Emma Auden

Toward A Better American End-of-Life Care System

In Dan Brown’s latest thriller novel *Inferno*, the main character Langdon states during a discussion with Sienna that he has read that "in the US some sixty percent of health care costs go to support patients during the last six months of their lives” (Brown 216). Is this statistic accurate? What do this statistic and the surrounding literature about US end-of-life care reveal about current cultural attitudes concerning death and the health care system? What can be said about the efficacy of this system? This paper will first explore the statistics and statistical analysis surrounding the debate on the cost of end-of-life care in the US. This section will identify the relative amount of resources spent on end-of-life care and compare these expenditures to those of other countries. Next, the paper will investigate the mentality behind our resource allocation by examining the Western mindset about death. Finally, it will explore the efficiency of the end-of-life care system in the US. In doing so it will attempt to identify whether the allocation of health care dollars represents a flaw in our system or is the result of intentional decision-making by the American population. The ideas presented here will allow the reader to see potential problems, as well as potential benefits, of the culture’s mindset and the health care system’s mode of operation.

It appears the statement that “some sixty percent” of health care costs go toward end-of-life care is a gross overestimate. Data from recent decades indicates that between twenty-seven and thirty percent of Medicare spending happens in the last year of life—half the expenditure over twice the time period of Langdon’s claim (Emanuel, et al). However, even this is an overstatement when looking at the general population, since end-of-life care makes up ten to twelve percent of the US’s total health care budget (Emanuel). Despite this exaggeration, the actual figures may still indicate a disproportionately high level of spending on end-of-life care. For example, while twenty-seven to thirty percent is far from a majority of yearly spending, it is nearly a third of the Medicare budget and covers only the five to six percent of Medicare patients who die in a given year (Emanuel, et al) Spending increases dramatically as death approaches; 40% of payments made during the last year of patients’ lives occur within the final month (Emanuel, et al). Part of this cause is obvious and inevitable. Many people, in their final years, months, or days, move residence to a hospital, nursing home, or some form of semi-permanent residence with round-the-clock care simply because it becomes difficult or impossible to execute this care from home. Staying in these institutions creates extra living costs for the patient or family, thus raising the costs associated with end-of-life care. It also seems logical that, given the progressively worsening condition of a dying person, costs would steadily increase given increasing treatments, and the increasing difficulty of maintaining a level of comfort with increasing pain. Because of these easily explainable cost increases, a different metric than cost alone is necessary to determine whether US end-of-life care costs are too high. A better way to measure this is to compare US expenditure to that of other countries. In a survey of over 39 countries, the US ranked 31st for cost of end-of-life care, receiving a score of 3.3 out of 10 on affordability (Economist). However, the *quality* of US end-of-life care is relatively high, gaining it a rank of 7th with a score of 7.8 (Economist). Looking at this data presents a conflict of interests and does little to resolve the efficiency question. While cost of end-of-life care is indeed high, attempts to reform the US end-of-life care system could end up compromising quality.

 Comparatively high end-of-life care spending in the US may simply be one manifestation of the US’s high spending on health overall. In other words, perhaps the proportion of money that flows toward end-of-life care itself is not the source of the problem, but rather is simply a result of the amount of money that is put into the country’s health care system as a whole. The US spends around twice as much per person on general health expenses compared with 23 other countries but yet allegedly lags behind most of these countries in health care results (Roche). This tells us that the high cost of our health care does not necessarily generate high-quality outcomes; therefore, the high quality rank of our end-of-life care may not be a result of the large sum of money that goes into it. There must be a way to curtail disproportionately high end-of-life care, given that other countries such as Australia and New Zealand rank highly both in quality and in cost of care (Economist). Perhaps this is facilitated by their differing political or economic climates, but the efficiency of their systems gives hope for the possibility of improvement of our own. However, past attempts to cut use of wasteful resources in end-of-life care have resulted in both effective and ineffective resources being reduced (Emanuel, et al). Instead of cutting costs and rationing resources, reform to the health care system may have to come from a structural change in the system.

To understand where the true inefficiency lies in the American end-of-life care, it is helpful to briefly explore both the historical and current mindset toward death and health care in Western culture. Twentieth century French historian Philippe Ariès explains that the attitude that prevailed in the West for the majority of human history was one that viewed death as something “familiar and near” (Ariès 11-14). While death may not have been something to rejoice over, it was accepted as an inevitable stage in someone’s life. Moving into the Middle Ages, evolving religious ideals began to shape the face of death. The idea of a final judgment became more individualized. Prior to this point, the religious population found peace in the idea that simply being members of their religion guaranteed them a spot in Heaven; the distinction between those sent to Heaven and those sent to Hell was a simple dichotomy between the religious and the non-religious. Now, however, this distinction became something individual—a final judgment applied only to one person based on weighing their good and bad deeds (51-52). Next, during the 16th to 18th centuries the depiction of death in artwork was often associated with erotic love. Ariès cites works of baroque theater such as *Romeo and Juliet* which connected themes of love and death, as well as *The Ecstasy of St. Theresa*, a sculpture which Ariès describes as “juxtapos[ing] the images of the death agony and the orgiastic trace”(57) (Figure 1).Like sexual intercourse, death came to be seen as a “break” from reality and from day-to-day life, a removal of sorts from the typical, the ordinary, and the known. As this idea spread, however, it lost the accompaniment of sexual imagery—and suddenly this view of death as a “break” transformed it into a deeply frightening thing (57-58). Death was now a separation from life, an irreversible departure from existence. More than fearing for one’s own nonexistence, attitudes toward death centered on a fear of others dying—a fear of losing loved ones (68). Then, in the mid-19th century, discussion of death in Western society became forbidden. This stemmed initially from the desire to protect a dying loved one from the emotional discomfort that knowledge of their own fate would bring. People began to avoid conversations surrounding the dead and the dying. The general trend toward repressing emotions in public in today’s culture contributes to the idea that society itself must be protected from the knowledge of death (85-86).

Figure 1

This idea of death as a forbidden concept, to be avoided at all costs, is still reflected in public attitude and even in the very literature that began this analysis. *Inferno* features a theme centered on human denial of death. Much of the book is a journey to stop the efforts of fictional scientist Bertrand Zobrist, who hypothesized that humans would cause their own extinction within a single century by overpopulating the earth. While according to Sienna this thesis was supported by reliable data, much of the medical community violently rejected his ideas. This was in part because of the inhumane solutions he proposed—stopping medical practice and creating disease in order to curtail the growing population—but also in part due to people’s natural tendency to deny the possibility of human extinction. When Sienna discusses this idea of denial of death, she calls denial a “critical part of the human coping mechanism” (Brown 214). She explains,

“Without it, we would all wake up terrified every morning about all the ways we could die. Instead, our minds block out our existential fears by focusing on stresses we can handle—like getting to work on time or paying our taxes”(214).

Even Langdon’s mistaken observation that “in the US some sixty percent of health care costs go to support patients during the last six months of their lives” contributes to the idea that this mindset is, in reality, very present in society. The fact that Brown presents this statistic as if it were fact shows people’s attitudinal aversion to death—it is, in fact, *believable* to the average reader that this inordinate amount of money would be willingly spent toward one specific type of health care, as long as this health care allows people to avoid discomfort and postpone death as long as possible.

Not only do members of current society suffer from fear of an unknown afterlife (or lack thereof), but this fear extends to the process of death itself. First off, family and close friends want desperately to avoid the emotional burden of death of a loved one. This fear of grief is incorporated into American capitalism in the form of commercialized funeral homes and embalmment— Ariès describes western society as viewing these embalmers as a sort of protection team against the emotional burden of death—“doctors of grief”. (Ariès 98) The other reason for fear of this transition is simply a concern for the comfort of the dying. Many people are afraid of either excessive or inadequate amounts of end-of-life care (Field). This fear reflects a level of distrust in the health care system—a worry that it will provide inadequate resources, and that it will fail to comply with patients’ wishes during end-of-life decision-making. This proves a valid concern, as somewhere between 60-70% of people are incapable of communicating their preferences when it comes down to decisions about limiting treatment (Center for Bioethics). These fears give us a basic idea of modern society’s motivation for avoidance and denial of the topic of dying.

Although it has been determined that the end-of-life care system is not as wildly inefficient as Brown indicates, it is clear that this system is not operating at peak efficacy. Its inadequacies must be addressed from a financial standpoint, as well as from an operational standpoint based on the democratic preferences of the American population. From an economic standpoint, the end-of-life care system can be looked at under the light of several different conceptions of utility, as economist Alan Haycox explains. First, health care can be looked at from a standpoint of economic cost-benefit analysis with societal welfare as the end goal. From this point of view, Haycox initially proposes that people in society seem willing to expend much more on palliative care2 than is reasonable assuming their aim is promoting the common good. Lower marginal benefits are gained from investments in a palliative care system than from investing the money into other parts of the health care system, indicating that the US’s spending on palliative care is too high to be economically efficient. To explain this discrepancy, however, Haycox posits a couple of ideas. First, he presents the idea of “private valuation” placed on goods and services in contrast to “societal valuation”. From the standpoint of an individual, and given the realization that their monetary resources will be of no use after death, the amount one is willing to spend in order to improve or extend their own life theoretically rises to infinity as death approaches (Haycox) (Figure 2).This, of course, assumes that individuals are purely selfish and rational, maintaining no consistency in their spending habits from earlier in life, and having no regard for the financial impact their spending might have on their family and friends during- and post-death. However, beyond this, Haycox provides additional analysis as to why investing money into end-of-life care might have unexpected utilitarian returns for society. These benefits include a feeling of peace for family and friends from the assurance that their loved one will have a “good death” with minimal suffering, as well as the emotional well-being derived from the security of high-quality end-of-life care for oneself, should it someday become necessary.

Figure 2

 In short, it is evident from multiple viewpoints that Americans are willing to spend high amounts of money on end-of-life care. The financial issue of this system is not one of excessive allocation, but rather is in congruence with the issues in the American health care system as a whole—patient affordability. If health prices are out of reach for an uninsured individual they may have to endure excessive suffering in the dying process. Solutions to this deal with the health care and the economy as a whole, not specifically with the end-of-life care system, and so will not be further discussed here.

 The operational problems in the end-of-life care system, though, lie in patients’ fear of inadequate or excessive care being given to them. This is fundamentally a problem of patient autonomy being respected. Some solutions to this are simple; since many people are deemed incapable of making decisions about end-of-life care when their time comes, it would improve the situation if their wishes were written out in a more timely and clear manner. Preferences of this sort can be written into people’s wills to make sure they are communicated properly and respected. Additionally, simply having these discussions with close, younger relatives would improve the problem and create a cycle of improvement by opening up more dialogue on the forbidden topic of death. Another way to improve patient autonomy is to shift the focus of end-of-life decisions away from doctors. While the US is known already for being particularly advanced in giving patients autonomy in end-of-life decisions (Sprung) and even has laws set up to check doctors’ power (Benbassat), how much choice a patient is given still varies considerably depending on the doctor (Benbassat). Even when doctors do not deliberately or directly control a patient’s fate, there still exists a semblance of paternalism in that doctors hold large amounts of power and influence over patient decisions by virtue of their knowledge and authority. This is problematic, firstly because a lack of autonomy alone tends to negatively impact health decisions. Studies have found that patients who ask questions and actively participate in their health care choices have better health outcomes and higher satisfaction with the care provided to them (Benbassat). Secondly, doctors’ high level of control over patient decisions means that health outcomes are arbitrarily controlled by the biases of individual doctors. One bias that factors into doctors’ decision-making is religion. Research shows that religion greatly impacts doctors’ end-of-life care decisions concerning limitation of therapy. In one study, Protestant or Catholic doctors as well as doctors with no religion were more likely to withdraw life support, whereas doctors who identified as Greek Orthodox, Jewish, or Muslim were more likely to simply withhold treatment. Other factors could also be seen to vary considerably based on religion of the physician, such as the median time from admission to ICU to the first limitation of therapy, median times from limitations to death, and the amount of discussion these decisions prompted with family (Sprung). In cases where patients’ religious values differ from their doctors’, the variability of practice based on religion means that doctors may make end-of-life care decisions that the patient would not have made themselves. Additionally, those patients whose religious affiliation does not line up with the majority culture in the region—those who either practice a minority religion in the area, or come from outside of the region itself—are more likely to belong to a culture initially marginalized by the region, and are more likely to be the victim of unwanted treatment or lack thereof due to religious inconsistencies. This only furthers the harms of the oppressive system toward many minorities. These problems can be solved by having medical education focus on making future medical professionals aware of this problem. It is necessary to develop training so that doctors are alert to their potential control and can take steps toward better communication with their patients and more patient control.

A full comprehensive model of a reformed end-of-life care system is beyond the scope of this paper. However, it has identified some potentially effective areas of change to focus on. The statistics of allocation within the health care system, as well as American attitudes and fears toward death, indicate that high spending on end-of-life care is not a problem; however, the cost of American health care itself may create an affordability barrier for many people. Addressing this barrier would do much to improve our system. Additionally, the system would benefit from increasing the amount of autonomy given to patients in end-of-life decision-making. This can be achieved through better communication within families surrounding the issue of death and end-of-life care, and by providing patient-autonomy-centered training to rising medical professionals.

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