little patient cost-sharing (mainly for outpatient prescription drugs, dental care, and optometry care). About one of 10 residents has supplementary private insurance that covers the individual's choice of specialist and faster access to elective surgery.

Eighty percent of the NHS budget is controlled by 152 primary care trusts (PCTs), which contract with physicians and hospitals to provide care to a geographically defined population. Hospitals are organized as trusts (responsible to England's secretary of state for health) with varying degrees of autonomy. Specialists are mainly salaried hospital employees, although many supplement their income treating private patients.

Since 2003, the NHS has purchased a small but increasing share of routine elective surgery and diagnostics from private providers. Primary care providers are mainly private, operate under an annual national contract, and are paid directly by PCTs through a combination of salary, capitation, and fee for service. The 2004 general-practitioner contract introduced a comprehensive pay-for-performance initiative that provides substantial financial incentives tied to achievement of clinical and other performance targets. Since 2003, a new payment framework has been gradually introduced, basing contracts with acute, mental health, ambulance, and community service providers on activity. Since 2009, a proportion of these providers' incomes are conditional on quality and innovation.

Demographic trends lent urgency to the need for improvement. The number of deaths, particularly among the very old, was certain to increase substantially over the next decade. This added an important, if implicit, economic dimension to the issue. Although the Strategy was not proposed as a way to save money, there was hope that such care could be improved without adding to the overall cost of health care. This objective seemed feasible, given that a review of the evidence by the U.K. National Audit Office suggested that many hospital admissions for patients at the end of life were avoidable, resulting from problems such as lack of access to timely advice and medications for people living at home and in nursing homes, as well as coordination problems among the different organizations that provided care near the end of life (e.g., ambulance services and out-of-hours general practitioners being unaware of patients' "do not resuscitate" orders).

Professor Sir Mike Richards, the London oncologist and palliative-care specialist who led both in the development and implementation of the Strategy, identified two additional matters that it needed to address.[19]

First, a general societal reluctance to talk openly about death and dying meant that few people were discussing their care preferences with relatives or friends and that professionals were reluctant to initiate conversations with patients about these matters. Second, end-of-life care had a low profile within the National Health Service and social-service organizations. Having not been identified as a priority, the quality of end-of-life care was variable and often low.

Shortcomings in end-of-life care in Britain may seem surprising because it was the place of origin for the modern hospice concept—to provide a more humane alternative to the ways in which people near the end of life were treated in hospitals. Beginning with Dame Cicely Saunders' St. Christopher's Hospice in 1967, hospices became widespread in Britain, and the idea of palliative care that was associated with hospices gained widespread acceptance in many countries. However, this does not mean that the hospice itself was integrated into the health care system. In Britain, hospices developed as charitable organizations that were external to the National Health Service and its hospitals and health professionals, though today some 40 hospices and a growing number of palliative-care consultant physicians are part of the NHS.

The success of hospices had a paradoxical effect. They came to be seen as providing Britain's standard of excellence for care of the dying, but this led to feelings of inadequacy in the hospital settings where most patients die. As Professor John Ellershaw, director of the Marie Curie Palliative Care Institute in Liverpool, has put it, the "hospice model of excellence can lead to the general- ist feeling that the only place patients can die well is in a hospice, resulting in de-skilling and a sense of failure within the health care staff who are not based within the hospice sector."[20]

In the mid-2000s only 16 percent of cancer deaths and only about 5 percent of all deaths occurred in hospices (Hospices were also involved in the care related to another 5 percent of deaths that occurred else- where.) If dying patients were to benefit from the end-of-life care expertise associated with hospices, such care needed to be transferred beyond these facilities them- selves. That was the idea behind the development of the approaches on which the end-of-life care strategy built.

THE END OF LIFE CARE STRATEGY:

The End of Life Care Strategy laid out 10 objectives, including the need to enhance public awareness, improve end-of-life care, and increase relevant knowledge and skills among health professionals (Exhibit 1). Several aspects of the Strategy are particularly notable. First, it emphasized the need for understanding and respecting the wishes of patients in how they are cared for at the end of life, as well as for offering people more choice about the care they receive, particularly with regard to location of care (e.g., home or hospi- tal). Professor Richards emphasized that the Strategy's approach existed within the "current legal framework" and thus did not involve euthanasia or assisted dying.

Second, the Strategy enunciated a vision of qual- ity of care based on what is involved in a "good death" for patients, including being treated as an individual and with dignity and respect, being without pain and other symptoms, and being in familiar surroundings in the company of close family or friends. There was an explicit recognition that there is no single end-of-life trajectory and that the process by which patients approach death is in part a function of the disease involved. Because the downward courses are typically quite different for cancer, organ-system failure, and frailty/dementia, for example, these variations need to be recognized in providing end- of-life care.[22]

Third, the Strategy was evidence-based in several respects. Research had documented the shortcomings in existing end-of-life care that the Strategy sought to address. Also, as is discussed later in this brief:

Exhibit 1. Objectives of England's *End of Life Care Strategy*

- Increasing public awareness of death and dying to facilitate people's discussion of their own preferences and help drive improvements in service quality.
- Ensuring that people are treated with dignity and respect at the end of their lives.
- Ensuring that pain and suffering are kept to an absolute minimum by providing access to skillful symptom management.
- Ensuring access to physical, psychological, social, and spiritual care.
- Ensuring that people's individual needs, priorities, and preferences for end of life care are identified, documented, reviewed, respected, and acted upon.

- Ensuring coordination of services so that patients receive seamless care.
- Ensuring that high-quality care is provided in the last days of life and after death in all care settings.
- Ensuring that caregivers are appropriately supported.
- Ensuring that health and social care professionals receive the education and training necessary for providing high-quality care.
- Ensuring that services provide good value for the money to the taxpayer.

Source: Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).

Strategy's ideas for improving end-of-life care came from pertinent models and research already in existence. And it was recommended that a strong research component be built into implementation, both for monitoring progress and assessing outcomes.

Fourth, a recurrent theme in the Strategy involved crossing boundaries that had previously limited the application of the best ideas and service models for end-of-life care. The Strategy was explicit about going beyond cancer care to meet the needs of all patients with advanced, progressive, and incurable illnesses. The Strategy recognized that good end-of-life care should be the province not only of hospices and palliative-care specialists and should not be limited to certain settings, whether hospice or hospital. (A complication for end-of- life care in Britain is that the general practitioners with whom patients have ongoing relationships provide care exclusively outside of the hospital, as do the providers of social care, while disease-specific specialists are usually hospital employees.) The fact that some necessary services are provided in the voluntary and private sectors as well as in the National Health Service provides additional boundary-crossing challenges, and so does the fact that the care homes where many frail elderly reside lie outside the NHS and beyond its care and quality-control capacities. An additional boundary involved timing. Under the Strategy, services oriented toward the end of life could begin a year or more before the patient's final days.

These and other central ideas for improving patient care were built into a "care pathway" that would be followed by professional and organizational providers of care and supported by the NHS's processes of plan- ning, budgeting, and contracting for services. The steps of the care pathway were:

- The physician identifies patients who are within a year or two of the end of life and initiates discussions of their care preferences.
- Care plans are developed for patients based on their needs and wishes, and these plans are regularly reviewed and modified as needed.
- A doctor or nurse coordinates a patient's care among the multiple organizations with which the patient might deal—hospitals (and their specialists), primary care doctors (GPs), care (i.e., nursing) homes, out-of- hours medical services,[23] district nurses who provide home care, social care providers, ambulance services, and hospices and specialist palliative care services.
- These and other pertinent organizations deliver high- quality services.
- Care—particularly "comfort care"—is provided to the patient in his or her last days of life.
- Care is provided after death (for the patient's body)

and for the needs of families and caregivers.

Notable among these steps were the focus on early identification of patients who are approaching the end of life, the emphasis on coordination, and the recognition that death does not end the need for services related to end of life. And crosscutting the six steps in the pathway were strands reflecting the need to provide spiritual care, to support families and caregivers, and to supply high-quality information.

The elements of the Strategy's care pathway were based on existing models and tools that had been developed in hospices and by the NHS but that were still only in limited use. The Strategy sought to transform end-of-life care by promoting the wider use of these models—namely, the Preferred Priorities for Care, Gold Standards Framework, Delivering Choice Program, and Liverpool Care Pathway for the Dying Patient—each of which had emerged in an ad hoc way in a particular location or sector of the health care system in response
to the needs of patients at the end of life. Although they have separate origins and different emphases, they have much in common. Each of these models merits brief description (Exhibit 2).

Preferred priorities for care.[24] Not an actual model of care, preferred priorities for care (PPC) is similar to the "advance directive" family of documents in the United States in that it can be put in place well before the need for end-of-life decision-making.[25] The PPC consists of a form on which people answer three open-ended questions about 1) what has been happening to them

Exhibit 2. Models and Programs Used in Developing the End of Life Care Strategy**Aim**

Facilitate care that meets patient's preferences

Liverpool Care Pathway for the Dying Patient

Model/Program	Implemented by	Focus
Preferred Priorities for Care	Patients	Document patient preferences for end-of-l care
Gold Standards Framework	Primary care teams	Guide care in patients' l year of life
Delivering Choice Program	Discharge and home care nurses	Facilitate end-of-life car at home for hospitalizec patients

Multiprofessional

teams in hospitals, Meet psychological, spiritual, and physical needs.

Enable patients to receive high-quality end-of-life care as much as possible at home

Enable patients near end of life to be cared for at home if they wish Provide dying patients with comfort, pain management, needs of patients in their last days and hours of life and relief from distressing symptoms

Source: Adapted by author from materials at the following sources: http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare; http://www.goldstandardsframework.nhs.uk; http://www.mariecurie.org.uk/en-gb/healthcare-professionals/innovation/Delivering-Choice-Programme/; http://www.liv.ac.uk/mcpcil/ liverpool-care-pathway/.

Regarding their health, 2) their "preferences and priori- ties" for future care, and 3) where they would like to be cared for in the future. There is also space for recording any changes in preferences and priorities as well as for contact information on people involved in the patient's care. The document containing this information is to be taken by the patient to the various places in which he or she may receive care; in that way, medical staff can follow the patient's wishes should his or her capacity be lost toward the end of life.

The Gold Standards Framework. The Gold Standards Framework (GSF), developed as a grassroots initiative by Yorkshire general practitioner Dr. Keri Thomas, is designed to assist primary care teams in providing the best possible care for people nearing the end of their lives. The Framework's goals are to provide high-quality care that is consistent with patients' preferences, anticipates and plans for their needs, and is more home-based than hospital-based.[26]

Application of the GSF begins with identify- ing people who may be in their last year or so of life, as opposed to hospitalized patients who are already close to death. Identification may begin with the so-called surprise question that doctors could ask themselves, "Would it surprise you if this patient died in the next year? The Royal College of General Practitioners has developed a set of clinical indicators to help clinicians recognize differences in the trajectory of dying with dif- ferent conditions (e.g., cancer, heart failure, HIV/AIDS, or dementia).[28] The second step is to assess the patient's current and future clinical and personal needs, taking into account his or her preferences and those of the family. The third step is to develop and carry out a plan to meet those needs and preferences. This involves the Cs": communication, coordination, control of symptoms, continuity of care, continued learning, caregiver support, and care of the dying.

Originally developed for cancer patients, the GSF can now be used in a variety of settings for any patient with a life-limiting condition. The National Gold Standards Framework Center has prepared guidance for physicians and nurses in primary care, care (nursing) homes, and hospitals in carrying out the GSF.[29] At the time the End of Life Care Strategy was prepared, esti- mates were that about 50 percent of the GP practices in England reported using the GSF, though not all of them were fully implementing it, and there was great regional variation.[30]

THE DELIVERING CHOICE PROGRAM.

The Delivering Choice Program was begun by Marie Curie

Cancer Care, one of Britain's largest health charitable organizations, which operates nine hospices and provides free nursing care to terminally ill people who wish to be cared for and to die at home, supported by their families. The program, aimed at overcoming locally identified barriers to the effective provision of end-of-life care, has several key elements. They include "discharge community link nurses" who facilitate discharge from hospitals by coordinating home care services, the provision of information and advice to patients, the conveyance of patients' needs to home health care teams, and "rapid response teams" that make emergency as well as planned visits to patients in their homes during off hours.

An evaluation of the Delivering Choice Program in Lincolnshire by the Kings Fund in 2007 found a substantial increase (from 19% to 42%) in deaths at home among patients who had used the pro- gram's services and no change among patients who had not.[31] No differences were found in hospital usage or in costs over the last eight weeks of life. A separate evaluation in Lincolnshire, based on assessments of patients and their families, found that rapid response teams (RRTs) were effective in providing care and support, particularly for cancer patients in crisis at night.[32] The Program enabled some families to keep patients at home until they died, and the availability of services by phone provided reassurance that help could be summoned when needed. One-third of the cancer patients who died in the two locales studied had used the service, and 73 percent of cancer patients who died at home had received RRT support.

The Liverpool Care Pathway for the Dying Patient. The Liverpool Care Pathway for the Dying Patient (LCP), which was developed in the 1990s by the Royal Liverpool University Hospital and the Marie Curie Hospice Liverpool,[33] focuses primarily on the last days and hours of life of hospitalized patients. It provides care- givers with guidance on meeting the physical, psycho- logical, and spiritual needs of dying patients, including comfort measures, anticipatory symptom control, and the discontinuance of interventions that are not confer- ring benefit. The LCP is brought into use for particular patients when a trained multi-professional team agrees that the patient is dying and that all possible ways to reverse the current situation have been considered and found to be either ineffective or infeasible.[34] The patient's need for comfort, pain management, and relief of dis- tressing symptoms are to be addressed and reassessed at least every four hours. Rescue treatment can be resumed if changes in the patient's condition warrant it.

The LCP lays out detailed steps regarding what information should be obtained and documented about the patient's wishes. The pathway also contains guid- ance about informing the patient and relatives when the focus of care has changed and about communicating after death with the patient's family and general practitioner. At the time the End of Life Care Strategy was published in 2008, the LCP had been implemented in at least three hospital wards in more than 80 percent of hospital trusts, but it had been introduced to all appropriate wards by only 17 percent of trusts.[35] The Strategy sought to increase the use of the LCP.

IMPLEMENTATION OF THE END-OF-LIFE CARE STRATEGY:

The Strategy laid out actions to make change happen.

One set of actions was focused on increasing public awareness that patient care at the end of life could be guided in ways that responded to patients' preferences. A second set was aimed at improving the capacity of purchaser organizations within the National Health Service (primary care trusts at that time) to carry out the responsibilities implied by the end-of-life pathway. A third set of actions involved providing guidance to, and creating expectations and responsibilities for, the organizations and professionals that provide care to patients at the end of life. And a fourth was the development of a set of mea- sures by which progress could be assessed.

Publishing a strategy is one matter; changing the services provided by the NHS and its 1.3 million employees to England's 50 million people (of whom about half a million die in a given year) is quite another. The number of people responsible for implementing the Strategy was remarkably small—fewer than half a dozen people each in the Department of Health and the NHS.

The End of Life Care Strategy was incorporated into the operating framework of the NHS, and it was made a priority in the overall quality-improvement effort known as the Next Stage Review. This effort worked through the structure of the 10 regional strategic health authorities, which oversee the 152 primary care trusts in England that purchase the services of general practitioners, hospitals, and other providers within the NHS. (In the wake of the elections of 2010, the regional authorities and primary care trusts are to be phased out in 2013 and replaced by physician-based purchasing arrangements.[37]) Specific implementation activities, often in the form of pilot projects, have varied across these entities, and lessons are being shared. For example, guidance (including information about "good practices") was published so as to assist in the purchasing of end-of-life services and in providing such care. Implementation made use of incentives as well, and also it included the collection of data indicative of progress. The Department of Health also had some new money (£286 million [US$460 million] over the first two years) with which to encourage implementation of the Strategy's directives. Some of this funding was used for workforce develop- ment, but most of it went to the primary care trusts for their use in purchasing services.

One of the most direct implementation tools, initiated before the Strategy was published (though while it was in development), involved the Quality and Outcomes Framework (QOF) that was part of the NHS's standard contract with general practitioners. Provisions related to palliative care were included among the QOF measures on which GPs received incentive payments for their performance.[38] To encourage providers to pay attention to the needs of patients who might be entering an end-of-life situation, the NHS gave GPs three QOF points for creating a list of their patients thought to need palliative care or to be in their last year or so of life; and the NHS awarded three additional points for reviewing those patients at multidisciplinary team meetings. Data reported for the one-year period ending March 2010 showed that 94 percent of the 8,305 practices reporting met the former target and 84 percent the latter. Though these physician actions did not themselves change patient care, they were essential steps in applying the Gold Standards Framework.

Markers of progress. The implementation of the Strategy, like its development, emphasized the importance of evidence. Soon after the Strategy's publication in 2008 the Department of Health drafted a set of "quality markers" for end-of-life care and then invited comment; in 2009 the agency published a revised set of quality markers based on the resulting feedback.[40] These markers were structure and process measures, as well as measures of compliance for use in audits and evaluations. There were separate measures for commissioners (purchasers) and for the various kinds of providers—e.g., primary care providers, hospitals, hospices, and ambulance services.

For commissioners, there were markers for activities in increasing public awareness, strategic planning, oversight of providers' activities and service capacities, coordination across organizational boundaries, workforce planning, and monitoring. For providers, quality markers focused heavily on capacity, with appropriate variations for the type of provider. (See Exhibit 3 for the top 10 quality markers for providers.)

Progress reports. The Department of Health issued progress reports one year and two years after publication of the Strategy. Progress was reported largely in terms of steps taken by strategic health authorities (SHAs) and primary care trusts (PCTs). Progress reporting was rather cumbersome, because both types of entities were given much autonomy in adopting the End of Life Care Strategy. For example, improving end-of-life care was one of 50 priorities from which PCTs had to choose eight, and SHAs could develop their own emphases one might focus on changing public attitudes, another on the use of electronic health records to coordinate care, and another on implementing the Delivering Choice Program (to help develop local services that enable palliative care patients to be cared for in the place of their choice). The hope was that the SHAs would learn from each other's experiences with different components of the overall Strategy.

Exhibit 3. Top 10 Quality Markers for Providers

1. Have an action plan for delivery of high-quality end-of-life care that encompasses all patients' diagnoses and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of caregivers are appropriately assessed and recorded.
6. Have mechanisms in place to ensure that care for individuals is coordinated across organizational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end-of-life training opportunities and enable workers to access appropriate programs relevant to their needs.
9. Adopt a standardized approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and results of end-of-life care and submit relevant information for local and national audits.

Source: Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).

In the first year, some 69 PCTs (close to half) designated improving end-of-life care as one of their eight priorities. The tools they possessed for achieving this goal were some funding for enhancing the training of health care providers, a reporting system for the percentage of deaths that occur at home, and the offering of incentives to general practitioners to recognize and pay attention to their patients who are nearing the end of life (the first step in the care pathway). The only outcome measure in this set was percentage of all deaths that occur at home. In recognition that additional outcome measures are needed, pilot testing has been taking place for a national survey (entitled VOICES) that solicits the views of bereaved relatives about the end-of-life care of their loved one.[41]

> The second annual report attested to continued progress on several fronts.[42] One was the launching in early 2010 of an Internet-based education program for health and social care professionals regarding end-of-life care. Another was the availability of capital funding for several new hospice facilities. Pilots were initiated both for the local registries of people facing end of life as well as for the VOICES survey of the bereaved. Two widely recognized experts in end-of-life care—Dr. Teresa Tate, the medical advisor for Marie Curie Cancer Care, and Professor John Ellershaw, who had led development of the Liverpool Care Pathway—were appointed deputy national clinical directors for end-of-life care. The report, and the implementation effort itself, continued to focus on identifying and publicizing examples of good practices, with the aim of encouraging their wider adoption.

There were also some early lessons. One was that the Vital Sign measure for end-of-life care—the number of people dying at home—was flawed; for many people, a nursing or care home had become their residence and was therefore an appropriate place for death for people not wanting to die in a hospital. The report thus stressed the need to recognize care homes in implementing the strategy.

Two other related problems were recognized as well. First, primary care trusts had been very uneven in their efforts to implement the strategy, leading to the concern that a post code (zip code in American terms) lottery would determine what care people received at the end of life. Second, the funds that had been allocated to PCTs for end-of-life care had not been "ring-fenced," and a third of them were unable to report on what they had done with that money. (The PCTs that had made best use of the funding were the same ones that had historically done well at end-of-life care.) But these problems resulted from limitations in the administrative structure for implementing a national strategy, not from the Strategy itself.

STRENGTHS OF THE STRATEGY

Although the NHS is still early in the 10-year horizon envisioned for implementing the End of Life Care Strategy, there is reason for optimism. This brief has already identified a number of strengths in the English approach to improving end-of-life care, including comprehensiveness; heightened public awareness; success- ful models of care to build on; enhanced training of health professionals; an emphasis on evidence; and the use of incentives, education, and oversight as levers of implementation.

A striking characteristic of the Strategy itself is its level of acceptance by the leadership of the relevant medical societies (British Medical Association, Royal College of Nursing, Royal College of Physicians, and Royal College of General Practitioners) and caregiving organizations (Macmillan Cancer Support and Marie Curie Cancer Care). Reasons for this acceptance may include the following: the participatory process by which the Strategy was developed, involving work over two years by a distinguished advisory board and six working groups plus consultations with 300 stakeholders, was widely admired; the clinical directors of all of the strategic health authorities were involved in the process; the development and implementation of the Strategy was led by an eminent palliative-medicine specialist, Sir Mike Richards, national clinical director for end-of-life care; the Strategy was built upon, and harmonious with, previous policy initiatives; and it fit into a much broader effort, undertaken in the

2000s, to improve care in the National Health Service—for example, a policy thread that the Strategy shared with several components of this overall effort was to expand patient choice.

CHALLENGES FACING THE STRATEGY: Several end-of-life challenges remain. First, successful implementation ultimately depends on the willingness of individual physicians to build the relationships and undertake the conversations that reveal patients' wishes— and to respond accordingly. Effecting behavioral change among physicians is always difficult, and the literature on the problem of diffusion of innovation in health care organizations is huge.[43]

A second challenge arises from the fact that the triggering act for initiating end-of-life care—recognizing when particular patients are entering the end-of-life situation can be difficult to do and is potentially controversial.[44] The Gold Standards Framework is envisioned for implementation a year or more in advance of patient's deaths. Regarding patients who die in hospitals, many do so unexpectedly and thus might not be subject to the Liverpool Care Pathway. On the other hand, the possibility that hospitalized patients could be incorrectly identified as dying raises the danger of misapplying the Pathway. A controversy developed in fall 2009 when six experts wrote a letter to the *Daily Telegraph* claiming that some patients were incorrectly being put on the Pathway. The problem, it appears, was less in the Pathway and its elements than in the need for better training of clinical personnel in making the difficult judgment that a patient is actually in the process of dying.

A third challenge, which can arise in any policy implemented by government, is the possibility that the party that champions it may be voted out of office. This in fact happened in England in 2010 with the replacement of the Labor government. In several interviews that the author conducted shortly before that election, no one believed the Strategy was vulnerable to a change in government because the need for improving end-of-life care was widely recognized and the Strategy had generated almost no organized opposition. Also, because the Strategy was clinically led and "owned," it was more about professional standards than political ones. But only a few months after the election the coalition government proposed to eliminate one mechanism by which the Strategy was being implemented—the strategic health authorities—and to replace the primary care trusts with a purchasing mechanism controlled by general practitioners. More reassuring has been the public statement by Paul Burstow, the current Minister of State, that the Strategy is to be taken further and faster.[45] End-of-life care is also addressed in several documents of the new government, including the Coalition Agreement (relat- ing to a per-patient funding system for palliative care). A review of how this system might be implemented is under way.

A final challenge pertains to marking progress. Mechanisms are in place to measure various structural and procedural aspects of the quality of end-of-life care, but measuring the outcomes of the Strategy itself is more difficult. The only available outcome measure is the percentage of deaths that occur at home or in the care homes that are the final residences of many people. The planned VOICES surveys to collect information on the experiences of bereaved relatives should provide additional useful markers of progress, as may the ongoing analyses of complaints within the NHS.

COMPARISON WITH THE UNITED STATES End-of-life care in the United States has already been hugely influenced by ideas associated with hospice and palliative care in the U.K. Thus, for example, the patient- choice issues that animate the English End of Life Care Strategy, including legal developments pertaining to patients' advance directives regarding end-of-life treatment, are now familiar to U.S. stakeholders. Americans, however, often go their own way, as with their organized payment system for hospice care, which is more advanced than its English counterpart; such services are built into the Medicare program rather than largely supported by charity, as in the U.K. And the share of deaths occur-ring in hospitals is smaller in the United States than in England—45 percent (37 percent if only inpatient deaths are counted) compared with 58 percent in England.[46]

Despite such differences, it is striking, when comparing end-of-life care in the two countries—which have such different health care systems—that the challenges in end-of-life care are so similar. There is a general reluctance in both countries to discuss preferences for end-of-life care, and there are shortages of professionals with the requisite training. Both countries struggle with what we described earlier as "boundary" challenges: going beyond cancer care to meet the needs of all patients with advanced, progressive, and incurable illnesses; extending end-of-life care beyond the province of hospice and palliative-care specialists; initiating services oriented toward the end of life but before the patient's final days; and gaining acceptance of the idea that palliative-care services can be appropriate no matter the stage of a patient's disease.[47]

Meanwhile, important elements of the British approach that do not depend on the existence of a National Health Service may be applicable to the United States. The Gold Standards Framework and the Liverpool Care Pathway both provide guidance that could be useful for American physicians and other health professionals, and research on the Delivering Choice Programme shows that the introduction of services such as discharge com- munity link services and rapid response teams can mark- edly enhance the feasibility of caring for U.S. patients at home during their final days, if that is their preference. The idea of using survey research (e.g., the VOICES project) to obtain survivors' assessments of the quality of end-of-life care of their loved one is another idea worth emulating, as was suggested in the Institute of Medicine report *Describing Death in America*.[48] The last federally funded mortality follow-back survey in the United States was done in 1993.

Other aspects of the English approach that may be useful in improving end-of-life care in the United States include: the strategies for encouraging and helping physicians to recognize when patients are entering one of the trajectories that may end in death and to implement approaches to care that are based on that recognition; the use of "death at home" as a metric for measuring prog- ress; the focus on improving the skills of clinical and care- giving personnel through the use of Web-based training; and the development of a national improvement pathway such as the Gold Standards Framework. However, the English approach that the government should try to increase awareness of the need for end-of-life care plan- ning contrasts strongly with the situation in the United States, where the idea of compensating physicians for having end-of-life care conversations with their patients prompted fears, however unfounded, of the creation of "death panels" that would determine who deserved to live.

When asked about important lessons for the United States, most of our English interviewees cited the End of Life Care Strategy itself—the fact that a set of ideas about patient choice and palliative care could be built into the very structure of the health care system. My own choice for the most important lesson pertains to the value of approaching end-of-life services as a quality-of- care issue for which measures are needed. Work on the development of such measures is taking place in both countries.[49]

Notes

[1] Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academies Press, 1997).

[2] Economist Intelligence Unit, *The* Quality of Death: Ranking End-of-Life Care Across the World (London: EIU, 2010).

[3] Department of Health, *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life* (London: Department of Health, 2008).

[4] Different versions of the strategy were implemented in England, Northern Ireland, Scotland, and Wales. For simplicity, we focus here on England.

[5] We follow two conventions in citing the strategy. First, the word is capitalized only when referring to the document itself. Second, the term "end-of-life care" includes hyphens except in reference to the document itself, which did not use hyphens.

[6] Interviews were done in person or by phone in April 2010 with Rachel Addicott, senior research fellow, Kings Fund; Maureen Baker, honorary secretary of council, Royal College of General Practice; Martin Bardsley, Nuffield Trust; Amy Bowen, assistant direc- tor of research and innovation, Marie Curie Cancer Care; Tony Calland, chair, British Medical Association Ethics Committee; Lara Carmona, head of policy development, Marie Curie Cancer Care; Jayne Chidgey-Clark, director of end-of-life care, Guys and St. Thomas's Hospital Trust; Jonathan Ellis, direc- tor of public policy and parliamentary affairs, Help the Hospices; Baroness Ilora Finlay, independent crossbench member of the House of Lords, past presi- dent of the Royal Society of Medicine, and professor of palliative medicine at Cardiff University School of Medicine; Irene Higginson, professor of pallia- tive care, policy and rehabilitation at King's College London and scientific director of Cicely Saunders International; Tessa Ing, head of end-of-life care, Department of Health; Tim Jackson, Guy's Hospital nurse director, South East London Cancer Network; Professor Sir Mike Richards, national cancer direc- tor and national clinical director for end-of-life care, Department of Health; John Saunders, chairman, Royal College of Physicians Committee on Ethical Issues in Medicine; and Teresa Tate, deputy national clinical director for end-of-life care at the Department of Health and medical advisor to the Marie Curie Cancer Care, and consultant in palliative medicine to the London NHS Trust.

[7] Harvard School of Public Health/Robert Wood Johnson Foundation poll, April 22–May 15, 1999.

[8] IOM, *Approaching Death*, 1997, 2.

[9] National Center for Health Statistics, *Deaths from 39 Selected Causes by Place of Death, Status of Decedent When Death Occurred in Hospital or Medical Center, and Age: United States, 1999–2005* (Hyattsville, Md.: NCHS, 2009), tabulated from the National Vital Statistics System, Mortality. Available at http://www.cdc.gov/nchs/nvss/mortality/gmwk307.htm, accessed June 21, 2011; and D. C. Angus, A. E. Barnato, W. T. Linde-Zwirble et al., "Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study," *Critical Care Medicine*, March 2004 32(3):638–43.

[10] G. F. Riley and J. D. Lubitz, "Long-Term Trends in Medicare Payments in the Last Year of Life," *Health Services Research*, April 2010 45(2):565–76.

[11] IOM, *Approaching Death*, 1997.

[12] D. E. Meier, "The Development, Status, and Future of Palliative Care," in D. E. Meier, S. L. Isaacs, and R. G. Hughes (eds.), *Palliative Care: Transforming the Care of Serious Illness* (San Francisco: Jossey Bass,

2010), 18–19.

[13] J. C. Hofmann, N. S. Wenger, R. B. Davis et al., “Patient Preferences for Communication with Physicians About End-of-Life Decisions,” *Annals of Internal Medicine,* July 1997 127(1):1–12.

[14] IOM, *Approaching Death,* 1997.

[15] This definition comes from Britain’s National Council for Palliative Care.

[16] M. Richards, “The End of Life Care Strategy: 16 Months On,” in R. Addicott and R. Ashton (eds.), *Delivering Better Care at the End of Life: The Next Steps* (London: The Kings Fund, 2010).

[17] Healthcare Commission, *Spotlight on Complaints: A Report on Second-Stage Complaints About the NHS in England* (London: Healthcare Commission, 2009); and Richards, “End of Life Care Strategy,” 2010, 24.

[18] National Audit Office, *End of Life Care* (London: National Audit Office, 2008).

[19] Interview in London, April 13, 2010.

[20] J. Ellershaw, “Care of the Dying: What a Difference an LCP Makes!” *Palliative Medicine,* July 2007 21(5):365–68.

[21] Office for National Statistics, *Mortality Statistics, Series DH1, no. 37* (London: Office for National Statistics, 2004).

[22] J. Lynn, *Sick to Death and Not Going to Take It Anymore: Reforming Health Care for the Last Years of Life* (Berkeley: University of California Press, 2004).

[23] The out-of-hours system makes care available to patients outside the time that doctors’ offices are open. That is, the system operates both at night and on weekends.

[24] http://www.endoflifecareforadults.nhs.uk/assets/downloads/ppc.pdf, accessed June 21, 2011.

[25] C. P. Sabatino, “The Evolution of Health Care Advance Planning Law and Policy,” *Milbank Quarterly,* June 2010 88(2):211–39.[26] Extensive information about the Gold Standards Framework and its application is available at http:// www.goldstandardsframework.nhs.uk, accessed June 21, 2011.

[27] Although this question sounds subjective, there is evidence that it has predictive value. See, for example, A. H. Moss, J. Ganjoo, S. Sharma et al., “Utility of the ‘Surprise’ Question to Identify Dialysis Patients with High Mortality,” *Clinical Journal of the American Society of Nephrology* Sept. 2008 3(5):1379–84; and Lynn, *Sick to Death,* 2004.

[28] Royal College of General Practitioners, *Prognostic Indicator Guidance Paper* (Walsall, England: National Gold Standards Framework Center, 2008).

[29] http://www.goldstandardsframework.nhs.uk, accessed June 21, 2011.

[30] Department of Health, *End of Life Care Strategy,* 2008, 85.

[31] R. Addicott and S. Dewar, *Improving Choice at End of Life: A Descriptive Analysis of the Impact and Costs of the Marie Curie Delivering Choice Programme in Lincolnshire* (London: Kings Fund, 2008).

[32] S. Payne, J. Seymour, C. Ingleton et al., *Independent Evaluation of the Marie Curie Cancer Care “Delivering Choice Programme”: Structured End Evaluation Report for Lincolnshire* (Lancaster: Institute for Health Research, Lancaster University, 2008).

[33] Ellershaw, “Care of the Dying,” 2007.

[34] Marie Curie Palliative Care Institute, *Liverpool Care Pathway for the Dying Patient (LCP) Pocket Guide* (Liverpool: Marie Curie Palliative Care Institute,2009).

[35] Department of Health, *End of Life Care Strategy*, 2008, 83.

[36] The various implementation actions undertaken dur- ing the first year after publication of the Strategy were summarized in the *First Annual Report*. See

http://www.dh.gov.uk/en/Publicationsandstatistics/ Publications/DH_102433, accessed June 21, 2011.

[37] The new government has proposed to replace the primary care trusts with consortia of general practi- tioners and altogether eliminate the strategic health authorities.

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