Introduction:

The New Economy of Dying
Individuals in crises do not make life and death decisions on their own. Who shall be saved and who shall die is settled by institutions.

Mary Douglas, How Institutions Think

In the summer of 2011, a nurse at a California hospital sent the Office of Inspector General an impassionate complaint entitled “physician fraud.” She wrote about one of the hospital’s patients, an 87-year-old woman, describing her as “quadriplegic and in a vegetative state.” This woman, I later learned from her medical record, had been uncommunicative and bedbound for many years following a devastating stroke. Like many people in her condition, she developed severe bedsores, which at some point impelled her family to bring her to the hospital. After examining the woman and obtaining her family’s consent, one of the hospital’s surgeons removed her damaged tissue surgically and provided a course of intravenous antibiotics to control related infections. The nurse was livid: “I believe that to perform surgeries on an elderly vegetative patient is unethical and costly to Medicare,” she wrote in her complaint. “This patient was admitted […] with no hope to benefit from this hospitalization. […] [The hospital] and the surgeon, Dr. Wallace, should reimburse Medicare for this futile and unethical behavior.” The nurse also notified a hospital ethicist about this complaint. “Palliative care [italics mine] should have been asked in from day one,” she wrote and added, “I don’t actually think anything will happen. There will be no investigation, no penalty, because there is
just way too much money made off of the dying bodies of old people. So, my dilemma is, I get paid by this monstrous organization, which I think makes me as much of a whore as Dr. Wallace. It’s not a good feeling.”

Such misgivings are hardly new. Criticizing U.S. medicine for being aggressive has become a truism, and so has recognizing over-diagnosis, over-treatment, and over-spending as chief and stubborn maladies of the U.S. healthcare system. Explanations for these maladies are plentiful. Back in the 1950s, sociologist Talcott Parsons attributed them to a certain “American culture,” which encourages combative medicine. American physicians, Parsons wrote, are “trained and expected to act” in the face of disease, and patients and families want to feel that “something is being done” even when treatment has little to no medical benefit. Some 20 years later, Eliot Freidson concurred that U.S. physicians feel “impelled to do something, if only to satisfy patients who urge [them] to do something when they are in distress.” This interventionist “culture” has also drawn attention from journalists: “American medicine is aggressive,” wrote Lynn Payer, “American doctors want to do something, preferably as much as possible. [...] They often eschew drug treatment in favor of more aggressive surgery, but if they do use drugs they are likely to use higher doses and more aggressive drugs.”

Then there is the profit motive—a well-warranted target for much critical scholarship. The U.S. healthcare system is unique in relying on a private industry, which operates in several interconnected markets. Many actors in this industry—pharmaceutical companies, medical device producers, and some hospitals and private practitioners—increase their profit margin the more care they provide. A
wholesale economy, unprecedented in its scope, has emerged around diagnosing and treating disease. This economy pours enormous amounts of money into medical research and healthcare delivery, making extreme interventions routine and standard practice.\(^5\)

The problems arising from this economy are particularly pronounced near the end of life. At stake are life and death decisions—whether or not to treat a condition that may be terminal—which are as consequential as medical decisions can be. These decisions are significant financially, since they involve very expensive high-intensity care. But cost aside, providing such care to severely ill patients is morally and medically questionable. It is very hard, for example, to justify putting terminal cancer patients on mechanical ventilators and prolonging their lives, despite great suffering and virtually no chance of long-term survival.\(^6\) In 2009, however, 6.7 percent of Medicare cancer patients whose providers were paid fee-for-service received mechanical ventilation in the month before they died.\(^7\) Such figures make one wonder whether the combination of a capitalist industry, which profits from delivering care, and a culture that glorifies aggressive medicine, leads to what the California nurse intimated: dying patients have become victims of medicine’s professional hubris and corporations’ avarice. Locked in purgatory—incapacitated, seriously ill, not dead and yet not quite alive—they helplessly watch physicians muster cutting-edge technologies, which merely prolong their anguish.

This book, however, is not about this economy, but about its negation: a counter-economy, which aims to put this one in check. It is about clinicians like this nurse, who, far from being an isolated iconoclast, expressed sentiments that many
people and organizations propagate. It is about medical practitioners, ethicists, patient advocates, economists, and corporations, who built a social movement, then formulated a professional approach, then gave rise to another multi-billion-dollar healthcare economy, whose purpose is drawing lines on how far medical care goes near the end of life. The nurse referenced this movement in her complaint: hospice and palliative care.

The ideas and actual practice of hospice and palliative care I will analyze in detail throughout the book. For now, it would suffice to quote the formal definition of the American Board of Medical Specialties, which in 2006 recognized “Hospice and Palliative Care Medicine” as a subspecialty:

...Hospice and Palliative Medicine provides care to prevent and relieve the suffering experienced by patients with life-limiting illnesses. [Specialists work] with an interdisciplinary hospice or palliative care team to optimize quality of life while addressing the physical, psychological, social, and spiritual needs of both patient and family.\(^8\)

A most important part of this definition is what it does not include: curing disease and prolonging life, which it substitutes for minimizing suffering and maximizing the quality of life during the time patients have left. In the U.S., hospice care takes place outside of hospitals, while most palliative care happens within them.\(^9\) Hospice patients are people who physicians have already diagnosed as dying: by Medicare standards, this means having a predicted life span of six months or less. Hospices cease attempts to prolong these patients’ lives and treat them for comfort only. Palliative care patients, by contrast, are usually still in the hospital: many of
them are at an earlier stage of their disease and still receive care from numerous specialists, which almost certainly involves life-prolonging or life-sustaining measures. The goal of palliative care is to facilitate conversations between patients, families, and clinicians about whether patients’ illnesses are terminal, how close to death they are, and how much life-prolonging care they should receive, if at all. It is a specialty that negotiates and enacts limits on life prolongation.

This specialty has become a remarkable force in U.S. medicine. In 2015, 46 percent of the deaths of Medicare patients took place in hospice and some 90 percent of the country’s large hospitals had an operating palliative care service. A growing number of clinicians from other specialties encounter hospice and palliative care principles in their training, medical journals, conferences, and workplace; some of them internalize and apply these principles at the bedside. In media outlets, clinicians and advocates of hospice and palliative care frequently participate in conversations on end-of-life care as authoritative experts. Similarly to the growth in curative medicine and life-prolonging interventions, growth in hospice and palliative medicine has been lubricated with money: by 2017, Medicare paid 16.9 billion dollars to a largely for-profit U.S. hospice industry. The true size and significance of this economy are even greater if we take into account private insurers’ payments and the money saved by utilizing hospice and palliative care and avoiding costly life-prolonging treatments.

Two economies therefore face each other: one aims to prolong life and cure disease, the other focuses on facilitating “good death” and minimizing suffering; one extracts profit from hospitalizations, medical devices, surgeries, and medications;
the other profits from counteracting life-prolonging care and containing spending on it; one dedicates itself to saving life (or prolonging it), the other draws on the conviction that life in disability and suffering is not always worth living. People tend to think of the economy as the realm of technical, utilitarian, and somewhat unimaginative quid-pro-quo monetary exchanges. End-of-life care is one among many examples that economic life consists of much more: emotions, conflicting moral values, diverging professional philosophies, and dense social relations.\textsuperscript{13}

This book is an account of the counteracting economy, which I will call \textit{the new economy of dying}. It examines the history of this economy’s emergence and analyzes its current operations in three California hospitals. At the center of my analysis are hospice and palliative care experts and advocates, who have played a pivotal role in creating this economy, through connecting between moral views, professional stances, and financial interests. This involved much entrepreneurial work: hospice and palliative care protagonists have spoken to the interests of corporations, garnered endorsements from politicians, and solicited support from funders. They trained, wrote, and spoke to clinicians of nearly all areas in medicine, trying to change how they practice medicine when treating severely ill patients. And they appealed to the general public and increased popular participation in the new economy of dying, mobilizing current patients, future patients, and their family members to doubt the virtue of life-prolonging treatments in severe illness.

Studying this new economy of dying is important because it has greatly impacted how people die in the U.S. The topic, however, also has broader significance. For one thing, it teaches us a general lesson about how economies
emerge in morally contested areas and on the role experts can play in this emergence. Moreover, studying the effort to draw lines on life-prolongation sheds light on a major transition into an era where humanity ponders upon the ultimate reach of progress. Discussions of boundaries and limits—scientific, fiscal, and environmental—are gradually taking the place of the endeavor to advance, grow, and conquer new grounds, which has guided modern societies for several centuries. Death is illustrative, in this respect: as Søren Kierkegaard wrote, death “has its own earnestness,” since it is the absolute limit on being, the human ability to control life, and the effort to transcend nature. Negotiating when to stop prolonging life means delineating this limit. It means placing a boundary on the reach of human agency—an undertaking of uttermost existential significance.

The enormity of the topic notwithstanding, how U.S. politicians, professionals, and laypeople address it is specific to our time and place. In the spirit of Cicero, who accused Cato of speaking in Senate “as if he were living in Plato’s Republic instead of this cesspit of Romulus,” my goal is not to develop ideal and abstract philosophical discussions on human existence, agency, boundaries, and limits. I leave these to ethicists. This book, rather, follows how people and institutions enact limits in the concrete reality of U.S. medicine, polity, and economics: in Congress and daily newspapers, in the training of medical practitioners and scholarly journals, in hospital administrators’ offices and by patients’ deathbeds. These are sites where a project of great proportions takes place: medical practitioners, policymakers, academics, patients, and family members draw and manage the most categorical limit on human existence: death.
Three Quandaries of Death

When asked about my research, I say that I study death panels. The term is manipulative, to say the least. But it captures the challenges and tensions in setting limits at the end of life in the most poignant and provocative way.

Throughout much of 2009, Americans ferociously debated the Affordable Care Act—a cornerstone healthcare legislation that became known as “ObamaCare.” One of the debate’s pinnacles was a provision, which paid physicians to discuss with patients what life-prolonging and life-sustaining treatments they would and would not want if their medical condition deteriorated. Sarah Palin, former Republican vice-presidential candidate and an outspoken public figure, vehemently opposed. First on her Facebook page, then in the open-editorial section of the Wall Street Journal, she bashed the intention to save an estimate of $400-500 million through such discussions and said it would amount to “death-panels.” This statement echoed a general point the Republican Party was pushing during the period: about a month earlier, House Minority Leader John Boehner and Representative Thaddeus McCotter wrote that the provision “may start us down a treacherous path toward government-encouraged euthanasia.” President Obama, on his end, responded that the provision would not “pull the plug on grandma.”

Quickly debunked and scolded, the death-panel allegation even won the disreputable “lie of the year” award. It was, however, a very effective lie: a 2011 poll found that 23 percent of U.S. adults thought that the Affordable Care Act gave government the power to make end-of-life decisions on behalf of seniors and 36
percent were unsure. The Obama administration had to remove the provision from the Affordable Care Act, and when it tried to pass a similar regulation a year later, it failed again. In the spring of 2012, as I was shadowing him in a hospital, a palliative care physician told me he could not bill for a conversation he just had with a Medicare patient about end-of-life care. ‘This would have been the death-panel!’ he said sarcastically and wrote in the medical chart that he managed the patient’s pain, which was billable. In another palliative care service, death-panels inspired moments of dark humor: when the service prepared for a staff picnic, one physician suggested printing team shirts with the writing “I Work for Obama’s Death Panel” on the front and “Ask Me about Your Granny” on the back. The death panel became a grotesque trope, which painted discussions of policy and care for the dying in macabre colors.

The success of this grotesque is revealing. Palin touched upon three major controversial quandaries that the new economy of dying engenders: how far to go prolonging life; how much money to spend toward this goal; and who should make these decisions. Her allegation was evidently false, but it can serve as a sociological Rorschach test, which evinced (and capitalized on) real moral concerns people have about these quandaries: that emotionally excruciating life-and-death decisions would draw on rigid bureaucratic criteria; cold monetary calculations would determine who would live and who would die; and “the state,” as a force majeure,
would violate individuals’ autonomy and terminate life-sustaining care unilaterally.\textsuperscript{25}

Since the 1960s, social science scholars have produced multiple accounts on death and dying in the U.S.\textsuperscript{26} Yet the main period that I study—the early 2010s—is different from the periods they examined. First, it is a period when these three quandaries congealed into a single political controversy. The first and third quandaries—when life should (not) be prolonged and who should decide on this—have been at the center of public, political, and ethical discussions for several decades. In the 1980s, for example, the U.S. media covered extensively the lengthy campaign to disconnect vegetative Nancy Cruzan from artificial nutrition, and in 1990-2005 right-to-die activists clashed with conservative advocates over the similar case of Terri Schiavo.\textsuperscript{27} It was only in the 2000s and 2010s, however, that questions of cost and finance became integral to such discussions, to the extent that a California nurse could argue in a complaint that prolonging the life of an unconscious patient was both “unethical and costly to Medicare.”

Second, by the 2010s, the medical profession assumed an unprecedented role in addressing these quandaries. Although people have been dying under medicine’s purview for over a century,\textsuperscript{28} medicine did not offer specialized treatment for the dying until the last few decades. Physicians used to treat patients with the goal of avoiding or postponing death, and when it became clear to them that death was inevitable, they lost interest in the patient.\textsuperscript{29} The development of hospice and palliative care, however, changed this situation: it made death and dying major
objects of clinical interest, and discussions of the proper ways to manage them medically, ethically, financially, and policy-wise flourished.

This change is palpable and consequential. In the fall of 1965, Elisabeth Kübler-Ross, a young psychiatry professor who would soon become the public face of the U.S. hospice movement, began interviewing dying patients about their feelings, experiences, and needs. The clinicians who treated these patients were hostile to her project, and some of them denied its very legitimacy:

My phone calls and personal visits to the wards were all in vain. Some physicians said politely that they would think about it, others said they did not wish to expose their patients to such questioning as it might tire them too much. A nurse angrily asked in utter disbelief if I enjoyed telling a twenty-year-old man that he had only a couple of weeks to live! She walked before I could tell her more about our plans.30

Despite this resistance, Kübler-Ross’s book, On Death and Dying, came out in 1969 and became an instant bestseller. Peppered with a myriad of psychological and sociological observations, it issued a riveting J’accuse of modern medicine, condemning it for what the author and many of her contemporaries called “death-denial.” This denial, Kübler Ross argued, had devastating consequences: “traditional” medical professionals were untrained and unprepared to talk to terminally ill patients about death and could not help them accept their condition. Instead of acknowledging death and supporting the dying, clinicians treated death as a professional failure, clung onto protocols, tried to treat the untreatable, and
caused unnecessary suffering to the terminally ill. The entire medical system, Kübler-Ross argued, was deaf and blind to dying patients’ needs and wishes: many of the patients she interviewed knew they were dying and had no interest in pretending they still had hope for cure. Pretending, however, was the main thing clinicians had to offer them.31

When I launched my own research, however, I encountered a very different reality. For one thing, death was a legitimate—and indeed, encouraged—research topic. Without exception, all of my interviewees knew what I meant by saying that I studied “end-of-life care,” and they all agreed it was an important project.32 Responding to my interview request, one ICU physician complimented me for having found “such an interesting topic to study.” She and many of my other interviewees expressed hope that my work would further “end-of-life care” and increase awareness to the problems care for the dying posed. Death was also high in demand in my academic community: anonymous reviewers in sociological journals wrote that the topic demanded “close attention by policy-makers and academics alike” and that my project “addresses an important and timely topic.” In job interviews, senior faculty who have faced the challenge of caring for aging parents or spouses and confronting “end-of-life decisions” reflected on how their own experiences compared to my findings. Harvard University Press offered me a book contract before I even completed my dissertation, and its social science editor said that the board of editors only wished they could publish the book earlier. Virtually any person that I talked to about my work—interviewees, colleagues, and random
people who sat next to me on flights—agreed that studying death and dying was “important,” “interesting,” and “timely.”

The widespread agreement that “death and dying” pose social and policy problems, which invite research and beg solutions, is the outcome of a process. As all social problems, death and dying became problematic because certain people constructed them as problematic and promoted particular ways of thinking, speaking, and writing about them. Hospice and palliative care protagonists—Kübler Ross among them—were principal actors that promoted this construction. They were not the only ones: bioethicists and right-to-die advocates, for example, had important roles as well, and they will make frequent appearances throughout the book. But hospice and palliative care has been the most consolidate cache of organized clinical knowledge and practices, which framed the problem of death and suggested solutions. The essence of the problem, as advocates defined it, could be summarized in the following way: medicine treats severely ill patients too aggressively, leads to immense suffering and excessive spending, and does so without taking these patients’ wishes into account. In the popular media and best-selling books; among health economists, physicians, journalists, and laypeople—the corollary conclusions have been recited: limits at the end of life should be set, “aggressive” and “extraordinary” measures to prolong life should be moderated, end-of-life spending should be controlled, and patients’ wishes should be respected and followed.

I do not seek to criticize this stance, but to turn an inquisitive eye toward it. First, I argue that this view has social origins: the argument that prolonged hospital
deaths are morally and financially problematic does not explain how people came to see them as problematic, let alone how they problematized them in the particular ways they did. (Similarly, there are countless critical studies on poverty, but very few ask how poverty came to be regarded as problematic.37) Second, I show that this view has already impacted health policy, much of the medical profession, and people’s attitudes toward death in general. Institutions, such as hospices, and professional orientations such as palliative care, have reshaped professional and public views of death. They transformed Kübler Ross’s J’accuse into a new set of expectations from clinicians (and patients) on how to behave when death approaches. They valorized, allowed, and encouraged certain attitudes toward death, while disparaging, disallowing, and marginalizing others.38 The new economy of dying that they enacted put forth new standards for good, normal, and legitimate care—a new ars moriendi,39 which governs how people die and merits renewed examination.40

Dying, Economized

I use the term economization—and its derivatives economized and economizing—to unravel two logics that underlie the new economy of dying. This term is multidimensional and carries multiple meanings and connotations.41 Instead of setting some of them aside and adopting others, I will deliberately embrace its polysemy to illuminate the new economy’s compounded nature.

A first meaning of economization originates in ancient Greek philosophy. Oikonomia—the art of household management—was of much interest to classical
philosophers. Oikonomia’s fundamental premise was the abundance of natural resources. Ancient Greeks regarded nature as providing more than what people needed for subsistence: “it is the business of nature to furnish subsistence for each being brought into the world,” Aristotle wrote. Economizing meant embracing a prudent disposition toward this abundance, so that one could use the surplus for non-material ends, such as friendship, politics, and philosophy. In discussing the new economy of dying, I will employ the term economized dying to characterize prudence, which people adopt in a similar fashion. Economizing dying would mean embracing a controlled and restrained self-conduct toward the abundant medical interventions that modern medicine makes available.

A second and more widespread meaning of economization originates in neoclassical economics. Economic theorist Lionel Robbins defined economics as “the science which studies human behavior as a relationship between ends and scarce means, which have alternative uses.” This definition takes scarcity, not abundance, as the defining feature of economization and sees economic behavior as instrumental and rational: people weigh desired alternatives and choose which ones best serve their goals within the limited resources that they have. Robbins and other neoclassicists applied this logic of economization to virtually all domains of human life. They transformed the rational individual actor into a prototype, arguing that people, households, states, and organizations of various kinds should be modeled, governed, and evaluated as such actors.

Critical theorists have used the term economization to characterize these imperial tendencies of economics and the consequent spread of instrumental
rational calculations into new domains. Examples range from macroeconomic policies to micro social interactions: states, which manage their populations and industries in order to increase their Gross Domestic Product; law schools, which formulate future plans with the goal of advancing in the ranking of the U.S. News and World Report; individuals who make financial decisions while taking into consideration how they affect their credit score; teenagers who try to maximize the “likes” they receive in social media websites; and scholars who dedicate their careers to publishing articles in highly ranked journals and maximizing their citation count—illustrate a pervasive trend, in which people and organizations internalize the neoclassical form of economization and embrace calculated, individuated, and rational self-conduct. In the realm of end-of-life care, economization in its neoclassical sense means formulating the quandaries of dying as a neoclassical problem of optimization. This involves representing patients as individuals, who possess preferences, confront several alternative treatment options, and need to choose how to maximize their utility under a dual state of scarcity: the finitude of resources in the healthcare economy and the inherent finitude of their life.

Drawing on both forms of economization, the new economy of dying operates as what Michelle Murphy called a “regime of valuation”: a set of patterned judgments of worth and value, which surrounds the end of life. Most defining of this economy is the judgment that, when it comes to the end of life, less is oftentimes better. This judgment is moral and financial at the same time: on the one hand, it casts doubt on the moral (and medical) value of providing life-prolonging care to
severely ill patients; on the other hand, it advocates to economize spending on this care. While traditionally, modern medicine targeted disease with maximal technological and scientific capacity, the new economy of dying presents a rationale to economize dying: restrain, adjust, and appropriate medical interventions, based on evaluations of their morality, cost, and utility. Applying this rationale, however, is full of challenges and contradictions.

Economizing in Practice

Virtually all developed countries have faced rises in medical spending and healthcare utilization and adopted measures to control them. The U.S. case, however, sheds light on the specific challenge of doing so through a market. Countries with nationalized healthcare systems could economize through centralized mechanisms, stipulate clear standards for rationing, and require that hospitals and clinicians follow them. An exemplar is the United Kingdom’s National Institute for Health and Care Excellence (NICE), which set £30,000 as the maximum recommended spending limit for treatment that prolongs life by one healthy life-year and subjected all exceptions to additional review. By contrast, the U.S. healthcare system has weak central and direct mechanisms of governance. Decisions on treatment are distributed among numerous organizations—insurers, hospitals, and various physician groups—each having different policies and considerations. When one of them does not approve of a treatment, patients may go to another that does. (Knowing this, pharmaceutical companies have long directed much of their marketing effort to patients). U.S ethicists, who attempted to define
what would count as non-beneficial and “medically futile” care failed to establish consensus; their critics specifically targeted the idea of enforcing unilateral definitions of futility on patients. Even Medicare—the federal program that insures patients over the age of 65—does not set clear limits on utilization and spending, in great part due to the country's ruptured political system, where such controversial measures are quickly exploited for political gain.

In the absence of a major centralized governing power, economization in the U.S. has assumed a diffused form, which draws on changing the intuitions and behaviors of individual patients, clinicians, and organizations. Limits at the end of life are not imposed extrinsically, as prohibitions that bind people, but intrinsically, through pervading people's professional, financial, and moral outlooks. Analyzing how people and organizations enact limits at the end of life therefore requires examining empirically how this pervasion has occurred: how the new economy of dying has won hearts and minds, making many clinicians, hospitals, administrators, and patients view limits at the end of life as moral, rational, and necessary.

This book does so by analyzing the history of hospice and palliative care and observing the contemporary practice of palliative care. Drawing on both primary and secondary historical sources, I examine how the ideas and practices that underlie the new economy of dying developed over time and how they became influential in U.S. medicine and the U.S. society at large. I surveyed books, articles, and reflective essays of hospice and palliative care advocates; hundreds of editorials, magazine and newspaper articles on end-of-life care; all Congressional hearings on the topic; publications and activities of advocacy organizations; and
academic research that the thriving community of hospice and palliative care has produced since the 1970s.

Between October 2011 and October 2012 I joined three California palliative care services to observe how they limit life prolongation at the bedside. I shadowed members of these services as they discussed diagnoses, prognoses, and care plans with seriously ill patients, their family members, and other hospital clinicians; I sat at meetings where palliative care practitioners told tearful children, spouses, and at times parents that their “loved one” was terminally ill or dying; I witnessed the often-slow negotiation over withdrawing treatment that kept this loved one alive; I stood by patients as they were taking their last breaths; I watched and listened to palliative care clinicians interact with other specialists, who disagreed with them on a patient’s prospects for recovery; and I interviewed 80 physicians of numerous specialties, social workers, nurses, chaplains, and administrators, who dealt with death in their day-to-day work.

With this mixture of historical, interview, and ethnographic data, I shed light on the different outlooks—professional, financial, and moral—that underlie the economization of dying in public discourse, among clinicians, and at patients’ bedsides.

The Professional Outlook

First and foremost, the economization of dying has hinged on changing professional views on end of life care and fostering a medical intuition that life-prolonging care in severely ill patients should be moderated.
This intuition negated U.S. medicine’s long historical trajectory of expansion. Organized medicine obtained virtual monopoly over U.S. healthcare services around the turn of the twentieth century. At the height of the modern age, when trust in science peaked, the medical profession drew its authority from a combination of dependence and social legitimacy: physicians did not have to force people to use their services – people did so voluntarily, out of need and conviction in medicine’s powers. The ethos of scientific progress opened the door to boundless professional ambition. Medicine’s jurisdiction expanded, and “labels of ‘healthy’ and ‘ill’” became “relevant to an ever-increasing part of human existence.” Within its jurisdiction, medicine’s interventions multiplied and intensified; by the last decades of the 20th century, the medical profession seemed to offer patients some treatment or another, almost regardless of their condition. When one line of chemotherapy failed, oncologists could offer a second, third, and even fourth lines; when one’s kidneys decompensated, nephrologists could put her on dialysis; when the function of livers, hearts, lungs, kidneys, or pancreas declined, the possibility of transplant surgery was available; and when a person’s heart and lungs stopped there were emergency care interventions—such as cardiovascular resuscitation—which could “bring them back to life.” As philosopher Giorgio Agamben suggested, death has become epiphenomenal to medicine: seemingly, death occurs only when physicians withdraw their interventions and allow it to occur.

Reflecting on the development of Intensive Care—a most emblematic medical frontier—sociologist Robert Zussman observed that “criticisms of intensive care—or, more precisely, of what goes with intensive care—are almost as old as the units
themselves.\textsuperscript{67} This argument applies to other medical specialties as well: oncology, surgery, and cardiology introduced innovations that were quickly reflected upon as mixed blessings, since they prolonged human life at the cost of great suffering. Throughout the 1960s and 1970s, numerous critics rebuked medicine for objectifying patients and using them as mere tools of scientific research: “once a hero, the doctor has now become a villain,” observed sociologist Paul Starr.\textsuperscript{68} The modern hospital attracted much criticism as well: “clothed with an almost mystical power, yet suffused with a relentless impersonality and a forbidding aura of technical complexity,” hospitals and the medicine practiced in them became symbols of dehumanizing professionalism.\textsuperscript{69}

The hospice approach very much emerged from this criticism.\textsuperscript{70} At times explicitly anti-professional,\textsuperscript{71} hospice pioneers promoted intuition, emotion, and personal attachment between patients and caregivers, and valued singular relationships—as opposed to standardized guidelines—as the most essential features of caregiving.\textsuperscript{72} The goals hospices set for themselves—assisting dying people in accepting death and helping them pass away comfortably and with dignity—turned medicine’s traditional goals on their heads. They replaced the effort to beat physical decline and postpone mortality with an embrace of death as a natural phenomenon.

Ironically, however, as hospices developed, their backlash against professionalism transformed into a professional approach.\textsuperscript{73} It made death and dying an object of great interest for a burgeoning community, which similar to what sociologist Steven Epstein observed in the case of AIDS, involves “doctors and
researchers, service providers and grassroots educators, lawyers and writers, politicians and policymakers—a complex of individuals, groups, and formal organizations.” Just like cancer, heart dysfunction, child medicine, infectious diseases, and intensive care, death and dying became a realm whose management required unique interventions, skills, and expert knowledge. The “correct” way to treat terminal patients became the hospice way: discussing how to phase out life-prolonging treatment, minimizing patients’ physical and emotional suffering, and helping patients reach acceptance.

In the following decades, the professional jurisdiction of hospice practitioners expanded. Palliative care, which developed from hospice in the 1990s, had the goal of starting conversations on death earlier in the disease process, before patients began dying and when they were still in hospital. Its influence gradually extended to general medicine: primary care physicians are today encouraged to talk to patients about end-of-life care and recommend that they plan for it even if they are healthy.

This professional development of hospice and palliative care is one component of the push to economize dying. Hospice and palliative care set forth a medical rationale that puts in check intentions to prolong the lives of seriously ill patients. This rationale stresses that it is morally imperative to question doctors, who pursue treatments that have little chance of succeeding, and to save patients from prolonged and torturous dying processes. Hospice and palliative care clinicians who work inside and outside of hospitals, and hospice organizations, which provide
designated care for the dying, spread a professionally and morally grounded way, which pushes to economize dying from within the medical profession.

The Financial Outlook

The second component of economized dying is fiscal: it is the notion that too much is being spent on people who approach the end of their life. The solution here has been economizing dying financially: scrutinizing, then reducing expenditure on end-of-life care.

Today’s clinicians and hospitals operate in a fundamentally different economy than the economy of the 1960s. The post-WWII decades were a period of medical expansion in the U.S.: following the Hill Burton Act (1946) and against the backdrop of great economic prosperity, the number and size of hospitals increased, new medical schools opened, medical specialization accelerated, and physicians’ fees grew rapidly. The growth of the private insurance market and the enactment of Medicare and Medicaid meant that unprecedented amounts of money became available for healthcare. The commercial, fee-for-service healthcare market of the period created incentives for physicians and hospitals to increase the reimbursable care that they provided, and by the early 1970s there was evidence for overtreatment.80 “In a short time,” Paul Starr observed, “American medicine seemed to pass from stubborn shortages to irrepressible excess, without ever having passed through happy sufficiency.”81 The physicians and hospitals fighting to prolong life in all circumstances had direct financial incentives to do so.
Evidence that over-treatment still exists in the U.S. healthcare system is abundant.\textsuperscript{82} As the California nurse's complaint letter suggests, some suspect that financial interest drives this over-treatment.\textsuperscript{83} Yet since the 1970s, the U.S. has gradually moved in the opposite direction: policymakers have focused on containing and controlling the increase in spending on healthcare, eliminating futility, and adopting mechanism of accountability.\textsuperscript{84} On the macro level, they have completely failed: U.S. expenditure on healthcare has climbed steadily, reaching the unprecedented and internationally incomparable rate of 17.9 percent of the GDP in 2016. Still, the multiple reforms to counteract this rise left an impact on day-to-day medical practice: managed care organizations pay many providers capitated rates and incent them to limit utilization;\textsuperscript{85} revisions in the Medicare and Medicaid codes limit payment for hospitalization days and pressure hospitals to discharge patients early;\textsuperscript{86} health corporations adopt cost-effectiveness standards and encourage physicians to meet them; and insurance companies send case-managers to visit hospitals, review patients' charts, and decline payment for treatments that they deem unnecessary.\textsuperscript{87}

In this context, the end of life has become a particularly intriguing site of financial valuation and cost-containment. Health economists regularly produce estimates of how much the nation spends on patients in the last months of their lives,\textsuperscript{88} and newspaper editorials debate the necessity and futility of this spending.\textsuperscript{89} Ethicists suggest ways to determine what level of spending near the end of life would be just and appropriate,\textsuperscript{90} and people speak of a duty to limit end-of-life spending for future generations' sake.\textsuperscript{91}
The end of life has become a realm where moral, professional, and financial values interact with each other in intricate and somewhat unpredictable ways. Financial calculus in the area became entwined with moral calculus: the further hospice and palliative care advocates went doubting the moral value of prolonging life in severe illness, the more futile and inefficient it seemed from a financial perspective. By presenting hospice and palliative care as a better and cheaper way of care, advocates connected policymaker’s interest in controlling spending and corporations’ interest in minimizing their cost with the moral endeavor to limit life-prolongation.

The palliative care services that I studied ethnographically consulted on many cases of patients or families who hesitated to sign “Do Not Resuscitate” (DNR) and “Do Not Intubate” (DNI) forms; patients who stayed in the hospital for long periods and whose medical condition did not seem to improve; patients who repeatedly came to the hospital for chronic illnesses or infections; and patients with terminal diseases, such as cancer, HIV, and heart failure, in their final stage. All of these patients were potentially expensive for hospitals: their illnesses were likely to result in long hospital stays, whose costs insurance companies were not fully covering. In the 1960s, allowing such patients to die in hospital was common. Glaser and Strauss’s classical account from the period, *Time for Dying*, noted that “unless a person dies abruptly [...] the dying trajectory includes a stage of ‘last days’ and perhaps even ‘last weeks’” that are spent waiting and preparing for death in the hospital. The current healthcare economy has made such waiting periods costly, and many hospital administrations funded palliative care services in hopes that they
would encourage seriously ill patients to reflect critically on their desired treatment and help discharging them elsewhere.\(^94\)

The push to economize dying has therefore been financial, moral, and professional. During the decades (1960-1980s) that medicine drew criticism for over-treating patients who had lost realistic hope for cure, people also criticized it for over-spending on these patients and driving the healthcare system and the entire U.S. economy bankrupt. Hospice and palliative care became a moralized financial solution—a way to treat the dying better and more efficiently, which spoke to policymakers’ and corporate administrations’ concerns. Yet economizing remained difficult, since it required the consent of the patients themselves.

Economized Subjects

Shortly after I began fieldwork, I sat for coffee with Nick, a retired hospice and palliative care physician. ‘Things have changed,’ he told me. ‘It used to be that families and patients were the ones who pushed for less care, and doctors were the ones who wanted to treat as aggressively as possible. Now, it’s usually the doctors who want to treat less and the patients who insist on getting more treatment. The culture of the hospital is screaming, “stop,” but many patients just don’t want to.’

Although I will qualify these observations later in the book, I find them generally accurate.\(^95\) In my fieldwork, I discovered hospital environments that were far more attentive to patients who wanted to eschew life-prolonging care than the environments Kübler-Ross described. The palliative care clinicians that I studied were important in facilitating this change: walking in Kübler-Ross’s footsteps, they
actively advocated throughout their hospitals against overly aggressive life-prolonging treatment and for respecting wishes to relinquish acute care. As Nick observed, however, the bulk of their day-to-day work involved conversing with patients and families, who were open to aggressive medical interventions that medical teams and hospitals were reluctant to give.

This inversion of clinicians’ and patients’ stances on end-of-life care—from a situation where many patients pled with doctors to withhold life-prolonging treatment and allow them to die, to a situation where many doctors pled with patients to accept their terminal condition and “let go”—is highly intriguing. It indicates a shift in the center of gravity of economization: much of the current healthcare system is oriented toward encouraging patients to accept death and forgo life-prolonging treatment, even when they initially hesitate to do so.96 At first blush, this seems all too similar to the notorious death-panels allegation—only that Palin’s provocation was far too shallow to capture this economy’s true character.97 What makes the new economy of dying so powerful is that, unlike the death-panels imagery, it does not impose external limits on patients, but relies on their consent; it does not base itself on the oppressive power of states or corporations, but on grassroots mobilization of clinicians, patients, and families; and it does not force impersonal standards on people, but acts through people’s own moral conviction that they are doing the right thing.98

Individualism, as Bellah and his coauthors put it, is “the first language in which Americans tend to think about their lives.”99 For much of the twentieth century, critics of the medical profession targeted medicine’s violations of people’s autonomy
and individuality. The medical gaze, the argument went, structured medical practice as a spectacle, not a dialogue; clinicians treated patients as bodies and not people, objects and not subjects. Critiques of this power-dynamic gathered steam during the 1960s and 1970s, when the patient-rights movement mobilized people against medical authority. One outcome of this mobilization was a reconfiguration of the medical gaze—a shift that bioethicists, who had a major role in this shift, described as a transition from *medical paternalism* to an orientation that focuses on *patient autonomy*. Medicine adopted a wide array of professional practices, which encouraged patients to express themselves, reflect on their condition, voice their fears, and participate in decisions. It enshrined patients as “authors of their own lives,” who are capable of “controlling, to some degree, their destiny, fashioning it through successive decisions throughout their life.” The main way to pursue and protect the rights of individual patients was facilitating choice: Advance Directives, living wills, and other forms and documents recorded patients’ wishes and preferences; declarations such as *A Patient Bill of Rights* (1973) and laws such as the *Patient Self-Determination Act* (1990) established the right of individual patients to know and influence the treatment they receive; more than just allowing patients to voice themselves in the clinic, medicine needed, demanded, and incited them to speak.

This focus on the individual patient, and the proliferation of clinical practices and legal structures geared toward making people reflect, express themselves, and choose, signals the coming of age of a new form of medical power. The question, in this context, is not how this new form of power liberates people from medical
authority, but how it enables certain patterns of self-expression and self-reflection, disables others, and prompts people to define and voice themselves in new ways.¹⁰⁷

Palliative care practitioners face a key challenge, which Nick highlighted above: while the new economy of dying has grown, making much of the U.S. healthcare system lean toward economizing dying, many patients and families hesitate to participate in economization and relinquish life-prolonging care. The push to economize is therefore often at odds with the wish to respect patients’ sovereignty and not impose decisions on them. A palliative care physician, who doubled as the director of her service, described this tension explicitly:

If [a family] would feel that “we put [mom] in the grave and we’re throwing dirt on her and she’s still alive [...]”, it’s hard to tell me that we should stop. If you look at it from resources – yes, I get that. And can you do this on each person? No, we’ll go bankrupt. We already are. [...] You do your best communication, you’re hoping that they understand, but if at the end of the day that’s how they feel... Yeah, you can pull out ineffective care policies and probably win, but I wouldn’t sleep well. I don’t think palliative care should have that agenda, to stop all this stuff on everyone because it’s not going to work, ultimately. We have to go where they are. [...]  

Q: There’s a possibility that patients and families will be feeling that—  
A: We might be saving two bucks, instead of really, really facing something that is inevitable [...]. We have to be careful [...], what do we say to them?
Q: What *do* you say to them?

A: Yeah, what’s the message? [Sarcastically:] This is the best we can do, and it’s cost-effective, and you know, at least you won’t suffer?

Like this physician, most of the clinicians I interviewed and shadowed considered economization appropriate and necessary, but were reluctant to enforce it when patients resisted. Palliative care’s way to address this tension was transforming patients (or their representatives) into agents of economization. Palliative care clinicians did not coerce economization on patients, nor did they employ simple persuasion techniques that convinced patients in the benefits economizing would have for them. Rather, they exercised what Nicholas Rose called a *conduct of conduct:*[^108] they interacted with patients as they mulled over their condition, digested it, and formulated their thoughts—in ways that increased the probability that patients would willingly endorse economization as their own value.

Palliative care practices maintained a delicate balance between force and consent; to paraphrase Antonio Gramsci, they drew on power that did “not overwhelm consent,” but was backed by it.[^109] Empowering patients—helping them articulate themselves, express their wishes, and have them followed—was not a mere masking of oppressive clinical (or corporate) power.[^110] Nor did it make patients autonomous individuals, liberated of all medical power. Facilitating patients’ self-expression was itself a form of medical power, since patients and families did not articulate themselves alone: they expressed their values and consolidated their preferences and stances in family conferences and bedside conversations, where clinicians played a major role.
When successful, the outcome of meetings between palliative care clinicians, patients, and families led to a general agreement not only about what a patient wanted, but also about who the patient was.111 If the patient herself leaned toward economizing dying, reasoned actively on what she did and did not want to do, and communicated it to the doctors, there was no need to force economization on her. The patient became an economized—and economizing—subject. 112 In Louis Althusser’s terms, clinicians interpellated patients by recognizing them as reflective and capable beings and inducing them to think and speak of themselves in certain ways.113 The new economy of dying operated not only through clinicians’ moral and professional sense and administrations’ financial calculations, but also through the most personal and intimate ways people thought of their and their family members’ wishes, hopes, and personalities.

The three hospitals I studied ethnographically were located in a single metropolitan area: “Public Hospital” (or “Public”) was the area’s safety-net institution; “Private Hospital” (or “Private”) was owned by a large private not-for-profit corporation; and “Academic Hospital” (or “Academic”) was a university medical center. I did not find significant differences in how clinicians practiced palliative care in each of these hospitals—a possible testimony to the standardizing power of professional education.114 However, since the hospitals treated markedly different patient populations (see methodological appendix), studying them allowed me to see how the new economy of dying operated on different patient populations. As I will show in the book’s empirical chapters, I found that economization was most likely to be successful, smooth, and effective with populations that we generally
recognize as privileged: middle class, highly educated, and Caucasian. The people who consented to economize their own dying became part of the new economy of dying; those who resisted it were likely to collide with clinicians who felt they were giving them futile treatment. Both groups, however, experienced the impact of the new economy of dying, which has become sizable and significant enough to influence U.S. deaths in general.

Clearly, hospice and palliative care have not achieved complete dominance over managing death and dying in the country. Other patterns of care for the dying still proliferate—from “heroic” medicine, where patients die in Intensive Care Units (ICUs) receiving life-support until their very last moments, to “death with dignity” (or euthanasia), which several states have made legal. Many deaths, particularly “heroic” ones, occur without palliative care clinicians ever being consulted. At the same time, the possibility of consulting a palliative care specialist, or moving a patient to “comfort care,” is ever available. Even when physicians do not mention palliative care to patients, federal regulations require, for example, that they inform patients about their right to refuse treatment and fill out an Advance Directive—two rights that hospice and palliative care clinicians have promoted and drawn upon for decades. The new economy of dying has therefore become pervasive and nearly inescapable: structured into formal law and informal institutions, it impacts even those who resist or ignore it.

Structure of the Book
The book has two parts. The first (chapters 1-3) outlines the emergence of U.S. end-of-life care and the drive to *economize dying*. This analysis partly draws on historical data; I also included ethnographic and interview data in each chapter, which show how the historical trends that the chapter outlines manifest in contemporary hospitals. The book’s second part (chapters 4-5) is ethnography and interview based: it documents palliative care practice at the bedside and shows how palliative care works to economize patients’ agency.

The first two chapters analyze the professional, institutional, and policy dimensions of the new economy of dying. Chapter one examines how the professional outlook of hospice and palliative care informed economization. It follows the development of the hospice and palliative care expertise and the emergence of end of life as an object of clinical management. It outlines the history of the U.S. hospice and palliative care movement, its expansion and institutionalization, and its success to spread and articulate professional doubts over the benefit invasive treatments attain when treating seriously ill patients. Chapter two focuses on how death and dying became financially significant. It analyzes how the end of life drew the interest of economists, administrators, and policymakers who viewed the end-of-life care as a domain where cost saving could be achieved.

The third chapter analyzes how dying patients’ and clinicians’ positions on end-of-life care have changed historically, based on data from an archive of a hospital ethics committee. I show how over the course of its history, the bioethics committee became more preoccupied with patients (or families) who demanded more life-
prolonging treatment than their doctors felt comfortable providing. Physicians were the ones who promoted more economized dying processes, and the main challenge in end-of-life care became bringing patients and families to embrace less invasive care and consent to economize dying.

In chapter four, I employ the concept of subjectification: the interactive process by which palliative care clinicians consolidate a shared sense of who patients are. I show that palliative care clinicians did not listen passively to what patients and families wanted, but instead worked actively to establish a sense of patients’ personhood. I document ethnographically the professional practices that palliative care clinicians employed in this process and show that clinicians’ goal was to elicit patient subjectivities that were reconcilable with the trajectory of economized dying.

The fifth chapter focuses on what I call “tamed autonomy.” Patients and families had various hopes and expectations that did not correspond with what clinicians and hospitals deemed feasible. Based on my ethnography, I outline practices that palliative care clinicians employed in order to “tame” patients’ and families’ wishes. None of these practices imposed any agenda on patients. They rather aimed to moderate wishes that did not resonate with the economized dying pattern.

The book’s conclusion discusses the concept of economization in some more detail, drawing several parallels between the case of the economization of dying and other economization projects. A description of my methodology, research process, and field-sites appears in the appendix. One note, however, is due now. In order to protect people’s privacy, I assigned pseudonyms to all clinicians, hospitals, and
patients. In several cases, I also changed some identifiable details, while trying to avoid affecting their sociological meaning. While I hold the view that anonymizing—or “masking”—should be avoided whenever possible, the sensitivity of the topic and the possibility that people involved would be personally affected by this account, merits an exception.\textsuperscript{121} Regardless, all of the events described in this book happened, and all of the people mentioned, quoted, and portrayed in it are as real and imperfect as people are.

2 Parsons (1951: 466-7).

3 Freidson (1970: 258).


5 Freidson (1979: 257-8). For more recent accounts, see Kaufman’s discussion of Internal Cardiac Defibrillators, hemodialysis, and kidney transplants (Kaufman, 2015) and Light’s critique of the pharmaceutical industry (Light, 2010).

6 Cancer progresses fairly predictably in its advanced stages, which makes the final decline toward death relatively foreseeable.

7 This figure rose by 13.5 percent between 2000 and 2009 (Teno et al. 2013: 473).

8 ABMS (2017).

9 Palliative care advocacy organizations have worked on expanding the practice into other institutions of curative care, such as outpatient clinics, nursing homes, and nursing facilities.

10 See Quill and Abernethy (2013).

11 This figure refers to hospitals with 300 beds or more. In 2014, an estimate of 44.6 percent of the total deaths in the country took place in hospice (see chapter 1, NHPCO, 2015).

12 NHPCO (2018).

13 For other examples see Zelizer (2005, 2010); Fourcade and Healy (2007); Quinn (2008); Chan (2012).
14 See Kierkegaard (1993: 73).

15 For a comprehensive discussion of this sociological significance of death see Bauman (1992).


17 Some ethicists have taken this goal with much alacrity; see Callahan (1987, 2009), Singer (2009).

18 This approach elaborates on Anspach (1993) and Zussman (1992). Both of these contributions rejected ethicists’ normative and prescriptive discussions, which focused on what should be done, in favor of empirical examinations of what clinicians do in practice. Anspach and Zussman substituted moralism with a sociology of morality: they examined how people approached moral problems, not whether or not their actions are moral. I share this stance, although I treat ethicists’ normative discussions as performative (Callon, 1998), i.e. as prescription, which inform and influence people’s behavior, if not completely prescribing them.


20 Boehner, John and Thaddeus McCotter. “Statement by House GOP Leaders Boehner and McCotter on End-of-Life Treatment Counseling in Democrats’ Health Care Legislation.” Press Release, July 23, 2009. Perhaps most outrageous was Republican Representative Betsy McCaughey’s allegation in a radio interview that the provision “would make it mandatory, absolutely require, that every five years people in Medicare have a required [sic] counseling session that will tell them how

21 NPR, August 12, 2009.

22 The award was given by PolitiFact.com; see Drobnic Holan (2009).

23 Institute of Medicine (2014), p. ix

24 To the surprise of many end-of-life care advocates, a later attempt to pass a Medicare end-of-life care benefit did succeed, ultimately. See Department of Health and Human Services (2016).

25 This is what Michel Foucault termed “state-phobia”: “the idea that the state possesses in itself and through its own dynamism a sort of power expansion, an intrinsic tendency to expand, an endogenous imperialism constantly pushing it to spread its surface and increase in extent, depth, and subtlety to the point that it will come to take over entirely that which is at the same time its other, its outside, its target, its objects, namely: civil society” (Foucault 2008: 187).

26 In particular, Glaser and Strauss (1965); Sudnow (1967); Zussman (1992); Anspach (1993); Timmermans (1999); Christakis (1999); Kaufman (2005); Shapiro (2012).

27 25-year-old Nancy Cruzan had a car accident in 1983, which left her with devastating brain damage. Initially optimistic, her parents agreed that doctors insert a feeding tube and provide her with artificial nutrition. Four years later, however, with no visible improvement in her condition, which “doctors defined as a persistent vegetative state,” the parents requested to remove the tube. The hospital refused and the parents launched a legal battle that lasted additional four years,
reached the Supreme Court, and led to a cornerstone ruling on the right to die.

Cruzan was removed from artificial nutrition and passed away. 29-year-old Schiavo collapsed at home in 1990 due to unknown causes. Like Cruzan, doctors diagnosed her in a persistent vegetative state: she could breathe independently, but needed artificial nutrition. The prolonged legal battle over her diagnosis, neurological condition, prospect of recovery, and appropriate treatment rallied the conservative Christian right and liberal right-to-die activists, making the matter more politically contentious than ever. Her husband supported disconnecting her from artificial nutrition, while her parents opposed it; after multiple dramatic turns in the plot—and with numerous “right to live” activist keeping vigil—Schiavo was disconnected from artificial nutrition and passed away more than 15 years after her collapse, her husband sitting at her bedside (Anspach and Halpern, 2008).


29 “From the physician’s standpoint, a case ceases to be medically interesting in the comatose, predeath stage” (Sudnow, 1967: 91; also Glaser and Strauss, 1968).

30 Kübler-Ross (1969: 36)

31 Kübler-Ross (1969).

32 These experiences are notably different from what Australian sociologist Alex Broom (2015) describes.

33 See Kaufman (2005).

34 For example, Gawande (2014).

35 Peterson (2004, Ch. 3).

Roy (2010). On the social construction of social problems see, for example, Jerolmack (2008); Murphy (2012).

See Hart et al. (1998); Timmermans (2005).

Artes Moriendi (in Latin: The Art of Dying) were treatises published in Europe starting the 15th century, which instructed people on how to conduct themselves during the dying process and die well (see Ariès, 1981: 107-110, 129-130, 303-305).

See Broom (2015); Clark (1999: 734).

See, Polanyi (1957)

Polanyi (1968: 98-99)

Aristotle (1995: 1258a35)

See Xenophon (1994, 11: 9-10); Aristotle (1934: 1177a), cited in Leshem (2013). Since the household (Oikos) was a metaphor for larger political frameworks (e.g. the polis (Owens 2015) the moral virtue of prudence toward abundance (Leshem 2013: 57) also applied to other forms of social organization.

Robbins (1945, p. 16). The definition’s origins can be traced back to Menger’s foundational book, “Principles” (Menger, 1950[1871]). In a later edition, Menger revised this rationalistic definition. It was, however, preserved, since Friedrich Hayek deliberately removed it from the book’s English translation (Polanyi, 1977: 21-24).

Max Weber’s definition added a subjective element to this emphasis on scarcity. Like Robbins after him, Weber saw economic action as one in which “the satisfaction of a need depends, in the actor’s judgment, upon relatively scarce resources and a limited number of possible actions, and if this state of affairs evokes specific
reactions. Decisive for such rational action is, of course, the fact that this scarcity is subjectively presumed and that action is oriented to it.” (1978: 339). Scarcity is therefore not an objective constraint that people face, but a matter of judgment and interpretation.

47 Foucault (2008: ch. 9-10)

48 Political philosopher Wendy Brown, for example, defined economization as the dissemination of “the model of the market [italics hers] to all domains and activities—even when money is not at issue—[and the configuration of] human beings exhaustively as market actors, always, only, and everywhere as homo oeconomicus” (Brown 2016: 30-31; cf. Bourdieu 1998).

49 Mitchell (2002); Murphy (2017).


51 See Fourcade and Healy (2013).

52 See Fourcade (2017).

53 Some have called this dynamic neoliberal (Foucault, 2008; Brown, 2016).

54 See, for example, Ashmore et al. (1989).

55 Murphy (2017: 5-6). Note that Murphy defined economization as a regime of valuation “hinged to the macrological figure of national ‘economy’” (ibid. 6): economizing something means instrumentalizing it for the purpose of bettering, growing, and optimizing the national economy’s performance. As I explain in the conclusion, my own definition is broader.

56 See also Boltanski and Thévenot (1999a, 1999b).
This transition mirrors the transition liberalism brought to sovereignty, which Foucault described in his lectures on biopolitics. The rise of liberalism meant a shift from a regime where the only limit on sovereign power was external (i.e. a kingdom’s borders and the existence of other kingdoms beyond them), to a regime where sovereign power was moderated internally. Sovereign action became legitimate only in as much as it was useful—“the fundamental question of liberalism is: what is the utility value of government and all actions of government in a society where exchange determines the true value of things”—and needed to be minimalistic. For example, while medieval kings used maximal power and violence to control crime, starting the 18th century the “mild punishment” principle emerges: the constant question about punishment is whether it is useful. This is the regime of truth that we now see in medicine: constant internal questioning of interventions’ usefulness, which follows decades in which the only restraint on medical practice was external: diseases that research has not yet concurred. Foucault (2008, in particular lecture 2, page 46). See also Sheldon Walin’s analysis of Machiavelli’s politics, which characterizes it as promoting “an economy of violence” (Wolin, 2016: 148-174).

On the history of the Quality Adjusted Life Years Metric see MacKillop and Sheard (forthcoming).

Conrad (2005); Best (2011, Unpublished.)

See Schneiderman et al. (1990); Jecker and Schneiderman (1992, 1995); Heft et al. (2000).

For example, see Brody and Halvey (1995), Smith (1995).
One could argue that social order of the market stifles economization—a counter-intuitive statement given the widespread tendency to identify markets, and capitalist markets in particular, with economies as such (Polanyi, 1977: ch. 1). While markets cultivate economization on the individual level, their twentieth-century advocates have rejected economization as a concerted and planned project organized on a macro national level (cf. Hayek, 2007).


This is what medical sociologists have called “medicalization” (Zola, 1972; also, Conrad, 2005). Aronowitz’s recently showed that medicine is now taking “risk”—the potential that disease would develop—as good enough a reason to intervene (Aronowitz 2015; see also Waggoner, 2017). On the modernist scientific project to control the human body through medical means see, Callahan (1987), Shilling and Mellor (1996), Turner (1987).

On the gap between the public image of CPR and its actual effectiveness see Timmermans (1999).


Zussman (1992: P. 21)


Rosenberg (1987).

We can find similar critiques of medicine as early as the progressive era (Rosenberg, 1987); they did not, however, institutionalize professionally, organizationally, and politically before the 1960s-1980s.
Thomas Hoyer, who worked for Medicare program and was among the people who drafted the hospice Medicare benefit (see chapter 2), wrote that hospice advocates “viewed the ordinary medical establishment, with its single-minded focus on curative care, with the same skepticism as had Ivan Illich in his 1976 book, *Medical Nemesis.*” (Hoyer, 1998: 64; cf. Illich, 1976).

The main people drawn to hospice were from the medicine’s professional periphery: nurses, clergy, psychiatrists, and a handful of critical physicians – people whose stakes in the preservation of medicine’s professional integrity was lower. (Clark, 1999).


This is comparable to the term “economy”, which, as Timothy Mitchell shows, became a concept that denotes a social sphere that economists can analyze and manage. (Mitchell, 2002; Fourcade, 2009).

Perhaps most famous was the Kübler-Ross model, which created a dichotomy between "denial" and "acceptance," and outlined five stages that terminal patients pass when transitioning between them – denial, anger, bargaining, depression, acceptance. The model delineated a clear professional goal for hospice care: helping patients reach acceptance. And while this model attracted much criticism within the hospice movement, it was not exceptional in the ways it determined new goals and criteria for good care: this was something that all hospice advocates did—and had to do—in order to promote the hospice way of dying. Later on, these concepts and goals spread to the rest of the medical profession. See, Borgstrom, Barclay and Cohn (2013).
As I show in chapter 1, so has the definition of what counts as “the end of life.” For a programmatic discussion of the co-emergence of disciplines and their objects of analysis, see Latour (1994).

This terminology is very specific to the U.S. In other countries, such as France, palliative care and hospice care are used interchangeably.

Recall that the Patient Self-Determination Act, which Congress passed in 1990, required medical providers to inform patients about their right to refuse care and fill out Advance Directive forms, which appoint surrogate decision-makers and document what life-prolonging treatments patients would and would want.

Rodwin (2011: 102, 110)

Starr (1984: 397)

Welch et al. (2011)

See Mahar (2006)

This is what Donald Light termed “countervailing powers.” The medical profession’s dominance and its ability to get “almost everything it wanted” led to buyers’ revolt, which targeted the high cost and variable quality of healthcare, as well as the general resulting excess in healthcare (Light, 1995, 2004).

By 2016, the Medicaid programs of 39 states contracted with Managed Care Organizations. “In 28 states—including 8 of the 10 states with the most Medicaid beneficiaries [...]—at least 75 percent of all Medicaid beneficiaries were enrolled in MCOs” (Paradise, 2017).
A illustrative reform is the DRG system discussed in chapter 2. Consequently, many conditions that had once been treated in the hospital were now treated at home.

Rodwin (2011: 142-143).

See chapter 2.


E.g. Callahan (1987); Scitovsky and Capron (1986).

For example, “Gov. Lamm Asserts Elderly, If Very Ill, Have ‘Duty to Die’”, New York Times Richard Lamm”, March 29, 1984. Also, see Amanda Bennett’s reflection on the cost of her husband’s death (Bennett, 2012).

Kaufman (2006: 131-146)

Glaser and Strauss (1968: 148-178)

While hospital deaths are still common, they are in decline (see Kaufman 2006: 89-91). Over one decade (2000-2009), they decreased by nearly a quarter, from 32.6 to 24.6 percent for Medicare fee-for-service patients (Teno et al., 2013). CDC data collected on all hospital patients indicate that in 1989-2007, hospital deaths declined from 48.6 to 36 percent of all deaths (National Center for Health Statistics, 2011: 105).

I have two main reservations. First, Nick’s description of the contemporary “culture of the hospital” is too unequivocal: there are still cases of patients (and
families) who resist the heroic measures that physicians prescribe. Second, Nick seemed to accept accounts such as Kübler-Ross’s too uncritically: even in the 1960s, 1970s, and 1980s there were many patients who favored “aggressive” medicine. Recall that Parsons (1951) and Friedson (1970) attributed part of U.S. medicine’s bent toward interventionism to patients’ expectations from doctors.

On a more basic level, it makes one wonder whether U.S. medicine—and the U.S. healthcare system in general—can be portrayed as death-denying in the Kübler-Rossian sense. Note that sociologists have long challenged the death denial thesis (Kellehear, 1984; Seale, 1998; Zimmermann and Rodin, 2004; Lavi 2005).

Of note, even non-manipulative critics from within the hospice movement, who did not share Palin’s politics, warned that hospices may end up imposing the ideas of “good death” on patients. As Timmermans argued: “relatives and the dying patient still have to ‘assent’ to the ideology of hospice care aimed at a particular kind of good death” (Timmermans, 2005: 998).

Notice, however, the ethicists who tried to establish clear definition for “futile treatment” during the 1990s: theirs was an explicit (and ultimately not very successful) attempt to put limits on patient autonomy and determine when physicians can decline requests for life-sustaining and life-prolonging treatments (see Brody and Halevy, 1995; Helft et al., 2000).

Belah et. al (2008[1985], P. xiv). Even more generally, as Nicholas Rose put it, the ethic of “the free, autonomous self seems to trace out something quite fundamental in the ways in which modern men and women have come to understand, experience, and evaluate themselves, their actions, and their lives” (Rose 1998).
This law required that healthcare institutions would inform patients about “the right to accept or refuse medical or surgical treatment and the right to formulate advanced directives” (sic). H.R. 4449 – *Patient Self Determination Act of 1990*, 101st Congress (1989-1990).

Arney and Bergen (1984: 46).


See Foucault (1991); Rose (1990); Rose and Miller (1992).


See, for example, Margolin, (1997). Similarly, Sharon Kaufman argued that this notion is built around an “illusion of choice”: while medical discourse hails choice rhetorically, in reality patients are heavily constrained by the limited options that medical professionals (such as physicians) and institutions (such as hospitals and insurance companies) give them. If a physician or a hospital does not present a patient with the possibility of having surgery (or conversely, transitioning to hospice care), this possibility remains outside of the patients’ realm of choice (Kaufman, 2006: 47-50). As I show in chapter 5, I agree with the empirical observation, not with the argument that it reflects an illusion of choice.
112 Some define the goal of palliative care as “aligning treatment with a patient’s goals,” using skills that are “complex and take years of training to learn and apply, such as negotiating a difficult family meeting.” Complex conversational skills are necessary because without them, patients’ goals will oftentimes diverge and even contradict the economized dying framework (Quill and Abernethy, 2013; see also Harris et al., 2016).

113 Althusser (2001, P. 115-120); see also Lahir (2011).

114 This is how Bosk (1979) interpreted the similarities between the surgery services that he studied.

115 See Karsoho et al. (2017).


118 Although I will not focus on heroic deaths in this book, they will constantly appear in the background: these are the deaths that palliative care clinicians would want to make people avoid, out of conviction that they result from bad medicine. There are numerous excellent accounts, from periods before and after the rise of hospice and palliative care, which analyze intensive care and “heroic” deaths very effectively. See for example, Zussman (1992); Chambliss (1996); Christakis (1999); Timmermans (1999); Kaufman (2005, 2015).

119 This is the Patient Self-Determination Act of 1990.

120 Douglas (1986).

121 Jerolmack and Murphy (2017).