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Dying, Economized.
Palliative Care and the U.S. Moral Economy of Death

By

Roi Livne

A dissertation submitted in partial satisfaction of the

requirement for the degree of

Doctor in Philosophy

in

Sociology

in the

Graduate Division

of the

University of California, Berkeley

Committee in Charge:

Professor Marion Fourcade-Gourinchas, Chair
Professor Neil Fligstein
Professor Aaron Cicourel
Professor Jodi Halpern

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Abstract

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Roi Livne

Doctor of Philosophy in Sociology

University of California, Berkeley

Professor Marion Fourcade-Gourinchas, Chair

Dying, Economized is a sociological account of the intersection between morality and economics in U.S. end-of-life care. It is based on ethnographic and historical analyses of hospice and palliative care—a new medical subspecialty, which has transformed the U.S. way of dying and is today the main designated discipline treating dying and potentially dying patients. The dissertation analyzes the emergence of end-of-life care as a professional, moral, and economic field and the efforts of the clinicians active in this field to reconcile the tensions it engrains. The first part (chapters 1-3) explains how in the 1960s, 1970s, and 1980s clinicians, economists, and policymakers began thinking of dying as a social problem: they argued that the dying were treated with inappropriate and costly medical interventions, which posed serious ethical and economic challenges. The hospice and palliative care solution to these challenges, which has gained much influence since the 1960s, is to economize dying, both medically and financially: to restrain the medical ambition to prolong life at all costs, nurture a culture that accepts death, and by that control spending. The second part (chapters 4-5) draws upon an ethnographic study that I conducted in three California palliative care services and on in-depth interviews with clinicians of various professions and specialties, whose work pertains to the treatment of dying patients. This part analyzes how palliative care clinicians negotiate the tension between the effort to economize dying and the ethical inclination to respect patients' wishes. Through this mixed-methods approach, the dissertation illuminates how expertise defines the relationship between moral and economic life in one of the most ethically challenging areas in modern medicine.

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Introduction

Between Death Panels and Economization

When I want to provoke people about my research, I say that I study death-panels. As distorted as the term is, the person behind it (Sarah Palin or her ghostwriters) should be credited for coining a most powerful catchphrase.

At the pinnacle of the debate over the 2010 Affordable Care Act ("ObamaCare") was a provision that reimbursed physicians for discussing end-of-life plans with patients: what treatments and procedures they would prefer to avoid if their medical condition declined. 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 discussion and said it would amount to "death-panels."[1] This statement resonated with a general point the Republican Party was pushing throughout the period: about a month earlier John Boehner and Thaddeus McCotter wrote that the provision "may start us down a treacherous path toward government-encouraged euthanasia."[2] Obama, on his side, responded that the provision would not "pull the plug on grandma."[3]

Quickly debunked and scolded, Palin's allegation even won a prize for "lie of the year."[4] But it was also very effective. 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.[5] 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.[6] In the spring of 2011, as I conducted my fieldwork, a physician told me he could not bill for a conversation he just had with a Medicare patient and her family 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.[*] Death-panels also inspired many moments of dark humor among clinicians: when a palliative care service that I studied prepared for a staff picnic, an attending physician suggested that they print team shirts with the writing "I Work for Obama's Death Panel" on the front and "Ask Me about Your Granny" on the back. Death-panels became a trope, an imagery linked to any thought or discussion of death and healthcare.

What accounted for this imagery's success? Like any good caricature, it manipulated key features of an issue that concerned people. First, the death-panels imagery capitalized on the moral uncertainty surrounding what counts as a life worth living. Defining the value of life in severe illness and deciding whether to prolong it is highly

[*] Throughout the book, I use single quotation marks to indicate paraphrased quotes, and double quotation marks to indicate direct quotes, which I audiotaped and transcribed in full.

challenging; alleging that such decisions will draw on rational and impersonal criteria hits a most sensitive nerve. Second, the imagery stressed the care-rationing dilemma—highly relevant to a country that spends nearly 18 percent of its GDP on healthcare. Containing the ever-rising spending in U.S. healthcare involves decisions on how to spend resources on life-saving and life-prolonging treatments; it requires thinking about a decision as emotionally and morally difficult as whether and when to stop prolonging life in monetary terms, which is bound to raise controversy. Finally, by invoking "death panels" Palin fed a general U.S. phobia that government would violate people's autonomy.[7] The fact that the debunking of her claims emphasized that conversations on end-of-life care are voluntary and focus on patients' own wishes and preferences (which cannot be farther from state coercion) shows how successful her imagery was.[8]

This book is a sociological study of death and dying. It joins an extensive social science literature on the topic.[9] Yet the period that I study—the early 2010s in the U.S.—differs from the periods that previous research engaged. First, it is a period when the three aforementioned challenges—how far to go prolonging life, how much money to spend toward this goal, and how patients should participate in life-and-death decisions—became the epicenter of political debates.[10] Second, it is a period when professionals assumed an unprecedented role in addressing these challenges. Although people have been dying under medicine's purview for over a century,[11] it did not offer specialized treatment designated for treating the dying until the last few decades. The development of *hospice* and later on *palliative care* changed the situation. Hospice and palliative care generated lively professional discussions on the proper ways to manage death and dying medically, ethically, and policy-wise. Palliative care clinicians became the main professional authority on end-of-life care in U.S. hospitals and instigated a major historical transition in how people die. The transition and its aftermath are the main topics of this book.

For a sociologist of expertise,[12] studying hospice and palliative care is an unusual experience. With the possible exception of psychiatry, it is hard to think of a medical specialty, which is as open to multi-disciplinary, as well as non-scholarly perspectives, as hospice and palliative care. Much of the thinking that inspired hospice and palliative care pioneers originated from outside of medicine, and many of the specialty's contemporary leaders write on moral, psychological, cultural, sociological, and policy issues, addressing the general public as they address their own profession. It is far more common for a hospice and palliative care clinician to read non-medical writing on death and dying and write to lay audiences than it is to, say, a cardiologist.

The profession's openness had a clear advantage to me: compared to other medical specialties, palliative care is very accessible to non-clinicians. Palliative care clinicians' main expertise is conversational: they specialize in talking with severely ill patients and their families about end-of-life care. Besides being able to follow and understand this work, I also felt that I had common language with many of the

clinicians I studied. We thought and cared about similar issues: the nature of social interactions and how social differences in class, race, and age affected them;[13] the relationship between organizational constraints and the personal and emotional dimensions of end-of-life care; and the policy implications of palliative care work. On the bookshelves of some of the practitioners that I interviewed were the same books that I kept in my office: Kaufman's "…And a Time to Die," Christakis's "Death Foretold," Anspach's "Deciding Who Lives," Timmerman's "Sudden Death and the Myth of CPR," and Starr's "The Social Transformation of American Medicine." Some of my interviewees published research and columns full of sociological insight. They knew and were interested in the sociology of health and medicine.

This was also the source of a challenge. Implicitly or explicitly, these people held solid sociological views—far more solid than mine—about the nature of "cultural" attitudes toward death, the sociological characteristics of U.S. medicine, and the ways the U.S. healthcare system should manage death and dying. Writing about hospice and palliative care clinicians means interpreting their sociological interpretations sociologically, or, to paraphrase Clifford Geertz, "winking at their wink."[14] Theirs is a very powerful wink. For one thing, the hospice and palliative care interpretation is very convincing: its advocates and practitioners have promoted it not only as a beneficial way to care for the dying, but also as a *moral* one. It is hard to criticize them, because they are the "good guys": medical professionals who not only want to promote "good death," but are also reflective enough to consider multiple definitions of "good death," while stressing the importance of respecting them all.

Many of the palliative care clinicians that I studied hoped my work would help improve their practice. My critique needed to have clear bottom lines, which would highlight professional shortcomings and suggest solutions.[15] I, on the other hand, preferred to remain "on the fence," as an outsider who could think and write about end-of-life care free from the enormous burden of responsibility that clinicians and policymakers carry.[16] Neither of us would like the outcome. On the one hand, this book does not propose applicable professional or policy reforms. Unlike most writers on the topic, I consider myself as neither an ally of hospice and palliative care, nor an opponent, nor a "critical friend."[17] My goal is not to promote or interfere with the growth of hospice and palliative care, but to outline how it came to be and how it operates: how certain views of what is good care at the end of life became widely accepted, who has promoted these views, and how they intersect with professional, financial, and political interests. On the other hand, my escapism notwithstanding, the book may have political repercussions. One cannot write critically on a topic as political as end-of-life care without leaving a political impact—intended or unintended. It is possible that my work will be used and abused to make arguments that I do not and will never support.

I should therefore clarify: No part of this book is meant to invalidate the hospice and palliative care approach, claim it is immoral, or advocate against it. Its professional peculiarities notwithstanding, hospice and palliative care is part and parcel of U.S.

medicine. Its ascent, I would argue, signifies an important period in the profession's history, which has some parallels in other social domains: a gradual decline in the appeal of progress, accompanied with increased discussion over the limits of science in particular and human agency in general. Conversations on how to live within limits—budgetary, scientific, existential—are gradually replacing the seemingly infinite modern race to advance and concur new scientific grounds. Within medicine, hospice and palliative care represent a noteworthy faction, which reflects critically on modern medicine's century-long project to develop new life-prolonging treatments. It raises doubt over the beneficence of many new and some existing treatments, while advocating that medicine should constantly question the usefulness of the procedures it offers and the meaningfulness of the lives it prolongs.

This is what I call *economization*. Economic theorist Lionel Robbins defined economics as "the science which studies human behaviour as a relationship between ends and scarce means which have alternative uses."[18] An economy emerges once people identify a certain resource as scarce and begin conducting themselves appropriately. They are likely to moderate their use of this resource (or at least debate ways to moderate it). They are likely to think about allocation and more generally, about how to manage themselves given the finitude of resources. The economization of dying involved two interlinked dimensions: first, a stance that medical progress has exhausted itself and that many recent advances are not beneficial to people. Medicine is coming up against an upper limit: it may progress, but this progress would not bring much good. Second, a financial strain—the result of an uncontrolled capitalist healthcare market, which has grown above and beyond a level that the national economy can support. These two dimensions resulted in a new moral economy of dying, in which scholars, medical practitioners, policymakers, and patients engage the challenge of limiting healthcare utilization near the ultimate and most categorical limit on human life: death.[19]

'Things Have Changed'

In 1969, a young psychiatry professor by the name of Elisabeth Kübler-Ross published a bestselling book entitled *On Death and Dying*. Laying out a plethora of psychological and sociological observations, she criticized what she and many of her contemporaries characterized as death-denying attitudes in modern societies. Modern medicine in particular, Kübler-Ross argued, epitomizes death denial in the emphasis it puts on prolonging life and postponing death. Physicians are untrained and therefore unprepared to talk to terminally ill patients about death and help them accept their condition. Instead of acknowledging death and supporting the dying, medicine treats death as a medical failure: clinicians cling onto their protocols, try to treat the untreatable, and cause unnecessary suffering to the terminally ill. If physicians only listened to the dying, she argued, they would learn that many of them were not seeking such heroic medical interventions at all.[20]

Some 42 years after the publication of Kübler-Ross's book, I sat at a café with Nick, a retired *palliative care* physician. 'Things have changed,' Nick 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,' he continued, '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.'

In 2011-2012, I conducted an ethnographic fieldwork in three California hospitals, which focused on *palliative care* clinicians. As Nick predicted, I found that things have changed. While I did come across Kübler-Rossian cases, in which patients resisted the heroic measures that their physicians offered, I found that the hospital environment was far more attentive to these patients than the environment that Kübler-Ross described.[21] 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 treatment and for respecting wishes to relinquish prolonged acute care. Yet the bulk of their day-to-day work pertained to other patients: the most challenging activity of palliative care clinicians involved conversing with patients and families, who were open to aggressive interventions that medical teams and hospitals were reluctant to provide.

This shift between clinicians' and patients' stances on end-of-life care—from a situation where patients beg their doctors to stop treating them and allow them to die, to a situation where doctors beg their patients to accept their terminal condition and "let go"—is highly intriguing. For one thing, it makes one doubt whether U.S. medicine can be considered as death denying in the Kübler-Rossian sense.[22] But more important is the assertion that the current healthcare system is in fact oriented toward encouraging patients to accept death and forgo life-prolonging treatment, even when they initially hesitate to do so. At first blush, this seems all too similar to the notorious death-panels allegation – only that Palin's buzzword is far too shallow to capture this orientation's true character. What makes the orientation so powerful is that unlike the death-panels imagery, it does not impose itself on people, 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.

A new *moral economy of death* has developed in the U.S. over the past half-century: an amalgam of moral attitudes, professional practices, and financial interests that have transformed the management of death and dying. This moral economy does not only pertain to the social, economic, and professional context in which people die. Rather, it manifests itself in people's intuitions, experiences, and feelings about death: in clinicians' intuitive sense of what is just or unjust and ethical or unethical; in how clinicians make decisions on stopping or continuing life-prolonging treatments; in the treatments clinicians use when caring for the severely-ill; and in the incentives that

health corporations and clinicians face when they treat patients whose life expectancy may be limited. The moral economy of death structures how people make life-and-death decisions and consequently, how people die and how they and their caregivers experience this death.

The essence of this new moral economy is a push to contain, moderate, or otherwise limit the treatment given to patients who approach the end of their lives—what I call *economized dying*. This term does not mean to imply that financial considerations are the sole drivers of end-of-life decisions. Following sociologist Viviana Zelizer, I treat the economy as a compound domain, in which finance is enmeshed in moral views, values, and social relations to the point of indistinction.[23] *Economized dying* is moral, medical, and financial at the same time. First, *economized dying* is the clinical sense that patients who approach death are often treated with excessive life-prolonging medical interventions, which leads to unnecessary suffering. From an *economized dying* perspective, it is immoral and medically wrong to treat dying patients with such "aggressive" treatments, hence clinicians should provide them with less life-prolonging and life-sustaining care. If during the 1950s, doctors felt morally obliged to attack disease with maximal medical interventions, the contemporary *economized dying* framework questions medical interventions' utility, considers many of them futile, and deems their use immoral.[24] Second, *economized dying* is financial: it is the notion that too much is spent on care at the end of life and hence spending less on end-of-life care would be better. In sum, *economized dying* is the approach that treating dying patients with much life-prolonging treatment is medically, morally, and financially wrong and that controlling and limiting such treatments is beneficial.[25]

Hospice and palliative care advocates have been the main promoters of this approach. They have framed what they thought was problematic with mainstream medicine's treatment of dying patients and proposed economized dying as a solution. They acted as what Howard Becker called "moral entrepreneurs": actors who adopt "strong humanitarian overtones" when promoting certain solutions to a situation, which they deem disturbing or evil.[26] They derived power from the "legitimacy of their moral position," which helped them "impress their moral vision on the rest of society."[27] Furthermore, hospice and palliative care clinicians are the primary agents who communicate economized dying to patients and families when the latter navigate the labyrinth of fears, hopes, and moral perplexity that serious illness involves.[28] My main concern in this book is a tension that emerged between economized dying and the wish to respect patients' self-sovereignty and right to decide on their own care. Economized dying comprises a coherent co-existence between the propagation of less "aggressive" treatment at the end of life and the interest to cut on healthcare spending. Yet recall Nick's observation: economized dying is often at odds with what patients and their families initially want.[29]

Since palliative care clinicians are the ones who specialize in talking to patients and families about end-of-life care, following palliative care clinicians in their work allowed me to analyze how they concretely reconcile economized dying with the

personal inclinations of patients and their families. My main argument is that palliative care clinicians bridge between economized dying and these inclinations: when prompting patients and families to voice themselves in conversations, the clinicians also channel them in more economized directions. In this way, palliative care clinicians facilitate patients' and families' consent to embrace more economized dying trajectories.

The Construction of the Problem of Death

Reflecting on the sparse research attention that death had attracted before the 1960s, psychologist Peter Steinfels contended that in academic circles, death "denial was almost total. […] The acknowledgement of death was for us [scholars] the equivalent of the acknowledgement of sex to the Victorian; it was a taboo."[30] Likewise, when Kübler-Ross began working on her research, she detected this taboo in clinicians' hostile reactions to her very intention to study morbidity:

> 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.[31]

"How often can a taboo be talked about […] before it's no longer a taboo?" asked historian Peter Filene. In the case of death, he observed that the death-denial argument "became its own refutation."[32] Kübler-Ross's book became a national bestseller, and her seminar on death and dying was taught to tens of thousands of clinicians. Steinfels published his reflections in a Hasting Center Report that he also co-edited, which was fully dedicated to interdisciplinary studies of death.[33] The more people highlighted and criticized death denial, the less accurate and relevant their criticism became. By criticizing "death denial" they also transcended it.[34]

Some forty years later, when I launched my own research, death was a widely recognized research topic. Without exception, all of my interviewees knew what I meant by saying that I study "end-of-life care" and all of them agreed it was an important project. "You have found such an interesting topic to study," one ICU physician responded to my interview request. She and many of my other interviewees expressed hope that my work would further "end-of-life care" and increase awareness to the problems that death poses today. Conveniently, death was also high in demand in my academic community: anonymous reviewers in academic 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, most of whom have faced the challenge of caring for aging parents and confronting "end-of-life decisions," reflected on how their own

experiences compared to my findings. Harvard University Press offered me a book contract even before I 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 laypeople—agreed that writing about death and dying was "important," "interesting," and "timely."

Death, as anthropologist Sharon Kaufman argued, has become a social problem: people have gotten used to thinking, speaking, and writing about it in very particular ways.[35] One part of this social problem lies in the fear of mistreating severe illness and making terminal patients suffer from prolonged dying process, hanging in the gray zone between life and death. The other part is fiscal: as physician and author Gregg Bloche put it, "our medical spending habits are unsustainable, […] the fiscal equivalent of global warming. Within twenty-five years […] we'll be spending nearly a third of our income on medical care, unless we learn to say no to pricey treatments that produce tiny benefits."[36] In the popular media and best-selling books;[37] among health economists,[38] physicians, journalists, and laypeople—the corollary conclusion is being recited: dying should be economized, "aggressive" and "extraordinary" measures to prolong life should be moderated, and end-of-life spending should be controlled.

This book does not seek to refute this argument, but to argue that it has sociological origins, which have hardly been discussed. Scholars have largely taken for granted that prolonged hospital deaths are morally and financially problematic, without explaining how people came to see them as problematic. (Similarly, there are countless studies on the circumstances that lead to unemployment, but few on how unemployment came to be regarded as a social problem.) Like any other social problem, the problem of death has been *constructed* as a problem; how clinicians tackle it very much depends on this construction.[39]

"Construction" is a loaded sociological term. Originating in phenomenological thought,[40] sociologists have predominantly used it to make *deconstructive* arguments, which doubt the factuality and objectivity of various social categories. By arguing that *gender* and *race* are socially constructed, for example, sociologists typically mean that the social categories of gender and race are fabricated: they do not truly and objectively exist, but instead, are collectively perceived or imagined.[41] They are real only in as much as people accept them as real and will melt into thin air as soon as their fabricated nature is exposed.

While ubiquitous in many sociological circles, this approach has several key weaknesses.[42] My (alternative) use of the term *construction* draws on Bruno Latour's work, which does not doubt the reality of constructed objects or ideas.[43] Conversely, for Latour, the fact that something was constructed accounts for its factuality. Just as the construction of a building results in the building's reality, solidity, and objectivity, the constructions of gender and race, quarks and electrons, and cancers and

tuberculosis create realities – be they objects, categories, or ideas.[44] Similarly to buildings, social constructions may vary in their stability: some constructed social problems are built more convincingly and solidly than others.[45]

When arguing that the problem of death and dying has been constructed, I mean four main things. First, I mean that the problem of death is *real*. The clinicians who work in proximity to death, the dying patients, and the people who accompany them grapple with real and most challenging moral quandaries. Dying people die in the most physical and objective way. And the actuaries who warn of bankruptcy refer to clear material consequences, which pose real threats to the U.S. government's solvency.

Second, I mean that the problem of death as it exists and experienced today is not inevitable. The problem of death developed historically, and as such, it has been contingent upon certain historical, sociological, and political processes. In different historical circumstances, one can imagine problems of death that would be constructed and experienced differently, and be tackled through different means than economized dying.

Third, I argue that the problem of death is anchored in multiple organizations, regulations, professional practices, and moral intuitions. This means that on the one hand, the problem of death *depends* on these different actors: for example, without recognition from hospital administrations and policymakers who regulate the U.S. healthcare economy, the problem of death would have manifested differently. On the other hand, these different actors habituate and naturalize the present framing of the problem of death. Changing the current framing of the problem would necessitate reforming numerous institutions: medical curricula, state regulations, organizational structures, and perhaps most challenging – people's intuitions.

Finally, I argue that the actors who constructed the problem of death had the *interest* to construct it the way they did. Following sociologist Pierre Bourdieu, I use the term "interest" in both of its senses: first, as denoting actors' personal and collective pursuit of symbolic, social, and economic benefits; second, as describing actors' genuine fascination and curiosity about a certain issue.[46] Most central among these interested actors have been hospice and palliative care advocates, who articulated the problem of death from a professional standpoint. Their interests were moral and professional at the same time: as idealistic care providers, they were disturbed by much of what they saw in their day-to-day work and articulated their moral ambivalence toward modern medicine's way of caring for the dying. These advocates also had a professional interest in promoting hospice and palliative care: by promoting their specialty and presenting it as a solution to the modern problem of death, hospice and palliative care advocates positioned themselves at the center of the medical efforts to manage death and dying. They transformed themselves into a professional authority, which is indispensable in addressing the U.S. problem of death.

In tandem, hospice and palliative care advocates developed an intellectual interest in the problem of death: the movement's pioneers came from the professional margins of medicine, which predisposed them to reflect critically on mainstream medicine, challenge it, and offer heterodox alternatives. This intellectual interest was, in Bourdieu's conceptualization, an outcome of a structuring structure: clinicians' structural position in the medical field endowed them with an interest, which in turn positioned them within the medical field and allowed them to reform it.[47] Today, the field of hospice and palliative care is organized and institutionalized: it has academic journals, professional associations, formal board examinations that doctors and nurses wishing to join the specialty are required to take, and a handful of textbooks that outline the essence of the specialty. There is a medical community, which rewards clinicians for critical ambivalence toward life-prolonging treatments and furthers highlighting the problem of death and the economization of dying as its principle solution.

Let me now outline three key features in the constructed problem of death in U.S. healthcare. First, the professionalization of care for the dying; second the financialization of death; and third, the championing of patients' self-sovereignty. The first two features comprise the notion of *economized dying*. The third conflicts with this notion, making up the main tension that this book investigates.

Dying, Economized

The Second Medicalization of Death

The problem of death has first and foremost been constructed as a *medical* problem. Paradoxically, this construction began as a backlash *against* medicalization, which questioned the benefit medicine attains by prolonging or sustaining the lives of seriously ill patients. Hospice and palliative care advocates have been the main promoters of this construction.

Medicine obtained virtual monopoly over U.S. healthcare services around the turn of the 20th century. At the height of the modern age, when trust in science and rationality peaked, the medical profession could successfully argue that it was necessary to protect it from the competition of other, dilatant, unscientific, and therefore untrustworthy healers.[48] As Paul Starr put it, medicine's authority relied on a combination of dependence and social legitimacy: doctors did not have to force people to use their services: people did so voluntarily, out of need and conviction in medicine's promise.[49] Throughout the twentieth century medicine's jurisdiction expanded and encompassed a growing number of life-domains, including childbirth, sexuality, and emotional life.[50] While dependence on medicine remained virtually unchallenged, its legitimacy began eroding in the second half of the century. Waning trust in medicine was part of a more general post-WWII atmosphere of ambivalence and disappointment with promises that science did not deliver and problems that it

created.[51] "Science has brought evil as well as good," declared the second Humanist Manifesto in 1973:

> We have virtually conquered the planet, explored the moon, overcome the natural limits of travel and communication; we stand at the dawn of a new age […]. Using technology wisely, we can control our environment, conquer poverty, markedly reduce disease, extend our life-span, significantly modify our behavior, alter the course of human evolution and cultural development, unlock vast new powers, and provide humankind with unparalleled opportunity for achieving an abundant and meaningful life. The future is, however, filled with dangers. In learning to apply the scientific method to nature and human life, we have opened the door to ecological damage, over-population, dehumanizing institutions, totalitarian repression, and nuclear and bio-chemical disaster.[52]

Medicine drew criticism for objectifying patients and using them as mere tools of scientific research. In the U.S., medical professionals are particularly notorious for their "interventionist bent."[53] "American medicine is aggressive", wrote journalist 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."[54] The modern hospital, which by the 1920s established itself as the most central site of medical practice, 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 over-rationalized, bureaucratized, and dehumanizing professionalism.[55]

Reflecting on the development of Intensive Care—a most emblematic medical technological frontier—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."[56] This observation very much applies to other medical disciplines: 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. The ethos of medical progress opened the door to boundless professional ambition, which aspired to address if not cure virtually any type of illness, almost regardless of patients' condition: when one line of chemotherapy fails, oncologists can offer a second, third, and even fourth lines; when one's kidneys decompensate, nephrologists can put her on dialysis; when the function of livers, hearts, lungs, kidneys, or pancreas declines – the possibility of transplant surgery is ever available; and when a person's heart and lungs stop there are emergency care interventions—such as cardiovascular resuscitation—which may "bring them back to life."[57] Death, as Giorgio Agamben observed, has become epiphenomenal to medicine: for a person to die, clinicians or family members have to decide actively to withhold or withdraw medical interventions.

This is the essence of what I call the first medicalization of death – an outcome of the fundamental modernist ambition to advance the scientific frontier and achieve human control over nature. By increasing its capacity to prolong life, medicine came to circumscribe death: death can occur only when clinicians, patients, and their families allow it to occur and decide to stop medical treatment.[58]

The second medicalization of death emerged as a backlash to the first one. It was an attempt to acknowledge the limits of human agency and scientific progress: a search for a medical diminuendo, which would replace an unmitigated crescendo. In the U.S., professional discourse critical of the first medicalization of death began institutionalizing in the 1960s, when groups of hospice advocates who were influenced by British hospice pioneer Cicely Saunders, appropriated her model of care.[59] Hospice advocates criticized medicine for treating death as an abnormality: a negative and traumatic event that should always be battled and postponed. Modern medicine, they argued, denied the finitude of human existence and treated disease as if life can be prolonged indefinitely. By contrast, hospices embraced death as integral to life and assisted dying people in passing away comfortably and with dignity. The hospice approach was anti-professional, valued intuition, emotion, and personal attachment between patients and caregivers, and saw singular relationships—as opposed to standardized guidelines—as the most essential features in caregiving.[60] Hospices liked to present themselves as "communities" rather than "organizations" and in many cases separated themselves from existing healthcare institution for fear that organizational rigidity would contaminate their ideals.[61]

Yet as hospices developed, their backlash against professionalism transformed into a new profession. For one thing, hospice advocates promoted their agenda in quintessential professional environments: lectures, seminars, workshops, and staff trainings. Hospice principles were taught and learned, creating a cadre of anti-professional professionals who used them to criticize and propose alternatives to mainstream medicine. These principles of hospice care valorized a very particular goal of care: palliating, i.e. minimizing dying people's physical and emotional pain and improve their quality of life. This goal was a uniting principle, which structured and hence institutionalized hospice practice.[62] Furthermore, hospice discourse delineated a distinctive object of professional management, which became clearer and more intelligible the further the movement progressed. This was the object I referred to when I approached clinicians, and this has been the object that policymakers, professionals, and economists invoke whenever they discuss death and dying: *the end of life*. The end of life has a colloquial meaning—the days, weeks or months preceding one's death—which has not necessarily changed over the past decades. Yet in contemporary hospitals and medical discourse, the term evokes fundamentally different attitudes, practices, and policies today than it did only 40 years ago. The end of life evolved into a distinctive realm of medical practice with its own clinical characteristics. Just like Cancer, Diabetes, Congestive Heart Failure, HIV/AIDS, Cystic Fibrosis, and Pneumonia, end of life has been recognized as a medical condition

whose management requires specific interventions, skills, and expertise.[63] The end of life thereby became the center of professional attention, which similarly to what 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."[64]

In the following decades, the professional jurisdiction of hospice practitioners expanded and so did the definition of what counted as end of life.[65] Palliative care developed from hospice in the 1990s: its essence was practicing end-of-life care inside hospitals, which meant starting conversations about death earlier in the disease process, before patients began dying actively.[66] The influence of palliative care gradually extended to general medicine: primary care physicians are today encouraged to talk to patients about end-of-life care and fill out advanced directive forms, which appoint surrogate decision-makers and document what life-prolonging treatments the patients would and would not like to have. Discussions of end-of-life care now apply to any person at any age and medical condition.

This professional development of hospice and palliative care is the first component of the push to *economize dying*. Hospice and palliative care set forth a professional logic that negates—or puts in check—intentions to prolong the lives of seriously ill patients. This logic relies on a moral intuition that in many cases, less treatment is better treatment: it is morally imperative to question ambitious doctors, who pursue treatments that have little chance to succeed, and to save patients from prolonged and torturous dying processes. The existence of hospice and palliative care professionals, who promote this logic of care in and outsides of hospitals, and hospice organizations, which provide designated care for the dying, makes limiting life-prolonging care feasible. Hospice and palliative care create a professionally and morally grounded way to economize, i.e. contain, the amount and intensity of life-prolonging and life-sustaining care.

Financial economization

The second component of economized dying is financial: over the past decades, the notion that *too much is spent* on people who approach the end of their life has become widely accepted. Similarly to the problem of over-treatment, the solution here has been economization, but this time economization is financial: it is a way to restrain expenditure on end-of-life care.

Clinicians and hospitals today operate in a fundamentally different economy than the economy of the 1960s. The post-WWII decades were a period of medical expansion: the number and size of hospitals increased, new medical schools opened, medical specialization accelerated, and physicians' fees grew rapidly. The period's physicians typically worked in private practices, which were relatively independent from hospitals, yet benefited from hospitals' growth since they could bill higher fees when

treating severely ill hospitalized patients.[67] The commercialized, fee-for-service healthcare market of the period created incentives for physicians to increase the reimbursable care that they provided; by the early 1970s, there was evidence for "overuse of medical services."[68] The physicians that hospice advocates criticized for providing unnecessary and unwanted treatment near the time of death had direct financial incentives to do so.

There is much evidence that over-treatment still exists in today's U.S. healthcare system.[69] However, unlike the 1960s, today's healthcare economy is designed to counterbalance it. Since the 1970s, U.S. policymaking has focused on containing and controlling the increase in public and overall spending on healthcare. At least part of this increase was attributed to the fee-for-service system.[70] In an effort to counteract physicians' tendencies to provide more care, policymakers created institutions and reimbursement formulae that would restrain healthcare: the attempt has been to confront hospitals and healthcare providers with the problem of scarcity the U.S. healthcare system faces on the macro level. HMOs and managed care organizations created the opposite incentive for physicians, who often "partnered with insurers and profited by cutting costs."[71] In 1982, Medicare began reimbursing hospitals through Diagnostic Related Groups (DRGs): predetermined payments in rates that are calculated based on patients' diagnoses, regardless of the actual cost of treatment and patients' length of stay in hospitals. The fee-for-service system is still widely used to pay physicians who work in private practice. However, hospitals and many salaried doctors who work for them are now financially incented to expedite patients' discharge and cut the cost of their treatment.

The privatization of Medicare and Medicaid programs created a large patient population, which public plans subcontract to private companies for a fee. It has strengthened the incentive to economize: insurers who work under this system put direct pressure on hospitals to expedite discharge. They employ case managers who review patients' charts and threaten to stop paying for days of hospitalization that they deem unnecessary. In order to survive financially, hospitals have to maintain the patient flow and discharge patients before they become too expensive.

These economic pressures created a financial motivation for hospitals to adopt palliative care. The palliative care services that I followed consulted on many cases where patients or families hesitated to sign "Do Not Resuscitate" (DNR) and "Do Not Intubate" (DNI) forms. In other instances, they consulted on cases where patients stayed in the hospital for long periods and their medical condition did not seem to improve. In yet other cases, palliative care teams consulted on "revolving door" patients, who were repeatedly admitted to hospital for chronic illnesses or recurring infections, and on patients whose disease reached their final stage, such as cancer, HIV, and heart failure.[72] All of these patients were potentially expensive for the hospitals: their illnesses were likely to result in prolonged periods of hospitalization, which insurance companies might not fully cover. Patients who are resuscitated are likely to spend at least several days in the ICU, and if their condition improves, an

additional period in a general medicine unit. "Revolving door" and end-stage patients are likely to return to the hospital for longer and costlier periods. In the 1960s, allowing such patients to die in the hospital was common. Glaser and Strauss's account, *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.[73] The current healthcare economy has made such waiting periods very costly for hospitals; by consequence, while hospital deaths are still common, they are in decline:[74] over one decade (2000-2009) they decreased by nearly a quarter (from 32.6 to 24.6 percent of Medicare patients' deaths).[75] Employing palliative care clinicians, who present less intensive treatment alternatives to patients and families, allows hospitals to increase the probability that these prolonged periods of hospitalization will be avoided.

The push to economize dying has therefore been financial as well as moral and medical. During the same decades (1960-1980s) that medicine drew criticism for over-treating patients who have lost any realistic hope for cure, it was also criticized for over-spending on these patients and driving the healthcare system and the entire U.S. economy bankrupt. Palliative care became a solution—a way to treat the dying better and for cheaper. Yet this push to economize faced a significant challenge, since during the same period, the place of the patient in medical decision-making began changing, and principles of autonomy gradually pervaded medical practice.

What Patients Want

Individualism, wrote Bellah and his co-authors, is "the first language in which Americans tend to think about their lives."[76] The ethic of "the free, autonomous self," argues Nicholas Rose, "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."[77] For much of the twentieth century critics focused on how medicine violated individuals' autonomy. The medical gaze, they argued, structured medical practice as a spectacle, not a dialogue: the goal of the clinical interview was to make patients report on their symptoms, render symptoms accessible to the physician, and allow the physician to connect between symptoms and diseases. Patients' more general experiences were deemed superfluous. In the eyes of the cardiologist, a patient's desperation is irrelevant to their heart function, and therefore this patient can be diagnosed as "doing well" even when she feels terrible.[78] Michel Foucault described the birth of the medical gaze as a "minute but decisive change, whereby the question: 'What is the matter with you?', with which the eighteenth-century dialogue between doctor and patient began […], was replaced by that other question: 'Where does it hurt?', in which we recognize the operation of the clinic and the principle of its entire discourse."[79] In some contrast to Foucault, under the American individualistic ethos, critics have described the medical gaze as limiting and repressing individuals. Medicine does not allow patients to be truly heard as

subjects and subtracts from patients the most fundamental elements that make them human – their self and the abilities to self-reflect, self-define, and self-sovereign.[80]

It was from this criticism that, beginning in the 1950s, and parallel to the backlash against the first medicalization of death, U.S. medicine reoriented itself around a new configuration of the medical gaze, which not only sought to acknowledge patients' selves, but also encouraged and stimulated patients to self-express. As articulated in the formal terms of the bioethics discipline, medicine shifted from a *paternalistic* orientation to an orientation that advocates shared decision-making between doctors and patients, and respects what it calls *patient autonomy*.[81] Legally, this reorientation involved establishing patients' rights to be informed, opine and influence how they are treated. Such rights were formally institutionalized in declarations such as *A Patient Bill of Rights* (1973) and laws such as the Patient Self-Determination Act (1990).[82] But more importantly, the new medical gaze meant that U.S. medicine developed a wide array of professional practices, which make patients speak, reflect on their condition, assert themselves, and influence medical decisions. Medical discourse not only enables "the patient to speak as an experiencing person, but *needs, demands,* and *incites* him [sic] to speak."[83]

There are numerous examples for such professional practices. Take the Affordable Care Act's (failed) attempt to reimburse physicians for holding periodic conversations with patients on end of life: it deemed communication about patients' wishes, values, and preferences as essential to quality care.[84] The increasing use of advance directive forms, which document patients' "end-of-life wishes," is another example. And finally, there exist extensive scholarly discussions of the usefulness of such conversations and forms, whether they collect accurate and trustworthy information that truly represents patients, and whether physicians use and follow up on this information at the bedside.

This focus on the individual patient, and the expansion of professional practices geared at inciting people to reflect and voice themselves, signals the coming of age of a new conjugation of medical power, which constitutes patients as subjects in new ways. The question, in this context, is not how this new conjugation liberates the subject from medical power, but rather how it enables certain patterns of self-expression and self-reflection, disables others, and prompt people to think and speak of their wishes, their hopes, and their preferences in certain ways.

The main challenge in palliative care practice Nick outlined above: while the U.S. healthcare system is, to a growing degree, geared toward economizing dying, there are many patients and families who hesitate to relinquish life-prolonging care. Consequently, the push to economize dying conflicts with the patient autonomy ethic, as well as with clinicians' more intuitive wish to respect patients' self-sovereignty and not to impose any decisions on them. As the director of a palliative care service put it:

> If [a family] would feel that "we put [mom] in the grave and we're throwing dirt on her and she's still alive, if we stopped [life-sustaining care]..." It's a 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. [...] It's very tricky to allocate resources at the bedside. 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? [And] we're at the same county that made it really hard for you to get to the oncologist in the first place? It's controversial.

What *do* they say? In order to respect patients' wishes and at the same time economize dying, palliative care clinicians have to garner patients' voluntary endorsement of economization. The essence of palliative care work is to identify and process attitudes and inclinations in patients, which can be reconciled with economized dying. Rather than coercively imposing the economics of the hospital and the moral views of the staff on families and patients, palliative care appeals to patients' and families' subjectivity, elicits their preferences, hopes, and wishes, and present them as corresponding to economized dying. They facilitate people's *consent* to more economized dying trajectories.

In hospitals, the term *consent* has a very narrow meaning. Typically, it refers to standard consent forms, which patients have to sign in order to receive treatment. These forms are, in fact, the opposite of consent: patients' complete dependence on care providers leaves them with little space for independent agency, without which consent is meaningless.[85] At best, consent forms are an empty ritual that masks hospitals' and clinicians' control over patients; at worst, they are a legal tool, which protect hospitals and clinicians from liability. I use the term *consent* in its deeper sociological sense: consent is a willing and voluntary agreement, which people who are relatively independent from external coercion can give.[86] This relative independence is in and of itself a social product: social structures are exactly what

establishes subjects as subjects, what invests them with the capacity to self-reflect, and what summons them to make decisions for themselves.[87]

Subjectivity, in Louis Althusser's terms, is the outcome of *interpellation*: one's identity as a subject consolidates when one responds to an external recognition. When a person is hailed in the street and turns – she identifies as the subject who was hailed; when one is given a first name, a last name, a gender category, and a social security number at birth, and uses these categories as properties that identify and characterize her, one is also subjected to them.[88] Palliative care interpellates individuals as subjects by recognizing them as reflective beings and inciting them to think and speak of themselves in certain ways. Palliative care "hold personhood—identity, selfhood, autonomy, and individuality—in place."[89] When successful, the outcome of meetings between palliative care clinicians, patients, and families leads to a general agreement not only about what the patient wants, but also about who the patient is.[90] When at the end of a conversation, a patient herself leans toward economized dying – the palliative care consult is successful. There is no need to impose economized dying on her: the patient readily embraces it and see it as her or his own goal of care, thus becoming an economized subject.

My ethnographic analysis follows how clinicians carry out this work. I show that the empowerment of patients—the effort to make patients articulate their wishes, voice them, and insist on having them followed—is not a mere masking of oppressive clinical power.[91] Clinicians genuinely seek to empower patients and families to participate in medical decisions, ensure that the hospital's financial interests do not trump patients' preferences, and guarantee that the care patients receive matches their wishes. Yet patients' and families' preferences are not expressed independently from the clinicians and the hospitals in which they work. These preferences are consolidated and communicated in very particular social circumstances: family meetings, bedside conversations, and conversations where clinicians discuss and reflect among themselves on previous interactions with families and patients. Rather than being predisposed preferences of isolated individuals, patients' choices are crafted in an iterative, interactive process. Palliative care does not oppress patients or prescribe their wishes: rather, it conducts patients' conduct[92] along an economized dying logic. Ultimately, the new moral economy of dying acts not only through clinicians' moral sense and administration's financial interests, but also through informing the most personal ways people think of their and their family members' wishes, hopes, and personalities.

Structure of the Book

The book is divided into two parts: the first (chapters 1-3) outlines the emergence of U.S. end-of-life care, the drive to *economize dying*, and the historical transition in patients' self-sovereignty and agency. This part mostly relies on historical analysis,

combining both primary and secondary materials. I included ethnographic and interview data in each chapter, which show how the historical trends 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 and shows how palliative care clinicians reconcile economized dying with the inclination to respect patients' self-sovereignty.

The first two chapters analyze the two components of economized dying. Chapter one analyzes the medical economization of death, by following 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 U.S. hospice movement's history, the movement's expansion and institutionalization, and its success to spread and articulate professional doubts over the benefit invasive treatments attain in treating seriously ill patients. Chapter two focuses on how death and dying transformed into phenomena that have financial significance. It analyzes how the end of life became an object of interest for economists, actuaries, and policymakers, and how end-of-life care transformed into 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 a research I conducted in an archive of a bioethics committee. I analyze documentation from 93 bioethics consultations from two periods: 1986-1991 and 2012. I show how in contrast to the first period, during the second period the bioethics committee was mostly 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 economize dying.

In chapter four, I introduce the concept of subjectification: the interactive process by which palliative care clinicians consolidate a sense of who patients *are* as people. Palliative care clinicians do not listen passively to what patients and families want, but instead work actively to establish a sense of patients' subjectivity. I ethnographically document the professional practices that palliative care clinicians employ in this process and show that clinicians' goal is to elicit patients' subjectivities that are reconcilable with the trajectory of economized dying.

The fifth chapter focuses on what I call "tamed autonomy." Patients and families may have various hopes and expectations that do not correspond to what clinicians and hospitals deem feasible. Using ethnographic data, I outline practices that palliative care clinicians employ in order to "tame" patients' and families' wishes. None of these practices *imposes* any agenda on patients. Rather they aim to moderate wishes that do not resonate with the economized dying pattern.

Fieldwork

This project developed in a rather gradual and unpredictable fashion. I would primarily define myself as an economic sociologist, and my first empirical project was about how states manage their public debts. In the fall of 2008, my third semester as a U.S. graduate student, I took an ethnography class, which I hoped would distract me from two arid semesters I had spent reading World Bank reports. I decided to write an ethnography of hospice care, which I thought would take me on a refreshing detour, away from economic sociology.

At hindsight, I can say that my first visit to the field framed my entire research orientation. I met with a hospice volunteer coordinator to inquire about the possibility of volunteering and writing about the place. Without me asking anything about economics, she sat me down and explained the hospice's financial model in great detail. She said that the hospice was mainly treating Medicare patients, and that Medicare paid a flat daily rate for each patient, regardless of the care the hospice provided. The hospice, in return, was responsible for addressing (within the boundaries of the hospice paradigm) any symptom that derived from the patients' primary diagnosis. I was told that this model was so successful that private insurance companies began showing interest in it as well: insurers often incur costly bills from seriously ill patients who visit emergency rooms, so by paying hospice a flat daily rate they could avoid financial risk.

The situation surprised me: I came to study death and dying, suffering, emotions, and dramatic medical decisions permeated by moral doubt; I met with a volunteer coordinator, whose work supposedly belonged to an altruistic realm of unconditional giving, yet here I was, sitting at an office, hearing her talk about money. Was economic sociology following me, or was it my own predilections, which made me focus on any mention of money and finance? Whatever it was, my ethnographic intuition that this economy was worthy of research strengthened the further the fieldwork developed, and the more I read about the history of the U.S. hospice movement, the ways it combined financial arguments with ethics, and the increasing role it played in managing death and dying in the U.S. The next summer, when Sarah Palin made care for the dying a focal point of political debates, I was confident that the topic deserved a deeper and more extensive look.

When I finished writing my article on the hospice,[93] I invited its manager for dinner. Although she did not read the article (I summarized the argument to her), she very accurately pointed at a major shortcoming: my chief interest was the intersection between finance and decisions to stop pursuing life-prolonging treatments. Studying hospices meant looking at patients who have already relinquished curative care. If I were to pursue the topic seriously, I would have to go to hospitals or clinics where people discuss whether or not to transition to hospice.[94] This was how I started work on this book.

The greater part of this book is based on ethnographic fieldwork, which I conducted over 13 months, between October 2011 and October 2012. After the dinner with the hospice manager, I approached several hospital physicians of different specialties, hoping that they would help me decide on which area in medicine I should focus. I quickly noticed that these interviews channeled me in the direction of palliative care. References to palliative care differed from each other. On one extreme were physicians who thought of palliative care as a self-contained specialty with clear jurisdictional boundaries: they saw palliative care physicians as death specialists, to whom you would refer patients when their condition declined. One cardiologist, for example, told me that she hardly came across death in her work, and when I asked if she never had a patient who declined and died, she responded that when such cases did occur she referred them to the palliative care service. She thought of jurisdictions as mutually exclusive: cardiology was curing, whereas palliative care was about letting patients die. Other specialists, however, did see death and dying as relevant to their work and consulted the palliative care service when they felt they needed additional help. An emergency care doctor talked to me about nursing home residents suffering from advanced dementia, who showed to the emergency room with chronic problems such as recurrent pneumonia. How and how not to treat these patients were questions he grappled with regularly, and he called the palliative care service when he felt addressing them was particularly challenging.

Regardless of how physicians used palliative care, they all recognized that treating patients whom they thought were dying was relevant to the specialty. And while it was clear that palliative care clinicians did not have a monopoly over treating dying patients—cardiologists, oncologists, intensive care physicians and others could choose whether or not to consult them—it was generally accepted that, as one physician put it, when it comes to death and dying, palliative care 'is a comprehensive way of looking at care, A-to-Z.' I decided to develop the research in this direction and make it a study of a medical specialty rather than a study of end-of-life decisions in general.

The book's focus on a specialty reflects a historical transition in how U.S. hospitals manage death. The first ethnographies of hospital deaths (published during the 1960s and 1970s) did not focus on any individual site within the hospital: people died in a general and non-professionally specific space, particularly in medicine units.[95] Ethnographies published in the 1990s tended to cover particular hospital units – intensive care units (ICUs),[96] neonatal wards,[97] and emergency rooms.[98] Sharon Kaufman, who began her project studying entire hospitals, reported that she ended up spending most of her time in ICUs.[99] Medicine's professional sequestration led to spatial separation of different deaths within hospitals, and consequently to sequestration of ethnographies that documented these deaths. The development of the palliative care specialty shifted not only the professional management of death in hospital, but also its spatial distribution: palliative care clinicians work nearly everywhere. They visit ICUs and medicine units, they see oncology, cardiology,

neurology and other patients, and they deal with patients suffering from failures of virtually all organ systems. Exceptions do exist, some obvious (orthopedics patients), others indicate the closure of some medical disciplines to professional outsiders (surgery referrals were relatively rare). Yet overall, studying palliative care meant visiting multiple hospital units, which is indicative of the sub-specialty's character: it does not isolate itself in any particular space, but seeks to communicate with other specialties and invest them with its logic of care.

I wanted to observe palliative care as it worked in different sectors in the U.S. healthcare economy. I selected a metropolitan area in California, which included several hospitals that served distinctive populations.[100] Within this area, I interviewed palliative care clinicians from six hospitals. In three of these hospitals—a public hospital, a private hospital, and an academic medical center, I also joined the palliative care teams in a total of 80 workdays.

These three hospitals differed greatly. The public hospital (henceforth "Public") was a safety-net institution serving an extremely diverse patient population. Its patients included destitute homeless and marginally housed people, undocumented and uninsured immigrants, trauma patients of various class and ethnic backgrounds (Public Hospital was the only trauma center in the area), as well as a significant population of lower and lower-middle class people, especially younger people, whose precarious employment status did not provide them healthcare benefits.[101] The hospital's chief budgetary resource was county budgets, which have been under threat for decades. I entered its palliative care service as a volunteer, usually visiting the service once a week. I attended the palliative care team's "rounds" in the morning, where an attending physician, a nurse, a social worker and two chaplains met and discussed the patients who were listed in the services' "census." I then went to see the patients that the physician thought were communicative enough to benefit from my company. Like most of the clinicians that I met in the hospital, members of the palliative care team were extremely competent professionally, and like other services they often expressed frustration of lack of resources. Virtually uninsured, Public's patients had to wait long periods to be discharged, since beds in the area's sole public nursing home were relatively scarce, and since many of them did not have a "stable living situation" for the clinical staff to consider them "safe" to discharge. Lack of resources and frustration from the hospital's bureaucracy also manifested in the service's difficulty to retain its non-physician staff: over the course of one year the service had three social workers who left it, and its chaplains were paid by a not-for-profit organization and a church, one of them adopting a Spartan and unsustainable lifestyle, which ended in a near emotional collapse and, ultimately, resignation.

The academic hospital (henceforth "Academic") was a large medical center connected to a medical school, which offered cutting-edge treatments in virtually every medical field. Academic was far better staffed than Public, and could offer more types of treatments to its patients: in cases where Public did not have the technologies necessary for treatment, it referred its patients to Academic. It served as a referral

center for hospitals from all over the state: cases that were too complex to treat in smaller and less specialized hospitals were regularly directed to Academic's more prestigious and better equipped units. The hospital prided itself in its professional ranking and prestige, which several people in the palliative care team referred to as a challenge. Fixation on offering the most advanced treatments could make physicians overlook the bigger picture, which was oftentimes very grim. At the same time, Academic had a very large and respected palliative care team: the hospital's doctors and administration seemed to embrace palliative care as one professional frontier among many that the hospital was advancing. Several of the physicians involved in the team invested the bulk of their time in research and in advancing palliative care nationwide. Like many other physicians at Academic, they worked as leaders in their field as opposed to clinicians who focus on day-to-day hospital work. In terms of staff, Academic's palliative care service was the largest of the three that I studied: on a typical day, it included an attending physician, two residents, two medical students, a social worker, a chaplain, and two nurses, in addition to chaplaincy and nursing interns who joined the service sporadically. It was fairly easy to merge into this large team: I was seen as one among many students. As such, I could join the team's rounds in the morning, shadow team members throughout the day, and attend trainings that were given on days where there was time. I joined the team's work once a week for a period of three months.

The private hospital that I studied (henceforth Private) was owned by a large not-for-profit corporation, which acquired it more than a decade before I started fieldwork. Many of Private's physicians referred to its formal non-profit status sarcastically; one physician defined it as "not-for-profit, but definitely for money." Physicians in another unit hung on their office wall a list of the corporation's executive salaries, which were all seven digits, and when I referred to Private's not-for-profit status in an interview with a physician, he chuckled and said, "this is such bullshit." The corporation that controlled Private was regularly criticized for diverting resources away from hospitals located in poorer neighborhoods and for its aggressive acquisition policy. Private hospital itself was considered as the corporation's flagship in the area. Virtually all of its patients were insured, and a significant proportion of them held more than a single insurance coverage, usually Medicare and a supplementary private insurance. With the ongoing privatization of Medicaid, and its gradual transition into a managed-care system operated by private insurance companies, Private began seeing a higher number of patients from lower class background. Employment patterns in Private were different from Public and Academic: while physicians in the latter two were salaried, many of Private's specialists were affiliated with physician networks, which insurance companies reimbursed directly, usually fee-for-service. (A growing number of Private's physician transitioned to salaried contracts, by many accounts, because of the cost and hassle of maintaining a back-office, which would process and charge multiple bills to multiple insurance companies.)[102] Since these physicians were typically reimbursed per-treatment, their financial incentive around end-of-life care was at odds with Private Hospital's. While Private lost money on

seriously ill patients who were hospitalized for prolonged periods, many of its specialists profited from such patients, since they were sicker and required many interventions. My fieldwork at Private lasted some four months, in which I joined the Palliative Care team about once a week. The core of the team included two physicians and a Nurse Practitioner, and once a week they met a larger group of clinicians, which included social workers, chaplains, Private's hospice liaison, and at times volunteers.

I conducted observations in multiple sites. On some days, I was able to shadow members of palliative care teams and observed them interacting with patients, families, and other clinicians. In Public Hospital, where I also volunteered, I saw and talked to some patients myself. In Academic Hospital, I was able to join teaching sessions, which exposed me to the socialization of young clinicians into the palliative care specialty. In all three hospitals I took part in team meetings ("morning rounds") and sometimes in informal conversations among the teams. In addition, I participated in nurse and physician trainings on end-of-life care, observed several "grand rounds" on the topic, and conducted observations in classes on cost awareness taught to physician interns. I usually took short notes during the day, and then extended them after the day was over. I also had several opportunities to share some of my ideas—in writing or orally—with palliative care people and hear their thoughts about them.

I complemented this fieldwork with in-depth interviews with clinicians whose work pertained to end-of-life care. Most of these interviews lasted 50-70 minutes, few extended beyond three hours. All in all, I conducted 80 interviews with physicians, nurses, social workers, chaplains, and some administrative staff. I spoke to people of a variety of specialties, including internists, intensive care physicians, oncologists, cardiologists, nephrologists, infectious disease specialists, surgeons, neurologists, and bioethicists. With several exceptions, where I was invited to interviewees' homes or sat with them at a café, I interviewed people at their workplace. I consolidated my list of interviewees through what can be called a directed snowball sample. Although I did not draw a random sample from a clearly defined population of interviewees, I directed the sample to include people from multiple specialties and professions, and to people who held various attitudes toward palliative and end-of-life care. That is, I made sure to talk to specialists who were relatively open to palliative care, as well as to people that palliative care clinicians defined as naysayers and hesitated to cooperate with the service. In several occasions, I approached specialists whom other interviewees mentioned, whose name came up in rounds, or whom I met as I was shadowing the palliative care teams. Some interviewees I reached through direct referrals from palliative care clinicians. In these cases as in others, I evaluated what interviewees told me against how other clinicians saw and what I saw in my fieldwork.

I analyzed these interviews as ethnographic documents: they are not to be taken as factual description of events, but rather as records of conversations that took place in a specific social setting. Facing me, interviewees were asked to spell out their views on end-of-life care, describe cases in which they were involved, and reflect on how

these cases were approached. Their responses are what Erving Goffman called a presentation of self, which they performed to a sociologist who inquired about end of life care.[103] They could not fully control any and every aspect of their self-presentation, yet much of their reflection was declarative: they made statements about end-of-life care, which were anchored in their experiences and illuminated how they thought the topic should be thought and talked about. They ordered their experience of end-of-life care in a certain narrative structure, and this structure was my main object of interest. I could clearly see, for example, physicians who declared their openness to palliative care and their support of its approach as a way of signaling that they are up-to-date professionally. When an Oncologist at Private Hospital said that he collaborated with the palliative care team closely, and a palliative care physician chuckled dismissively, 'yeah, he calls us two days before his patients die,' I could conclude not only about the gap between their accounts, but also about how important it was for the oncologist to declare his acquaintance and professional commitment to palliative care. His statements were at the same time validating of palliative care and of his own professional value: he classified palliative care as a valuable medical approach and himself as an informed physician who uses it in practice.[104]

I originally envisioned this project as a comparative ethnography that I thought would illuminate variations in how hospitals manage dying processes. Yet despite the clear differences between the three hospitals, I found that their palliative care teams applied very similar practices. This finding reflects the power of professions in general and of palliative care professionalization in particular: regardless of organizational, sociological, and economic contingencies, and despite idiosyncrasies and personality differences between clinicians, the palliative care professional toolkit had strong constant features.[105] And still, these similar practices were applied in fundamentally different material contexts and toward people endowed with different social, cultural, and economic capital. Rather than a comparative ethnography, this study is a multi-sited ethnography, which examines how clinicians apply the palliative way of care in different contexts.

In order to protect people's privacy, I assigned pseudonyms to all clinicians, hospitals, and patients. Other identifiable details were also changed in a way that did not affect their sociological meaning. In several specific cases, where interviewees shared with me sensitive details, I took extra precautions and further obfuscated their identity: there are several places where I referred to the same person by different names and others where I did not indicate in which hospital she or he worked. When referring to patients and their families I took similar precautions, and changed specific details that could lead to their identification by a third party. At the same time, 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.

Chapter 1: The Palliative Care Gaze

I was walking with Scott (a palliative care physician) to see a patient, when he spotted in the adjacent room a pale elderly woman breathing heavily and appearing minimally conscious. Nearly bumping into us, the woman's bedside nurse asked if Scott came to see her, and Scott responded: 'no, but it looks like I will be called soon.' 'It would make sense,' the nurse agreed, 'but they're discharging her to her nursing facility today.'

About an hour later, sitting at the nurse station, I noticed Scott was splitting his attention between writing a note on his own patient and following two heavy men wearing EMT (Emergency Medical Technician) badges, who came with an ambulance to drive the woman to the nursing facility. One of them asked the nurse if the patient had a Physician Order for Life Sustaining Treatment form (POLST)—a bright pink paper, which instructs clinicians on whether or not to resuscitate, intubate,[†] insert tube feeds, and re-hospitalize a patient if her or his condition declines. Scott interrupted him assertively and said that asking if the form existed was not enough: 'you should *make* them do a POLST!' The EMT man stepped closer to us and said Scott was completely right, but Scott still looked unsatisfied: he insisted that the man should demand that everybody be clear about what would happen in any situation that developed. As they were still talking, the man's colleague waived a white piece of paper at him, saying 'it's okay, this is a legal form.' The two of them moved the woman to a stretcher and disappeared down the elevator on their way to the ambulance parking.

Some fifteen minutes later, the bedside nurse walked into the station and informed everybody that the ambulance driver called and said they thought the patient was decompensating. 'They're bringing her back to the ER.' 'But they just left!' said another nurse. Scott's loud guffaw could probably be heard in other units too. 'What did I just tell you?' he asked several times; 'I always say, don't say what you're not going to do, say what you *are* going to do if X happens.'

This chapter analyzes the historical development of Scott's medical gaze and the impact this gaze has in hospitals today. Peeking at an open door of a room he was not called to visit—and without conducting a physical examination, reading the woman's medical chart, or knowing anything about her diagnosis—Scott recognized that she was nearing death. A cardiologist once told me that in 95 percent of the cases, she could recognize cardiac problems just by looking at her patients and hearing their stories; the more elaborate laboratory tests and imaging she used only to corroborate her intuitions and fine-tune the diagnosis. Scott exhibited a similar ability within his own expertise: he identified a patient who was at the end of her life just by looking at

[†] During intubation, physicians insert a tube into a person's mouth or trachea in order to open an airway. In hospitals, the procedure often involves connecting the patient to a mechanical ventilator.

her; had he been called to see the patient, he could have also supported his intuition with clinical tests.

But Scott's expertise went beyond clinical diagnosis: it also involved organizational astuteness. Knowing the U.S. healthcare system, he correctly predicted that without unequivocal instructions stating otherwise, the ambulance staff would turn back to the hospital's Emergency Room if the woman's condition declined. What would happen next was harder to predict, and Scott did not want to take the chance: the woman could be assigned to ER clinicians who have already come across her during a past hospitalization and knew her medical problems, but she could also be treated by a team who would see her for the first time. Like Scott, this ER team would not know the woman's medical history. But the team would most likely see a completely different patient than the one Scott saw – a patient in acute medical distress, who requires emergency measures to stabilize her condition and save her life. "If all you have is a hammer," one of Scott's palliative care colleagues once told me, "everything looks like a nail." Seeing a sick person, nephrologists would tend to think of their medical problems in terms of their kidney function, cardiologists would tend to attribute them to the heart, and hepatologists would focus on the liver. From the perspective of Emergency Medicine specialists working at the ER, a woman whose organs decompensate needs emergency interventions: they would resuscitate her, intubate her, and connect her to the respirator; they would apply pressors to sustain her blood pressure, and by the time they would examine her chart, learn about her medical problems—which could involve a terminal cancer or other incurable and irreversible diseases—the woman could already be connected to life sustaining machines.

Holding a different "hammer," Scott saw another "nail." Having trained and worked daily as a *palliative care* specialist, he saw an elderly woman who was at the end of life and needed a specific set of clinical and organizational interventions that would be appropriate to this condition. She needed a POLST: a form that would set clear and legally binding boundaries on the treatments health providers would give her. At the end of her life, medical discussions should focus on when to phase out and how to moderate life-sustaining and life-prolonging interventions. I characterize this medical gaze, which takes the *end of life* as its main object of interest, as an *economizing gaze*, since its essence is to question and doubt the benefit medical interventions may have for patients. The economizing gaze delimits and checks an abundance of medical interventions that medicine can offer; its main carriers in hospitals—palliative care clinicians—have gradually anchored themselves in the U.S. medical profession, in the organizational environments of a record number of hospitals, and in the intuitive moral sense of numerous clinicians, policymakers, and laypeople.

I begin outlining the history of the economizing medical gaze in the 1950s. The first section analyzes the development of U.S. hospices, which emerged as a grassroots movement from the margins of U.S. medicine and institutionalized, not without resistance, into a medical specialty during the 1970s and 1980s. The second section

traces the expansion of the field's boundaries during the 1990s and the 2000s, when several philanthropic funders—most notably, the Robert Wood Johnson Foundation and the Open Society Institute—invested more than $200 million in developing *end-of-life care* as an expertise, a research topic, a professional movement, and a topic of public discussion. Over less than a decade, they prompted an explosion of professional and policy oriented writing related to death in the U.S. and expanded the breadth of end of life discourse beyond hospices and into hospitals. The third section discusses ethnographic data showing how palliative care clinicians apply and spread the economizing medical gaze in the hospital environment.

1. The Ascent of U.S. Hospices

Origins of the Field

In 1974, Hospice Inc. of New Haven formally admitted the first U.S. hospice patient. Less than forty years later, U.S. hospices were serving an estimate of 1.65 million people, and 44.6% of all deaths in the country happened under the care of a hospice program.[1] This growth is no less than a revolution: by and large, hospices have assumed professional jurisdiction over managing death in the country. The revolution is particularly significant since unlike other medical disciplines that grew during the period (e.g. Intensive Care and Oncology), hospices did not introduce new medical interventions that had not been previously known: hospice is a medical philosophy, not a treatment per se, and although it has not achieved complete dominance in U.S. healthcare, it has certainly gained much ground remarkably fast.

The origins of hospice can be traced back to several "homes for the dying poor," mostly founded and run by religious institutions in the nineteenth and twentieth century. Care in these institutions included nursing with "little medical involvement" on the part of physicians.[2] Cicely Saunders—universally recognized as the most prominent early pioneer of modern hospice care—began her career at two of these institutions: Saint Luke's Hospital (opened 1893) and Saint Joseph's Hospital (1905) in London. Saunders trained as a physician in 1951-1958, when, as she wrote, "many of the drugs, whose use we now take for granted, were introduced," making doctors assume an ever-growing agency in treating sick bodies and prolonging people's lives.[3] This was the period McGehee and Bordley called the "Period of Explosive Growth," in which antibiotics, early chemotherapies, polio vaccines, anti-psychotic drugs, and later on – pacemakers, open-heart surgeries, cardiac catheterization, and hemodialysis became part of the medical toolbox.[4] Upon her graduation from medical school, Saunders began a decade's work at Saint Joseph's, a 150-bed hospital, which kept 40-50 of its beds for "patients with terminal malignant disease."[5] In this position, she became an active and articulate advocate who argued that treating dying patients required a distinctive approach to care, which was at odds with the direction modern medicine was taking. Medicine's goal was to postpone death as much as

possible, and in cases where this goal became impossible, doctors saw no apparent reason to continue treatment. “It appears to me,” Saunders wrote in 1958, “that many patients feel deserted by their doctors at the end.”[6] For one thing, Saunders wanted to guarantee that doctors remain responsible to their patients, even when hope for recovery is lost. For another, she wanted these doctors to provide medical care that suits dying patients’ unique needs.

As she was still working at Saint Joseph’s, Saunders began preparing her most eminent project: the foundation of Saint Christopher’s Hospice—a free standing institution located in London, fully dedicated to the care of the dying. Already a known hospice protagonist, Saunders traveled to the U.S. in 1963 and divided her time between soliciting donations for Saint Christopher’s, lecturing in multiple universities, visiting eighteen medical institutions, and meeting with academic, religious, and medical figures who were interested in hospice. Saunders’s charismatic appearances drew hundreds of clinicians and academics to her lectures, some of them continued corresponding with her, visited Saint Christopher’s when it opened, and invited her to subsequent visits in 1965 and 1966.

These lectures outlined the principles of hospice care as Saunders practiced it. First, Saunders defined hospice care as focusing on the patient as a *person* and criticized medicine’s impersonal and technical character, best epitomized in the “specialist without heart”[7] who treats body parts, but not people.

Second, Saunders challenged medicine’s tendency “to go on pressing for acute, active treatment at a stage when a patient has gone too far and should not be made to return.” [8] This, she argued, “is not good medicine. *There is a difference between prolonging living and what can really only be called prolonging dying*” (italics in the original).[9] Instead, Saunders advocated for accepting death as integral to life: death should be thought of as “life’s fulfillment,” an event that “helps us find the real meaning” that both dying and the people mourning them need.[10] Quoting a student who worked at Saint Joseph’s, she suggested that “death really isn’t anything to be frightened of, but sort of homecoming.”[11]

Finally, Saunders envisioned hospices as cohesive communities, which blur boundaries and dismantle hierarchies between professional and non-professional work and between clinicians and patients.[12] Although hospice did have a specialized technical component—the use of medications to alleviate patients’ physical pain—and although professional physicians were the ones in charge of this component—Saunders insisted that the essence of hospice work lied elsewhere. She promoted hospice as an unorthodox and holistic form of care, which addressed physical, emotional, and existential suffering at the same time. Her model was anti-professional and deliberately challenged the compartmentalization and sequesterization of care that medical specialization created: hospice was interdisciplinary, relied on nursing, combined much general volunteer care work, and had a strong religious component (prayer and religious rituals were daily routines in

Saunders's hospice).[13] The drug regimens Saunders used were also unorthodox: many of them were illegal (she regularly prescribed heroine and found interest in LSD treatments), others reminded of folk medicine, which Saunders used, quite simply, to make patients happier and more comfortable: gin was integral to pain treatment at Saint Joseph's and Saunders encouraged relatives to bring whiskey bottles to her patients as gifts.[14] Saint Joseph's nurses, Saunders reported, were "young Irish girls who come over and do apprentice nursing with us before they go and get further training elsewhere. Since they have not yet been taught to hurry, as many a trained nurse will, they are well suited to work with dying patients." One patient Saunders described as showing

> "her loving response to an *unsophisticated little nurse* who is just enjoying her as she is, demonstrating her pleasure in just meeting her… Now this simplicity is a quality we too often lose, but I notice that the young seem to have it almost by nature, if they choose to come into this kind of work" (my emphasis – R.L.).[15]

Taken together, Saunders's hospice model pushed care for the dying several steps away from mainstream medicine: it doubted the usefulness of invasive and specialized clinical care in dying patients, mingled intuition and amateurism in its day-to-day practice, and aspired to replace the clinical settings of the hospital with a mixture of professional and non-professional elements. The Victorian tone Saunders adopted when speaking of Saint Joseph's staff is indicative: young, Irish,[16] "unsophisticated," and "little" women represented minimal professionalism and maximal ability to care. This was an early and most important pillar in the medical economization of death: Saunders questioned the merit of medical interventions in dying patients and argued that in certain situations, treating less was treating better.

As provocative as they were, these ideas were not completely new to U.S. medicine. In 1940, for example, Harvard physician Alfred Worcester published a poignant essay on the treatment and mistreatment of aging and dying patients.[17] Outlining a comprehensive vision on how to care for the elderly, he called physicians to accept "ageing as a perfectly natural process" and to refrain from treating the physical decline in old age as a pathology. Care for the elderly, Worcester argued, necessitates "a regressive régime," which gradually moderates medical interventions as the natural decline of patients' bodily function occurs. He specifically recommended that physicians who found tumors in aged patients should not treat them, given "how common in the aged cancerous tumors are, and also how much less malignant they are than in earlier years."[18] More controversial from a contemporary perspective, Worcester went as far as defining the loss of teeth at old age a "natural safeguard […] against overeating," and argued that dentists and cooks violated this safeguard: "artificial teeth and culinary triumphs are the disguised enemies of a healthy old age."[19] Providing life-prolonging treatment to patients who are naturally dying is a disturbance, Worcester argued, and "all such disturbance of the dying patient is inexcusable."[20]

Not unlike Worcester, many U.S. medical specialists reflected critically on how to properly limit life-prolonging treatments as soon as these treatments became available. In the 1950s, following the invention of chemotherapy, oncology journals printed elaborate discussions on how much chemotherapy was too much. Early chemotherapies could not cure cancer, and oncologists explicitly referred to their work as "palliative care": in the absence of curative powers, their goal was to control the disease's symptoms, alleviate pain and at the same time try to prolong life.[21] Saunders actively corresponded with U.S. cancer specialists,[22] and in 1960 she published an article in a cornerstone six-volume set on cancer treatment.[23] These professional circles did not embrace hospice, yet hospice ideas certainly spoke to issues that concerned them. The resonance with the intuitions of many non-hospice clinicians continued in the years that followed. In January 1972, North Carolina physician William Poe published in the New England Journal of Medicine a sarcastic call to start a new medical specialty – Marantology. This specialty:

> Should help people endure losing. It should not use silly euphemism such as rehabilitation and convalescence for its losing patients. It should not send its dear old people to intensive-care units to be treated as winners. It should not embarrass or tempt surgeons to do dramatic things such as operating on dissecting aneurisms. […] Marantologists are not winners; they have become good losers. […] There should be an Ameircan Journal of Marantology with contributions such as "The Uselessness of Speech Therapy in Mute Octogenarians". […] What satisfaction could a Marantologist get in his work? […] He could […] debunk any number of doctrines propounded by haughty professors who never saw the true end results of their work. He could face honestly the fact of dying and death that our profession as a whole has not yet faced. […] If I were a dictator, I would dictate that the entire profession have grand rounds in a Marantology ward each fortnight to get a maintenance dose of humility.[24]

These words were printed in one of the two most prestigious medical journals in the country, and Poe testified in the first Congressional hearing on Death with Dignity that summer. In the news magazine of the American Academy of Pediatrics, Dr. Wolf Zuelzer wrote on ICU technologies: "When do we turn the machines off? When should we have turned them on in the first place? The beep of the oscillography is becoming the voice of the new barbarianism."[25] "I have the distinct impression that we are slowly but perhaps rightly moving toward choosing death in some instances as a way of avoiding the oppression of misapplied medical technology and of easing the burdens of the sick and their families," declared Yale pediatrician Raymond Duff.[26]

Hospice ideas also resonated with extra-professional social and political dynamics in the U.S. From the 1950s and to a growing degree during the 1960s and 1970s, public interest in death, dying, and the cultural, political, and moral questions related to them exploded. Historian Peter Filene described this as a "public obsession, [which]

had almost a prurient quality to it, as if death had joined the erotic revolution of the sixties." The period's political climate—the iconoclastic, anti-institutional, and anti-authoritative spirit of the civil rights movement—colored this interest in death. Over the course of one decade, public trust in institutions such as the presidency, Congress, the army, universities, and the church plummeted. Modern medicine—an emblem of empathetic and personalized care turned standard, technical, and bureaucratic—was an obvious target: trust in doctors declined from 72 to 56 between 1965 and 1973. Patients' demands to pass away in their own terms, free of professional, institutional, or political coercion appeared regularly in media outlets, books, and articles. These voices came to be known as the *Right-to-Die* movement, and gained much steam during the 1970s, when the high profile case of Karen Ann Quinlan unfolded.[27] While many U.S. hospice protagonists were very careful to distinguish themselves from the *Right-to-Die* movement, hospice spoke to the sentiments that fueled its advocacy. Hospices' emphasis on humanizing care, de-institutionalizing the dying, and personalizing treatment by de-professionalizing it corresponded to the main criticisms directed at medicine during the period.

In sum, we can attribute the ascent of U.S. hospices to two main factors. First, the U.S. medical profession's preoccupation with both internal and external criticism of medical progress made many clinicians open to alternatives such as hospice. Second, a Zeitgeist of hostility toward authority and institutions, which developed during the period. This created fertile grounds for reformist ideas: in the next years, a "large contingency" of liberal and highly educated professionals and academics began advocating for hospice care, presenting it as a necessary reform.[28]

The Evolution of the Hospice Professional Field

This favorable environment notwithstanding, within U.S. medicine, hospices were extremely marginalized. This partly stemmed from reasons of professional politics: like any professional newcomer, hospice advocates had to fight to make already established professionals accept their approach as viable and legitimate.[29] Hospices were also looked down upon because they were feminized: the public figures promoting them were mostly women, and within the dominant medical patriarchy, their emphasis on nursing and amateur volunteer work was prone to be dismissed and undervalued.[30] The content of the hospice approach was also key to its marginality: by rejecting many of modern medicine's most basic intuitions, hospice advocates positioned themselves in the place of radical critics who challenged medicine's establishment. The professional institutionalization of hospice care thus occurred from medicine's margins: hospice advocates established a professional center, whose core uniting principles contradicted conventional medicine.

The first U.S. hospice project began as pilot program—it was also known as an "experiment"—in Yale during the late 1960s. Its most prominent leader, Florence

Wald, was appointed Yale's Dean of nursing in 1958. An avid supporter of nursing's professional integrity, Wald wanted to establish a distinctive intellectual, research, and clinical nursing approach, which would be independent of medicine and other related disciplines.[31] Saunders's vision of hospice as a comprehensive philosophy of care, which placed nursing at its very center, was very appealing to Wald. She and Saunders met during the latter's 1963 visit to Yale, continued corresponding after Saunders returned to London, and met again when Wald re-invited Saunders to Yale as a visiting professor in 1965. In 1967 Wald resigned from her position as Dean and travelled to Saint Christopher's Hospice for a sabbatical. When she returned to Yale, she gathered a small group of clinicians and began working on her own hospice pilot study, which took place in the Yale New Haven Hospital during 1969-1971.

Members of Wald's group mostly came from medicine's professional periphery. They belonged to undervalued health professions (nursing and chaplaincy), relatively peripheral medical disciplines (psychiatry and pediatrics), and social sciences that health professionals and policymakers all but ignored (anthropology).[32] Most illustrative of the group's character was its members' strenuous relationship with two other, more "mainstream" physicians who also participated in the project. Wald wanted to enhance cooperation with clinicians in the hospital's wards and invited Oncologist Ira Goldenberg, who according to hospital nurses was the type of physician who would not "abandon terminally ill patients," and internist Robert Scheig, whom Goldenberg recommended.[33] From the pilot project's very beginning, Goldenberg and Scheig criticized Wald's approach for lacking scientific rigor and for focusing too much on bedside care. "I think you have to stop thinking entirely of how it's best to treat the patient and also start thinking about the fact that you're doing a study," said Goldenberg in one particularly heated moment.[34] The group's other members felt Goldenberg and Scheig were reluctant to commit more time to the project because they were avoiding the topic of death and could not accept the centrality of nursing to the hospice model. Within the hospice milieu these were accusations of blasphemy. "We're really not working through the decisions in a collaborative way," Wald lamented about a year into the project. "I'm thinking that [Goldenberg] thinks… that he's the doctor and I'm the nurse."[35]

The Yale pilot study was also regarded with much ambivalence within the hospital and the university. One physician criticized Wald's involvement in his patient's care, saying that it was "polarizing" and stifled the creation of a united professional front when the staff met with the patient's family. In 1971, when the pilot was concluded and Wald and her group sought ways to start a permanent hospice service, the hospital administration hesitated. The group then decided to pursue a more independent hospice model, similar to Saint Christopher's. As they were looking for funding sources, Wald and Edward Dobihal—a chaplain who was central to the project since its beginning—found that state agencies were as ambivalent as professionals. They met a representative from the Department of Health Education and Welfare in Washington D.C. and applied to multiple federal programs for care of

the poor disable and the elderly – all showed little support for hospice. Most contemptuous in his rejection was Arthur Jarvis of the Connecticut State Department of Health, who said the group's application was "fuzzy" and expressed concern over their way of "segregating" terminally ill patients. He recommended that Wald and her colleagues "go to a mountain top somewhere; I might give you a lot of nuns just so I don't have to be involved and see what you're doing."[36]

This blend of, one the one hand, rejection from the medical establishment, and on the other hand, resonance with the intuitions, feelings, and interests of numerous clinicians and non-clinicians of the period, was a key characteristic of U.S. hospices' development in their first two decades (1970s-1980s). Hospice advocates were torn between quixotic iconoclasm, which took the rejection of institutionalized medicine as its defining feature, and a more pragmatic drive to formalize and professionalize hospice in order to establish it as a medical subspecialty, spread its message, and expand it. This tension's organizational and financial dimensions I discuss in more detail in the next chapter. Here I want to emphasize how hospices gradually distanced themselves from Saunders's original vision of shifting away from medical professionalism.

In 1971, Wald and her group founded the free standing *Hospice Inc.*, which quickly became a national professional hub. Hospice Inc.'s leaders had a tight relationship with Saunders, who provided them with managerial advice in the months leading to its opening. Even in a new field, whose promoters rejected authority and formal codes of professional reputation, proximity to a founding mother meant prestige. The year Hospice Inc. opened, Wald and her colleagues organized the first "annual hospice day" in New Haven—a national conference that attracted 150-200 attendees.[37] They spoke at events as practitioners representing not only themselves or their institution, but the hospice approach in general.[38] While several other groups of clinicians began organizing hospice programs, none could match Hospice Inc.'s organizational power: by 1973, it had more than 200 members, friends, and advisors, including representatives from business, city planning, insurers, and a community healthcare center. The Rockefeller Foundation, Wald wrote to Saunders, was "strongly interested in picking up the big tab."[39]

In 1975 Hospice Inc. created the *National Advisory Council*, whose declared purpose was to promote hospice "by reform in the existing institutions and by replication of New Haven's Hospice."[40] Hospice Inc. made itself a prototype for replication, and by the end of the decade, New Haven was a Mecca for hospice care: a 1978 Congress report found 59 healthcare organizations "providing at least one hospice-type service" and 73 organizations "were in various stages of planning";[41] that year, Hospice Inc. was guiding some 100 local hospice groups from all over the country.[42] Somewhat paradoxically, anti-professional ideas of care, which challenged institutional hierarchies, were now spreading from a professional center.

The professionalization of hospices involved a finer definition of the field's turf: hospice practitioners and researchers shared an interest in studying, treating, and managing *death and dying*. Through the 1960s, as hospices were acquiring their professional shape, dying people—and hospital patients in particular—were studied in the hundreds. In the 1960s, the U.S. Public Health Service's Division of Nursing funded three major projects on death and dying: the Yale pilot program, sociologists Barney Glaser and Anselm Strauss's studies on hospital deaths,[43] and a study by pediatrician Ray Duff and sociologist August Holligshead on patients' and families' experiences in hospitals.[44] Across the Atlantic, Cicely Saunders documented the treatment and dying trajectories of 1,100 patients in Saint Joseph's Hospice and built a database of their clinical notes as well as "commentary" that they gave in interviews.[45] U.S. psychiatrist Elizabeth Kübler-Ross interviewed dozens of dying patients and mapped the psychological phases that they passed between receiving their terminal diagnosis and dying.[46] There was a growing body of data, analysis, and theoretical concepts related to "death and dying," which inspired a flourishing medical and intellectual discourse on the topic: universities offered courses, seminars, and workshops in Thanatology and multiple popular and scholarly books explored cultural, historical, sociological, psychological, and spiritual aspects of death. The *International Journal for the Study of Death and Dying* (OMEGA) published its first issue in 1970, becoming an important venue for scholarly communication on the topic. *The Hospice Journal* and *The American Journal of Hospice Care* began publishing in 1984, followed by *Journal of Pain and Symptom Management* (1986) and later on *Journal of Palliative Medicine* (1998), *Journal of Hospice and Palliative Nursing* (1999), and *Palliative & Supportive Care* (2003). "Death and Dying" became target of research and clinical practice, as well as an existential category: terminally ill people, living in great proximity to death were managed as subjects with distinctive physiological, psychological, and spiritual characteristics and needs (see figure 1.2 below).[47]

The further hospices crystalized professionally, the more distinctive they became from other forms of medical care. Early hospice ideas did not reflect such a distinction. In her practice, lectures, and writing, Cicely Saunders often spoke very generally about necessary reforms in patient care: refraining from abandoning dying patients, being attentive to patients' physical and non-physical needs, and facilitating communication between physicians, nurses, and patients. Hospice was meant to impact all medical specialties in all institutions – not isolate and restrict itself to a bounded professional jurisdiction. But hospice advocacy achieved the exact opposite outcome. Needing to prove to funders and policymakers that they had a unique contribution that other medical disciplines were not providing, advocates found themselves delineating specialized characteristics that their approach had.[48] In grant proposals, the New Haven group defined hospice as "offering specialized, coordinated terminal care, which focused on quality of life for patients who were unable to be cured or rehabilitated." This specialized care they presented as distinctive, since dying patients were "both an unwanted and feared population within the curative medical milieu."[49] Hospice Inc.'s decision to part with Yale's medical center added an

organizational distinction. "Palliative care" given in *hospices* became the opposite of "curative care" that *hospitals* provided: it was either that physicians treated patients to cure, or that they focused on alleviating their pain and refrained from invasive, life-prolonging treatment.

This binary manifested in the criticisms that conventional physicians were directing at hospices. During the first Congressional hearing on "Death with Dignity", which featured a host of hospice advocates, Dr. Laurence Foye from the Veterans Administration in Bathesda argued very passionately:

> Every physician can […] describe a number of patients for whom he predicted a rapidly fatal outcome—saying, "I knew they were going to die"—and was wrong. The patient who was told by his doctor that he had 6 months to live but is alive years later is legendary. […] If a physician withholds maximum effort from patients he considers hopelessly ill, he will unavoidably withhold maximum effort from an occasional patient who could have been saved. Patients will die because of the physician's decision not to treat actively. This approach and concern cannot be fostered or condoned, legally or otherwise.[50]

Advances in medical research made such positions highly intuitive in fields that were on the cutting edge of medical research. Contrary to their predecessors (see above), 1970s oncologists saw curing cancer as a mere matter of time, and hence, contended that life should be prolonged and death postponed to the longest possible.[51] "A recently developed group of specialists in death and dying are teaching physicians how to accept the mortality of man," warned the editorial of a leading clinical cancer journal. "While this new philosophy certainly has merit, […] it must never become an excuse for lack of aggression in saving lives and lack of knowledge about what can be done to preserve a life."[52] "In the last several years," echoed an oncologist, "we have seen the development of a 'death and dying' cult that is antitherapy and antitherapist. These 'patient advocates' often fail to recognize that oncologists who are technically skilled also have a genuine humanitarian concern with their patients."[53] These rancorous reflections, directed from one of the most prestigious medical specialties to medicine's margins, show that these margins developed a coherent and significant enough set of ideas and became a center in their own right, worthy of criticizing.

And these margins knew how to organize themselves and act politically. In 1978, the National Hospice Association was founded and began federal and state level advocacy. Over the next four years, they lobbied for creating a special hospice benefit (see chapter 2) and battled other advocacy organizations—specifically the National Hospital Organization and to some extent the National Association for Home Health Agencies—which claimed they were providing similar services to the ones hospice intended to provide.[54] When Congress authorized a Medicare benefit in 1982, it formalized a separation between hospice and other forms of care. The benefit defined hospice as care "provided to a terminally ill individual" by an interdisciplinary

program and specified what services needed to be included in it.[55] Since the legislation approved payment for two periods of 90 days, it established that hospice patients would be people with a prognosis of six months or less.[56] The distinctiveness of hospice care and hospice patients was inscribed in regulation: with Medicare recognition, a steadily growing number of distinctive and independent hospice organizations were treating distinctive hospice patients through distinctive hospice methods.

The emergence of social fields, as Bourdieu observed, is a hierarchical process: fields are spaces that have core and periphery, which hierarchize people along their differential endowment with pertinent cultural, symbolic, social, and economic capital. The characteristics of U.S. hospice co-emerged with the field's center. By the beginning of the 1990s, the field had established and widely recognized clinical principles, professional associations that promoted them, clinicians that practiced them, examinations that certified the clinicians, free-standing organizations that hired them, public insurers who paid the organizations, and patients whose condition required hospice care. There were people who achieved centrality in the field: clinicians and researchers who published in hospice journals and advocates who assumed leadership positions in professional association. One could pursue a hospice career and be rewarded with recognition from a thriving professional and clinical community.

2. Projecting Death in America

At the center of the first phase in the history of economized dying in the U.S. was hospice: a grassroots movement, which somewhat unwittingly became more professional, formal, and institutional. The second phase in this history involved a far more coordinated top-down mobilization that expanded care for the dying beyond hospices and reached into hospital care. What drove this mobilization were monetary contributions from some of the largest philanthropic organizations in the country. Over eleven years, (1994-2005) the Robert Wood Johnson Foundation (henceforth RWJF), the Open Society Institute,[57] and several other funders[58] invested more than $220 million in transforming how U.S. clinicians, hospitals, policymakers, and the U.S. society at large think, approach, and manage death. These initiatives' comprehensiveness was impressive: they supported clinicians who would advocate for changing care for the dying in their institutions, scholars who would study the topic, and professors who would teach about it; they funded professional associations for hospice and palliative care, organizations that "educated" communities about death and dying, policy organizations that authored reports and promoted policy change, artists and authors whose work engaged death, and organizations that sustained the field after it exhausted its seed money.

This mobilization created both demand and supply for what became broadly known as *end-of-life care*. On the one hand, it increased the topic's visibility in public discourse, cultivated public sentiments supportive of economized dying, and garnered existential reflections on the use and misuse of medicine, on what counts as a good and bad death, and on wishes and expectations people have from medical personnel. On the other hand, it established a new medical subspecialty—palliative care—which economized dying in hospitals and worked toward making clinicians, administrators, and policymakers more favorable of end-of-life care, so that medical institutions could meet the new demand.

Greater Commitment and More Forceful Measures

During the early 1980s, a retrospective RWJF account tells us, many of the foundation's leaders began reflecting on "personal experiences" they had had with care of the dying.[59] These experiences made them concerned that "elderly, fatally ill persons were likely to be vigorously treated in intensive care units, at great financial cost and suffering, even if their families objected."[60] The leaders convened a meeting on the topic in 1985, and then invited William Knaus and Joanne Lynn, who over the next three years consolidated a design for "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment"—also known as the SUPPORT study.[61] SUPPORT quickly became the field's most ambitious flagship project: with a $29 million budget,[62] its research team had dozens of clinicians, who studied 9,105 severely ill patients in five hospitals.[63]

In their first two years of research (starting 1989) the SUPPORT team worked on proving the need to change end-of-life care in hospitals. Examining over 4,000 cases of seriously ill hospital patients, they found that only 47 percent of the physicians whose patients refused CPR were aware of this preference and about half those patients did not have formal Do Not Resuscitate (DNR) orders. Nearly half of the DNR orders that did exist were filed two days or less before patients died, and among the patients who died in hospital, 38 percent spent 10 days or more in the ICU and 46 percent received mechanical ventilation in the last three days of their life. No less indicative was that half of all conscious patients who died in hospital "experienced moderate or severe pain at least half the time during their last 3 days."[64] In SUPPORT principle investigators' eyes, these data added up to a grim picture: conventional U.S. medicine was oblivious of death; it treated patients aggressively and invasively until the very last moments of life, fighting to extend life even after all realistic hope for recovery or improvement was lost. Physicians failed to recognize dying patients' needs and acknowledge their preferences even when patients or their family members stated them clearly. Rigorously demonstrated and more pertinent than ever, medicine's ineptitude in treating dying patients invited new specialized interventions, which would somehow economize dying.

SUPPORT's second phase meant to demonstrate the efficacy of two such interventions: first, increasing doctors' awareness of patients' prognosis; second, improving doctors' communication with patients. The researchers split 4,804 additional participants into an intervention and a control group: physicians in the intervention group received data on their patients' six-month survival rate, the expected outcomes from CPR, and their predicted level of disability; in addition, the intervention group included trained nurses who talked to patients and their families about their prognosis, inquired about pain, clarified the likely outcomes of attempted resuscitation, brought up the possibility of writing an advance directive, and reported the conversation back to the physicians.[65]

RWJF had so much faith in these interventions that it prepared a major media campaign to advertise their success before the results clarified. But the results did not come. Physicians in the intervention group did *not* file DNR forms earlier than in the control group, resource utilization and the number of ICU days were similar in both groups, and patients in the intervention group were slightly *more* likely to report pain. "The intervention had no impact on any of [the] designated targets," SUPPORT's principle investigators summarized.[66] Perhaps most perplexing was that patients and families in both groups were satisfied with the treatment.[67] The first article the SUPPORT researchers published began with the declaration that the wish to economize dying originated from patients: "Many Americans today fear they will lose control over their lives if they become critically ill, and their dying will be prolonged and impersonal. This has led to an increasingly visible right-to-die movement."[68] In the article's conclusion, however, the tone changed:

> One could conclude that physicians, patients, and families are fairly comfortable with the current situation. Certainly, most patients and families indicated they were satisfied, no matter what happened to them. […] Perhaps physicians and patients in this study acknowledged problems with the care of seriously ill patients as a group. However, when involved with their own situation or engaged in the care of their individual patients, they felt they were doing the best they could, were satisfied they were doing well, and did not wish to directly confront problems or face choices.[69]

In the eyes of the researchers, patients became part of the problem as well as the problem's victims. The conclusion was unequivocal: "to improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed."[70] With its media campaign ready to launch and study results that completely contradicted it, RWJF had to change plans. It reoriented the campaign to emphasize "how entrenched problems are in care at the end of life" and stress "the urgency to address this issue."[71] The campaign presented SUPPORT's failure as reflecting negatively not on the attempt to economize dying, but on physicians who refused to embrace it and patients who did not recognize the benefit it had for them.

The media campaign carried this framing to T.V. networks' studios and newspapers' headlines, and SUPPORT very much marked the direction the entire field took in the next decade. Its unprecedentedly rich and detailed dataset yielded over 62 research articles by the decade's end, followed by many others in the next years.[72] No less importantly, it was a compass for the extensive projects that followed it starting the mid-1990s.

Most prominent among these was Project on Death in America (PDIA), which the Open Society Institute (OSI) announced several months before SUPPORT's results came public. PDIA's official history used a very familiar narrative to describe what motivated it: the personal experiences of OSI's founding president, George Soros, whose mother passed away two years earlier. Soros found his mother's dying process far more satisfying than what he had experienced with his father decades earlier: he felt that he and his family were more "present" and supportive of his mother and wanted to facilitate similar experiences on the institutional level. In the early 1990s, some twenty years after Hospice Inc.'s opening, finding professional figures interested in care of the dying was fairly easy, and OSI officials quickly gathered a professional board to lead the project. Soros's words at PDIA's unveiling event in New York echoed arguments that hospice advocates since Saunders had made: "we have created a medical culture so intent on curing disease and prolong life that it fails to provide support during one of life's most empathic phases—death. Advances in high technology interventions have deluded doctors and patients alike into believing that the inevitable can be delayed almost indefinitely."[73] Dying shall be economized.

PDIA board's first call for grants was fairly general and yielded 2000 requests; as the board discussed the applications—and against the background of SUPPORT's findings—its members gradually began "to forge the view that it was essential to change the culture of medicine in hospital and nursing homes, where 80 percent of Americans die."[74] Expanding specialized care of the dying beyond the institutional confines of hospice and into the bastions of curative medicine meant redrawing professional jurisdictions: "palliative care" became the name of end-of-life medicine practiced in hospitals. Its professional authority crossed a delicate line: hospices treated patients who were unquestionably dying; palliative care, however, engaged decisions on whether patients *were* dying, how far they were from death, whether a clear line between serious and terminal illness could be drawn, and what type of care would be appropriate given their prognosis. PDIA moved the professional discussion on death upstream, toward the grey areas where death's imminence and the likelihood of cure or improvement were less certain.

Building a Professional Field

PDIA's most central initiative was the Faculty Scholars Program, which began in 1995 with the goal "to identify and support outstanding clinical and academic leaders in

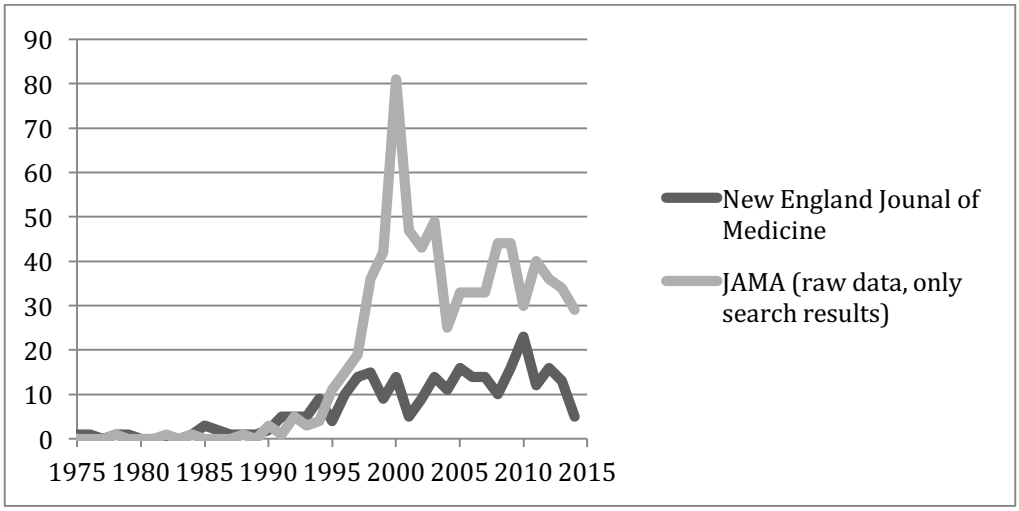
medicine and nursing who could change medical culture from the inside."[75] The program's highly selective character—it admitted 87 fellows in eight cohorts over nine years of existence—reflected its organizers' deliberate strategy to create a professional elite, which would advance the field from the top. Funders were explicit about this strategy:

> For a medical field to gain legitimacy it should be built into prestigious organizations [...], as well as backed by highly respected professionals with top-ranked academic backgrounds, and who publish in peer-reviewed journals. [...] Standards and certification are important as well. [...] Physicians listen best to other physicians, particularly those within the same specialty. [...] [The] call for action was heard because the experts involved were powerful enough to affect change. [...] In line with this analysis, staff from RWJF and PDIA developed what they called an "elite strategy."[76]

Beyond creating a hub of professional leaders, paying their salaries for two years, and supporting their research, PDIA also promoted "the visibility and prestige of [the fellows] in end-of-life care and enhanced their effectiveness as academic leaders, role models, and mentors."[77] In effect, the Faculty Program crowned its fellows as leaders by providing them the prerogative (and resources) to delineate the specialty's boundaries and principles.

The program acted on several fronts. First, it fostered scholarly discourse on "end of life": its fellows authored over 2,000 articles by 2003 and raised more than $113 million for research in the area.[78] The term "end of life" became visible in leading medical journals during these years (figure 1.1) and gradually replaced "death and dying" as the field's main object of management (figure 1.2): fellows made it a recognizable medical category—a more widely defined turf for their expanding specialty. Second, the Faculty Program trained fellows to become agents of change in their hospitals once they graduated, and its ultimate goal was to establish "at least three permanent faculty members who promote end-of-life care in all 144 U.S. medical schools."[79] "Medical students learn by watching interns, residents, and faculty who are further along in their career," reflected PDIA board member Peter Selwyn, "the culture will change when these role models embrace palliative care."[80] Empowering a cadre of role models and replanting them in their hospitals was an effort to impact not only research, but also clinical practice. Finally, program fellows advanced educational projects: a number of studies that fellows authored reviewed medical textbooks in a variety of specialties and pointed to "major deficiencies" in their discussion of "care of the dying."[81] In 1999, PDIA and RWJF co-sponsored a conference, which gathered doctors, nurses, textbook writers, editors, publishers, and advocates to discuss strategies to change the situation. Several years later, PDIA announced the deficiencies "have largely been identified and addressed, and clear guidelines for end-of-life care context have been instituted."[82]

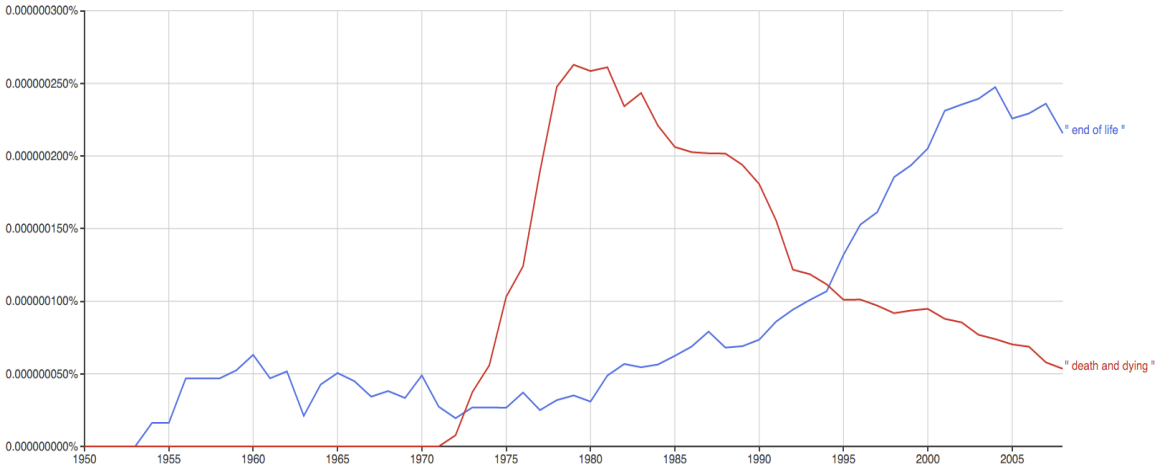
Figure 1.1: The Visibility of "End of Life" in Top U.S. Medical Journals



PDIA helped disseminate its fellows' work. Already before the program began, two of its board members—Kathleen Foley and Robert Burt—lobbied the Institute of Medicine (IoM) to write a comprehensive report on end-of-life care. Burt later said that while IoM did not do much independent research, the report it ultimately published in 1997[83] proved helpful in summarizing scholarship in the field, pointing to future research areas, and making policy recommendations. Editing the report involved approaching bodies such as the National Institute of Health and inquiring about the research they have done in the area: "it had impact [...] in terms of shaming the National Institutes of Health about their funding for research," Burt reflected several years later. "We asked everybody from the National Institutes, institute by institute, to come and tell us what they were doing in end-of-life care [...] so they would come in one after another and they would tell us they're doing nothing."[84] PDIA distributed more than 4,000 copies of the report "to diverse constituencies" and co-sponsored other synthesizing reports the Institute of Medicine published on the topic.[85]

The further end-of-life care professionalized, the more hierarchical, physician-oriented, and male-dominated it became: 60 percent of PDIA's faculty fellows were men; women, furthermore, were clustered in the less prestigious nursing (as opposed to physician) profession.[86] Only 9 of the faculty fellows were nurses, all but one were women. (The faculty fellows program's chair later attributed the low number of nurse fellows to physicians' dominance in the review committee.)[87] Many of PDIA's nursing and social work initiatives took place outside of the Faculty Fellows Program. The palliative care field was interdisciplinary, yet not trans-disciplinary: it fostered cooperation between different professions, but did not blur boundaries the way the early hospice movement aspired to do.

Figure 1.2: The Replacement of "Death and Dying" by "End of Life" as the field's main turf (1950-2008)



Source: Google Books Ngram Viewer; Smoothing 3. http://books.google.com/ngram

In 1999, PDIA funded the Nursing Leadership Consortium on End-of-Life Care, which convened 43 participants representing twenty-three nursing specialty organizations, as well as other organizations, to develop a collaborative end-of-life "nursing agenda."[88] The consortium led to the establishment of the "National Nursing Leadership Academy" at Johns Hopkins University. In line with PDIA's general top-down approach, it envisioned the Academy as a center for palliative care nursing "leaders" who would publish in nursing journals, present in professional conferences, and design curricula for nursing schools as well as for continued professional education.[89] The nine nurses who participated in the Faculty Scholars Program also contributed toward these goals: two of them, Marianne Matzo and Deborah Witt Sherman, developed palliative care nursing curricula,[90] and together with other nurses authored two textbooks on palliative care nursing.[91] This group also initiated the End of Life Nursing Education Consortium (ELNEC)—a seminar on end-life-care, which would train thousands of palliative and non-palliative care nurses in the next years.

PDIA's engagement with social work was even more separate from its flagship Faculty Scholars Program. The Faculty Program did not include a single social worker, but in 2000 PDIA launched "the Social Work Leadership Development Awards," with the now-usual goal of developing "leaders in the field." The awards supported 42 social workers (82 percent of them women) in 2000-2003, who organized conference, symposia, training manuals, certification programs and fellowships[92]—all meant to add content on palliative care, end-of-life care, and bereavement to social work education. Much of this work culminated in 2011, with the publication of The Oxford Textbook of Palliative Social Work, which two of the

program's graduates edited; the book included 84 chapters, many of them authored by other program graduates.[93]

The social work and nursing projects, however, were both marginalized within PDIA and enjoyed far less funding than the physician-focused projects. PDIA leaders criticized the nursing Academy for what they thought were modest outcomes compared to the Faculty Scholars Program (in the first three years, the Academy published eighteen related articles in nursing journals, organized six national conferences on nursing and palliative care, and advanced two organizations that wrote curricula.) David Clark, whom PDIA commissioned to write its history, mentioned that the nursing consortium "was an initiative where it was hard to trace major tangible outcomes and were obvious 'products' were difficult to identify."[94] Social work projects suffered from similar difficulties: in 1999, for example, PDIA launched a "community and bereavement initiative," which funded multiple bereavement programs in schools, prisons, and a variety of community organizations. It was virtually impossible to present quantified outcomes from such projects, which made it very hard for organizers to secure additional funding. Years later, Robert Burt, who was in charge of the initiative, said that "nothing lasting" came out of it.[95] Given PDIA's constitutive influence on the entire end-of-life care field, its emphasis on educating and empowering physicians and the consequent marginalization of nursing and social work resulted in long lasting hierarchies in the field.

Part of PDIA's effort to sustain this professional center involved supporting palliative care associations and organizations. PDIA's series of "exit grants," which it awarded when the project ended in 2003, gave the highest support to The American Academy of Hospice and Palliative Medicine—the most central palliative care physician organization in the country. Smaller grants were given to the Hospice and Palliative Nurse Association, the National Hospice and Palliative Care Organization, and the Harvard Medical School's Program in Palliative Care Education and Practice—all organizations that would promote the field on the educational, scholarly, and institutional fronts. A particularly suggesting grant PDIA gave to the American Board of Hospice and Palliative Medicine, so that it implement "standards for fellowship programs in palliative care and […] begin the lengthy application to establish palliative medicine as a subspecialty."[96] In 2006, the American Board of Medical Specialties formally recognized Hospice and Palliative Care as a subspecialty, and in the next years, the physicians wishing to specialize in hospice and palliative care had to work for a year as Fellows and pass a formal board exam.

The field's resourcefulness attracted many young professionals. A PDIA fellow told me that as a young physician he was interested in bioethics, but the existence of a developed and well-funded palliative care field changed his trajectory:

> Suddenly there was a lot of interest, not only on the part of Soros, but the Robert Wood Johnson Foundation and a couple of other major private funders, in end-of-life issues and death and dying. And then that

> spurred a certain amount of interest from public funders too. So there was a big shift. A lot of people who had initially been interested in medical ethics, suddenly found themselves as end-of-life and palliative care specialists, because that's where the money was.

Like hospice before it, palliative care became a career. Physicians could train in it, publish in numerous journals, apply for research funding, teach on the topic, and starting the late 1990s and to a greater degree the 2000s, work as palliative care specialists in hospitals. In 2000-2005, the number of palliative care programs in U.S. hospitals increased from 632 (15 percent of the hospitals in the country) to 1240 (30 percent).[97] By 2015, 90% of the large hospitals in the country (over 300 beds) had a palliative care service.[98] This growth owed much to organizations that in one way or another originated from PDIA. Particularly notable was the Center to Advance Palliative Care (CAPC), a national organization led by PDIA fellow Diane Meier, which promoted palliative care programs throughout the country. CAPC has developed training curricula for palliative care teams and has offered seminars to clinicians who start palliative care services, which instruct them on how to advance the service within the hospital, present it to administrations, and establish relationships with other hospital clinicians. In its effort to promote the expertise, CAPC began grading states by their level of palliative care services. Two thirds of the states received A and B grades and the rest got Cs and Ds (none failed).[99] With two exceptions (Florida and New Mexico), the latter group only included traditionally red states.[100]

"We've gotten ourselves a real field of palliative care," said Susan Block in 2003, when PDIA shut down.[101] This field was at the same time professional and organizational: palliative care had relatively clear and recognized principles, and clinicians could be counted as its opponents or proponents. The field had an object of management that defined it—the end of life—which was broader than "death and dying," which hospices managed. The profession also had particular health institutions where it anchored—hospitals—and palliative care advocates continued work on expanding it to new institutions, such as nursing homes, Long Term Acute Care Facilities, and outpatient clinics. Health organizations, policymakers, and individual clinicians could count as open or close to end-of-life care and palliative care advocates could praise or shame them for that.

Transforming the Culture of Death

If the Faculty Scholars Program aimed to create supply for palliative care—professionals who delivered it and hospitals that employed them—other PDIA engagements sought to create demand by engaging and organizing a public, which would want to receive palliative care services. In 1995, when PDIA announced its grant program, it listed among its focus areas "arts and humanities" and "educational programs for the public about death and dying." Focus on these areas reflected PDIA's

ambition to "transform the culture of death." Consider this goal as an attempt to tackle a great dissonance the SUPPORT study highlighted: the fact that despite experiencing torturing dying trajectories, patients and their families still expressed satisfaction from the care they received. These projects embroiled wider publics in the U.S. in end-of-life discourse, seeking to stimulate what an RWJF report called "an impassionate consumer movement," which would pressure the U.S. medical profession, healthcare institutions, and policymakers to embrace end-of-life care.[102]

Take the project of a Montana physician, Ira Byock, which RWJF and PDIA began funding in 1996. Byock engaged an entire town—Missoula, MT—in an effort to improve end-of-life care in it. He first created "a picture of dying, death, and bereavement in Missoula" by following 250 families that experienced death over one year and gathering data on how a variety of healthcare institutions in the town cared for dying people. "Because this area had been so neglected in American life, most dying people and their families expect very little palliative care, and as a result make few demands for better treatment," wrote David Clark. One of Byock's main goals was therefore to *create* such public expectations and encourage people to demand more palliative care.[103] Another project was the "Vermont Voices on Care of the Dying": researchers from the Vermont Ethics Network interviewed 388 Vermont residents in 42 focus groups, asking them about their experiences with "end-of-life care for someone they knew intimately." The report summarized their answers in nine concise statements, which ostensibly expressed public expectations from medical personnel who treat severely ill and dying patients. Among these statements, which were all written in first person plural: "when we are ourselves approaching the condition of being dying persons, we want to hear about it sooner and more clearly than people do now—but we want to be told in a way that is sensitive to our varying abilities to absorb bad news"; "we want to have adequate opportunity to understand the various care options that are available, and then to choose what fits us best"; "we want, while still relatively well, to have the help of doctors and nurses in preparing advance directives that will really work to bring us the kind of care we would want when we can no longer speak for ourselves"; and "critically—we hope our caregivers never forget that we are all unique individuals; that no generality applies easily to any of us; and that we need a unique partnership with those who are helping us."[104]

Such initiatives incited thousands of people to think about their expectations from end-of-life care, to voice them, and demand that they be followed. They mobilized people to be part of an end-of-life discourse: even healthy people, once expressing preferences on how they would like to be treated when facing serious illness, became subjects of end-of-life care. Some fifteen years later, sitting at a lecture of advocates who promote the use of advance directives, I heard this idea presented to hospital clinicians:

> 'By the way, the last time I checked – let me know if I'm wrong – a hundred percent of us will die [laugher]. Everybody. So there's no way out, and you can remind your patients that accidents happen. How

> many people say, "Oh, I might be hit by a bus"? You might *be* hit by a bus. Especially when you're in our city, and you ride your bike – that's really true. And there are a lot of young bicyclists who have been hit by buses, or other things, and I care for many of them. None of them had advance directives, and I've see the pain that their families went through. It's so important: it would have helped them so much if they had known what their loved one would have wanted before they were comatose.'

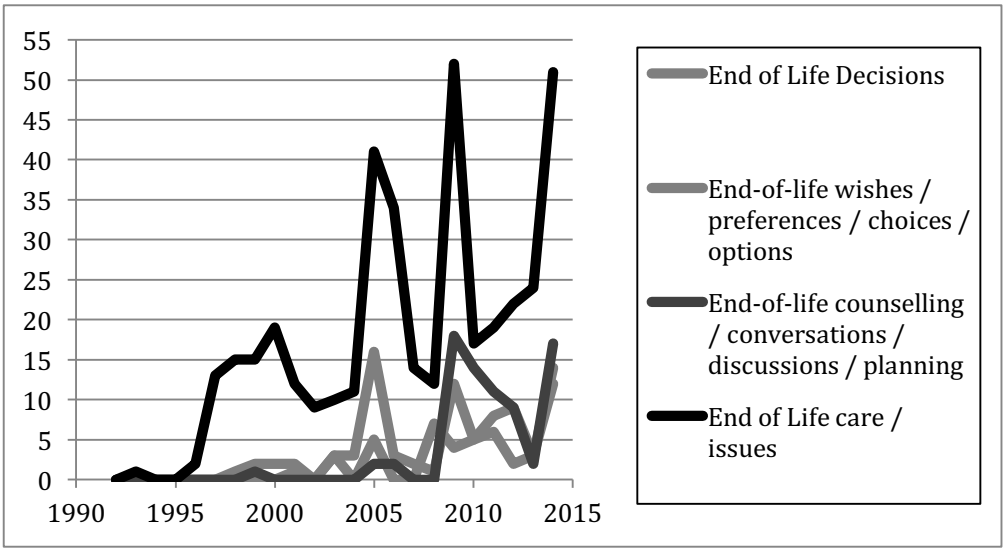
PDIA also supported organizations like the Medicare Rights Center, which worked to "educate consumers, families, caregivers, professional counselors, and clinicians, about Medicare hospice and home health benefits for the terminally ill."[105] They not only encouraged people to think and document their end-of-life wishes, but also gave them practical information on how to pursue these wishes.

PDIA channeled some $680,000 to more general public discussions of death. In 1998, historian, ethicist, and PDIA board member David Rothman began chairing PDIA's Arts and Humanities Initiative, which in the next years supported projects of "video, photography, poetry essays, dance, and artwork to express individual and community experiences of illness, death, and grief and to encourage conversation and thoughtful reflection."[106] Among the fifteen projects it funded were the art exhibit, book, and documentary *Aging in America: The Years Ahead*; fabric panels by artist Deidre Scherer;[107] the documentary *Auburn*, which followed the lives of elderly people ageing 80 to 100 in Auburn, Nebraska; Alan Shapiro's haunting poetry book *The Dead Live and Busy*, which dwelled on family relations around ageing, physical decay, serious illness, and death; and Lisa Schnell's *Learning How to Tell*, which recounted her grieving following her daughter's death.[108] Similarly to other non-medical initiatives, investment in culture and the arts encountered much criticism within the PDIA board; "we probably wouldn't have funded some of those people… as far as our mission to move the field forward and be more visible is concerned, we would have been more discriminating and tougher," said Patricia Prem.[109]

Less doubted were investments in media campaigns and popular media productions. In 1997, RWJF created the "Last Acts" campaign, which ran through national and local media outlets, as well as through a coalition of professional and community organizations. Last Acts worked with journalists, authors, reporters, documentarians, television and radio producers, and newsletter and industry publication editors "to encourage their participation in addressing the culture and experience of dying in America." One of the campaign's most famous outcomes was Bill Moyers' PBS documentary series *On Our Own Terms: Moyers on Dying*, which aired in 2000 and had an estimate audience of 19 million people.[110] When Moyers applied for PDIA support, the review committee noticed that "about 90 percent of the people he was going to interview […] were PDIA grantees" – a figure that indicated the program's immense influence on the field. PDIA feared that funding Moyers "would look too self-serving," and he ultimately relied on RWJF's support: the series had a $2.6 million production

budget, in addition to $2.5 million that were allocated to "outreach." 70 national organizations and numerous local T.V. stations facilitated and coordinated public discussion on the series, which also drew much coverage in national newspapers and magazines. Barnes and Noble featured the program on its website and offered its customers a selection of books on end-of-life care in 900 stores. Local "coalitions" on end-of-life care held over three hundred town hall meetings and public discussion forums about the series,[111] making it the most influential popular cultural product on death and dying since Elizabeth Kübler Ross's best-selling "On Death and Dying." This orchestrated and generously funded buzz stimulated media interest in "end of life." Starting the mid-1990s, media discussions of "end of life," which were rare in previous years, became highly common (e.g. figure 1.3).

Figure 1.3: Mentions of "end of life" in the New York Times (1990-2014)



To be clear: I do not argue that public and professional concerns over how people die in the U.S. derived solely from the monetary investments of PDIA, RWJF, and other philanthropists. As I showed, critical discourse on death and dying predated these investments, and, one can argue, inspired them. (George Soros could not have reflected critically on how his father died without having experienced the opposite dying trajectory of his mother, who joined the Hemlock society and died at home, surrounded by family.)[112] I do argue, however, that these investments acted on sentiments that already existed in the U.S. For one thing, they enhanced these sentiments and engaged larger populations with them. For another, they carved them as a hierarchical and institutionalized professional movement, which advocated for economizing dying.

This movement should be analyzed in context. Its *raison d'être* lied in counteracting the greater historical trajectory that U.S. healthcare has taken, toward a more industrial, commercial, and technologically advanced medicine. The ethos of medical

progress, infused with the ever growing power of what Arnold Relman famously called "the medical-industrial complex,"[113] set U.S. medicine on a seemingly infinite course of expansion to advance one medical frontier after the other. By the 1990s, big pharmaceutical companies, medical device producers, and biotech industries have grown into an enormous economy that had immense influence on healthcare delivery. With these industries' sponsorship, the number of clinical trials of various treatments and technologies skyrocketed: in the 1990s, over $50 billion were spent annually on medical research, yielding over 250,000 controlled clinical trials and an estimate of 2 million medical articles.[114] (OSI and RWJF's contributions seem modest compared to these amounts, although palliative care is inherently cheaper). Once this vast research establishes the usefulness of various drugs and devices, physicians and patients somewhat automatically embrace them as new norms of treatment. This is what anthropologist Sharon Kaufman called "ordinary medicine": a taken-for-granted set of life-prolonging and death-postponing medical practices that both physicians and patients use unquestionably. The "chain of connections among science, politics, industry, and insurance," Kaufman argued, is the foundation of this ordinary medicine, which "offers no inherent facility, no clue or advice for physicians with which to evaluate when *more* is no better and for putting on the brakes."[115]

But I argue that "clues" and "advice," which negate this trajectory, have developed elsewhere, in a very organized fashion. The professionalization of palliative care, its spread into healthcare institutions, and influence over policymaking are certainly not complete. But they have conquered enough ground to provide a pertinent alternative for a growing number of clinicians. For many clinicians palliative care has itself become ordinary medicine – a taken for granted knowledge, which they practice unquestionably. "The good news," said PDIA associate Director Mary Callaway, "is that nobody is against us—nobody thinks it's a bad idea to improve care for the dying."[116] It has become almost universally clear that treating less aggressively and invasively for the purpose of prolonging life and postponing death means improving care for the dying.

3. Economizing Dying in Hospitals

Forests and Trees

Within the mix of medical specialties practiced in hospitals, palliative care has a unique position. On the one hand, with some resonance to Cicely Saunders's legacy, it is an anti-specialist specialty: an integrative approach that seeks to transcend the compartmentalization of care that specialization created. Time and again, I heard palliative care clinicians criticize other specialists who they thought were looking at the small technical details in the function of individual organ systems, instead of on what they called "the big picture": "the specialty services […] are really more focused on […] [say,] this person's heart," told me one social worker, and then emulated a

dramatic speech: "'What's going on with this person's heart?' You're reading ICU notes, and I'm like, are [they] talking about a human being, or are they talking about a machine?" At another hospital, I talked to a palliative care physician whose contract required him to work 25 percent of his time at a medicine unit as a general internist. He found this part of his job unappealing, because as he put it, he did not like to 'look after people's potassium.' At a palliative care meeting, another physician spoke critically of one cardiologist, who reportedly suggested that 'we [cardiology] can treat [a patient's] medical stuff, and you [palliative care] can talk to [his family] about all the other issues' (the main issue was the family's hesitation to disconnect the patient from life support). And Scott, a palliative care physician whom I mentioned earlier, frequently warned young physicians of "mistaking the forest for the trees," i.e. being fixated on solving individual medical problems while overlooking patients' more general disease trajectory.

At the same time, palliative care clinicians applied their integrative stance to a very particular domain, i.e. the end of life. To the extent that they saw forests where others saw trees, their training and day-to-day work made them likely to see very particular forests. Sarah, whom I met during her Hospice and Palliative Care fellowship[117] at Academic Hospital, said that before beginning her fellowship she hardly encountered death. As a palliative care fellow, however, she saw or discussed many of the deaths that took place in the hospital and consulted on dozens of cases of patients who were close to death to varying degrees. Death and dying were what she dealt with, every day and nearly all day. Hospitals were full of end-of-life cases for her and her colleagues, just as they were full of cancers for oncologists and failing kidneys for nephrologists. Administrators recruited palliative care physicians to treat dying patients in the same way they hired cardiologists to treat patients with heart diseases. Palliative care work consisted in identifying end-of-life cases and assisting in managing them. "We eat what we kill," a palliative care physician with a particularly controversial sense of humor told me. Such self-deprecating jokes, always prevalent in the medical world,[118] assumed an especially dark tone around the end of life.

This was also how other clinicians perceived palliative care teams: "Oh, the death squad," an Infectious Diseases specialist cheerfully greeted a palliative care nurse and me as we were walking to see a patient of hers one day. Earlier I mentioned a palliative care doctor whose team prepared for a staff picnic and suggested printing on the front of his team's T-shirt "I Work for Obama's Death Panel" and "Ask Me About Your Granny" on its back. His fellow suggested "I See Dead People," whose gruesome double meaning we all found quite witty. This image of palliative care physicians as "death doctors" was something that many of them tried to battle: after all, the main thing that distinguished them from hospice was that they began treating patients earlier in the disease process, before they started dying. "They're not dying," one palliative care physician told me solemnly when I casually referred to patients on her service as dying. Yet reputation is hard to control: at the end of the day, palliative

care carried similar connotations to those priesthood carried for long centuries – it was the hospital's death harbinger.[119]

Beyond any general perception of the specialty, the practices palliative care clinicians exercised specifically targeted the end of life. Take Heidi, a palliative care attending physician, who spent her mornings visiting and examining the patients on the service's list ("rounding") together with a team of medical students, interns, and residents who each joined ("rotated with") the palliative care service for periods of two to four weeks.

> The seven of us walk into a patient's room. Lying in bed is an old white woman who stares at Heidi with her eyes wide open and jaw dropped. 'Hello, Mrs. Andrews,' Heidi says softly, stroking the woman's shoulder. (Ms. Andrews does not respond.) She takes Ms. Andrews' hand in hers, and then moves further down to feel her feet. 'She's still warm,' Heidi says to the group, 'we're gonna listen to your lungs,' she says to Ms. Andrews; Heidi and one of the medical residents put their stethoscopes on Ms. Andrew's chest; she still stares at them silently without moving. Heidi turns to the rest of us: 'you see, she's using more of her stomach in breathing, which is something that they sometimes do' (Heidi moves her hand in circles above Ms. Andrews' stomach). 'Respiratory distress isn't necessarily forty breaths a minute,' she says, 'they can also be breathing like that.'

Objectification—so commonly criticized in palliative care—was rather blatant here. Heidi used a person's body as a teaching tool, referred to its temperature, movement, and sounds in the third person—'she's using more of her stomach, which is something that they sometimes do'—as if the patient was not present. Such behavior violates a taken-for-granted moral distinction between objects and subjects: people cannot handle living bodies as they handle things, i.e. grab, move, and manipulate them as they do, for example, with car keys. Objectification often signifies an extreme application of oppressive power, such as the one found in prisons, military boot camps, and other much-dreaded asylums.[120] Medical objectifications are integral to clinical practice: doctors discussing kidneys, hearts, and lungs treat the physicality of the human body as detached from the people, i.e. subjects, who both *own* and *are* these bodies.[121] The objectification in this particular case, which at hindsight Heidi would probably regret, reveals the object Heidi trained her team to discern: the end of life. She familiarized students, interns, and residents with the symptoms that make a human body a dying body in the same way a cardiologist would introduce her students to the symptoms that indicate heart disease.

Minutes later, Heidi's pager beeped, and she and her team rushed to the ICU to respond to a call from one of the interns there:

Heidi […] walks straight into the ICU alcove. She stands by the bed, grabs the patient's hand, and touches her face gently. 'We're here to care for you,' she tells the patient and asks if she's in pain. I see no response. I look at the monitor by the bed: it shows a pulse of 38 per minute. I look back at the patient: she stares at Heidi with her jaw dropped underneath an oxygen mask. Heidi turns back to the bedside nurse who stands by the alcove's entrance: "can we get OxyContin?" The nurse hesitates for a second, and Heidi repeats in a more urgent and assertive tone: 'OxyContin, morphine, I don't care, whatever you got around!' She asks Nicky, the medical student, to take her place by the bed and walks toward the ICU hallway. An older nurse (perhaps more senior?) approaches her right by the alcove's entrance, Heidi says quickly, 'we're the palliative care team, we need OxyContin, morphine – any opioid you have!' She speaks calmly, but with clear and great urgency. Behind me, in the hallway I hear someone asking 'is she actively dying?' Heidi goes back to her place by the patient's bed, on the other side I see Naomi, a young chaplain, holding the patient's hand. Hanna, another student who is rotating with the team, enters her user-name and password into a computer in the alcove's corner, and I hear Hassan, the other resident, repeating Heidi's orders to the nurses in the hallway, 'we need OxyContin or morphine.' He comes back to the alcove and takes charge of the computer, looking at the possible doses they can administer from the screen: '12.5-25,' he says. 'Yes, make it 25,' Heidi responds quickly and tells Naomi she can be with the patient. Naomi begins speaking to the patient gently, practically whispering; I hear her saying 'we're all here to help you, there are three women around your bed and they're all here with you.' Several ICU nurses enter the alcove, I see one male nurse who just stands there watching. Heidi asks them if the patient has any family. One of the nurses responds that she has no family, but there's a friend from her retirement home who is her main contact. Heidi asks them to contact the friend and let them know 'what's happening.'

[…] Naomi and Nicky each takes one side of the bed, holding the patient's hands. The monitor indicates a heart rate of 33, then rebounds to 38. I note to myself that the patient is breathing, although the breaths sound more like hiccups. Heidi looks impatient and annoyed with how long it takes the ICU nurses to bring an opioid. […] Perhaps two or three minutes later, the older nurse comes in, takes the left side of the bed and injects a clear liquid into the patient's IV. Nothing dramatic happens, but I notice a slightly softer and calmer expression on the patient's face. Her eyes close for a few seconds, then reopen. I look back at the monitor and see her heart rate is now zero. The older nurse is massaging her hand softly. Looking around the alcove, I see a

> few overwhelmed faces. It takes me a few seconds to realize the patient has just died. The nurse grabs a scanner, leans over the patient, and approaches the plastic bracelet attached to the patient's other arm, which has a barcode on it: a faint beep sounds, similar to what you hear at supermarket registers. The nurse returns the scanner to its place by the computer and continues rubbing the patient's now-dead hand.
>
> The monitor comes back to life a few seconds later. I hear a voice behind me, "she's back," and notice a few breaths. Then the monitor goes back to zero. I follow Heidi's eyes, which shift between the monitor and the patient's face. It goes on for a minute or two. […] Then I see Heidi rushing out, chasing Hanna, who left the alcove crying. She catches her outside the ICU door and embraces her. Less than a minute later the entire team joins them. […] Hanna is now smiling, but her eyes are still wet. Heidi says she's happy we managed to give the patient the OxyContin; somebody asks if she was conscious and Heidi says she doesn't think we can know. 'We couldn't really prepare for it, because we were really called in the very last minute by an intern, but I'm glad we made it,' she says to the team. 'There was some confusion, because it was an intern who called us, and nobody really knew who we were, so it took them time to follow the order.' She adds that we should contact the ICU team later again and see how they're feeling. She thinks this is one of the roles that palliative care teams should have: not only care for patients and families, but also for the clinical staff that's taking care of them.

Palliative care was both recognized and practiced as a death expertise in this case. Noticing that a patient was "actively dying," an ICU intern called the experts who handle death. The experts responded: they administered a drug, advised to call the patient's emergency contact person, and provided the patient with other forms of care: the chaplain whispered in her ear and the doctor and medical students stroked her hand. These interventions seemed minor and were not very satisfying: as Heidi put it, 'we couldn't quite prepare for it,' because the intern called the team at the very last minute. In this situation, when a team rushes to see a dying patient it has never met before, it has little to offer more than morphine, soothing whispers, and hand strokes. Just like any other specialist, the palliative care physician wished she had been called earlier, when the patient was approaching "the end of life" and not yet dying "actively." It is the end of life that palliative care truly aspires to manage; yet from the specialist's perspective, it is often hard to define where the end of life begins, which makes the palliative care jurisdiction highly elusive.

Eva, an Infectious Diseases (ID) specialist described this elusiveness when I interviewed her. As an ID physician, she saw a relatively wide variety of patients: oncology patients who developed infections due to their compromised immune systems, HIV patients suffering from opportunistic infections, transplant patients

receiving immunosuppressant medications, patients with hospital-acquired infections, and others "from the community" who "presented to the hospital" with infections. Many of her consults she deemed hopeless:

> We call it "Rabbi consults."[122] You know, nobody should die without a Rabbi consult... The patient is in an extreme [condition], they've been in the hospital for a month, there's nowhere else to go, and the family says "we want everything done," just to make sure that there's no stone left unturned. So they call us in when the chart is yay-thick, there's just no chance in hell it's gonna work [chuckles] and we basically bless the patient and do the Rabbi consult, you know… We joke. It's really too late, we should have been consulted when the chart was yay-thick [indicates a thin gap between her fingers] as opposed to yay-thick [widens it]. Those are the worst.

These would typically be the *dying* patients. The "end of life," however, is a wider category, which Eva described as a "grey area." Here you would find, for example, patients whose infections may be treated, but who also suffer from a serious underlying disease that often causes these infections, such as cancer. "If we get through this [infection]," Eva presented the dilemma, "what's the [patient's] quality of life? Are we doing [him] a favor by bringing him through the infection to live this horrible quality of life? Will they survive? Will they have a meaningful quality of life?" When I asked Eva how *she* made these decisions, she answered:

> It's in the gut. You know, I think it's like pornography – you don't know how to define it, but you know when you see it. […] You have a gut instinct. […] I know there was times where I felt that there was hope, that I [wanted] to treat something or do something, and the decision was made not to. And it's never black and white. It's always shades of grey. You know, these are decisions where there's no right, no wrong, and you acknowledge that. You're doing the best you can. And so, it's like, I feel that we should go on a little further, but I can't totally disagree if everybody wants to stop.

When a group of clinicians discusses a patient's condition, clinicians may have different instincts and opinions. Compared to other specialists, the position palliative care clinicians take in such cases almost always leans toward less life-prolonging procedures. This, of course, reflects on other specialists just as much as it reflects on palliative care. Recall the hammer metaphor that Scott's colleague invoked: "if all you have is a hammer – everything looks like a nail." Specialists would tend to approach patients with their professional toolkit of diagnoses and interventions, and in this sense, palliative care clinicians approach patients with their own framework, which tries to counteract other specialists' almost categorical tendency to prolong life.

> Standing at the nurse station, Scott is reading the patient's chart. Immediately after he opens it, he points at the name of the patient's primary care physician and tells me she's a pain. 'She's this hands-on doctor, she never lets you do anything, really protective of her patients, and she talks a lot but she hardly ever comes to see her patients here.' He continues reading the chart. […] 'That's a classic example of a patient who shouldn't be here [in the hospital].' I ask why, and he responds quickly, 'because he's dying. He's demented and he has problems swallowing. He's malnourished and he also has terminal stomach cancer.' I ask if he's getting chemo, and he says that oncology haven't even been consulted, and if an oncologist decided to give him chemo it'd only be for the money. […] He continues reading the chart, says 'if he's in such condition and not even a chemotherapy candidate and he's having difficulties swallowing, which puts him at a high aspiration risk, and ultimately likely to develop pneumonia, why do you continue screening him for cancer?'

Scott's expert contribution to this case was to identify an illogical aspect in the care a patient was receiving: although the patient was too sick and weak to receive chemotherapy, his physician still admitted him to the hospital and conducted various screenings and tests on him. In other cases, I heard palliative care clinicians criticize specialists for over-ambition. A palliative care physician told me about a case of a 48-year-old man with colon cancer, which his doctors initially treated with a surgery and chemotherapy. A year and a half of treatment "had done, I think, pretty well," the physician reflected, but not long after, his doctors found a metastasis that reached his liver. The doctors recommended a surgery to resect the metastasis; according to the palliative care physician, in such cases, where the cancer does not spread beyond the liver, "a small number of patients will be cured." But the surgery revealed a very aggressive incurable cancer, which "you can treat with chemo, but it would always come back, and the remissions would get shorter and shorter until the patient would die." Based on the pathology report, the patient's oncologist predicted a life expectancy of "one or two years." The palliative care service dissented:

> This guy, very rapidly, went into liver failure. This tumor was growing and infiltrating the liver so fast that his liver failed. That is a terminal condition, [but the oncologist] wanted to treat him. […] He was responding to one specific bit of information, which was the pathology of the cancer. […] Knowing that the cancer has a chance to respond to chemo, as opposed to one you know isn't gonna respond, […] is a useful bit of information, but it's not the *only* bit of information. The patient is *yellow*. Bilirubin is 17 [normal range is 0.1-1]. He is *infected*. There are lots of other contributing bits of information that say this guy is not gonna make it. He's not a guy who will do well in the ICU. And my point was: okay, fine. Treat him with chemo. But don't go that far. Don't put

> him in the ICU, because if he gets that bad – he's not gonna make it. […] So of course, he gets treated with chemo, and then he continues to decompensate. And the oncologist's point […] was that this could be a complication of chemotherapy: "He's septic […] because I gave him chemo that knocked his immune system back." Well, that was partly true. He was septic, he was also going into fulminant liver failure. We have no therapy for that. When the liver shuts down, if you don't have the ability to get a liver transplant—you're dead. […] You are not eligible for a liver, ergo – this is a terminal situation. Find the false premise! […] Anyway, this was my point to the oncologist, who had chemoed this patient, probably inappropriately, and now was going to try to treat him through what he perceived were chemo complications, where it was very clear to me that it was not a complication of chemo. It was a complication of cancer and dying. And we had this fight in the ICU, it was not angry, he's a friend, I said: "respectfully, I think you're crazy. I think you decided something on Monday and you're gonna stick with it on Wednesday, not matter what happened on Tuesday." This guy had pneumonia of 750 – I've never seen pneumonia that high. Ever. […] I mean, this is one dead liver! It can't clean the body's toxins. I said, "this is the tail wagging the dog. You've given chemo and you're letting that decision determine what the right thing to do is." […] He disagreed. And what do you think the family wanted? They wanted the optimistic doctor.

The palliative care physician tried to stop what he thought was bad medical care. The oncologist, who also relied on some laboratory results that indicated some improvement in the liver function (which the palliative care physician did not mention to me), believed there was a chance the patient would stabilize and be able to continue chemotherapy. (This chemotherapy was not expected to cure the patient, but to prolong his life in a year or two.) To this end, the oncologist considered the many life sustaining interventions the ICU could offer helpful: a ventilator to sustain the patient's breathing, hemodialysis to replace his kidneys (which started failing following the liver), and pressors to bring blood pressure to a level that would enable hemodialysis. The possibility of using CVVH—a continuous hemodialysis treatment, which replaces the kidneys completely—also came up. "It's logically insane," the palliative care physician said enthusiastically when we talked,

> Because we have the capability we have a very hard time saying 'no.' All we're doing is dragging like that at the margins. […] I could march people down a logical game: I could say, 'okay, well, what are you gonna do when the patient's oxygen starts to drop […]? Are you gonna wheel the ECMO [heart-lung] machine over? And they'd be like, "of course not." Well, why not? What's the difference? You know, it's just a step beyond what you were willing to do. Well, a lot of people are

> uncomfortable when I'm very firm about not intubating somebody. I happen to draw the line before other people.

This is the essence of the economized dying clinical intuition—and while there are numerous clinicians who would not espouse it when making medical decisions on their patients, few would doubt its merit, particularly in the contemporary U.S. healthcare system, when it is substantiated and institutionalized professionally and morally. The existence of palliative care clinicians in the hospital environment means that there are clinicians whose professional predilections lean toward economized dying and who would advocate for at least somewhat more moderate and limited medical interventions than those other clinicians offer.

On the other side of the line the palliative care physician drew, I came across several cases where non-palliative care clinicians criticized specific misguided decisions that derived from what they thought were crass and careless application of economized dying. These stories were exceptional, but they still reflected the degree to which "end of life" and "economized dying" institutionalized as clinical categories. A general internist told me:

> I had one intern who basically single handedly made a patient [sign] DNR/DNI and comfort care without telling me, and said, "well, it just seemed like he had a long road ahead of him." I was like, "What?! No-no-no!" This [patient] was a pretty young guy, who was delirious at the time, so he didn't have capacity to make the decision anyway, and I said, "there is no reason why this guy is not going to get through this." [...] I don't know that this particular intern really appreciated that he had just decided to end care that would sustain this man's life. Like, this was a father, and the intern convinced the family that he wasn't gonna get [better]. I found out about it through my resident, who was furious. And it was not a good situation. It actually stuck with me; it was hard for me to trust this intern for the rest of the time we worked together.

In another hospital, an oncologist criticized the palliative care service and clinicians in the medicine unit for classifying one of her patients as being in the end of life too hastily:

> This patient was referred to oncology with no diagnosis, in the presumption by the people that were seeing him that they knew what was going on, that he had far advanced lung cancer. And I looked at the data and said, actually, that's probably not what he has at all. And by the way, there's this thing in this guy's liver, and it's growing rapidly, and you haven't biopsied it. You need to do that. And so I sent an email out to hepatology, and eventually they [did] it. [Meanwhile,] the patient is in the hospital, and the house staff in the hospital, they don't have access to all the emails that we sent back and forth [...], and they called

> the palliative care service and had this long conversation with the patient, assuming he was dying of lung cancer. In fact he has a treatable cancer. [...] So in the last few days, there's all this backtracking.

Both speakers presented these cases as examples of dysfunction and malpractice. In the first case, an intern took the liberty to change a course of treatment without properly discussing it with the team's senior physicians. The second case is an extreme example of miscommunication between specialists, internists, and palliative care clinicians in the hospital. Palliative care is *not* the reason for malpractice in these cases. But these cases show how readily available the labels of "dying" and "end of life" are for clinicians today. Within the mixture of professional perspectives and orientations, there exist one that advances a more economizing stance, questions the usefulness of curative, life-prolonging, and life-sustaining medical interventions, and challenges the more ambitious medical specialists.

Say the D-Word

On an early Tuesday morning, Private Hospital's grand rounds featured two physicians from a local community organization. They spoke about two forms—advance directives and POLST (Physician Order for Life Sustaining Treatment)—which hospital staff uses to document patients' end-of-life preferences. The speakers emphasized the importance of filling out these forms and following the orders written in them. They also spoke of the more general social and economic context that makes these forms so important in the U.S. healthcare system: 'the U.S. population is aging, and every day, 10,000 people in the country turn 65' one speaker said. 'Of the population of 65 and older, 1 out of 8 has some form of dementia, and by the age of 85, 1 out of 4 people requires full time care in daily living activities. This is what they call "the silver tsunami," and I think that in medicine we've put it on the backburner for too long.'

The lecture went on to mention several laws that were passed in the area, specifically the relatively recent California Right to Know End of Life Option Act (2009): 'it mandates that physicians who are treating patients with terminal conditions talk to them about their end-of-life options, including the right to refuse treatment, to obtain hospice and palliative care, [and] to refuse food and drink.' One of the speakers cited a World Medical Association 2003 declaration that 'a patient's duly executed directive should be honored, unless there are reasonable grounds to support that it is not valid.' And she also cited from studies such as SUPPORT, showing that many physicians are not attuned to patients' wishes to suspend invasive and life-prolonging treatment. The speakers presented POLST and advance directives as two ways to remedy these problems and comply with legislation: these forms document patients' wishes formally and make it easier for physicians to ensure that they are respected. The speakers said that filling out advance directives has multiple benefits for patients

and families: they have been shown to improve their satisfaction, reduce stress, anxiety, and depression in surviving relatives—and in addition they increase hospice referrals and involvement of palliative care, and lead to "less aggressive medical care." This tendency to treat a patient aggressively, she said, may also result from 'biases on the part of the hospital, that are due to our profession, that are due to our own emotional investment in the case, that are due to research biases and other motivations, that we don't carefully consider when we're talking about continuing aggressive care or planning aggressive care for patients who are near the end of life.' At some point one speaker was almost threatening: "Following POLST is *legally mandated*," she emphasized. 'If you go against a POLST, someone is DNR (Do Not Resuscitate) on their POLST and their surrogate stands by it and they receive life sustaining resuscitative measures – you can be held accountable.'

After some forty minutes of lecture, the speakers opened the stage for questions. I was sitting next to Natalie, a longtime liaison from a hospice affiliated with Private Hospital, who worked closely with the palliative care team. 'Oh, I'm dying to hear what the doctors are going to say!' she said to me quietly, referring to several specialists who were sitting in the auditorium. I had heard palliative care clinicians making similar comments on these specialists, saying that they belong to an old conservative guard, who practiced dogmatic medicine and refused to open up to the challenges that palliative medicine highlighted. (Palliative care clinicians often described themselves as a subversive island within an otherwise close-minded and death denying professional environment.)

But the questions this "old guard" asked were devoid of any antagonism toward palliative care. First stood a senior cardiologist in his 70s who was notorious among the palliative care service for his obstinate resistance to the service. He said that POLST and advance directives would not help a person who collapses in the street and does not want to be resuscitated. When that happens, the paramedics would not look for a form in your purse before starting resuscitation, so it's important for people to have Do Not Resuscitate (DNR) bracelets or any other sign on them that would be familiar to the paramedics in the city. The second question came from a elderly oncologist. Responding to the speakers, who mentioned that POLST forms are valid in any place in the state of California as long as patients hold on to them, the oncologist asked what would happen if he filled out a POLST with patient who would then fly to Florida. Natalie snorted and whispered to me: 'do you know who he is? It's Williams, the shittiest hospice referrer in this hospital. He's notorious for late referrals – sending patients to hospice just a few days before they die. He also doesn't know how to talk to people, so he always leaves the conversation to somebody from palliative care.'

There was much criticism directed at the oncologist from a hospice and palliative care specialist, but little to none in the other direction. The oncologist asked a question that Natalie thought was minor and somewhat beside the point: there were far more cardinal issues to discuss about POLST forms, for example, how to ensure that

physicians like himself fill them out in the first place, even with terminal cancer patients who do not travel to Florida. But notice that his question—as the question that the cardiologist had asked—*validated* the importance of using instruments such as POLST and advance directives and expanding their use to address multiple scenarios. A similar experience I had with an oncologist that a palliative care physician said was doing "crazy shit" to his patients. His approach, another physician told me, was that "nobody should die. Ever." In the interview itself, however, the oncologist insisted that he almost always agreed with the palliative care team.

Differences between what people do and say they do are common and unsurprising. As Jerolmack and Khan argued, "talk is cheap."[123] But the nature of such differences is revealing: in this case, specialists treated patients more aggressively than they admitted to me in interviews or to their colleagues at a public lecture. Clearly, economized dying has not completely anchored itself in all medical domains, but it has become widely accepted as good medicine, so habituated that clinicians try to hide or deny their opposite professional predilections. One clinician who did not deny it, did so with humor: I was introduced to Dr. Lum (an oncologist) by a palliative care physician, who said I was 'a PhD student from Berkeley who studies the economy of end-of-life care.' Dr. Lum laughed and said 'yeah, I'm one of the reasons why the cost in the last days of life is so high.' 'Ever heard of the Lum factor?' the palliative care physician shot back. 'However long he says somebody's going to live, divide it by 10—this would be your best prognosis (I heard the same joke from other physicians too). The moral of this tong-and-cheek exchange was clear: Dr. Lum does not economize death sufficiently – his prognoses are too optimistic, hence he treats too aggressively and expensively.

Palliative care's greatest educational efforts are with younger clinicians, specifically those still in training: medical students, interns, and residents.* One morning, I shadowed Scott in an Intensive Care Unit, where a large team of doctors—an attending, several residents, and several interns—discussed a patient he was treating. The team stood in a large circle, and a young male intern, appearing anxious and uncomfortable, talked about the patient's condition: he reviewed in much detail each of her organ systems and cited dozens of numbers that came back from her laboratory tests. Two more senior residents looked bored and dismissive of this overplayed display of expertise. They somewhat flamboyantly opened a laptop and began reviewing an MRI scan of another patient. Standing next to me, Scott was visibly annoyed and impatient. Perhaps in response to these gestures, the ICU attending interrupted the intern, saying 'you're talking about all the things that are working, maybe you should talk about what's not working?' I noticed the rest of the people in the team sharing a few smiles, then the intern said quickly that the patient's

* In hospitals, interns are physicians in their first year after medical school, residents are physicians on their second and third year after medical school, and attending physicians are the senior physicians in charge of them.

kidneys are in very bad condition and the left kidney does not function at all. “Oh!” the attending exclaimed, drawing laughter from the rest of the team.

Scott took a step forward. “Did you talk about it with the family?” he asked the intern, who said he did not: ‘the daughter was focused on helping her get over the infections, so she can continue chemotherapy.’ But Scott insisted: “you may be able to win small battles and improve all sorts of smaller things in the overall picture. But this would be confusing the forest for the tree: the big picture is that she’s not going to make it. She has metastases everywhere! Her kidneys don’t work! I understand that maybe there’s some resistance from her daughter and maybe even from you, but what I’m asking is why didn’t you talk to her about her mother’s overall condition?’ Protective of the intern a resident joined the exchange, saying that she felt there was ‘some level of resistance’ that came from the daughter, so it was difficult to talk about it. The daughter came in for only two days, so the team didn’t know her well enough to talk about the topic. ‘It doesn’t help,’ Scott agreed, ‘but you’ve been here for a week – why didn’t you talk to her?’ The intern who presented the case initially asserted himself again: ‘it’s a very difficult conversation, and I found that it was hard for me to have it.’

A more senior resident confronted Scott more directly: ‘I think that it’s hard to come to an ICU intern and ask “why did you not have this conversation” when there’s an oncology team involved and when the oncologist is not only an attending, but also the person who knows the family for the longest time. Besides, the patient is an oncology patient and they’re the ones who make the clinical decisions about him, so it’s not easy for an intern to intervene in the relationship between an oncologist and a patient’s family.’ ‘Okay’, Scott replied,

> ‘But the people who are managing the patient right now are not oncology – they’re you. On the bottom line, when something happens, you’re the ones who have to manage it, give her pressors or intubate her. And you should make sure that the family knows how the patient is doing. And you know what the prognosis of patients with metastatic cancer in the ICU is, right? They have a very, very short prognosis [the intern nods]. Calling palliative care whenever you have to convey such news is not enough – you also need to communicate with the family yourself!’

At the end of the exchange, Scott took the telephone and called the patient’s daughter to inform her about her mother’s condition. ‘I will talk to the nephrologist, because this may be an issue,’ he told me, knowing the patient’s kidney specialist was an “aggressive type.” The intern and one of the residents who talked earlier approached him by the nurse station. ‘Even when a patient is an oncology patient,’ he told them, ‘you shouldn’t hesitate to make your own diagnosis. Talk to the family, update people about her condition. Tell them that she’s not going to make it very long. If you see that she’s dying – you can say it. Say the d-word!’ They nod. ‘You heard how I talked to the daughter on the phone,’ he says. ‘I was very clear in the fact that she was not going to

get more chemo. I made the point that she would not benefit from dialysis, and I also presented the possibility of hospice as the best-case scenario. When you present hospice as the best case scenario, you make her look at hospice more positively, and then if she does manage to improve so it's safe to discharge her, it'll be easier to transfer her to hospice.'

Such interactions expose young physicians who are still training to palliative care. Scott did more than just asking the intern and the resident to consult him when patients are dying: he demanded that they internalize the palliative care approach, talk to families and patients about death, and think when economizing dying is appropriate.[124] Physicians in training have far less power than attending physicians. Not only do the attending physicians have the final word on how to treat patients, they may also influence residents' and interns' future career trajectories. It is difficult, as the resident pointed out, for an intern to challenge a senior oncologist and argue that his patient should be treated less aggressively.

The presence of Scott and his colleagues counteracted this difficulty since they were authoritative attending physicians who leaned in the opposite direction, i.e. toward economized dying. Interns and residents who thought more economized treatments would be appropriate in certain cases could find support from Scott and his palliative care colleagues. Furthermore, in cases such as this one, palliative care physicians confronted the interns and residents who were reluctant to economize dying. One resident even told me that Scott reproached her when he thought she did not properly follow an economized dying decision they reached: the situation was particularly uncomfortable, since she was applying for jobs and counted on Scott's recommendation letter.

Such dynamics may not be what the PDIA leadership imagined when it launched the Faculty Fellows Program. Yet there is a clear line that connects between Scott's interactions with interns and residents and the elitist professional strategy PDIA adopted. Palliative Care does not dominate hospitals, but the presence of senior palliative care clinicians in hospitals means that it has sway, particularly on less senior staff. In this way, the palliative care team does not only economize dying, but also increases the probability that non-palliative care physicians would do so.

Conclusion

This chapter outlines the emergence and current practice of the medical economization of death: a professional and moral intuition by which when it comes to end-of-life care, less treatment is better treatment. This intuition developed in a historical context where medicine became more influential and capable than ever: doctors are able to offer some form of life-prolonging treatment in virtually any situation. When to stop, scale back, or limit such medical interventions is an ever relevant question: death is inevitable, yet managing and circumscribing it is very

much a matter of decision making. I show that these decisions are patterned. The ascent of a specialty whose main focus is managing the end of life means that clinicians follow certain frames of thought and action when they treat end-of-life cases.

Much of the power of the hospice and palliative care expertise lies in professional competence: a good palliative care clinician can compile a comprehensive picture of a patient's condition and recommend on the appropriate ways to economize this patient's dying. No less important is the *moral* power of hospice and palliative care, namely, its success to define what people generally consider to be benevolent and virtuous care. The movement for hospice and palliative care very much transformed how laypeople and professionals think about death and dying. The view that medicine should avoid over-treatment and prioritize comfort and "dignity" over life-prolongation near the end of life is hardly challenged publically and in medical circles. Clearly, there are numerous hospitals in the U.S. that have no palliative care services, and even in those that do, palliative care does not consult on many relevant cases. (See, for example, the case that opens this chapter: Scott was never called to see the patient and she died without a palliative care consultation.) But the expertise's power is still growing and its moral stance on end-of-life care is becoming ever influential.

The hospice and palliative care movement economized dying by creating both supply and demand for it. Beyond training and empowering professionals and spreading the palliative care way of dying in healthcare institutions, the movement also engaged the public and nurtured sentiments that resonated with economized dying. This laid the fundamentals for the new moral economy of death. The next chapter discusses its financial and organizational aspects.

Chapter 2: The Financial Economization of the End of Life

> I recoiled when Sarah Palin invoked the notion of a "death panel" […]. That was wrong and unfair. But I was left uneasy by her phrase. Had I not been one of a handful of bioethicists over the years who had pushed to bring the need for rationing of health care to public attention and proposed ways to carry it out?
>
> Daniel Callahan[1]

"The end of life" acquired financial significance around the same historical period it became a medical and moral category. During this period, numerous social actors explicated *why* it posed a financial problem, *how* to solve this problem, and *who* can solve it.[2] These actors described the end of life as an area of excessive spending and argued that less should be spent on it: it should be economized financially. These arguments were embedded in the medical economization of dying, which I described in the previous chapter. The further the hospice and palliative care movement went economizing dying medically and doubting the necessity and morality of many life-prolonging procedures, the more dubious spending on these procedures became. Health economists who identified conventional care at the end of life as costly became the strange bedmates of progressive hospice and palliative care activists.

This chapter outlines what I call *the morphology* of end of life's financial economization: the assemblage of actors that made the end of life a financial matter[3] requiring economization. Each of the chapter's four sections examines one of these actors. The first section focuses on hospices. I outline the financial history of U.S. hospices and show how the hospice movement became entangled with the U.S. healthcare economy and how hospice advocates began making financial arguments about death and dying. The second section follows the writings of "death economists," who during the 1970s and 1980s, began recognized the end of life as a potential area for cost-saving. The third section is dedicated to the agency of hospitals, specifically their attempts to cut spending in general and near the end of life in particular. I describe several policy measures from the 1970s-1980s and characterize the economy that these measures created: hospitals' financial interests became unclear and financial uncertainty was prevalent. Hospital administrations sought strategies to cut on their spending and became interested in end-of-life care as one possible area of action. The fourth section tackles the economics of palliative care. I show how in the context of this financial uncertainty, as hospitals faced high risks that made strategizing extremely difficult, palliative care advocates worked to redefine hospitals' financial interests, convincing many hospitals that palliative care would be financially beneficial.

Through this process, the specialty of hospice—and later on, palliative care—became a way to solve the financial problem that end-of-care came to represent.

1. Hospice and Finance

I'm not an economist, but…

Elisabeth Kübler-Ross was not an economist. One has to scrutinize her writings thoroughly, perhaps unfairly so, in order to find comments that pertain to economics in some way or another. No generalization of the few haphazard, somewhat careless, comments that she made on financial affairs would do her justice: Kübler-Ross refrained from articulating any programmatic stance on the financial economy of the U.S. healthcare system of her time, the very same system she dedicated her life to changing.

A model psychiatrist, Kübler-Ross wrote her Magnum Opus, *On Death and Dying*, along her discipline's conventional dichotomy: "denial" on the one hand, "acceptance" on the other hand. She characterized the U.S. society and its medical system as "death denying," i.e. as persistently avoiding acknowledgement of human life's finitude. This denial, which Kübler-Ross saw as emblematic of modern western cultures in general, prevented an institutional acceptance of death: it was what made hospitals as organizations, and physicians as professional authorities, provide the most technologically and scientifically advanced treatment available to combat any disease and prolong all life, as if death could always be avoided. The power of hospice, in Kübler-Ross's mind, was its ability to support patients in passing the five psychological stages necessary to reach acceptance and die peacefully: Denial, Anger, Bargaining, Depression, Acceptance.[4]

In one rare paragraph of financially-minded reflection, at the beginning of *On Death on Dying*, Kübler-Ross blamed commercial interests for taking advantage of death denial:

> There is no law in this country that prevents business-minded people from making money out of the fear of death, that denies opportunists the right to advertise and sell at high cost a promise for possible life after years of deep-freeze. These organizations exist already […]. They actually show the fantastic degrees of denial that some people require in order to avoid facing death as a reality.[5]

It is no coincidence that this criticism of "business-minded people" was directed at Cryonics—a relatively exotic and marginal phenomenon, uncommon outside of the U.S. society's wealthiest circles. Kübler-Ross did not seek to challenge the mainstream of the U.S. healthcare economy and did not suggest, for example, that physicians and hospitals, who profited from prolonged and more aggressive treatment, took

advantage of death denial and promoted it by expanding specialized medical care.[6] Her reference to deep-frozen bodies criticized mainstream cultural tendencies in the U.S., not dominant financial interests.

This careful approach characterized Kübler-Ross for the rest of her career. Yet as her life-project materialized, and her theory of death, denial, and acceptance was translated into seminars and trainings with tens of thousands of participants nationwide, her relationship to finance became more complex. Like most of the rest of the hospice movement, Kübler-Ross continued presenting financial questions as secondary to hospices' main goal to change medical and cultural attitudes toward death for the benefit of the dying. But these questions kept coming up, one way or another. In 1972, Kübler-Ross joined several other key figures in the developing hospice movement, and pilgrimed to Washington DC to appear at the first congressional hearing on the question of "Death with Dignity."[7]

The festive words of many of the hearing's participants betrayed their wish to cement the occasion as a landmark historical event. Only three years after the publication of her book, Senator Frank Church (D-ID), the hearing's chairperson, referred to Kübler-Ross as "the author of [a] classic," and quoted from it in length.

> Dr. Elisabeth Kübler-Ross, who wrote the book, is one of our witnesses this morning, and we will want to hear more about her conclusions […]. But for Members of Congress, her indictment has special meaning because so many actions taken by Congress within recent years are directly related to the type of institutions available to most Americans.
>
> It has been said, and I am sure it will be said at these hearings, that Medicare puts entirely too much emphasis upon institutionalization of patients, thereby increasing costs of treatment and anxiety among patients. That criticism is being acknowledged by the Department of Health, Education, and Welfare at least to the extent that many statements are made about the need for alternatives to institutionalization.[8]

The direct reference to costs and monetary considerations—so obvious in the context of a congressional hearing—reflected the transition of hospice from theory to practice: in the form of theoretical insights printed on paper, Kübler-Ross could limit her theory to moral discussions and cultural reflections. But when she arrived at Capitol Hill, the hybrid of hospice economics emerged. Her medical-ethical criticism translated into an attempt to shift federal funds from one type of care to another. The idea of hospice became pertinent to another problem, which Senator Church defined as "increasing costs of treatment."

"What," asked Senator Church, "in your opinion, has been the effect of Medicare and Medicaid upon the problems that you have discussed this morning?"

> Dr. Ross: "I am not very good in money matters, but I know that both Medicare and Medicaid tend to enhance institutionalization. The very first response is, 'Let's hospitalize the patient.' I think many of these patients could be taken care of on an outpatient basis, if the financial and other necessary help would be forthcoming." […]
>
> Senator Church: "In other words, if the program[s] were modified in such a way that the financial help that is now given to pay for the hospitalization, or the nursing care and treatment, […] could be available to promote care in the home, that this would be a great step forward?"
>
> Ross: "A tremendous step, not only to the patient but also to the family. You see, the patient and the family have to go through the stages of denial: the 'no, not me' stage; the anger; the 'why me?' stage; the bargaining 'yes me, but' stage; and finally the depression and final acceptance. […] If the patient and family can reach the stage of acceptance the patient dies very peaceful, and the family who is left has no grief work to do afterwards."[9]

With this promise to eliminate grief-work after a loved one's death, the case for transferring money from hospitals to hospices was substantiated. Lobbying converted a professional distinction between hospice and hospitals into a budgetary distinction: it translated an effort to find an alternative to death-denying and dehumanizing care in hospitals, into a budgeting decision to divert funds from hospitals and nursing homes to hospice care at home. The caveat "I am not very good in money matters," maintained the distinction between the hospice vision and economics, and connected Kübler-Ross to the former rather than the latter.

Many hospice advocates conducted themselves similarly and expressed reluctance to engage financial questions, while making quintessential financial arguments. The depth of these arguments, however, developed as time passed, hospices increased in number, financial evaluations were published, and political circumstances changed. Roughly five years after this first hearing, as Congress committees and subcommittees contemplated various ways to fund hospices, Kübler-Ross explicitly highlighted the lower cost of hospice, compared to care in hospitals:

> When terminal patients are treated in hospitals, costs can run about $300 per day, but at home, using the Brompton cocktail for pain control [as done in hospice – R.L.], medication materials costs ran about 80 cents per week![10]

This signified the transition in Kübler-Ross's approach to the financial aspects of death and dying. At first, it bordered on disinterest: finance was virtually absent from her doctrine. Then, as abstract thought about reforming the American way of dying became reality, Kübler-Ross advocated for funneling federal funds to hospice care at the expense of other healthcare institutions. Finally, Kübler-Ross explicitly

emphasized a financial advantage that hospices had over hospitals: the care that they provided was not only morally and medically superior, it was also less costly. Hospice became a cheaper way of dying.

Better care for cheaper

This gradual—and always equivocal and ambivalent—adoption of a more financially informed stance characterized the entire hospice movement. In contrast to modern medicine's technicism, hospice discourse was contemplative, intellectual, and reflective. Philosophical, historical, and sociological observations frequently appeared in hospice literature, and hospice advocates presented their medical credos as responding to ethical and existential questions that confronted the entire human race in modern times.

Discussions of money, budgets, and finance, however, were not integral to this discourse in its beginning. The first manuscripts that hospice advocates and practitioners published in the 1970s included few explicit mentions of these issues. Bibliographical lists of hospice literature in the 1970s did not include an "economics" or "costs" section, and did not mention any books that focused on the topic. Psychologist Herman Feifel's two anthologies, which collected much of the intellectual origins of hospice work, included lengthy discussions on psychology, culture, religion, art, literature, law, education, clinical management, and the history of death in the U.S. and abroad.[11] "Money matters" were briefly mentioned only in four pages, which cited the burden that the high cost of dying in the U.S. put on families;[12] no article, let alone section, was specifically dedicated to finance.[13]

Like analyzing Kübler-Ross's approach to the monetary economy, constructing a history of early hospice pecuniary thinking requires a subversive reading of hospice texts, one that often goes against the authors' original intentions. A loose outline of implicit hospice philosophies in the area can only be charted by collecting brief comments, sidetracks, and afterthoughts that hospice pioneers added to what they saw was their main contribution: reshaping cultural and medical attitudes towards death.

This reluctance to reflect on "money matters" had disciplinary, moral, and institutional roots. Early hospice protagonists were idealist clinicians, not economists. When they did opine on "money matters," they did so as concerned professionals who were economic dilatants, not as reformers who sought to revolutionize the U.S. healthcare economy. The staunch anti-institutional stance that early hospice advocates adopted was also a factor.[14] Recall Florence Wald, leader of the New Haven group, which in 1971 incorporated the first U.S. hospice—Hospice Inc. As she reflected: "we were as apt to meet at vigils for peace, meetings in the black ghettoes of New Haven on behalf of their civil rights, as we were in corridors, clinics and meeting rooms of the medical center."[15] During their first decade (1970s), U.S. hospices

developed as a small, grassroots, and volunteer-based social movement—characteristics that many advocates saw as fundamental to the hospice cause.[16] In 1979, before listing the core principles of hospice care, a Comptroller General report stated that "there is no standard definition of a hospice, or what services an organization must provide to be considered a hospice."[17] Many advocates embraced this indefiniteness and favored care based on intuition to medicine based on standardized guidelines.[18] Without clear institutional definitions, it was hard to formulate a vision for hospice finance, and many practitioners resented thinking about an emotional and morally dense topic such as death and dying in rational "business" terms.[19]

This resentment led to somewhat contradictory stances on finance among hospice protagonists. One thing is clear, however: most hospices in the 1970s suffered from an acute dearth of resources. In 1979, only two out of nineteen hospices that reported their finances to the Comptroller General had income from Medicare and only three were paid by private insurers and self-paying patients.[20] The overwhelming majority of hospices relied on combinations of grants, donations, and volunteer work, with one hospice reporting annual operating expenses of $17,202 that were used to serve as many as 171 patients.[21]

Under this stark scarcity, hospice advocates sought to provide care for all, regardless of patients' ability to pay.[22] This was a particularly difficult task given people's reluctance to talk about money. The Hospice of Marine, for example, did not charge its patients any fees, because:

> (1) We hoped to be able to establish the practicality of hospice home care without having to focus on reimbursement, (2) we were concerned that if we developed a billing program along conventional lines, hospice care might not be seen as a unique addition to the medical care delivery system.[23]

Providing treatment without reimbursement relied on a volunteer economy, where hospices' little monetary income came from gifts and donations. In this altruistic gift economy, which crystalized spontaneously and in an unplanned fashion, some hospice figures went as far as tackling financial difficulties with spirituality and faith, contending that since the hospice cause was noble enough, money for hospices was bound to appear somehow, miraculously. When the director of a small hospice in Sussex wondered how to fund its work, a clergyman responded, "This work is vitally necessary, isn't it? Then if you all do your part well, it will succeed."[24]

Such an economy, however, was limited in size and could not accommodate the ambitions of the most central faction within the hospice movement. Hospice Inc., which became a professional hub during the 1970s, was also a center of political and organizational power. In 1973, its board hired Dennis Rezendes, who had worked with New Haven's mayor and with Connecticut's governor as a political consultant. A

year later, Rezendes became Hospice Inc.'s executive director,[25] and by 1975, Hospice Inc. created a National Advisory Council, whose main goals were to "help the Connecticut leaders build a *market* for hospice"[26] (my emphasis) and spread the hospice care model throughout the country. Names of the Advisory Council reflected its professional, intellectual, and political clout, as well as its progressive political leanings: Elisabeth Kübler-Ross, Jesse Jackson, Erich Fromm, Hubert Humphrey, and others.[27]

Any lobbyist would pride herself in what Rezendes achieved over the next years: in 1976 he successfully lobbied for liberalizing Connecticut's Medicaid eligibility criteria for home care, which provided Hospice Inc. better and more flexible funding opportunities. In 1978, he patented the term "hospice" in Connecticut, and successfully promoted legislation that designated hospice care as a distinct form of care.[28] That year, he joined Don Gaetz and Hugh Westbrook, two hospice entrepreneurs from Florida, and founded the National Hospice Organization (NHO). They then organized the first NHO conference in Washington D.C., where Joseph Califano, Secretary of the Department of Health, Education, and Welfare, declared that "the government would fund and study hospice demonstration projects to learn about the organization and cost of this new model of care."[29] A commemorative NHO publication noted that Califano was "lobbied hard," by Connecticut Governor Ella Grasso, in whose office Rezendes had worked before joining the NHO's ranks.[30]

200 applications for participation in the demonstration project were submitted, 26 of them were approved. The project, entitled "the National Hospice Study", took place in 1980-1982 and provided the 26 hospices with a stable, albeit temporary, source of funding.[31] In the meantime, Rezendes continued his efforts to have hospice care approved for Medicare reimbursement. In 1980, Rep. Leon Panetta introduced a bill to add a Medicare hospice benefit, which died in committee. NHO members, however, began redrafting the bill,[32] and during 1982 some "two or three dozen committed individuals, most of them from demonstration projects,"[33] met monthly in Washington D.C. for this purpose.

Accounts of participants in those meetings reflect the chasm that emerged within the NHO during those years. On the other hand, a core of entrepreneurial and politically minded people sought to institutionalize standards for hospice care, make hospice legally recognized, and provide hospices stable sources of income from Medicare and Medicaid. On the other hand, idealistic grassroots practitioners battled to protect what they saw as the unique characteristics of hospices from institutionalization: "smaller hospices absolutely objected to structure and accountability of any kind," noted Mary Taverna, a meetings participant and a volunteer hospice nurse:[34]

> Those meetings were tense and high energy, with fervent debate bordering on anger because people were so passionate. We'd stay 10 hours and then a group of us would march up the hill to the Capitol.

> Some staffer would come in and say, "that will never get passed." So we'd have to go back and start over.[35]

But while activists within the hospice movement were debating about institutionalization—whether hospices should subject themselves to standard definitions, regulations, and audits—the movement was fairly united toward the outside, mainly because the outside debate revolved around another topic. Discussion in Congress was less about institutionalization: it was obvious that for Congress to fund hospices, clear definitions and standards for what hospice care is would have to be determined. Congress debated a monetary question: whether or not hospice was cheaper than conventional care. Around this question, hospice advocates agreed that hospice was a better *and* cheaper way to care for the dying.

Both arguments that Kübler-Ross made in the 1970s were raised in that period: first, advocates pointed out that Medicare was biased toward inpatient hospital care and hardly supported homecare.[36] Second, and more strongly, they claimed that hospice was cheaper. As many hospice protagonists noticed, "the success of hospice proponents in negotiating funding for […] reimbursement is affected by their ability to demonstrate hospice care systems' cost-saving potential."[37]

This last argument made much intuitive sense: pain medications were far cheaper than life-prolonging treatments, and homecare was incomparably cheaper than inpatient care in a hospital or nursing facility.[38] But demonstrating this intuition empirically proved difficult. Several studies in the late 1970s that evaluated the relative cost of hospice were rather equivocal. The 1979 Comptroller General report noted that:

> Any cost saving available from the hospice concept would appear to depend on the ability of hospices to care for patients at a lower level of care (home health instead of skilled nursing facility or skilled nursing facility instead of inpatient hospital). We were unable to obtain sufficient information on U.S. hospices to reach conclusions about whether hospices have this ability.[39]

A year later, a "Hospice Project Task Force" studied the cost effectiveness of hospice in order to determine whether it should be included in California's Medicaid program (Medi-Cal). In its final report it stated:

> At the present time there is not enough conclusive evidence on the efficacy of hospice care to allow the Department of Health Services to recommend including hospice as a benefit of the regular Medi-Cal program. Although the potential cost saving to the Medi-Cal program from hospice care may be substantial, the data are only suggestive and establish a basis for further investigation.[40]

The largest and most comprehensive demonstration project, the National Hospice Study, was supposed to provide a final judgment on hospices' cost-efficiency. The Health Care Financing Administration (HCFA), which was in charge of the study, was highly doubtful about hospices' cost-efficiency and recommended waiting for the study's results. But NHO continued pressure on Congress, citing its members' impression that data analysis was conducted slowly. Even without conclusive evidence on the lower cost of care in hospice, hospice advocates made the case in every congressional hearing convened on the topic. Rezendes, for example, cited a small demonstration project that NHO conducted with Blue Cross / Blue Shield and the American Hospital Association in Rochester New York, which showed that care under a home care hospice program "resulted in $152,236 in savings."[41] As Mor and Birnbaum, two chief investigators in the National Hospice Study, observed "the [hospice] legislation was formulated on the basis of limited information. While there were case study reports and anecdotally based vignette describing hospices […] no systematic data were available."[42]

Complemented with well-orchestrated lobbying efforts in Senate, this anecdotal evidence proved sufficient. The hospice benefit was the only new healthcare entitlement approved during Reagan's first administration at a time of great fiscal austerity; indeed, it passed *because* its advocates convinced legislators that hospice would serve austerity and help economize dying financially.[43] Rep. Panetta defined the passing of the hospice benefit as "nothing less than an organizational and political miracle."[44] Reflecting on the reasons for this miracle, Tom Hoyer, an official who participated in drafting the hospice regulations observed that "the argument for hospice's cost containment had been a masterful sales pitch."[45] And Reverend Hugh Westbrook reflected: "the number of cosponsors on the hospice law […] went up dramatically when the Congressional Budget Office reported that the […] hospice benefit would save the Medicare system over a $1.9 million over 5-year period."[46]

This "sales pitch" left its mark on hospice regulations. Medicare's hospice reimbursement relied on prospective payment—a mechanism that regulators introduced to the U.S. healthcare system during the same period. Hospices were paid a lump sum for every day that they served each patient, regardless of the services provided: hospices that spent more than the reimbursement rate had to absorb the cost. In this way, Medicare made hospices carry financial risk: the level of maximum reimbursement for each individual hospice was set at 40% of the average cost for cancer patients receiving conventional care (cancer patients were the overwhelming majority of hospice patients at the time).[47]

The hospice movement, which initially tended to avoid any type of monetary exchange, ended up institutionalizing itself as an economical way to care for the dying. Hospices also cemented an actuarial evaluation of death and dying in Medicare's regulations. This shift can be best grasped by evaluating two indicative quotes from the early days of the hospice movement against the historical trajectory

the movement ultimately took. In her 1972 appearance in Congress, Kübler-Ross said she

> would be very leery if the care of the dying patient would become another subspecialty. I would be opposed if we have some modern death houses, which are institutions just for the dying. [...] I would be much more in favor that we train nurses, physicians, and social workers here who love to work with old and dying patients. Then you will not need special institutions for the care of the dying patient, and the majority would be allowed, at least for the final care, to be at home.[48]

Only a decade later, NHO lobbied for distinguishing hospices from other healthcare institutions, and for securing a separate reimbursement system for distinctive hospice services.

The financing of hospice care changed in a similar manner. During the hospice movement's early years, the desire for hospices to operate as not-for-profit organizations was often too obvious to be spelled out explicitly.[49] A 1978 report of the Institute on Health and Healthcare Delivery expressed concern that "given the carrot of possible reimbursement [...] the potential for misuse of the hospice philosophy and concept is obviously high."[50]

Figure 2.1: Change in the Number of Medicare Hospice Patients and Medicare-Certified Hospices*

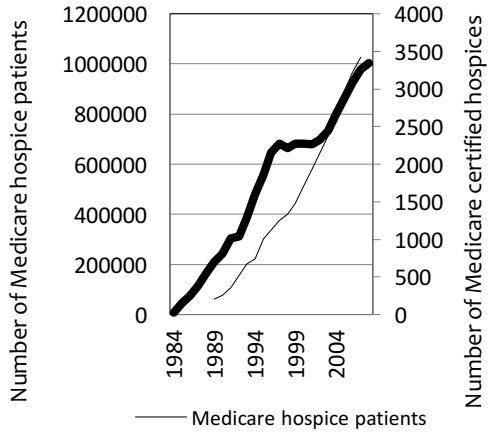
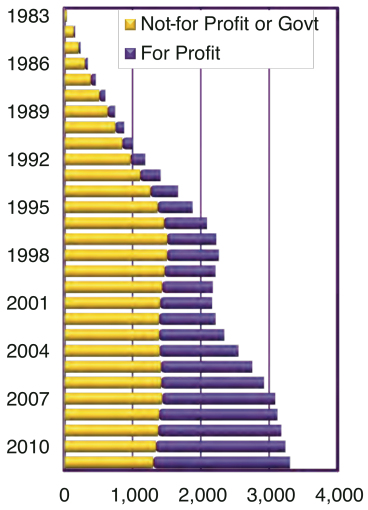


Figure 2.2: Medicare-certified hospice providers by Profit Status†



* Source: Hospice Association of America.
† Source: National Hospice and Palliative Care Organization, 2012 Facts and Figures.

What counts as "misuse" is a matter of definition, but the reimbursement carrot certainly changed hospices: following the approval of Medicare's hospice benefit, hospices were corporatized. Since the mid-1980s, hospice agencies have grown in both size and number; in the period between the mid-1990s and early 2000s, there was also a sharp increase in the average size of hospices that treated Medicare patients (figure 1). Starting in the late 1990s, the number of for-profit hospices began rising significantly and surpassed that of not-for-profit hospices in the mid-2000s (figure 2). This last transition was accompanied by a 509% rise in Medicare spending on the hospice benefit in 1998-2008.[51] The story of one hospice agency is perhaps most emblematic: Hospice Care Inc. of Florida, whose leaders were among the founders of NHO, is today the country's largest hospice agency: a for-profit investor-owned corporation called "Vitas."

Most significant, however, is the role the hospice industry has played in constructing a market whose entire rationale is to economize dying financially—i.e. reduce spending near the end of life—even if its ability to do so is still debatable.[52] The steady growth of the hospice market meant an ever-high number of corporate actors, which profit from treating patients defined as "dying." As hospices instituted themselves as a cheaper alternative to end-of-life care, they infused financial significance into the end of life.

This was one driver of end of life's financial economization in the U.S.

2. Economists of Death

The end of life as a target of cost containment

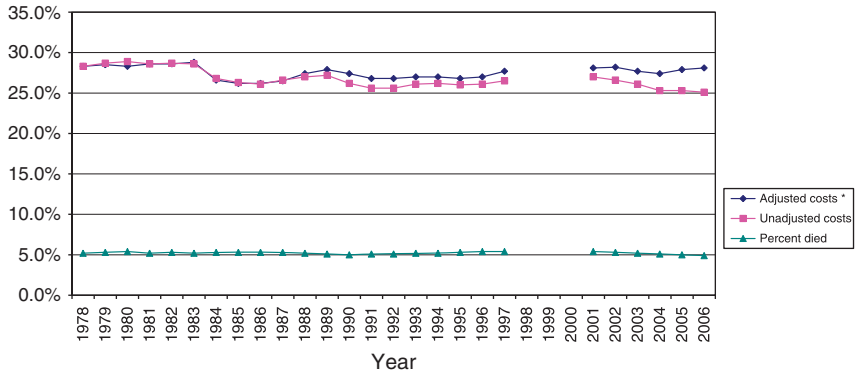
Hospices, however, were not the only drivers of the financial economization of death. Another driver were health economics scholars, who during the 1970s began identifying the end of life as a cost-center. These scholars reacted to two historical developments, which took place in the 1960s. First, the passing of Medicare, which funneled unprecedented amounts of money to the care of people older than 65, who represented about two-thirds of the people who died in the country. In 1964 and 1965, the two last years before Medicare's implementation, 58 percent of the people who died at 65 or older did not have hospital insurance, and 69.8 percent of them did not have surgical insurance.[53] Insuring this population, which was the most needy of medical insurance, increased spending on healthcare in general and on care near the end of life in particular. Second, the 1960s and the 1970s were the decades in which the modern Intensive Care Unit (ICU) developed,[54] introducing a plethora of hyper-intensive and highly costly treatments. Respirators and dialysis machines did prolong life, but this life was often not of high quality and required lengthy and highly expensive hospitalizations. The promise of medical progress was overshadowed by fears of its financial cost.

Inflation in healthcare spending was not restricted to the realm of end-of-life care, however: since the 1970s, healthcare spending has risen across the board and the share of overall expenditure on patients in the last year of their life has remained stable (figure 3).[55] And still, end-of-life care was constructed and presented as a distinctive domain that posed a specific moral-economic problem: how much is appropriate to spend on saving the lives of critically ill patients? References to this problem began appearing in medical literature in the early 1970s, when data on Medicare's expenditure on deceased patients became available, and when the Nixon administration sought to moderate Medicare's fiscal impact. In 1973, a "brief report" in the Social Security Bulletin presented data from 1967-8 (the first years after Medicare's implementation) and observed that

> Deaths are relatively frequent in the population aged 65 and over and often are preceded by serious illnesses requiring substantial expenditures for medical services. Many of these aged decedents were among Medicare beneficiaries for whom large reimbursements were made under the program. In light of the concern with rising Medicare costs, it is important to examine the size of reimbursements for decedents, as their services and charges represent a relatively inflexible proportion of the total.[56]

Data in this report were presented as statistical facts accompanied by little interpretation. This changed in the following years. The fact that people who ultimately died consumed, on average, more resources than "survivors"—and the fact that a small minority of patients accounted for most healthcare expenditure in the U.S.—fascinated several researchers who presented them as problems that could be solved. ICUs were a prime focus of analysis. Joseph Civetta, for example, followed a Massachusetts ICU, showing that although average charges on ICU patients who died were only slightly higher than on survivors ($10,064 versus $9259), their average daily charge was more than twice as high. Civetta also identified the source of this difference: the hospital he studied billed more than double for a day in the ICU than for a day in a regular hospital room, and patients who died had longer ICU stays than survivors. "Overall", Civetta noted, "the intensive care costs generated by prolonged utilization of this type of facility seem to be inversely related to the probability of patient survival."[57]

<u>Figure 2.3</u>: Percent of Patients Dying and Percent of Medicare Payment Spent in the Last 12 Months of Life, 1978-2006*



This evocative statement was not causal: nobody claimed that higher spending led to increased mortality. But given the rising spending on healthcare and political interest in controlling this rise, the potential to avoid "futile" spending was very tempting. Such saving could only be possible by predicting accurately who will die and who will survive, and Civetta's data showed how difficult it would be. Although patients who died had more complications than those who didn't,

> prediction of survival could not be based on the parameters of length of stay or complications. The difference in costs [...] is only apparent at the end of hospitalization...[58]

Civetta's solution was therefore *not* to withhold treatment from the sickest and most expensive patients, but to identify patients whose severity of illness did not require all of the services that ICUs provide, and ensure that they receive only the care that they need:

> Few patients develop many complications requiring prolonged intensive care and generating huge hospital costs. The mortality in this group is over 50%. Most of the patients who utilize the intensive care facilities, however, recover quickly with few complications and thus require a shorter intensive care stay, which in turn costs far less. It would seem that future efforts should be directed to improve the prophylactic [preventative – R.L.] management of such patients to reduce the number of patients who enter the high risk, high cost, low yield group. [...] Specifically defining patient's risks and severity of

* Source: Riley, Gerald F. and James D. Lubitz. 2010. "Long-Term Trends in Medicare Payments in the Last Year of Life." *Health Services Research* 45(2): 565-576. Figures are for Medicare fee-for-service, and exclude managed care. (Adjustments are for the age, sex, and survival status of the 1978 sample.)

> illness encouraged proper, efficient, and more economic use of intensive care facilities.[59]

This was also the logic behind "Therapeutic Intervention Scoring System" (TISS)—a method designed to evaluate severity of illness and ensure that ICU beds were used only to treat those who need them.[60] Later on in the 1970s, however, scholars began identifying the most severely ill not only as a source of high expenditure, but also as a potential source of saving. In a 1976 New England Journal of Medicine article, Cullen et al. examined 226 critically ill patients who had average hospital charges of $14,204 per patient: 73% of them died within a year and only about 12% reached full recovery. This spending, Cullen et al. claimed, could have consequences for other patients, since "resources may be diverted from many moderately sick patients to few very sick patients." [61] If this were to happen, spending on the severely ill should be reconsidered:

> In the United States, an estimated two million patients die per year. If each patient 'benefited' by a terminal illness averaging $14,000, the charge for final hospitalization, excluding physician fees, would be $28 billion, 69 per cent of the most recent estimate of a year of hospital expenditures. […] Quite properly, those responsible for advancing medical frontiers do not consider the financial impact of providing increasingly costly, high-quality intensive care on a large scale. Yet, economically, these costs are becoming intolerable and will be self-limiting in yet undetermined ways.[62]

Cost control thus moved to the care of the truly severely ill—not because costs were unsustainable, but because they could become unsustainable if every Medicare patient died in the ICU and fully utilized all possible clinical interventions. Aiming to ensure that the ICU would be free of financial judgment, Cullen et al. suggested that "once a patient is accepted for intensive care, cost considerations should not compromise efforts or be factors in providing less than the best care available." Instead, they wanted to control spending either by "not accepting patients for whom intensive care is inappropriate" or by "discontinuing intensive care in patients whose survival to a successful outcome is highly unlikely."[63] This monitoring of ICU admission and elimination of patients with "highly unlikely" chance to survive became a convenient ethical solution:

> There can be no 'half-hearted' intensive care. The first question, that of who should be admitted, as difficult as it is philosophically, is easier than the second one[:] once instituted, how can treatment be stopped when further deterioration leaves little realistic hope.[64]

In 1979, Turnbull et al. reported on their success to reduce mortality rates in an ICU from 22 to 18 per cent, by "an informal policy," which required consulting ICU senior staff before ICU admissions. The staff made decisions on acceptance "based on

current physiological status, availability of additional therapy, and a subjective appraisal of prognosis."[65] Informality was required because of resistance to instituting any formal criteria for rejecting critically ill patients from ICU care:

> because of the moral and ethical implications, some colleagues were reluctant to evolve and enforce an acceptable policy, but all cooperated with what was, initially, an informal and subjective approach.[66]

The informal policy was formalized later on, however. And while the study did not involve cost assessment, its authors cited costs as a main reason to adopt similar criteria in other hospitals. Aside from fiscal consequences on the national level, they mentioned fears for physicians' professional autonomy: if costs were not contained, "cost benefit analysis by third party payers or government will become an unavoidable, and less satisfactory, alternative."[67]

Over the course of the 1970s, solutions to the high cost of dying inched toward reducing expenses on care for the most severely ill patients. In 1973 Civetta suggested saving money by ensuring that only patients who were truly critical would be treated in ICUs: savings were achieved by identifying those whose illness was not acute enough to justify high spending. By the end of the decade, researchers started contemplating saving money by identifying patients who were too sick to justify high spending. Dying was economized, and the development of the hospice market in the 1980s created an opportunity to save money by transferring these patients to hospice.

A Self-Fulfilling Prophecy?

Saving costs by withdrawing acute care from terminally ill patients required accurate prognosis,[68] which could distinguish between terminally and severely ill patients. Prognosis, however, was a skill that medicine and medical education all but ignored.[69] This posed a cardinal ethical problem: prognoses could very well become self-fulfilling prophecies, as once a patient was deemed too-sick-to-spend-on, treatment would be withdrawn and the patient would indeed die. As health economist Anne Scitovsky observed, "it is easy enough […] to designate a patient as terminal or as dying retrospectively but an entirely different matter to do so *prospectively*."[70] There was "very real danger of policies being formulated which would relegate very sick patients, and especially very sick elderly patients, to a 'terminal' group before their time to die [had] come."[71]

Scitovsky's cornerstone 1984 article, "'The High Cost of Dying': What do the Data Show?" challenged many of the intuitive assumptions of scholars who defined the end of life as a target for cost-reduction. The increased attention on the high cost of dying, Scitovsky argued, was not a response to an objective growth in expenses near the end of life. The percentage of people dying in acute care hospitals did not rise significantly

in 1960-1980, and there was no evidence that the intensity of treatment in critically ill patients grew disproportionally to intensity in care in general in 1973-1983. From an economic standpoint, since only a small portion of the deceased incurred very high medical expenses, saving on their care would not make for a transformative saving in Medicare's budget – only about 3.5%. Probably most important were the many cases in which high cost care proved life-saving:

> It should be noted that about 5,000 Medicare beneficiaries who did *not* die had Medicare reimbursement of $30,000 or more, and about 25,000 beneficiaries had reimbursements of $20,000 or more, amounting to $652 million, or about 3.6 percent of total Medicare expenditure. In retrospect it is easy to regard these latter expenses as justified and to question the appropriateness of the expenditures for those who died. But it is likely that prospectively the distinction between those who would die and those who would live was not nearly so clearcut. […] The data available at present […] do not support the frequently voiced or at least implied assumption that the high medical expenses at the end of life are due largely to aggressive, intensive treatments of patients who are moribund.[72]

This observation remained valid later in the 1980s. In 1988, Scitovsky found that about 73,000 decedents required Medicare payments of $40,000 per year or higher; a similar number of survivors (70,000) belonged to the same expenditure category.[73] The reason for the increased interest in the economy of end of life was therefore that overall healthcare spending became a significant budgetary burden. Since end-of-life costs have risen proportionally to the rise in healthcare costs in general, the source of this rise lies in healthcare spending in general, not in care for the dying per se.[74] "Care at the end of life has not become disproportionately more expensive and technologically intensive than other care in recent decades," summarized the 1997 Institute of Medicine report on end-of-life care.[75]

Yet despite these observations, cost evaluations of death and dying flourished throughout the 1980s and into the 1990s.[76] The mere fact that a small part of the U.S. population accounts for a disproportionate share of national healthcare spending—an obvious situation in any insurance market—led scholars to declare that high spenders were "an appropriate target for cost containment."[77] Care was particularly expensive in the last months of patients' lives, making researchers wonder whether terminal diagnosis could be made earlier, before spending peaks.[78] Perhaps the most explicit and unequivocal statements were made by bioethicist Daniel Callahan, who attributed the higher spending near the end of life to fallacies structured into modern medicine: its increased emphasis on curing and its general view that "what can be done medically ought to be done."[79] All of these statements resonated with hospice ideas and were based on them. Callahan radicalized the call to save costs at the end of life; since it is hard to prospectively predict who will die, he defined the entire elderly population as a cost containment target:

> *After a person has lived out a natural life span, medical care should no longer be oriented to resisting death*. No precise chronological age can readily be set for determining when a natural life span had been achieved—biographies vary—but it would normally be expected by the late 70s and 80s.[80] (emphasis in the original – R.L.)

The challenge of medicine, Callahan claimed, was no longer developing new cures and life-saving treatments, but rather to guarantee that medical development would be moderate and economically sustainable.[81] Some politicians embraced these statements: "we've got a duty to die and get out of the way with all our machines and artificial hearts and everything else like that and let the other society, our kids, build a reasonable life," declared Colorado Governor Richard Lumm.[82]

This alarming tone could bring one to the conclusion that the impending bankruptcy of the U.S. healthcare system results from physicians who insist on treating elderly, impaired, and extremely sick people with extraordinary measures. Yet the little data that were collected on the appropriateness of care given at the end of life reflected a far more complex picture. Riley et al. showed that for most diagnoses, the older a decedent, the lower the amounts spent on her care;[83] Scitovsky and Roos et al. showed that nursing homes, rather than intensive care, accounted for much of the higher costs of treatment of old patients, both dying and surviving.[84] In Scitovsky's words:

> Despite the generally recognized difficulties of predicting when death will occur, and in the absence of a formal rationing program such as the one suggested by Callahan or institutional constraints on the use of medical resources, high-cost medical services may already be allocated to the elderly in their last year of life in a more rational manner than is generally assumed, with their age and functional status taken into account.[85]

Data were highly equivocal, and one can only speculate whether death economists would have presented the end of life as a cost-containment target with such ethical conviction had the hospice movement not existed. Hospice advocates' claim that they could treat dying patients better *and* cheaper was at the same time a claim that non-hospice care was comparatively bad and expensive. The further hospices grew, the more excessive end-of-life spending seemed: why should so much money be spent on care whose benefit more and more people doubt? Many death economists invoked hospice as a way to solve the financial problem that they highlighted. They did not need to recommend that clinicians withhold care to save money: they could simply point out that hospice care, which many considered better anyway, decreased end-of-life spending.[86] By providing what Bayer and colleagues called a "humane cost containment,"[87] hospice made end-of-life spending appear redundant and wasteful. Put differently, by suggesting a *solution*, hospice advocates also constructed a problem, which was financial in its character.

3. The Construction of an Uncertain Hospital Market

A third driver of the financial economization of death lied in the market for hospital care. Hospitals have been broadly recognized as actors that increase healthcare spending. The legislative effort to counteract this increase relied on market mechanisms, and during the 1980s-2000s uncertainty in the hospital market reached the point that hospitals were no longer clear about the business strategies they should adopt. Hospice—and later on, palliative care—advocates offered cost-cutting solutions and explained how these solutions would match hospitals' financial interests. By that, they further contributed to the economization of death.

Since the early 1970s, U.S. policymaking has focused on counterbalancing the steady increase in healthcare spending. In 1969 Nixon declared that the U.S. healthcare system was in a "health cost crisis" and imposed temporary price controls on Medicare.[88] The cost-containment measures that administrations have adopted since then have been path-dependent: centralized systems such as the UK's NHS could contain costs by establishing comprehensive allocation mechanisms, which rationed care and funded only treatments that were deemed sufficiently effective.[89] In the U.S., however, there was no single payer or single provider who could enforce such a policy, and the effort to control spending was pursued within the boundaries of the market economy. Policymakers deployed a patchwork of regulations, incentives, and new types of organizations, which ultimately constructed a convoluted and uncertain healthcare market.

The main shift during Nixon's presidency was toward Managed Care through Health Maintenance Organizations (HMOs).[90] The HMO Act of 1973 designated grants for HMOs that offered comprehensive benefits, charged fixed-rate premiums, and were open to all patients.[91] Other spending control measures included direct limits on what hospitals could charge for days of hospitalization (1972)[92] and a health planning system overseen by federal agencies (1974).[93] The Reagan administration, however, stopped federal health planning and state regulation of hospital rates: it considered competition to be the best and only legitimate way to address cost increases and pursued it zealously.

Four consequences of this approach made the hospital market volatile and uncertain.

First, there was a sharp increase in the number of uninsured patients. Reagan's administrations promoted insurance under Preferred Providers Organizations (PPOs), envisioning PPOs as market mediators who would negotiate lower prices with providers. At the same time, PPOs were not saddled by Managed Care caps and were allowed to set premiums based on the characteristics of their patient population. In addition, PPOs systematically excluded high-risk patients,[94] and did so in a period when labor rights were under attack and many employees lost their healthcare benefits. By 1992, 37.1 million people in the U.S. had no health insurance, even though 84 percent of them had jobs or were dependents of people who had

jobs.[95] The percentage of employees of medium and large businesses who received healthcare coverage from their employer fell from 96 percent in 1983 to 82 percent in 1993.[96] Hospitals were therefore serving riskier pools of patients who yielded unpredictable revenue; "dumping" uninsured patients was common, and public hospitals, which operated with extremely scarce budgets, had to carry most of the burden.[97]

Second, the growth of the for-profit hospital sector further burdened community and public hospitals: in 2008, 19.6 percent of hospital beds in the U.S. were for-profit, compared to 12.4 percent in 1980.[98] For-profit hospitals typically narrow their specialization to diagnoses that bring high return on investment and serve well-insured populations. The expansion of for-profit healthcare deprived other hospital sectors from important sources of revenue, as profitable patients were disproportionately treated at for-profits.[99] With fewer paying patients, hospitals exceedingly practiced "fee shifting": they billed higher amounts to insured patients in order to cover losses from treating uninsured and poorly insured patients. Insurance companies, which resented paying higher fees, used utilization review and negotiated aggressively over hospital rates in order to limit what hospitals could bill them. The pricing of healthcare—i.e. bills for days of hospitalization, diagnostic tests, medical procedures, and medications—turned obscure: prices were determined in behind-the-scenes negotiations between insurers and hospitals, and varied across dozens of contracts that hospitals had with different insurance companies. In the rare occasion that transparent and official hospital prices were quoted, the amounts that they stipulated were an exercise in smoke-and-mirrors: they did not represent the cost of care and did not reflect the actual payments that ultimately change hands. The impact this pricing chaos has had on healthcare spending figures and hospitals' ability to manage themselves financially is yet to be comprehensively studied: clearly, it has increased uncertainty in the hospital market.

Third, in 1983, Medicare adopted a prospective payment system called Diagnosis-Related Groups (DRGs). "Rather than simply reimbursing hospitals for whatever costs they charged," Medicare started paying "a predetermined, set rate based on patients' diagnosis."[100] Medicare classified diseases into 500-some Diagnosis-Related Groups, and priced them according to the average expenditure on treating each diagnosis. Hospitals had to limit their expenditure to these predetermined DRG rates, or, as one figure in the industry put it, "eat the loss."[101] Combined with cuts on Medicaid rates, which the first Reagan administration instituted eagerly, the financial pressure on hospitals made them seek ways to lower spending. Specifically, given the high costs of hospital stays, hospitals had the incentive to decrease patients' length of stay in the hospital. This incentive impacted healthcare delivery in hospitals: in 1983, the national average length of a hospital stay was 10 days; by 1995, it had fallen to 7.1 days.[102] Later DRG-related reforms put further pressure on hospitals. The 2010 Affordable Care Act, for example, sanctioned hospitals that had too many patient readmissions within 30 days.[103] Hospitals are therefore losing money not only on

patients who have prolonged hospitalizations, but also on patients whom they try to discharge and get readmitted to the hospital shortly after.

Finally, throughout the period, medical decision-making has largely remained in the hands of physicians: physicians are the ones who decide whether to hospitalize patients, when to discharge them, what tests to order, and what treatment to recommend. Most physicians are still paid on a fee-for-service basis and have the incentive to treat patients aggressively and for longer periods. As surgeon and author Atul Gawande observed, "the most expensive piece of medical equipment […] is a doctor's pen. And as a rule, hospital executives don't own the pen caps. Doctors do."[104] Squeezed between the scarce resources available to them on the one hand, and physicians' uncapped pens on the other, hospitals bear the risk of absorbing the costs of tests, treatments, and hospitalization days that their physicians prescribe.

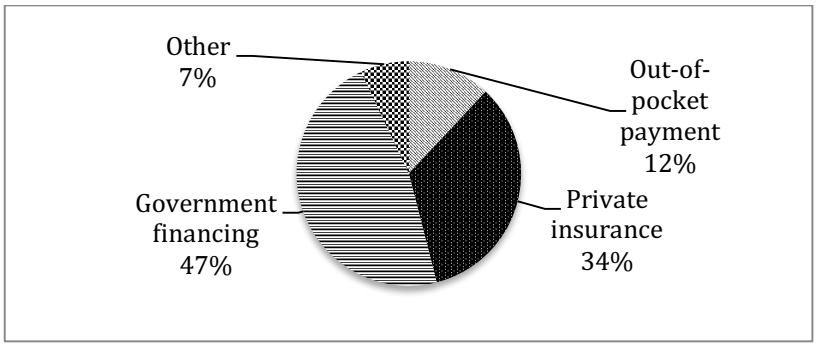
These four shifts prompted what Neil Fligstein called a "transformation of corporate control" in the U.S. healthcare market. According to Fligstein, periods of regulatory changes transform how firms perceive their financial interests, and more fundamentally, how firms structure themselves and define their business goals.[105] U.S. hospitals tried to adapt to the new market regulations: during the 1980s and 1990s there was a wave of horizontal and vertical mergers in the hospital market.[106] New organizational forms—such as large networks that connect several hospitals, clinics, and physician groups—became common. Hospital administrators pursued such mergers and partnerships in the hopes of achieving economies of scale and securing more referrals of insured patients from partnering organizations. The bigger and more diverse the hospital, they assumed, the better it would deal with market uncertainty and the more immune it would be to future policy changes. However, as Burns and Pault show, hospitals have overall failed to secure concrete economic benefit from mergers.[107]

The hospital market thus remains precarious and unpredictable; competition over profitable diagnoses is fierce, and risk from unprofitable diagnoses and uninsured patients is high. Prior to the implementation of the Affordable Care Act (ACA), 17 percent of the people in the U.S. were uninsured and many of the 53 percent who were privately insured had very limited coverage.[108] While improving the situation, ACA has not solved it. Hospitals rely on dwindling federal and state funding (figure 4). The entire U.S. healthcare market has been sustained by government financing, which on the one hand, insures the sickest, poorest, and oldest patients, and on the other hand, provides a badly needed, dependable, and predictable source of funding for hospitals.

Resources in the healthcare market are haphazardly allocated, as a contingent outcome of negotiations between insurers who try to minimize expenses and pass risk to providers, physicians who try to bill high, and hospitals that try to remain afloat. Regulators pursue cost-containment by creating incentives for hospitals, not by allocating budgets directly. And hospitals operate as individual business units,

which struggle to adjust to an ever-changing and always unpredictable market, often without success.

Figure 2.4: National Health Expenditure (2009)*



In this context, hospitals have used several strategies to pressure physicians to moderate the treatments that they offer, and changes in physicians' employment status granted hospitals some leverage. During the 1990s, the percentage of physicians working in group practices grew: 62 percent of them did so in 2001, compared to 32.6 percent in 1991.[109] The percentage of salaried physicians has also risen: by 2001, 35 percent of the physicians in the U.S. worked as salaried employees.[110] Hospitals that hired physicians for a wage could hope that the employer-employee relationship—and the fact that physicians' income was disconnected from medical decisions—would eliminate incentives to practice expensive medicine. Hospitals that contracted physicians groups could include an incentive component in the contract, which would reward them for making medical decisions that were profitable for the hospital. Some Managed Care Organizations (MCOs), for example:

> gave physicians incentives to limit service through *risk sharing*, which varied their compensation based on the cost of their patient care. Sometimes MCOs reserved part of physician payment to cover shortfalls if the cost of designated services exceeded a specific level. Alternatively, MCOs paid physicians a bonus if treatment costs were lower than specified.[111]

Many of these strategies were outlawed during the 1980s and 1990s, yet hospital administrations continue encouraging medical decisions that would be profitable for hospitals. This is by no means easy since on the one hand, hospitals depend on physicians to supply them referrals, and on the other hand, hospitals need to ensure that costs of treating these patients do not exceed the amounts stipulated in Medicare's DRGs or Managed Care contracts. Findings such a "sweet-spot" is

* Source: Martin A. et al. 2011. "Recession Contributes to Slowest Annual Rate of Increase in Health Spending in Five Decades." *Health Affairs* 30:11-22.

challenging. As a physician who occupied a senior position at the private hospital that I studied bluntly told me in an interview:

> "Well, I mean, certain doctors, at some point, you gotta talk to. [You] can't leave the patient in the hospital. You just can't. I know you [the doctor] try to do the right thing, I appreciate that you're trying to do the right thing – [but] we need to work on a discharge plan, okay? And ultimately, if you can't work on a discharge plan for a patient who doesn't meet criteria for being in the hospital, then it becomes a disciplinary issue. You can stamp your feet, get upset - I don't want to reach that point. How can I help you come up with a good plan. That's sort of conflict resolution one-on-one."
>
> Q: "How would you discipline [this doctor]?"
>
> A: "Well, eventually you can lose admission privileges. […] Meaning, you're not allowed to admit patients to the hospital. I mean, hospitals don't want to do that, because that's what drives their profits. So, you know, somebody who creates a lot of business for the hospital will probably have a bigger hammer to swing in that negotiation than somebody who doesn't admit very often, but is a pain in the ass when they do. Because what does it matter to me if you […] only admit to this hospital three times a year, or [you] only admit your sickest more difficult patients here, and save all you good admissions for [other] competing hospitals. Fuck you. I'm willing to piss you off, because you're not doing anything for me. Whereas, when you're a high volume guy, of course you're gonna get away with more. If you're bringing in good business, it's just kind of the way that it goes. [To me:] I hope I'm not making you upset."

Hospitals' pressure on physicians to discharge patients early has become central to clinical work. Yet in the context of the highly uncertain hospital market, where private and public insurers can shift risks and costs to hospitals, hospitals can hardly be confident that their strategies would indeed prove lucrative. Even when applying direct pressure on physicians, hospitals have to play a complex game: they have to ensure that physicians would still refer patients to them, and that they would not lose profitable patient admissions.

This was the financial problem that palliative care claimed it could solve.

4. Making "The Business Case for Palliative Care"

The performativity of hospitals' interests

Look at one ironic history. In the 1990s, Blue Cross of California relinquished its not-for-profit status and became a for-profit corporation. After legal battles with consumers groups, it created endowments that established two of the country's largest charitable foundations: the California Endowment and the California HealthCare Foundation.[112] The latter had a pivotal role in promoting hospice and palliative care in California; among other things, it helped substantiate the claim that palliative care would be financially beneficial for hospitals. A not-for-profit turned for-profit (Blue Cross) created the not-for-profit (California HealthCare Foundation) that funded the making of the business case for palliative care.

Similarly to hospice ideas, palliative care ideas were not economic, and palliative care advocates were morally driven clinicians, not economists. They sought to deepen and expand the moral logic of hospice: instead of limiting pain control, psychological support, and spiritual care to separate hospice organizations, they wanted to start them earlier, during patients' hospital stay. And still, palliative care clinicians and advocates were "not economists, but" too. In the early 2000s, the hospice market was already standing on its feet; the end of life was broadly recognized as a cost driver; and hospitals were facing growing economic pressures, as they were dealing with diminishing reimbursement rates from Medicare and Medicaid and a growing population of uninsured and underinsured patients. Palliative care in hospitals was promoted by several advocacy organizations, which cooperated with funders such as the California HealthCare Foundation (CHF). It was through this cooperation—and in this historical conjuncture where dying was deemed expensive, the hospice industry was in place, and hospitals faced financial uncertainty—that the business case for palliative care in hospitals could be made successfully.

In 2007, CHF sponsored four foundational reports on palliative care; one of them, entitled "The Business Case for Hospital-Based Programs," focused on economics. As the report stated in its beginning:

> The primary purpose of creating a hospital-based palliative care service is to improve the quality of care delivered to patients with serious, life-threatening, or terminal illness. The main goal is not to save money. However, it is usually the case that tailoring care to reflect patient and family preferences [by palliative care teams] has the secondary effect of reducing hospital costs.[113]

After making this "not an economist, but…" disclaimer, the report went on to explain why palliative care services would be economically beneficial to hospitals. Relying on previous actuarial evaluations of death and dying—and producing one of its own—the report noted that

> More than 25 percent of Medicare program expenditures are directed to the care of people in the last year of life, with half of those dollars being spent in the last 60 days immediately preceding death. In 2002, 5 percent of Medicare beneficiaries accounted for 48 percent of annual program spending and the costliest quartile accounted for 88 percent.[114]

This is the population that palliative care targeted: "high cost beneficiaries […] with multiple chronic conditions, those with acute care admissions, and those who were in the last year of life."[115] This population was spread in different hospital units and suffered from a variety of diagnoses. Palliative care bundled them together: it suggested that hospitals classify people who suffer from different diseases—cardiac, oncology, Alzheimer's, or liver patients—under a single category that includes "patients who die" (sic) and "patients with serious, life-threatening illness." This category of patients would be managed by palliative care specialists, and the business case for palliative care highlighted its economic significance:

> Such patients, referred to in this report as the palliative care 'target population,' have distinct resource use patterns characterized by frequent admissions, long lengths of stay, and high costs per case. They also have a common set of needs, including clarifying treatment goals, expert pain and symptom management, and help accessing care across multiple settings. Palliative care services can help meet the needs of target population patients and, in doing so, alter the volume and types of resources used by this group.[116]

Given the plethora of payment methods, contracts, and types of insurers that reimburse hospitals, it is hard to think of a single strategy that would be profitable in all patients for all hospitals. Yet the report claimed that palliative care could provide exactly that. In the context of an uncertain economy, in which hospitals have difficulty predicting whether revenue would cover expenditure on patients, the report presented palliative care as having the potential of creating some economic certainty. Palliative care, we learn, is not "designed to attract new-revenue generating business." Rather, it "contributes to the bottom line by improving the efficacy and efficiency with which complex cases are managed." Put differently, unlike specialties such as transplant surgery or neurology, which are lucrative because they treat diagnoses that insurers reimburse generously, palliative care helps hospitals avoid the cost of treating particularly expensive and severely ill patients: "Compensation for acute care services is such that hospitals are generally rewarded for controlling costs, either by reducing expenses within a given stay, or in some cases, by avoiding admissions entirely."[117]

For hospitals operating on "global budgets", which are available to them regardless of the volume of services they provide, the financial benefit of palliative care is obvious. These hospitals "are particularly incented to manage resource use," the report

contends: the less they treat, the lower their expenses, the higher their surplus.[118] Hospitals whose income depends on the volume of treatment that they provide are more complex, however. The report mentions a "misperception" among these hospitals' administrators, who think that "cost-avoidance won't work for us because we see lots of fee-for-service patients." Yet, even in these cases, the authors clarify:

> the payer mix for palliative care appropriate patients almost always differs from that of the general hospital population. Patients with advanced, complex illnesses tend to be older, meaning that Medicare is by far the most common payer for these patients. […] A full 70 percent of the patients who die in California hospitals have Medicare as a primary payer, as so do over 60 percent of palliative care appropriate live discharges. […] With the exception of indemnity insurance and discounted fee-for-service, the cost-revenue relationship created by the above-described payment models is such that *hospitals are rewarded in one way or another for controlling the cost of acute care services*. [my emphasis, R.L.][119]

If hospitals wish to maximize their financial benefit from palliative care, the report argued, they should encourage early referrals of patients to palliative care teams, when there is still potential to save on the cost of their treatment. This should be achieved through both "marketing" and "educational efforts":

> Marketing and educational efforts aimed at the providers [usually physicians – R.L.] most likely to refer patients to the palliative care service can be an effective means of maximizing capture rate and influence. Providers who care for large numbers of target-population patients need to be educated about the benefits palliative care can offer them (e.g., a reduction in the amount of time they will have to invest in managing complex discharge arrangements).[120]

This business case for palliative care was not a *representation* of hospitals' financial interests. Rather, by putting together numbers, charts, models, and various economic arguments, palliative care advocates attempted to *define* what hospitals' financial interests were and convince hospital administrators to adopt this definition. In Michel Callon's terms, palliative care economics was not descriptive, but *performative*: analyses of the cost of dying and evaluations of hospitals' business strategies infused a certain economic agency into hospitals.[121] Certain perceptions of administrators were defined as "misconceptions," and alternative perceptions were promoted. As one palliative care advocate told me:

> For sure, one by one, [we talk to] hospital administrators to make the case for palliative care. And one thing [our advocacy organization] has done very strategically is to think about what is the evidence base necessary to demonstrate value for palliative care. […] Looking at the

> financial impacts of palliative care services, which is really important. Trying to think strategically about what is the evidence base necessary to do this. To push it. You know, having a business model for palliative care has been a really important part of the growth. Not the only reason: people also care about why we do it, and they shouldn't do it to save money, but it turns out that you can afford to do it, because it happens to save you money.

Convincing hospital administrators that palliative care would be economically beneficial to their organization required elaborate accounting. Cost-saving is a far less visible outcome than revenue-generation. As one hospital's Chief Financial Officer told the report's authors, "I can't spend avoided costs."[122] Advocates needed to visualize the costs saved, and they did so by developing methods to evaluate their saving. The report's appendixes explain how accounts of cost-saving should be kept, and training seminars organized by groups such as the Center for the Advancement of Palliative Care (CAPC) have taught leaders of palliative care teams how to collect and present economic data to administrators.[123]

The fragmented and decentralized character of the market for hospital care makes such accounting highly challenging. The various forms of reimbursement—from capitated Managed Care to fee-for-service—are hard to quantify systematically and require laborious data collection. Yet the Affordable Care Act (ACA) was expected to simplify this highly convoluted reimbursement system and make the case for palliative care more straightforward. Another advocate told me:

> The need to quantify the financial benefit of palliative care will remain incredibly important, it'll just be done in a different way. And it will be done in an environment where there are far few obstacles to recognizing the benefit than there [are] now, [with] disjointed, fee-for-service misaligned incentives, [which make it] hard to tell exactly what you did. [With ACA] you'll be able to tell things from a patient perspective. You know, over the course of the last two years of life, how did palliative care influence the costs of providing healthcare. You'll be able to look at things per-beneficiary cost per-year, instead of teasing out how much you reduced the cost of this specific admission.

The financial "benefits" of palliative care are not obvious. Unlike what a crass rational choice approach would suggest, hospitals have not adopted rational profit-maximizing strategies spontaneously. For one thing, the hospital market has been too convoluted and uncertain to lend itself to rational calculations. Strategies that hospitals have adopted—such as mergers—have failed time and again. What explains the financial agency of hospitals in treating severely ill patients is therefore the mobilization of actors who redefine what hospitals' financial interests are. By communicating with hospital administrators, putting together evaluations of palliative care's budgetary impact, and mobilizing clinicians to keep accounts of their

work and share these accounts with administrators, palliative care advocates prompted a certain pattern of economic thinking in hospitals.

Alliances within Hospitals

Targeting hospital administrations was strategic in the sense that hospitals' financial interests could be presented as consonant with palliative care's financial impact. Moreover, targeting administrations had organizational benefits: when advocates convinced an administration that starting a palliative care service was in its interest, there were higher chances that the service would institutionalize and outlive the individual clinicians promoting it.

> It is much more common now for hospitals, for a hospital administration to say [to a clinician]: "we need a palliative care service, you go to this training." Or, "you've talked about [starting a palliative care service] to me for years, you go to this training and we make it happen." When we have this level of top-down support, things tend to happen more quickly, because people are actually given time to do the work, and there's not a struggle to get the money. Early on, it was much more common for it to be the grassroots sort of thing, when you had providers who really felt that it was necessary, help us to explain it to our hospital, so that they agree that it needs to happen. But [top-down support] is much more common than this now, in 2012. And it's also a much more predictable success. I should say – immediate success. If your CEO tells you to do it, and you can't do it – they'll find somebody else who can do it, you know. So it's a different… It's working within the hierarchy, working within the resource allocation structure, as opposed to trying to get into there.

Approaching hospital administrations as economic allies has also helped palliative care teams counteract the medical specialists who treat patients more aggressively. Take, for example, an exchange between the head of a palliative care program in one private hospital and a colleague from an affiliated hospital, who consulted him about how to start a palliative care service there:

> Rick [head of the Palliative Care team] mentions the name of the Vice President of [consulting hospital]. Rick says that the Vice President will be her main ally: she should talk to him about how to educate physicians to use palliative care, how to reach out to specialists and make sure that there is more openness to palliative care. "Because under the new system," Rick tells her, "the way healthcare is changing, the hospital is not going to survive if they don't do it, and he [the VP] knows it" [he laughs].

As I showed in the previous chapter, such educational efforts have much impact, particularly on younger clinicians. Very few of the people that I interviewed presented outright critiques of the move toward palliative care, and many specialists and general internists self-presented as professional allies of the palliative care team, even when palliative care clinicians reported that they often disagreed professionally. Clinicians found several benefits in cooperating with palliative care teams. Many clinicians felt that palliative care teams improved the quality of care given to patients: members of the palliative care team had excellent communication skills and had the time necessary to talk to patients at length. But additionally, clinicians also cited palliative care's organization and economic advantages: they mentioned that palliative care consulatations could facilitate patients' discharge from hospitals and that they could address—if not solve—a financial problem that the hospital, as well as the entire healthcare system, was facing.

Perhaps most indicative was the attempt of a general internist whom I interviewed to convince me to take an explicit stance in favor of palliative care and in criticism of what he saw as futile and costly treatment:

> I have pretty solid opinions about it, just because I'm doing it – [and when you do it] you see it. But you know, I don't know what thesis you want to [write] […]. I guess your thesis is, you know, about decision making, but I would try to figure out… Not a stand, but just something that you can almost argue, or something. You know what I mean? My stand is that, you know, things are broken, and things need to be fixed […]. And that attitudes need to be changed. You know, I think things are changing. But I think doctors are not fast enough, in a lot of ways. […] Because we don't want to do all this stuff. We're doing futile care because it's a conflict for us. It's hard, you know. It stresses us out. Because, it's hard to deal with it for everyone. […] You feel that it's not right for the patient and for the system. And so, every time you have that dissonance, you feel frustrated from the system and whatever.

I had a rather similar exchange at the end of an interview with an ICU physician at Public Hospital, who also saw research on end-of-life care as directly connected to economics:

> Q: "Thank you so much for your time, I really appreciate it."
>
> A: "Yeah! I hope that you fix the problem."
>
> Q: [laughs] "What is the problem?"
>
> A: "What's the problem? The problem is we are burning SO much money taking care of people who have no chance of recovery, and… We don't have a good way to stop them."
>
> Q: "Where's the problem? Here?"

> A: "Everywhere. Everywhere. I mean, every ICU I've ever worked in - we were having an 88 year old person with a massive stroke, who would never be independent, who would be on life support for reasons that are just, I think are faulty. Primarily because there's pressure from somebody, somewhere, usually a family member, to continue all that kind of treatment. And we don't have a good way of unilaterally stopping it."

Physicians' cognition may therefore be medical and financial at the same time: in certain cases, when physicians look at their unit, they do not only see medical diagnoses and symptoms, but also high spending, futility, and inefficiency. Some physicians are less comfortable invoking the high cost of care for terminal patients than the two quoted above. When made at the bedside or in conversation among physicians, arguments for palliative care hardly ever rely on outright financial reasoning: they focus on patients' best interest and on patients' preferences (see chapter 4). Yet institutionally, there is cooperation between palliative care and hospital administrations' effort to cut spending. Palliative care teams are in hospitals, in part, because they are financially beneficial.

Hospitals' efforts to promote cost-awareness among clinicians coincided with palliative care work, and some clinicians recognized palliative care as a solution to an economic problem. Just as in the case of the hospice movement and the actuarial evaluations of death, the ability of palliative care clinicians to *solve* a financial problem in a morally acceptable way has made raising and highlighting this problem more morally legitimate. Once a palliative care team exists in the hospital and can help solve complex end-of-life cases, it is also possible to point to the financial benefits of the team's work, and to the financial necessity of having this team in the hospital.

This is the contribution of palliative care to the financial economization of the end of life.

Conclusion

What drove the financial economization of U.S. end-of-life care?

My account in this chapter follows the role of four historical factors. First, the hospice movement: hospices were initially averse to any discussion on money, yet starting the late 1970s, changed and adopted more financial tones. The hospice movement transformed from an iconoclastic anti-institutional group to a largely for-profit industry that generates monetary value from caring for dying patients. Throughout this process, the movement justified its existence on financial as well as moral grounds, claiming that it could lower the costs of treating dying patients while improving their quality of care.

Second, "death economists" defined the end of life as a principle target for cost-containment. These economists were more intentional in the pursuit of financial economization than hospice protagonists were: they constructed explicit and deliberate financial evaluations of care near the end of life. The difficulty of prognosticating and accurately defining who should be considered as terminally ill (as opposed to just severely ill) cast a significant shadow over their efforts. But the development of hospices helped remove this shadow: once an alternative, morally viable, and cheaper care option for the dying was available, it became easier to argue that the cost of end-of-life care was too high.

A third factor was the transformation of the hospital market. Changing regulations and increasing market uncertainty made hospitals eager to find business strategies that would help them remain solvent. Diminishing reimbursement rates and the increase in the population of uninsured patients made hospital finance ever more uncertain. Hospital administrations sought strategies to cut costs and increase revenues. The high cost of treating patients near the end of life, and the attention the end of life had received, highlighted this area as a potential realm for cost saving.

Finally, the movement for palliative care attached itself to the uncertain financial situation of many hospitals, and worked to persuade hospital administrations that it could serve their economic interests. Similarly to hospice advocates, palliative care advocates promoted a medical and moral solution and presented it as financially beneficial. Once this solution was available to policymakers, administrators, and practitioners, it was easier to present the cost of end-of-life care as overly high.

My account sheds light on two theoretical approaches to financial economization. First, I show that structural economic explanations, which conceptualize economization as the sheer outcome of fiscal forces, may offer only partial and insufficient answers for how such an economization occurred. Economists see economization as an imperative: resources in the world are finite, and when costs rise unsustainably, actors must economize.[124] Yet, as my account shows, prices have risen in the entire healthcare system, not only around the end of life. The specific constitution of end-of-life care as a financial problem was therefore no more necessary than the financial constitution of any other domain in U.S. healthcare. Clearly, attempts to save costs occurred in other medical domains as well; but hospice and palliative care stand out as fields whose very emergence hinged on economization. One cannot fully understand this peculiar economization of the end of life by merely pointing out that end-of-life spending has risen.

The alternative sociological explanation, which I present here, focuses on the social forces that make end-of-life care economic. This explanation very much resonates with Fligstein's *Markets as Politics* framework, which analyzes market economies as political orders, thoroughly structured by state regulation. Stronger economic actors can use the state to define regulations that suit their interests; these regulations mitigate competition and instability in markets, maintain market orders, and inscribe

social and economic in the structure of markets.[125] The construction of economies and the reproduction of hierarchies within them are therefore quintessential political projects, where some actors successfully shape rules that place them in more advantageous positions

Instead of judging whether hospices pervaded the established healthcare system, or whether the established healthcare system absorbed and coopted hospices, I chose to outline a morphological history of the end-of-life economy. A morphological account focuses on how different components of a certain field assemble to create it. The four components that I outlined are the building blocks of the new U.S. moral economy of dying: they generate the monetary value of end-of-life care, shape patterns of exchange between actors, inform how these actors perceive their interests, and define the regulations that govern the field.

Ultimately, this moral economy of dying instilled two interrelated notions, which underlie discussions of end-of-life care today: first, treating dying patients with *less* life-prolonging procedures means *treating better*; second, *spending less* on such procedures means *spending better*. These two notions comprise what I call economized dying, and the next chapters analyze the challenges of applying them at the bedside.

Chapter 3: What the Dying Want

"My friend sought my advice. After talking with his surgeon and another knowledgeable medical colleague, I told my friend that removal of the gall bladder was not mandatory. We then discussed his two options—removal or non-removal of the gall bladder—and their consequences. […] My underlying message was: *The* right decision was *his* decision. He understood me well."

Jay Katz, *The Silent World of Doctor and Patient*[1]

"DOCTOR: Do you think that we, as physicians, should speak to people who face fatal illness about their future? Can you tell us what you would teach us if your mission was to teach us what we should do for other people?"

From an interview with a 17-year-old terminally ill patient, quoted in Elisabeth Kübler-Ross's *On Death and Dying*[2]

When U.S. hospice advocates began promoting economization, they invoked two moral justifications to support it. First, they argued that economizing dying was better medicine, since it meant reflecting honestly and thoroughly on the beneficence of different medical interventions, avoiding futile treatments, and facilitating more dignified deaths. Second, they argued that patients themselves wanted to economize dying: aggressive care at the end of life did not represent their preferences, which clinicians should respect.

This chapter examines the latter justification. This justification is rooted in a pattern of ethical thinking, which has become hegemonic in U.S. medicine. Around the 1960s, medicine began tackling moral and ethical qualms by turning to patients. The right way to treat Jay Katz's friend became following *his* decision, and the best advisors on how to talk with dying patients became dying patients. Medical discourse recognized patients as ethical compasses: they could orient medical practice in ethical directions.[3] The bioethics discipline, which developed during the period, harbored this orientation. In a reflexive historical account, Fox and Swazey dated the origins of bioethics to the 1950s and 1960s, when public and professional discourse filled with discussions of several key issues: experiments in humans, assisted reproduction, euthanasia, and later on organ transplantation and intensive care technologies.[4] The general concern to protect patients' rights, as individuals, from medical institutions and professionals reverberated throughout these discussions. This is what bioethicists have termed *patient autonomy:* an approach that relies "on the principles

of 'respect for persons', as well as 'respect for autonomy'"[5] and identifies the patient as having an inherent right to self-govern, resist so-called medical paternalism, participate in decisions on her or his medical care, and refuse treatment.[6]

Paradoxically, in order to guarantee self-sovereignty to patients and protect them from professional institutions, autonomy advocates had to create new institutions. By the mid-1970s, wrote David Rothman, "the authority that an individual physician had once exercised covertly was […] subject to debate and review by colleagues and laypeople."[7] Institutional Review Boards, which scrutinized research protocols, hospital bioethics committees, which reviewed clinical decisions, and lay cadres of judges, lawyers, community representatives, administrators, and politicians weighed in and influenced medical practice.[8] As John Evans argues, this transition made ethical discussions thinner—more rational, methodical, and procedural.[9] A significant gap emerged between intuitive moral thinking and the formal casuistry of ethical reasoning.

Much criticism of the patient autonomy approach tackled this tension. Take two particularly illustrative discussions. First, many scholars and practitioners raised concerns that patient autonomy places the high burden of medical decisions on patients and their families. "Scenarios in which families are offered choice […] when death is near," wrote Sharon Kaufman "reveal the dark side of autonomy – full of anguish, guilt, and above all the absence of knowledge about medical outcomes."[10] Giving patients voice and allowing them to decide what care they would and would not want passes responsibility to people who may not want it. As legal scholar Carl Schneider argued, "many patients reject the full burden of decision autonomists would wish upon them."[11] Autonomists had to discuss how to practice participatory decision making without straining patients and families.[12]

Second, as Jodi Halpern points out, patient autonomy has itself become impersonal. Its typical application involves listening to what patients (or families) say; in line with liberal thinking, it adopts a negative conception of autonomy: autonomy is the absence of external constraints on individuals, hence clinicians refrain from doubting and challenging what patients express. In effect, they embrace medicine's traditional detached concern attitude: they sympathize, but hardly empathize and patient autonomy loses its humanistic essence.[13]

This chapter highlights another tension that emerged from the rise of patient autonomy. This tension has less to do with how clinicians practice patient autonomy at the bedside and more with the consequences that medicine's turn to patients had for the new moral economy of dying. Historically, advocacy for patient autonomy emphasized patients' right to refuse treatment. Cases of patients who rejected life-prolonging treatment that their physicians offered were emblematic, and advocates invoked them in scholarly, public, and policy discussions. Other cases, if existed, were virtually invisible. In the chapter's first section, I examine Congressional hearings on death and dying from the 1970s and show how the voice of patients and caregivers in

these hearings resonated with economization. In the second section, I present evidence that indicates a possible change in this stance. I examine files from the archive of a hospital ethics committee and show that the most common ethical dispute this committee discussed in 2012 involved patients and families who wished to continue life-prolonging treatment against medical advice. The voice of autonomous patients now collided with economization. The third section raises several potential explanations to this change and examines the sociological significance of the tension that emerged between economization and the motivation to take patients' wishes into account when making medical decisions.

1. What Dying Patients Want

Mr. and Mrs. Average Go to Congress

In the early 1970s, the U.S. Congress began holding hearings on care for the dying. All of these hearings summoned health experts—both academics and practitioners. Many hearings also included ordinary people from various "communities" in the country. In the eyes of Congressional committee members, these ordinary people's testimonies carried much weight. "We have heard from many experts, […] but I really think the real experts on this subject are the people who have to face the subject very directly," said William Oriol, majority staff director of the Senate's Special Committee on Aging.[14]

These ordinary people, however, came from a particular range of social backgrounds. Many of them lived in relative proximity to the Washington DC area, most came from middle and upper class backgrounds, and in high likelihood, all of them were white. As one can expect from witnesses in Congressional hearing, they held clear opinions about the hearings' topic: how policymakers should reform care for the dying. Less obvious was the similarity of their opinions: as represented in these hearings, dying patients and their caregivers supported economization very eagerly.

Starting in the first hearing on the topic (1972), Congressional committees heard patients and family caregivers who resented the medical system's over-ambition, preferred "death with dignity" to combating their or their relative's disease, and favored dying at home to institutionalization in hospitals or nursing homes. The first witness at the first hearing was 94-year-old Arthur Morgan, whom the committee's chairperson presented as "a very distinguished citizen of this country." Morgan was the former president of Antioch College and the first chairperson of the Tennessee Valley Authority—stature and credibility, which could not be doubted. He talked about his late wife's, Lucy Morgan, essay, "On Drinking the Hemlock," which the Washington Post had published in the 1950s and the Hasting Center Report later reprinted in its first volume.[15] "The average duration of life in America has increased greatly in the past half century," wrote Lucy Morgan,

> This change is usually referred to as an unmixed blessing. But is it? […] I see as I never did before that one element of the increase in average age is largely a prolongation of senility, and that it must be heavily paid for by the rest of society. […] I find an almost unanimous feeling that we will never suffer ourselves to be such a burden to our children […]. None of us [is] afraid of the grave and [has] no feeling of desire for life when usefulness is over. We do not want to give up our present comfort in order that exposure might bring us to a timely end, and we do not want to disgrace our families by anything spectacular.[16]

Morgan's words acquired a particularly tragic meaning when decades later she fell, cracked her skull, and suffered a devastating brain injury. "For a good while," testified her tearful husband,

> the affection between us was enough to give joy and cooperation. […] Later, her responses were largely ended and life was mostly a burden. […] She was trying to keep from being fed, and they were prying her mouth open to feed her. I instated that they should not compel her to eat if she didn't want to eat, and they shouldn't inject medicine into her body.[17]

Two days later, the committee heard a panel of three women who echoed the Morgans' sentiments. "Mrs. William Heine," wife of an elderly man who had advanced prostate cancer and suffered a stroke, said "we have discussed what life is now to him compared to what life was and what life is for me, because the members of the family feel it very strongly. […] All I can do is express for Mr. Heine and myself how we feel about it."

And these were the feelings she shared with the Senators:

> We are scared, scared to death now that he is getting to the point where he is more comfortable lying down than he is being on his feet. […] He has the feeling, and I agree with him, that everybody has a right, if you have lived with dignity and respect all your life, […] to decide to die with dignity. Because there is nobody to keep you alive after your mind goes and after everything that really matters is gone. Just to keep you alive on a heart-lung machine and with glucose is not life enough for everybody.[18]

Another panel participant was 78-year-old Gertrude Clark, a retired Greek Civilization school teacher from Silver Spring, Maryland, who recounted how she serendipitously became a euthanasia advocate. After receiving and signing a "living will" that the Euthanasia Educational Fund of New York sent her, Clark was approached by neighbors in her retirement home, who said they wanted to sign the document too. "At intervals, […] each time the resident expressed strong support for what the 'living will' attempts to insure," she testified, "until this last week, about 25

persons had approached me quietly with this in mind, and I had become persuaded of how widespread […] the belief is in this and how general is the desire that a way be provided by which their wishes can be assured." The daily *Washington Star* featured an article on Clark, which led to "a veritable explosion of expressions of approval" from even more neighbors. Her retirement home, she contended,

> is a microcosm of the world of older people in the United States and can be considered a kind of laboratory for testing attitudes of that age group about this idea. […] I have been telephoned and people have leaned over the table in the dining room and they have met me in the halls, sought me out. It is unanimous from them. I hear that other people have said the same thing and I began to get a fan mail yesterday.[19]

The Euthanasia Educational Fund distributed the form that Clark, her neighbors, and her fans endorsed so enthusiastically in 90,000 copies.[20] Its text was a most powerful statement:

> If the time comes where I can no longer take part in decisions for my own future, let this statement stand as the testament of my wishes: if there is no reasonable expectation for my recovery from physical or mental disability, I, _____, request that I be allowed to die and not be kept alive by artificial means or heroic measures. Death is as much a reality as birth, growth, maturity and old age—it is the one certainty. I do not fear death as much as I fear the indignity of deterioration, dependence and hopeless pain. I ask that drugs be mercifully administered to me for terminal suffering even if they hasten the moment of death.
>
> This request is made after careful consideration. Although this document is not legally binding, you who care for me will, I hope, feel morally bound to follow its mandate. I recognize that it places a heavy burden upon you, and it is with the intention of sharing that responsibility and of mitigating any feelings of guilt that this statement is made.[21]

This was a standardized and mass produced individual plea to economize dying. The form summarized a myriad of experiences, feelings, doubts, and emotions in two poignant paragraphs, which thousands signed: medicine prolongs my life for longer than I want; the reader has a moral obligation to stop it.

Lay witnesses who appeared in later Congressional hearings expressed very similar stances. In 1978, Ruth Molendyke, a widow with four children from Pompton Plains, NJ, testified that "My mother, too, always said that she did not want to go to a hospital or a nursing home." Don Keating of Maple Heights said that his own 88-year-old mother "would rather die than be put in a nursing home. Even the best homes in our

areas are understaffed. The staffs are not properly qualified and in some instances there is a lack of supervision. Quality of service is not as good as the people could obtain at home."[22] The elderly preferred to die than be treated, and home was superior to medical institutions.

By 1984, when Congress debated the proposed payment schemes for hospice care, advocates could summon a new type of "ordinary person" to testify: family members of deceased hospice patients. Many of the witnesses from the early 1970s, such as Arthur Morgan, identified with Right to Die ideas and expressed opinions that did not always resonate with hospice. "I do not want to talk about *dying* with dignity, but […] about *living* with dignity," said Elizabeth Kübler-Ross at her first testimony, trying to distinguish herself from euthanasia advocates who testified before and after her.[23] Family caregivers of hospice patients, on the other hand, could give testimonies that were far closer to hospice views: they experienced hospice first-hand, and hospice influenced their thoughts on care for the dying. When appearing in Congress, they talked about their deceased relatives as having been unequivocally terminal: not people who rejected life and wished to die, but ones who accepted their inevitably impending death, which physicians diagnosed without any doubt. Recounting her mother's last weeks, Ann Rosenfield of Bethesda, Maryland stated:

> The unique care she received [in hospice] was responsive to <u>her</u> distinctive physical and emotional needs as a terminal patient. Indeed, hospice's special understanding of those needs, and of the needs of her family, made the last weeks of her life bearable. She was able to live with dignity until she died. (emphasis in the original)[24]

Rosenfield was either well-versed in hospice rhetoric, or very well-coached by the hospice advocates who invited her to testify: her statement practically reiterated the fine distinction, which Kübler-Ross drew between "dying with dignity" and "living with dignity" more than a decade earlier. Rosenfield's remarkable ability to invoke hospice ideas articulately and at the same time speak as an ordinary person showed when she responded to a challenge from conservative Congressperson Michael Bilirakis:

> Bilirakis: The word "hope" is something that is awfully important to all of us and certainly to a person who is ill and to a person who is terminally ill. I wonder, do they lose hope? […] I know that the doctor has probably depicted that they are terminally ill but I mean, does hope leave them? What have you seen?

A Right to Die advocate may have responded that when reaching a certain stage of terminal illness, life is worthless and people should be allowed to end their lives. Rosenfield, however, articulated her answer very carefully and diplomatically, in a way that served hospice advocacy and did not clash with Bilirakis's religious predilections:

> Rosenfield: […] I know my mother probably lived longer with the hope that when she opened her eyes she would see one of us there. That when she called, someone would come. I know that she would have lost hope if she had opened her eyes at one point in the night and couldn't breathe and had to wait for help. She might have died at that moment. So she had the hope of seeing us, the hope of having what she loved.
>
> Bilirakis: So you feel that kept her alive longer?
>
> Rosenfield: Probably. Probably so.
>
> Bilirakis: But that will to fight, which sometimes, by God's miracle, provides a person with the type of strength that may beat a disease even though supposedly they are terminal. Do you feel that they lose that hope as a result of the program, if you will?
>
> Rosenfield: No, by being able to control the pain and the terrible symptoms that they are experiencing, they are actually able to have more inner strength because all of their resources aren't being depleted with the fear of not being medicated, with the fear of being left alone, with the constant absolute pain. They are able to have more hope, really, I think.
>
> Bilitakis: OK. And you have not experienced, I mean from other people, any instances where they may have lost hope or were losing hope as a result of, you know, this final type of thing?
>
> Rosenfield: No. It is hard to explain but the family and the patient come to a gradual acceptance that, yes, you are going to die, that you are all going to lose each other in the end. It is a question of how that end occurs. That is the significant thing. And there was hope every day that she opened her eyes, not that she would recover but that we had more time together. And that the quality of that time was more bearable for her, for us.[25]

Rosenfield represented economizing dying as a way to prolong life. Coming prepared to the testimony, she could answer difficult questions by drawing on hospice arguments that others had tried before her. She was a new type of ordinary person, who identified with the hospice ideology, agreed to come to Congress to represent it, and was able to express it very articulately. Her voice joined other ordinary voices and infused the discussion with individual patients and their family members' support in economization.

Being tagged as ordinary, unremarkable, or average is oftentimes thought of as a weakness. At the same time, much power lies in the social position of the ordinary. For one thing, ordinariness may grant a person the legitimacy to speak in the name of an entire population.[26] When recognized as ordinary, one's experiences become common and one's views become average and representatives. Some witnesses

assumed this role voluntarily: Lucy Morgan and Mrs. Heine used plural pronouns—"none of *us* [is] afraid of the grave"; "just to keep you alive […] is not life enough for *everybody*" (emphases mine)—and Gertrude Clark described her Maryland retirement home as a "microcosm of the world of older people in the United States." At other times, committee members pushed witnesses to make generalizations and extrapolate from their personal experiences to the experiences of all patients and caregivers. Unlike expert witnesses, lay and ordinary people were not expected to prove these extrapolations' methodological soundness: their ordinariness vouched for their credibility and the empathy their touching stories elicited helped advocates garner support.

The power that lies in the average is not distributed equally among all social groups. For one thing, the average does not represent many experiences and opinions, which are on the margins. Even if on average, U.S. adults say they would not want their life prolonged when facing severe illness, there are still many who would and whom the average does not represent. Moreover, few people get invited to testify in Congress, and those invited tend to come from very particular social backgrounds. The average person is therefore hardly ever in the position of representing the average; the average, rather, represents her. In the case I describe here, lay witnesses who appeared in Congress represented dying patients and their family caregivers as univocally endorsing economized dying.

Studying What Dying People Want

Much of the period's scholarly work offered very similar representations. Take Kübler-Ross's Magnum Opus, *On Death and Dying*. Patients' wishes, thoughts, and feelings were major foci of the book, which Kübler-Ross wrote was "simply an account of a new and challenging opportunity to refocus on the patient, […] to learn from him [sic] the strengths and weakness of our hospital management of the patient." Kübler-Ross presented her own expert judgments as secondary to patients' own voices: "we have asked [patients] to be our teachers so that we may learn more about the final stages of life […]. I am simply telling the stories of my patients who shared their agonies, their expectations, and their frustrations with us."[27]

In line with what ordinary people said in Congress, Kübler-Ross described a fundamental tension between patients' wishes and the care provided in hospitals. Senator Frank Church, chair of the Senate Committee on Aging read her description aloud when he opened the first hearing:

> Her [Kübler-Ross's] basic point is that the patient may be treated like a thing rather than a person. Decisions are frequently made without his opinion, even on major questions of treatment. He becomes, as the book says, "an object of great concern and great financial investment. He may cry for rest, peace, and dignity, but he will get infusions,

> transfusions, a heart machine, or tracheotomy if necessary. He may want one single person to stop for one single minute so that he can ask one single question, but he will get a dozen people around the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram, or pulmonary functions, his secretions or excretions, but not with him as a human being. He may wish to fight it all, but it is going to be a useless fight since all this is done in the fight for his life, and if they can save his life they can consider the person afterward. Those who consider the person first may lose precious time to save his life!" […] To the patient, exhausted and tormented by pain, the will to resist [disease] may seem to be merely a way of prolonging agony. […] To the physician, the disciplined determination to maintain life may overcome all other judgments.[28]

The book's full title summarized its argument on the typical relationship between dying patients and clinicians: "On Death and Dying: What the Dying Have to Teach Doctors, Nurses Clergy, and their Own Families." Dying patients knew something about death, dying, and proper ways to care, which professionals still needed to learn. About 90 percent of the physicians Kübler-Ross encountered during her research "reacted with discomfort, annoyance, or overt or covert hostility." They had a "desperate need to deny the existence of terminal patients in their wards."[29] One physician yelled at Kübler-Ross that she should not have talked to a certain patient, who did not know how sick she was; Kübler-Ross responded that the patient wanted to talk to her *because she knew* she was dying.[30] Another patient spoke with contempt about "those physicians who can only care for a patient as long as he [sic] is well but when it comes to dying, then [the physicians] all shy away." "This was my man!" Kübler-Ross wrote, adding that the interview with him was "one of the most unforgettable […] I have ever attended."[31]

"It appeared that the more training a physician had the less he was ready to become involved" in care for the dying, Kübler-Ross observed. Professionalization made physicians lose an openness to the topic, which they had previously possessed. The same applied to other medical professions. Although compared to physicians, nurses were more open to the topic, Kübler-Ross found that "only one out of twelve nurses felt that dying patients, too, needed their care."[32] Even chaplains—the traditional harbingers of death in hospitals—were in acute denial: many of them "felt quite comfortable using a prayer book […] as the sole communication between them and the patients, thus avoiding listening to their needs."[33]

Contrary to clinicians' overwhelming denial, terminal patients "responded favorably and overwhelmingly positively" to Kübler-Ross's research. Only 2 percent of the people she approached for interviews turned her down and only one out of more than 200 consistently refused to "talk about the seriousness of her illness, problems resulting from her terminal illness, or fears of dying."[34] This particular patient, she wrote, was in the stage of denial—of which many others spoke to her

retrospectively.[35] Like clinicians, terminal patients who wanted to prolong or sustain life were denying death. Acceptance meant embracing economization: understanding that death is near and forgoing the futile attempts to postpone it is preferable.

Some later research echoed these observations. In 1984, a team of San Francisco researchers surveyed 152 severely ill and healthy patients. Of the respondents who reported thinking "a lot" or "a moderate amount" on the topic, large majorities said they would not want to be treated with intensive care (73%), resuscitation (71%), and feeding tubes (75%) if they were demented. A small majority (53%) also said they wanted to refuse antibiotics and hospitalization for pneumonia if reached this condition. Respondents who were older than 65 were almost twice more likely to say they would decline feeding tubes (80%) than younger patients (42%). The researchers did not report the answers of those who said they thought little or did not think at all about the topic.[36] Seemingly, insufficient thought on the topic made them unqualified to decide whether they would want these procedures. Another study from 1988 found that in its sample of 75 elderly patients, only 9 percent said CPR should be performed on any person who had cardiac arrest, regardless of her medical condition. A minority said they would want CPR performed on them if they had terminal cancer (28%), irreversible heart failure (41%), or if they were in irreversible coma (25%). In the late 1970s and to a greater degree in the 1990s, major public opinion research centers did more comprehensive surveys on the topic. Some of these surveys, which asked people about their end-of-life preferences, yielded even stronger results. In two Gallup polls (1992 and 1996) 9 out of 10 respondents said they would prefer care at home to institutionalization if they met the Medicare hospice criterion: a terminal illness with six months or less to live.[37]

Advocates and scholars of end-of-life care cited these and similar figures as testimonies that the U.S. public is overall supportive of economized dying.[38] Notice, however, that there were many different ways to frame these findings. For one thing, as in any survey, people's answers depended on how questions were worded.[39] The Gallup polls, which asked *where* people preferred to die found an overwhelming public preference for home care. Other studies, which confronted people with questions on specific medical procedures, documented lower support in economization. Indeed, later research documented even more diverse positions on end-of-life care. Recall the SUPPORT study, which found that families of deceased patients were satisfied even though the care their relatives received was more "aggressive" than what they initially declared that they wanted.[40] Several years later, researchers compared the end-of-life wishes of people in various age groups and medical conditions. Contrary to the 1984 study, they found that sicker and older patients valued life in severe illness more than healthier ones and were more open to life-sustaining care. For example, among the young and healthy adults surveyed, about two-thirds considered life in coma worse than death, compared to 57 percent of the older adults, and only 44 percent of the terminal cancer patients.[41] Another team of researchers found that 58 percent of the terminal patients they sampled

wanted to receive medical treatment even if it could prolong their life by one week. Similarly to the SUPPORT researchers, they found that these preferences had no significant impact on how clinicians ultimately treated these patients.[42]

These findings aside, the most prevalent narrative researchers told about end-of-life care described physicians who prolong terminal patients' lives against their wishes.[43] Readers will easily recall cases of people who fought to withdraw life support against legal, medical, religious, political, and organizational dogma: Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo. These were milestones in the glorious history of people fighting for their individual rights and sovereignty, and no account on U.S. end-of-life care is complete without them. Opposite cases, of patients and families who struggled to continue life-prolonging treatments are far less known. While such cases appear in media outlets occasionally, they are quickly forgotten and have never added up to a coherent historical narrative. Scholarly discussion on them is also lacking: in 1990, a case report on clinicians who against a mother's wish, refused to prolong the life of a severely ill and incapacitated baby, mentioned that "literature on physicians' refusal of patients' demands is sparse."[44] Almost a decade later, there was still "no definitive court ruling on the subject nor a consensus in the bioethics or medical communities" on "physician refusal of ineffective or so-called futile treatment."[45]

The assumption that patients and families typically want less aggressive care than clinicians also informed legislation. In 1989, the preface to a bill that eventually became the cornerstone Patient Self-Determination Act of 1990, determined that "recent advances in medical science and technology have made it possible to prolong dying through the use of artificial, extraordinary, extreme, or radical medical or surgical procedures."[46] Based on this risk, the bill (and ultimately, the law) required health providers to inform patients on their right to make decisions on their care, inquire on whether they have filled an advance directive, and ensure that such a directive, if exists, will be followed.[47] The bill's language treated any patient wish—rejection or acceptance of treatment—symmetrically and sought to guarantee patients' right to influence their care regardless of what their wishes were. The rhetoric of the bill's original preface, however, betrayed the scenarios that its authors and sponsors had in mind: describing care with adjectives such as "artificial," "extraordinary," and "radical" was a clear statement against the use of life-sustaining treatments in terminal patients and for patients' right to reject them.

In summary, since the 1970s, medical literature, public discourse, and legislative discussions emphasized cases where doctors prolonged or sustained patients' lives against their wishes and portrayed them as the chief and most quintessential problem that needs to be addressed in end-of-life care. By highlighting physicians' aggressiveness compared to patients they also made an argument that typically, patients' wishes resonated with economized dying and therefore, economization was a win-win-win strategy: it provided better care, for cheaper, and at the same time reflected what patients wanted.

2. The changing nature of ethical qualms

I decided to collect data on bioethics consultations when I noticed a substantial difference between the arguments hospice and palliative care advocates made and what I observed in my fieldwork. Historically, advocates described their goal as assisting terminally ill patients who refused life-prolonging treatment. This was also the situation that many palliative care clinicians described to me in interviews. But when I shadowed them in their day-to-day work, I saw that they spent most of their time dealing with opposite cases, in which patients (or families) wanted to pursue life-prolonging treatment against the opinion of many if not all physicians.

This finding should be taken in context: like any ethnographer, I observed very particular parts of the hospitals that I studied. There could be numerous cases of physicians who prolonged patients' lives against their wishes, which the palliative care service did not know about and I did not observe. But as an account of the palliative care specialty and the new moral economy of death, this finding is meaningful and important: it helps characterize the relationship between palliative care and the attempt to economize dying on the one hand, and the agency of patients and families on the other hand.

The archive that I studied belonged to the bioethics committee of a California hospital. It included documentation of nearly all of the cases that the committee discussed since its beginning—by definition, situations, which clinicians and in some rare occasions patients and families considered ethically problematic enough to refer to a bioethicist. Studying this archive had three methodological advantages. First, it added a historical dimension to my ethnographic fieldwork. Ethnography has the disadvantage of being restricted to the present: participant observers can only see things that happen when they are in the field and can analyze past occurrences only through the mediation of storytellers.[48] Obviously, archives are mediators as well: they do not document everything and the documents they do include may omit details that their authors preferred to hide. When I compared patients' medical charts with my field notes, I noticed that charts often downplayed conflicts and disagreements within the medical staff—a particularly important challenge given my interest in differences between patients', families', and clinicians' stances on end-of-life care. At the same time, the nature of the archive guaranteed that conflicts would show, even implicitly: the bioethics committees typically discussed disagreements: if everybody agreed on what was right to do, there was rarely a reason to refer the case to the committee. One way or another, files had to acknowledge and characterize these disagreements.

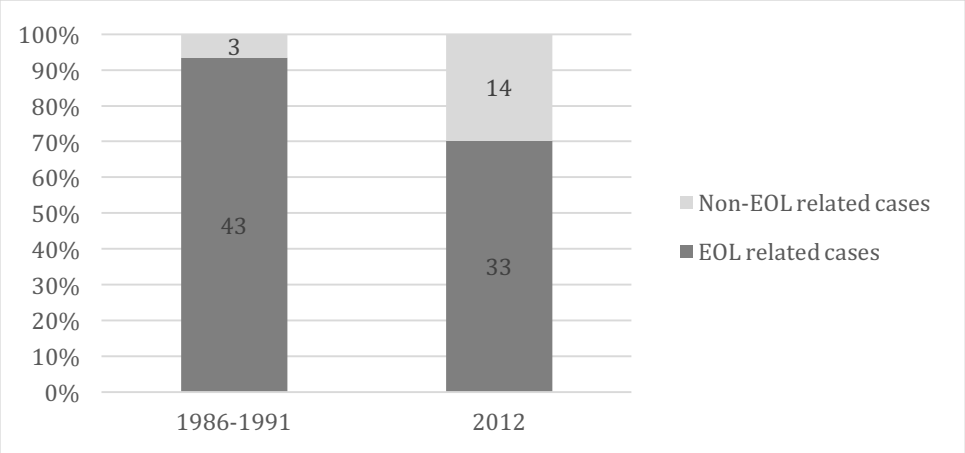
The second methodological advantage lied in this quality. The archive allowed me to observe how ethical disputes in the hospital have changed since the committee began working. I was less interested in the committee's recommendations and more in the nature of the disputes that led people to consult a bioethicist. Specifically, I wanted to map the relative positions clinicians and patients took on end-of-life care—who

leaned toward more (or less) life-prolonging and life-sustaining care—and see whether and how these relative positions have changed over the past decades.

Finally, reading cases from the archive allowed me to broaden my empirical examination beyond the palliative care service. Files in the archive included notes from a variety of medical specialists as well as general medicine physicians, who in some cases disagreed with the palliative care team. This still left me with the very likely possibility of a selection-bias: first, for various reasons, some controversial end-of-life cases may not have made it to the bioethics committee. Second, people's definition of what counts as an ethical problem that the bioethics committee should discuss may have changed over the years; by consequence, clinicians could refer to the committee different types of cases in different periods. This selection-bias, however, is exactly what I want to evaluate: my goal is to look at how the framing of what counts as an ethical problem has changed in this hospital over the years: whether ethical disputes were of patients resisting the care offered to them, or whether physicians were the ones trying to economize dying, against patients' wish to stay alive.

The archive included hundreds of files, each dedicated to one case of one patient. The earliest files were from 1986, the year when the committee began working. Documentation in the 1980s and early 1990s was shorter and less detailed than documentation in the 2000s: the files included few notes from the patients' medical charts, and I had to rely on minutes from the bioethics committee's meetings, where committee members discussed cases collectively, in order to gather sufficient information. The committee discussed far less cases on its first years than it did in the 2000s: in order to review a comparable number of cases, I had to read all the files from the years 1986-1991 (46 files), then compare them to files from 10 months in 2012 (47 files). Of the files the bioethics committee discussed in 1986-1991, 43 (93%) involved the treatment of patients at the end of their lives, compared to 28 (67%) in the second period (figure 3.1). This reflects an expansion in the committee's jurisdiction: while in the past "ethical cases" were almost synonymous to end-of-life cases, by the 2010s people framed a variety of other problems in the hospital as ethical.

Figure 3.1: Share of End-of-Life Cases Discussed by the Ethics Committee



After reading the files and summarizing them, I classified them into three categories with the help of a research assistant. We then compared our classifications, reaching agreement on all but one case, which we removed from the sample. Let me define each of the categories that we used.

(a) The Economizing Patient

In *economizing patient* cases, patients or their families took a more economized stance than their physicians. The cases that Congresspeople heard in the 1970s are representatives of this category. In the hospital that I studied, most of these cases were of physicians who had viable ways to prolong or sustain a patient's life, yet the patient or her family rejected them. What made physicians consult the bioethics committee was the fear that complying with this rejection and allowing the patient to die was unethical—perhaps even equivalent to assisting suicide.

Take one example. Mrs. Davenport, an 81-year-old woman, suffered from a severe lung disease and ulcers. A hospital surgeon operated on her ulcer, which led to numerous complications. Mrs. Davenport's lungs failed, and the medical staff intubated her. At this point, her husband requested to take her home and continue caring for her there; the attending physician, however, refused, stating that "discharging the patient would put her life in severe jeopardy," and referred the case to the bioethics committee. The wish to economize was Mrs. Davenport husband's, hence we included the case in the economizing patient category.

In many other economizing patient cases, patients (or families) requested to economize dying, while the medical staff disagreed or showed ambivalence. Mr. Evans, a marginally housed 78-year-old man, lived in the most devastated neighborhood in the hospital's area. His neighbors reported not seeing him for several days, which eventually led them to call 911. The EMS paramedics who

responded to the call found Mr. Evans sitting in his feces and his room "in total disrepair." When they lifted him, the noticed that some skin fell off his neck, exposing what a hospital physician later diagnosed as a tumor. At the hospital, Mr. Evans told the doctors he has had difficulties getting to the food in his room: he used a Swiffer mop as a walking stick, which apparently did not give him enough support. He reported treating the tumor, which started bleeding, with Kleenex tissues and said he had never consulted a physician about it. One medical note described the tumor as "quite extensive and dramatic. The floor is extremely friable and bleeding and extends all the way anteriorly to the right side with destruction of the lower two-thirds of his right ear." Still, Mr. Evans "seemed fairly unconcerned by the wound."

The attending physician's note read as a mixture of frustration and puzzlement:

> I have recommended biopsy of this lesion for further histopathologic diagnosis. [The] patient has declined. I also recommended imaging of the head and neck to see the extent of [the] disease with a CT Scan as a start. The patient has also declined that. I extensively discussed the possibility of early death; however, the patient is insistent that he does not want treatment for his tumor. I have fully discussed the risks, benefits and alternatives for his plan of action and he understands.

The physician ordered a neuropsychiatry consultation to evaluate if Mr. Evans could make decisions for himself, as well as a bioethics consultation. In the meanwhile, "given his general refusal of aggressive medical care and overall focus on comfort and independence,"[49] he also called palliative care. In his note, the palliative care physician agreed with the neuropsychiatrist that Mr. Evans was competent and could make decisions:

> At the time that I am seeing the patient, he is awake and alert, speaking clearly. He is able to introduce himself, inform me of his extensive political views, and hold forth in detailed conversations and song. He answers my questions easily. […] He does not have much recollection of the events leading up to his hospitalization, but recalls falling after trying to get ice cream from his freezer. Although his speech and stories are somewhat tangential, he usually will eventually get to the point if given enough time.

The palliative care physician wrote it was unclear if the patient's debility was from his tumor or from his general "self-neglect." Regardless, he observed, "neither of these things can be altered." He wrote that Mr. Evans

> is very committed to a plan of care that defers medical interventions and hospitalization. He likes being in his apartment, and likes being in control of his [unclear] and surroundings. He agrees with a plan that avoids [hospitalization], focuses on insuring his physical comfort, and allows him to stay at home, even if we do not necessarily agree that it is

> safe. Having evaluated him along with [other doctors], I agree that he is a poor decision maker, but not an unimpaired one. He does have the ability to articulate the consequences of his actions, including infection, bedsores, and early death if he does not get appropriate help. He agrees with a hospice plan of care fundamentally. He does not want to be re-hospitalized and wants to focus on his comfort when his tumor progresses. […] Our neuropsychology service as well as our ethic service [found him] to have decisional capacity, even if he is making decisions with which we do not agree.

Based on this assessment, the palliative care physician recommended setting as many services as possible to assist Mr. Evans at home, including home hospice. He noted, however, that in the long term, since Mr. Evans lived alone, these services would be insufficient.

The reason the attending physician called the ethics consultation was a certain ambivalence he had about the case: he thought it was right to treat the tumor and at the same time felt he could not impose this on the patient. The palliative care physician agreed that treating the tumor would be a good decision, but thought that since Mr. Evans had a clear, persistent, and competent economized dying preference, they should all respect it. Mr. Evans, like Mrs. Davenport' husband, leaned toward economizing dying more than the clinical staff, hence we considered this an economizing patient case.

(b) Economizing Professionals

In "economizing professionals" cases, clinicians leaned toward economized dying more than patients and families. In some cases, patients or family members actively resisted economization; in others, they were indecisive, conflicted, or could not communicate because they were unconscious or demented. Clinicians associated resistance to economized dying with patients of very particular social backgrounds. Talking about end-of-life conversations that he regularly had with families and patients, one palliative care physician told me:

> Well, it's an easy conversation to have with these very literate smart people. [After a good meeting with a family], I was walking into the fishbowl—the room where all of the nurses and the doctors sit on the unit—and I said, "Gosh, that was what life would be like if all I did was take care of uber-literate aristocratic white griffons. You know what I mean? We're horribly politically incorrect in our team. […] We're just completely bigoted and awful. I take care of a lot of Chinese patients at the hospital. They're hard, man!
>
> Q: Russian Jews.[50]

> A: [quickly:] Russian Jews are BRUTAL. They're fucking hard. I mean, go back far enough, and I'm Russian Jew. I don't know, I think my family told me they're from Russia, Poland, or Ukraine—you know, eastern European ghetto trash, basically. It's embarrassing. They're so hard. […] The Chinese are VERY hard. The Koreans are BRUTAL. […] South Asian patients—Indian, Pakistani—[…] of the ten or fifteen cases I probably had, probably seven or eight of them have turned into a HORRIBLE […] mess. […] I'm speaking totally in generalities, because the individual patient… Every once in a while you'll get a Chinese family coming in and saying, "we just don't want mom to suffer. We want her to be hospice." And you're like "what happened?" You were preparing for the battle of the three dragons and the next thing you know is like, "wow, that was easy."

I noticed that many clinicians had similar expectations from African American and Latino families, yet very few of them mentioned it in interviews explicitly. The few who did attributed this resistance to mistrust in the medical establishment, which derived from U.S. medicine's historical relationship with the African American "community." The racialized thinking remained, but references were covered in a thick layer of political correctness, which immigrants, particularly from relatively privileged backgrounds (e.g. Russia, Korea, China, India, and Pakistan), did not benefit from.

An illustrative economizing professionals case was Mrs. Poliakova's. When I gave a presentation on this chapter to the bioethics committee, my first slide included only the first sentence from Mrs. Poliakova's chart: "Patient is a 96-year-old Russian woman with advance dementia." I asked the committee members how they thought the case unfolded, and got a loud collective laughter as a response: the answer was all too obvious, because of the ethnic stereotype. When laugher stopped, I waited additional 5-6 seconds and repeated my question, until one of them, a chief bioethicist, said quietly "they insisted on everything."

Mrs. Poliakova's case validated the stereotype. As the medical chart recounted, she arrived at the ER after staff in her nursing home saw her short of breath, "coughing and gagging on her dinner." She "had increased work of breathing and tachypnea [fast breathing], which prompted EMS to be called." A palliative care nurse who consulted on the case wrote that according to Mrs. Poliakova's son, when healthy, she could sit in her wheelchair and "speak a few words, maybe up to about seven at a time. She may or may not understand or recognize people." The nurse also listed no less than 21 medical problems that the patient suffered, including Congestive Heart Failure, Parkinson's disease, Hypertension, and Coronary Artery Disease.

The ER Physicians admitted Mrs. Poliakova to the ICU, where she received IV antibiotics and oxygen. A day later, when her lung condition improved, the doctors decided to transfer her to the medicine floor and call a palliative care consultation.

The palliative care nurse spoke to the son, "specifically regarding feeding tubes." His mother had been hospitalized twice earlier that year, for what physicians diagnosed as aspiration pneumonia: pieces of food, which got into her lungs and infected them. For the clinicians, this was a clear sign that Mrs. Poliakova was losing her ability to swallow: eating has become hazardous and additional life-threatening pneumonia episodes were certain. In order to avoid them, physicians could start feeding her through a tube. But given her other medical problems and her declining quality of life due to her Alzheimer's, this did not feel right to them. "End result," wrote the palliative care nurse, "is that I hope that [the son] will not put a feeding tube in his frail mother and deprive her of one of her last remaining joys, which is nutrition by mouth."

The son said he would defer to the staff on the issue of feeding tubes, but at the same time requested to keep his mother "Full Code:" if she choked on her food again in a way that risked her life, he wanted the doctors to resuscitate her. Referring to this request, the palliative care nurse wrote: "I strongly believe that the son at the end of the day will not want to see her suffer and if he […] witnessed what we do, the shock of what we do may be sufficient to help him rethink the current plan." The attending physician at the medicine unit sounded less hopeful and wrote that he "would favor unilaterally withholding aggressive support on the patient on the basis of non-beneficial care if the family persisted in their request for aggressive interventions." In consultation with the bioethics committee, and against the son's wish, he signed a unilateral Do Not Resuscitate order, although intubation and connection to the respirator still remained a possibility. A few days later, her condition stable, they discharged Mrs. Poliakova to her nursing home. A week later, she came to the ER again.

This time, oxygen was not enough to stabilize her breathing and the ER physicians intubated and transferred her to the Intensive Care Unit. The palliative care nurse, who was called again to consult on the case, complimented an ICU resident for drawing a line in the sand:

> Our superb resident, Dan Lee, spoke with [the son] […] on the phone yesterday morning. He stated this is the fourth admission for aspiration pneumonia this year and three of those admissions have been in the last three weeks. […] Dan then spoke to him that she was critically ill with no realistic chance of survival and that when she died, we would not be instituting any further heroic measures.

After an additional conversation with the attending physician, who "discussed the lack of realistic options and reviewed [Mrs. Poliakova's] advance directive, which said she would never want to be kept alive artificially if there was no realistic hope of recovery," the son agreed to transition her to comfort care. "I am very pleased that the son has finally chosen to honor his mother's wish and is acting in her best interest," wrote the palliative care nurse in the chart. Economization in this case came

from the medical staff, who worked hard to bring Mrs. Poliakova's son to "finally" withdraw life-sustaining care. In the situation that developed, an advance directive form indicated that Mrs. Poliakova did not want to have her life prolonged, but her son insisted on continuing her treatment; the patient-and-family's preferences were equivocal, although since Mrs. Poliakova was uncommunicative and her son was her only representative, their voice at the hospital resisted economization, loudly, clearly, and actively.

In other economizing professionals cases, patients' wishes were far less clear. Mrs. Armstrong, whose chart described as "a very odd and unfortunate 88-year-old Caucasian female" was hospitalized with "dehydration, acute [kidney] failure, sepsis, a-fib, poor mental status, with limited medical h[istory] of hyperlipidemia [high blood fat level]." She was estranged from her family, except one daughter in law who was reportedly not very close to her. The paramedics who brought her to the hospital for "inability to care for herself" found her at home "with multiple ulcers and dry, thick, scaly skin indicating she had not bathed for a long time and extremely long toenails." After her condition stabilized, Mrs. Armstrong was admitted to the hospital's Skilled Nursing Facility. About two months later, many of the staff there questioned whether treating her multiple medical problems, which they thought would require surgery, was appropriate and called an ethics consultation.

A bioethicist, who talked to Mrs. Anderson's only friend and surrogate decision maker, wrote in the chart:

> The patient was always extremely independent. […] She has been complaining that people are trying to make her eat. [The friend] thinks that she is probably cognitively impaired for some unknown reason. It may be a rapid acting dementia. She has lost all the things that are valuable to her in life, especially her independence and her family. […] When I asked about what he was hoping for the patient, he said he hoped that she would have a comfortable dying. He again endorses a comfort care plan and says this is what the patient would want if she could speak for herself.

Because of Mrs. Anderson's dementia, the medical staff was unclear about her wishes. From the way they conducted themselves, however, it is clear that they somewhat leaned toward economizing her dying: they were uncomfortable with prolonging her life and recommending invasive procedures, which would likely cause an elderly demented woman (who experienced much pain and discomfort even from eating) much suffering.

(c) Ethical Validation Cases

In "ethical validation" cases, patients, families, and clinicians agreed to economize dying, but were unsure if it was ethical. They contacted the bioethics committee because they needed validation that economizing dying was ethically acceptable.

Take the case of Baby A. Born in a "complicated and protracted childbirth," she experienced respiratory distress and a physician performed an emergency C-section on her mother. Baby A had no pulse and regained it only after 30 minutes of resuscitation efforts. She was put on a respirator and the physicians ordered an EEG to evaluate her brain function. Having learned that she suffered a severe brain injury due to lack of oxygen supply, Baby A's parents said they did not want to keep her on a respirator. According to the pediatrician's medical note, they were "insistent about taking this approach [withdrawing life support], since they justifiably feared that keeping Baby A on a respirator might leave her in a prolonged vegetative state. The pediatrician concurred, yet called a bioethics consultation "to ascertain that there were no ethical problems that he was overlooking."

In another case, despite an overwhelming consensus that economizing dying would be beneficial, one staff member still felt ambivalent and called the ethics consult. Mr. Chang, an 80-year-old Chinese-American man, had been diagnosed with colon cancer about five years before his admission to the hospital. His physicians treated him with radiotherapy and chemotherapy, which as they predicted, slowed the cancer's progress but did not cure it. They also recommended a surgery, yet when the time came Mr. Chang reportedly refused it. "He has been followed, albeit not closely, by [his physician of] choice, Dr. Norton, ever since," one clinical note indicated. Two months prior to his hospitalization, Mr. Chang fell and broke his hip, and as his family recounted, his mental condition changed significantly. He was "waxing and waning"; one day, they brought him to the ER for "decreased appetite" and "poor urination"; the ER physicians ordered a CT scan of his abdomen, which "revealed metastatic colon cancer." Three days later, Mr. Chang came to the ER again and was hospitalized. Over the first five days of hospitalization, his condition declined rapidly. His organs began failing, and before becoming unconscious, he said he wanted to go home.

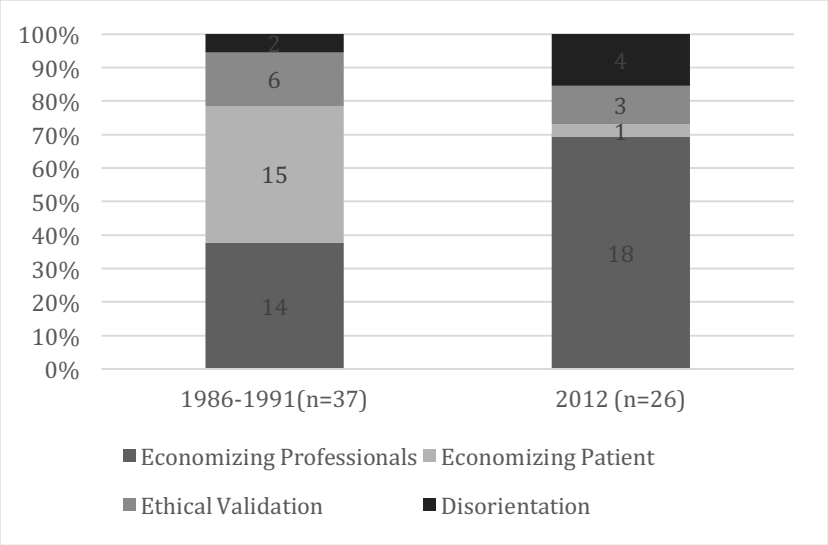
The palliative care nurse who consulted on the case talked to Mr. Chang's family with the assistance of an interpreter. "According to the family [Mr. Chang] has made multiple statements about not wanting aggressive care and preferring to die rather than to suffer a prolonged illness," she wrote. "He was apparently very discouraged by both his recent hip fractures as well as the previous episodes a number of years ago when he received chemotherapy. He did not want follow-up care." As the clinical note of the bioethicist revealed, "the medical team was in agreement that the patient was not only terminal, but had a prognosis of hours to days based on the acute event a couple of days ago and the terminal stage of his cancer." When I asked the bioethicist who called the consultation, she said that one of the bedside nurses disagreed with the rest of the team and thought the patient was unresponsive

because of the sedatives they gave him. This nurse, however, was a clear outlier within the rest of the medical staff, who agreed the patient's life expectancy was very short due to his terminal cancer, and considered the two acute organ failure events he experienced an indication that his cancer progressed to the inevitable point of terminality. Given this one voice of dissent, the team needed affirmation from the bioethics committee, which indeed provided it.

It is worth highlighting an interesting characteristic of ethical validation cases: in all of the cases that I reviewed, clinicians sought ethical validation only when they economized dying. I did not read or observe any case where a clinician asked ethicists to validate decisions to pursue additional curative, life-prolonging, or life-sustaining treatment. Such cases were outside the purview of bioethicists: it was obvious that when everybody agrees and consents, prolonging life and curing or slowing down a disease is ethical. But withdrawing or forgoing such treatment, even when done in a completely consensual manner, could still raise ethical doubts and lead physicians to call the bioethics committee. This asymmetry reflects an important feature in the ethical framing of end-of-life care: clinicians problematize economization far more than life-prolongation.

When processing the data, I dropped thirteen cases where we could not characterize the inclinations of the staff, the family, and the patients. In addition, I created a separate category for cases where neither clinicians nor patients and families had clear and agreed upon view as for what should be done ("Disorientation"). The results indicate a significant historical change in the cases the ethics committee discussed. While in the first period, there was a fairly even share of economizing patient and economizing professionals cases, the second period included only one case of an economizing patient—Mr. Evans, whose story I summarized above (figure 3.2).

Figure 3.2: The historical change in ethics consultations (end-of-life cases only)



This is a major transition that the hospital saw, and some anecdotal evidence suggests that it characterizes other hospitals as well. In 2005, Lachlan Forrow, director of the ethics program at Beth Israel Deaconess Medical Center in Boston, told the New York Times that "about 15 years ago, at least 80 percent of the cases were right-to-die kinds of cases" (what I called Economizing Patient cases). "Today, it's more like at least 80 percent of the cases are the other direction: family members who are pushing for continued or more aggressive life support and doctors and nurses who think that that's wrong." Similarly, Lisa Anderson-Shaw, co-chair of the ethics committee at the University of Illinois at Chicago said she consulted on eleven such Economizing Professionals cases in 2004, up from 2 in 1998.[51]

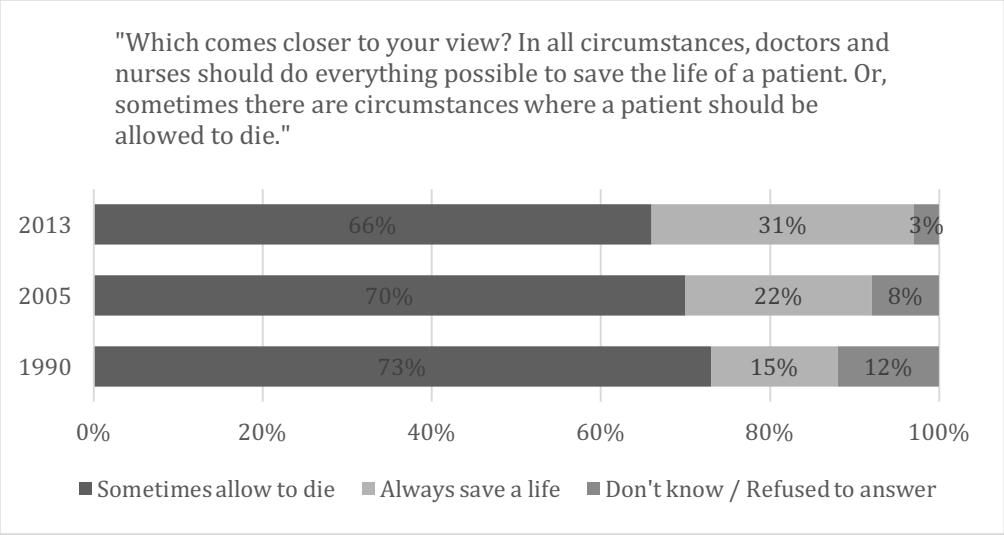
What explains this change?

3. An Age of Economizing Professionals

Rise in Vitalist Patients

A first explanation lies in a change in patients' and families' stances on life prolongation. We can see several indications for this change. The Pew research center surveyed the U.S. adult population in 1990, 2005, and 2013, asking respondents which statement they preferred: "in all circumstances, doctors and nurses should do everything possible to save the life of a patient," or "sometimes there are circumstances where a patient should be allowed to die."[52] While in each of the surveys a significant majority preferred the second and more economized statement, this majority has declined from 73 to 66 percent (figure 3.3).

Figure 3.3: General Positions on Life Prolongation



Source: Pew Research Center. 2013. *Views on End-of-Life Medical Treatments*.

Importantly, the size of the minority, which supports prolonging life in all circumstances, more than doubled in 1990-2013. This growth occurred in all age groups, education backgrounds, racial identities, and religious affiliations. Even among people who said they dedicated "a great deal of thought to end-of-life wishes"—presumably, a population that engages and reflects on the topic—support in the "always save a life" statement climbed from 9 to 24 percent during the period.

There were, however, significant and important differences in the *levels* of resistance to economization between social groups: in 2013, Latino (59%) and African American (52%) respondents were far more likely to endorse the "always save a life" statement than White respondents (20%).[53] Research on end-of-life care has targeted race and ethnicity as central to explaining different end-of-life preferences.[54] Furthermore, people with no college education were more likely to endorse it (43%) than those with with some college education (22%) and college graduates (18%). Finally, respondents who attended worship services weekly endorsed the statement in higher rates (36%) than those attending them weekly or monthly (30%) and those who seldom or never attended services (25%).[55]

Questions on personal end-of-life preferences revealed similar, albeit weaker patterns. The survey presented respondents with the scenario of having "a disease with no hope of improvement:" in 2013, 35 percent said they would tell their doctor "to do everything possible" to save their lives, even if they suffered a great deal of physical pain, compared to 28 percent in 1990. 46 percent said they would do so even if it was hard for them to function in day-to-day activities (40 percent in 1990). Finally, 37 percent said they would ask to "do everything" even if they were "totally dependent on a family member or other person" for all of their care (31 percent in 1990).[56]

What are the sources of this growth in such "vitalist" attitudes—stances that everything should be done to prolong any life? Anthropologist Sharon Kaufman argued that in the U.S. today, "most deaths, regardless of a person's age, have come to be considered premature. […] For every ambivalent [patient], there is another patient who aggressively pursues treatment in the hope of staying alive, and there are others (though far fewer) who firmly reject treatment."[57] Kaufman attributed this to the dramatic growth of the U.S. medical-industrial complex. The private pharmaceutical and medical device industry's expansion created an enormous market, which inundates people with information about treatment options to themselves or their family members. Websites targeting healthcare consumers, internet forums, billboards, and T.V. ads that encourage people to "talk to your doctor about" a new device, therapy, medication, or surgery create the impression that miracle cures are out there, waiting for proactive patients to find them. Even a person who, in principle, would not like to have her life prolonged in all circumstances, may act differently when facing a serious illness with three or four treatment options that have come to her attention. Such "options" are hardly ever curative, yet once they are on the table, they are very hard to reject.

One of the most recent ethics cases that I reviewed was of Mrs. North, a 94-year-old woman, who throughout her life was very clear she would *not* want her life prolonged if she faced a terminal illness. She filled out an advance directive, which her physicians read as unequivocal: one medical note described it as outlining "a clear Do Not Resuscitate order and the hope to avoid a prolonged end of life." Mrs. North also talked to her husband about her wishes, who, according to a bioethicist, understood them and wanted to represent them properly. Following an operation to remove a bowl-obstruction, Mrs. North had an acute kidney failure; The surgery service opined that "while potentially she could be operated on [again], it was unlikely she would return to her former level of independence and quality of life and her risk of mortality was high." The service saw her best case scenario as a "prolonged ICU stay," followed by a "very long" stay at a nursing facility. Three other physicians, including the ICU attending, agreed with this prognosis.

Yet Mrs. North's cardiologist dissented, predicting that her "abdominal issues should be resolved soon." With this far more optimistic prognosis, the family, which was very involved in Mrs. North's care, became interested in treatment options for her kidney failure, specifically dialysis. "Her family is asking good questions," wrote the palliative care physician after talking to them, "but they realize that at this point, […] the question is whether the current plan for supportive care will lead to a quality of life that she will be happy with, or whether this will only [be] prolonging a state of chronic illness and debility." The family agreed to not "escalate" care, but at the time requested to continue artificial nutrition and antibiotics for 2-3 additional days, hoping that Mrs. North's condition would improve.

'It was a big time team conflict,' one of the people involved in the case told me:

> 'It's a case of a healthcare provider, a professional, who lacks understanding about end-of-life care. And then surrogate decision makers knew what the patient wanted but were unable or made to feel guilty for what they were doing. […] [This attending is] elderly. His privileges have also been restricted because of these kinds of problems. He also doesn't believe in pain medications.'

While dismissed as an "elderly" who "lacks understanding"—some outdated remnant from a distant professional past—the cardiologist's medical opinion was anchored in the present: the hospital where he worked *had* dialysis machines, multiple trained surgery teams, and many other means to prolong life in severe illness. Using them was an option, and once a physician recommended them, even people who were confident and firm about their economized dying preference ended up hesitating. Mr. North, as the palliative care physician described him, "focused mostly on [Mrs. North's] kidney function." While the case could potentially be one of a conflicted medical team facing an economizing patient, the disagreement within the team quickly turned into ambivalence within the family. (We included the case in the "disorientation" category.)

In summary, part of the significant decline in economizing patient cases derives from changes in the attitudes of patients and families. U.S. clinicians today see more patients and families, who enter the hospital with vitalist predilections than they saw 20 years ago. Furthermore, in the context of an expanding healthcare market, where people make decisions amidst an industry that offers numerous life-prolonging interventions, even the most economizing patients may tilt toward vitalism.

The Rise of Economizing Clinicians

The second driver of the decline in economizing patient cases lies in the medical profession. As I showed in chapter one, since the 1960s, parallel to the growth of the medical-industrial complex and rise in vitalism, some of the U.S. medical profession moved in the opposite direction, toward economized dying. This move has not achieved complete dominance in medical practice: as the case of Mrs. North shows, there are physicians whose clinical intuitions are very far from it. But the power of the movement to economize is growing, not only thanks to the rise in the number of palliative care clinicians and services in hospitals, but also because of the moral authority they have assumed. Discussions of economization have pervaded even the most acute care environments. A study that compared mortality in two ICUs found that in 1987-1988, decisions to withdraw or withhold life support preceded 51 percent of the deaths, compared to 90 percent in 1992-1993. Physicians in these ICUs performed CPR in 49 percent of the deaths in 1987-1988, compared to only 10 percent of the deaths in 1992-1993. In the authors' words, "90% of patients who die in these ICUs now do so following a decision to limit therapy."[58] "Limitation of life support prior to death is the dominant practice in American ICUs," the authors concluded elsewhere.[59]

Patients (and families) who are not interested in life-prolonging treatment are today more likely to find professional allies within the hospital than they were in the past: palliative care and other clinicians who have been exposed to hospice and palliative care. In some cases, these allies would confront and counter their more "aggressive" colleagues; in others, the would call a palliative care or a bioethics consultation, which would often present comfort care as an alternative to life-prolonging treatments.

Conclusion

This chapter describes a historical shift: since the 1980s, the average U.S. patient moved several steps away from economized dying, while the average hospital clinician moved several steps toward it. By consequence, "economizing professionals" disputes, in which professionals struggle to convince patients and their families to forgo or withdraw life prolonging care, have become more common. In the first two

chapters I described how economization became highly attractive to both professionals and policymakers, and how it became considered a better and cheaper form of care. This chapter shows an emergent discrepancy between economization and the agency of many patients and families. I have also outlined the social inequalities embedded in this discrepancy: White, highly educated, and relatively secular people are more likely to identify with economization and their personal inclinations tend to match the direction medicine has taken.

Historically, these socially advantaged groups also had the power to represent patients in general. They spoke in Congress, wrote open-editorials, published memoires, and established the image of the average dying patient as a person who fights against faceless, heartless, and rational men of science who seek to prolong life her without recourse to her preferences. They successfully presented their own views and experiences as the average views and experiences—hence views and experiences, which in some way were relevant to the general population. The hospice and palliative care movement embraced and promoted these speakers as credible. Patients who supported economizing dying not only provided the movement moral legitimacy, but also a professional raison d'être: it was these patients for whom hospice and palliative care advocates worked. Invited to comment on the first article I wrote on the economization of dying, the "president and CEO" of the National Hospice and Palliative Care Organization seemed happy to agree that hospice is a "fundamentally moral endeavor." He was more ambivalent, however, about my argument on finance. "If you are providing patients and their families with the most appropriate information about the true nature of their illness," he told a Stanford Social Innovation Review author, "and if they dis-elect the most aggressive therapy, there naturally will be a cost saving."[60] This approach has been fundamental to the hospice and palliative care movement since its inception. The movement's advocates presented economized dying as a win-win-win situation: it provided better care, which patients and families wanted anyway, and which happened to be less expensive.

This chapter unpacks the second link in this tripartite triumph. While at least according to survey data, most U.S. adults support economization to some degree, it appears that the closer people are to the end of life, the more interested they become in life-prolongation. Asking a healthy person whether she would want her life prolonged if she was bedbound and dependent on machines is very different from asking a bedbound and machine-dependent person if she would want to be let die. This chapter shows that such patients, even though not the majority in the U.S. population, account for an overwhelming majority of the ethical disputes in the hospital I studied. There is clear, significant, and consistent resistance to economized dying, which its bioethics committee discusses regularly.

Hospice and palliative care practitioners tend to portray themselves as professional underdogs, and for long decades, this is what they were. Their success to promote their movement, however, means that the reality it criticized in the 1970s has

changed fundamentally. The movement is now an established medical field, in which the economization of dying is the rule. Clearly, this field competes with other fields: yet it has gained sufficient ground to create new contradictions. This chapter highlights one principle contradiction: the fact that there is an increasing population whose inclinations conflict with economization. The further U.S. medicine moves toward economization, the deeper the tension between vitalist patients and medical professionals will become, the more necessary bridging it will be. The next chapter examines this work of bridging between the professional and organizational pressure to economize and patients' inclinations.

Chapter 4: Making the Dying Subject

In December 2013, 13-year-old Jahi McMath of Oakland, California underwent a surgery to treat her sleep apnea. During recovery, she suffered massive blood loss and a cardiac arrest. The hospital's neurology team diagnosed her as brain dead, but McMath's mother refused to accept the diagnosis. In the weeks that followed, she and a group of supporters launched a legal battle to reverse the diagnosis and make the hospital "keep Jahi alive." Independent experts confirmed that McMath was brain-dead, and the court concurred. The mother, however, appealed and demanded that the hospital keep her connected to a ventilator and feed her artificially. After settlement talks, the hospital allowed McMath's mother to transfer her to another facility. The county coroner office issued McMath a death certificate and she was transferred to an undisclosed location, where as of April 2016, she is still connected to a ventilator and a feeding tube.[1]

Shortly after the court ruling, Academic Hospital organized a panel that discussed the case. Rick, a palliative care physician who participated in the panel, found similarities between McMath's mother's resistance and the resistance that he and his colleagues encountered regularly. 'This case is tragic,' he spoke slowly and empathetically. 'These are traumatic and difficult deaths. If you look at a brain dead person – these people don't look dead. Their chest goes up and down, their hands and feet are warm […]. Families tell you that there is meaningful response while none of us [clinicians] sees it.' The McMath case, Rick said, 'was the tip of the tip of the iceberg.' Academic Hospital's neurologists diagnosed brain deaths regularly, and Rick had seen cases where families refused to accept these diagnoses. In even more frequent cases, physicians thought their patients had poor prognoses and life-sustaining care merely prolonged their suffering, while families demanded to keep them alive (see chapter 3). Very few of these cases, however, reached court and none captured the national media's attention. 'Most of the conflicts are resolved very quickly, within days. These are issues that can be resolved with good communication,' Rick said. He and the rest of the palliative care team knew how to do so.

Listening to Rick, I thought he did not take enough credit. He was right that he and his colleagues were superb conflict resolvers, but he did not mention that in most cases, they economized dying without even letting conflict emerge. This chapter analyzes the different techniques palliative care teams employ and explains how they economize dying without conflict and how they mitigate conflict when it does develop. All of these palliative care techniques center on the patient as a *subject*. Palliative care practitioners negotiate the tension between the rise of patient autonomy and economized dying not by prioritizing one over the other, but by infusing the former with the latter: engaging people in reflections about themselves and their family members, which ultimately increase the probability that these people will embrace economization.

The chapter's title—"making the dying subject"—evokes two meanings of the word *subject*.[2] First, a *subject* means *a person*—a self-aware being, capable of reflection, judgment, and purposeful action. In the U.S., people typically associate subjectivity with *individuality*: what makes one a subject are the individual choices she makes and the actions she takes.[3] Aging and dying erode subjectivity: loss of capacity to reflect, articulate, and act on one's wishes mean that clinicians have difficulties taking it into account when making decisions.[4] This chapter shows how clinicians who work with dying patients *make dying subjects*—i.e. make dying patients' agency manifest despite the decline in their mental and physical capacities.

A second meaning of the word *subject* is in its conjugation as a verb: *subjecting* means placing something (or someone) under control. Following Michel Foucault and Louis Althusser, I argue that the process of *subjectification*, in which people become self-aware subjects capable of expressing themselves, combines empowerment with control.[5] In interactions with palliative care teams, people do not only articulate and voice themselves, but are also *expected* to articulate and voice themselves, and in the process of doing so, their selves become subject to professional management.[6] Palliative care clinicians discuss what patients say—and what their families say about them—as genuine representations of who patients *are*. They base medical decisions upon these representations: when palliative care clinicians *make dying subjects*, they also *subject the dying to* palliative care and by consequence, to economization.[7]

The previous chapter discussed final and fairly firm positions that patients, family members, and clinicians took in various cases: their support, ambivalence, or resistance to economization. This chapter analyzes how such positions emerged in interactions between patients and clinicians: how people came to decide and articulate what they thought and felt, how clinicians incited them to process and express these thoughts and feelings in certain ways, and how clinicians made their own minds about what was moral to do based on what they understood about patients. I follow the ambivalent, conflicted, and equivocal moments, in which people were unsure whether they should economize dying. In these moments, palliative care practice—specifically, how palliative care clinicians consolidated a sense of what patients wanted and who patients were—pushed moral ambiguity toward economization.

The chapter's first section shows that respecting patients as subjects was a central moral principle, which guided clinicians' work near the end of life. For the clinicians that I studied, economizing dying and saving patients from overly "aggressive" care was only one among several moral considerations. Acting in line with patients' personalities, preferences, and wishes was no less and in many cases far more important to these clinicians. In several occasions, they decided to prolong patients' lives against their best medical judgment, just because they thought patients wanted them to do so. This leaves the question of how clinicians concluded on what patients wanted—a particularly difficult task given that many severely ill patients were uncommunicative. The second section analyzes how palliative care clinicians made

dying subjects—namely, how they constructed a sense of who their patients were, what they thought, and how they felt in situations where these patients were communicative or uncommunicative, articulate or inarticulate, expressive or reclusive. Finally, in the third section, I show that when making dying subjects, clinicians also tended to *subject* patients *to* economized dying and bridged between the patients and economization.

1. In Their Wishes We Trust

The Moral Compass

Leslie Small had advanced liver cancer, which a Public Hospital oncologist diagnosed as terminal. Because of her old age and poor condition, she did not qualify for a liver transplant. In consultation with the medical team, she and her family agreed to sign Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders. They also agreed to have her discharged to hospice, but then changed their mind.[8] She was admitted, discharged, then readmitted to Public Hospital, "maybe a good four times since the first time I […] met her," Dr. Anna Nelson, a general internist who treated her said in an interview about a month after Ms. Small passed away,

> And each time it was from home, from the family who was taking care of her around the clock. You know, [she was admitted] for various infections, and decompensation of her liver, and in the course of these multiple returns, multiple other medical teams had conversations with [her and her family] about hospice, and [about] going home and not coming back to the hospital.

But Ms. Small and her family insisted that they did not want hospice. Whenever her condition declined, they wanted her to be admitted to the hospital, be stabilized to the extent that was possible, and then be discharged back home, until the next decline and hospitalization. They knew that the underlying cause of her illness, her cancer, could not be treated, but they also saw that the individual problems that the cancer caused—for example, multiple infections—could be isolated and solved for the short-term if she was admitted to the hospital.[9] A palliative care physician from another hospital described this way of care as 'patching patients up, then sending them back home.'

Like other doctors, Dr. Nelson thought Ms. Small would be better off in hospice. "When it's right to advocate for the person to not continue coming back [to the hospital] – I will do so," she told me. Moreover, Dr. Nelson thought that treating Ms. Small in the hospital was "not a great use of our resources." She was working in the scarcely resourced environment of U.S. public medicine, where people's access to even the most basic medical services was compromised. Providing intensive treatments that had questionable benefit did not feel right to her. Unsure whether she

was helping Ms. Small or just prolonging her suffering, Dr. Nelson leaned toward economizing dying. But she was still unsure. For one thing, she thought it would be illegal for her to refuse to provide life-prolonging treatment to Ms. Small:

> I have never signed anything that says, "It's medically futile for this person to continue coming back to the hospital." I've never done that. […] If the family member, or somebody else says [that they want to be hospitalized] then there's nothing out there for me. I don't say I don't do anything to keep that from happening. I might think that it's not a great thing, but I don't [think] there's anything legal in place that allows me to say, "no, I don't think this person should come back to the hospital."

Not all physicians were as wary of potential legal proceedings. Dr. Nelson was fairly young—in her mid 30s—and she had started working in the hospital only a few months before the case began unfolding. A young physician who makes her first steps at a new hospital is likely to be conflict avoidant. But I talked to more senior physicians, who insisted that hospitals should not shy away from litigations when it was clear that treatments were medically futile. Some of them even doubted that hospitals faced a legal risk: courts rule on compensation based on patients' lost life years and lost earnings, which are both very low for elderly and severely ill people.[10]

Yet Dr. Nelson's reluctance to discharge the patient from the hospital was not only due to her fear of litigation. She also had *moral* qualms about imposing a hospital discharge, since she wanted to respect what she understood was Ms. Small's genuine wishes:

> The patient was very lucid, and she was lucid enough to say, "I want to come back to the hospital." […] And someone who has the presence of mind to do so, I think that we're less comfortable telling you "no, you can't do that." At the end of the day - you're dying. And we like to honor people's dying wishes. […] So in the case of this woman, even though her coming back to the hospital repeatedly was not a good use of resources, and not a good use of her time or anybody else's - we still allowed that. I don't think anybody felt there was anything wrong with it. […] Really, we didn't think that coming back [to the hospital] was helping her so much. But I think we were all comforted in knowing that at least this was her own wish. And that the family […] hadn't forced it on her.

Four things validated Ms. Small's wish to be in the hospital. First, she was "very lucid" and had "the presence of mind" to insist she wanted to be hospitalized. Second, her family did not seem to force the decision upon her. Third, Dr. Nelson found the family credible, because it was very dedicated and took care of Ms. Small "around the clock." And finally, Dr. Nelson valued the family's intellect and judgment: she told me it was

"actually, a very medically sophisticated family. And they understood, she was DNR, DNI from very early on, they understood that her condition was not reversible." Strong family ties and an intellect that impressed her physician endowed Ms. Small with social power: her wishes were articulated, voiced, and understood, and Dr. Nelson and her colleagues were "comforted" in knowing that whether medically right or wrong, they were fulfilling them. Certainty regarding Ms. Small's wishes mitigated the moral uncertainty over the benefit of prolonging her life. Having a sense that, dubious as it was, the treatment they were providing corresponded to what Ms. Small wanted was reassuring.

The significance of patients' wishes for clinicians' moral comfort manifested in opposite cases as well: *uncertainty* over what patients wanted often led to moral doubt and distress. Several clinicians in another hospital shared with me their unease about a case that was unfolding for about two years, of a patient in a persistent vegetative state whose son insisted that he be dialyzed twice a week. The patient, I was told, had originally written an advance directive stating that he did not want his life sustained in a vegetative state. Yet his son, whom he listed as a Durable Power of Attorney, said that before losing consciousness, the patient told him he changed his mind.

Many clinicians thought the son was not credible. They cited his rare visits to the hospital, which they thought reflected he was not truly close to his father, and mentioned that he had a financial interest in keeping his father alive: the father received monthly pension payments from which the son benefited. A general internist who treated the patient told me:

> We brought this up at the ethics meeting […], got the lawyers involved, got the palliative care [and] ethics team involved. The totally wimpy ethics team said "[the son is] a Durable Power [of Attorney], he says that's what he wants, we haven't gotten a legal stand on it, we're gonna keep dialyzing him." So everybody's so afraid of the death panel, when all that they will have to do will be to meet with this son, say to him, "bring your lawyer, okay? This has been going on for years, so there's no chance in the world that [the patient] will ever come back [and regain consciousness]." [Fast, impatiently:] But [the son is] hoping for a miracle, that's his point.
>
> […] The patient was aspirating, [because] we fed him too much through his tube. And I put a long note in the chart, saying: "If we feed him below this level he doesn't aspirate. If he has any sensation, aspiration would be worse than hunger, therefore let's feed him less." And I thought I had a program that would starve him. But somebody turned up the tube feeding, and I guess he's tolerating it, and now his weight stabilized.

This reported surreptitious attempt to indirectly euthanize a patient reflects deep moral discomfort. The physician thought the patient was being abused and was frustrated with the hospital's reluctance to confront the son. Unlike Ms. Small's family, the son failed to prove his closeness to his father and doctors found his motivations suspicious. This lack of credibility led to disagreement regarding the patient's wishes and conflict that threatened to reach the court.

Clinicians treated patients' wishes as an important moral compass. Knowing that a patient wanted a certain treatment was orienting, and this orientation was extremely important in cases where the boundary between beneficence and maleficence was murky. At the same time, concluding what patients' wishes were was often difficult. The more doubtful and obscure these wishes were, the more strenuous and ambivalent was the decision-making process. The clearer and more trusted the wishes were, the more certain and confident the involved parties were in embracing or rejecting economized dying.

Solving a practical problem

Clinicians' interest in patients' wishes also had a practical dimension: taking patients' wishes into account increased the chances that patients and families would embrace and identify with decisions on their medical care.[11] Listening to patients was useful *organizationally*. Although it consumed time, it helped build relationships between clinicians and patients and families, which ultimately helped formulate agreed upon and more feasible care plans with little conflict. Palliative care clinicians had an important role in this effort. One palliative care physician told me:

> Most of the times I let them talk. This [interview] is probably the most talking I'll do all day. I feel like a lot of time my job is to listen. Most physicians spend a lot of time talking *to* patients - which is great, because you need to share medical information, right? […] But I feel like sometimes we talk *at* people rather than listening *to* people. So oftentimes, when I meet someone for the first time, I will just sit and listen and say very little. People can talk for 40 minutes straight, which feels like a really long time, but it makes it actually faster, because they've told the whole story, they know that you kind of understand where they're coming from, so I think that builds a lot of trust. […] It's mostly a trust issue. I spend a lot of time listening, trying to understand what's important to people.

In a conversation at a palliative care meeting, a fellow physician from the same service said that listening to patients and families increased the probability that they would forgo resuscitation and intubation and economize dying:

> 'It's important to let families talk. […] I actually got the sense that when you come in[to a meeting] with your list of things that you want to say, and you just go through them, and come out of the meeting and think to yourself, "great, I covered everything that I wanted," eventually it turns out that these patients stay Full Code.'*

"Listening" to patients and families also meant taking note of their non-verbal behavior. Palliative care clinicians observed the actions of paitents and families and treated them as cues for their wishes. On one of my days at Academic Hospital, I heard of an elderly patient who suffered from a combination of heart and kidney failure. Her son and daughter-in-law treated her very closely; a resident who had met them the day before mentioned that they were both chemists, who thought of illness in very rational and technical terms. 'They document everything,' he said to the palliative care team. The son 'was able to tell me that she [the patient] coughed nine times since the morning, and also in exactly how many of them she had bloody product.'

That afternoon, I joined the palliative care social worker to meet with the patient and her son. The meeting, I wrote in my notes, went very slowly: the patient did not talk at all, and the son's attention was mostly dedicated to nursing her. The conversation between the son and the social worker was constantly interrupted: "He [the son] feeds her, puts ice in her mouth, suctions liquids from her mouth whenever she coughs (and she's coughing several times as we speak), changes her position in bed." The social worker validated the son's style of caring, saying, 'it's okay, she's the most important person in the room.' In between this laborious bedside care, the social worker talked to the son about palliative care: she emphasized that palliative care was not necessarily hospice, and that many of the patients they consulted were not discharged to hospice. She explained about the different types of nursing homes and home-care services the patient could use after being discharged from the hospital, and at the son's request, gave her contact information for future reference.

Noting to herself how intensely the son was caring for his mother, the social worker ruled out the possibility that he would be interested in anything close to hospice care. Outside the patient's room she told me:

> 'It's crazy. I've seen many families like that, you've been here for a month and a half and you've already seen two, so imagine how many I've seen. They're just so detail-oriented, so intense in the care that they're giving her, that it's impossible to satisfy them. When you look at the patient, she's just full of fluids: in her mouth, in her body [the patient's legs were swollen – R.L.] – she's full of fluids that she just spits

* A Full Code status means that physicians would attempt resuscitation and intubation if a patient's heart stopped.

> out because she can't absorb them [hence the need to suction her frequently]. And she's still connected to the IV fluids and the blood transfusions because the son insists on giving them to her.' She laughs. 'No chance I'm going to send them to hospice. It's just not going to work.'

Neither the son nor the patient expressed an explicit wish to not go to hospice; the social work concluded about the wish from the son's behavior. Beyond her wanting to respect this wish, the social worker simply thought she would not be able to convince the son otherwise. Following this presumed wish was a practical solution: she tried to economize dying by other and more moderate means—moving the patient to a nursing home instead of keeping her hospitalized.

In some cases, listening was virtually impossible. When patients were uncommunicative, the medical staff faced difficulties in deciding what they wanted. Mr. Bennett, a homeless man in his 70s, who clinicians thought suffered from stomach cancer, was hospitalized in Public Hospital in a condition that seemed to his doctors as terminal. "Thought" and "seemed"—since none of the staff managed to have a significant conversation with him, and consequently, his diagnosis was unclear: according to the oncology service, he refused a biopsy, and the clinicians relied on patchwork of past medical records, which they collected from different sources. Although Mr. Bennett spoke clearly and heard reasonably well, he rejected every person who tried to communicate with him. His bedside nurse, a gentle young man who had been treating him for a few days when I first met him, told me 'he usually just says "no" to everything.'

The palliative care social worker began looking for people who knew Mr. Bennett in some way or another and could help her and the rest of the team to better understand his condition and wishes. Over several days of work, she organized a large meeting with hospital clinicians from several services, a social worker from a homeless shelter Mr. Bennett frequented, and a community doctor who had seen him sporadically about a year or two earlier. Also in the meeting was one of the hospital's case managers, who voiced the hospitals' financial considerations on the case.

Sitting around a Formica table in a T.V. room that for one hour served as a conference room, different doctors, nurses, social workers, and other workers talked about their repeated failure to engage Mr. Bennett in meaningful conversation. A psychiatrist who came to evaluate Mr. Bennett's capacity to make medical decisions explained at length the cognitive tests he used in his work, only to admit at the end of his presentation that Mr. Bennett refused to complete any of the tests, and he could therefore not evaluate his capacity. The psychiatrist suggested that since Mr. Bennett refused any biopsy or treatment of his cancer, 'his preference is probably to get discharged home.'

From clinicians' point of view, Mr. Bennett posed a problem: on the one hand, they could not treat him since he rejected even being talked to or touched. On the other hand, he was badly ill, utterly destitute, had no home or known family who could take care of him, and thus could not be safely discharged from the hospital. The community physician, who had seen Mr. Bennett in the past, said that his impression was that he had a very short time to live, and therefore there were three treatment options: they could keep him in the hospital; send him back to a shelter, which given his condition, he noted, was not a good idea; or find him a nursing home. The case manager immediately dismissed the first option, arguing that there was no justification to keep him hospitalized: he refused care and his futile hospitalization was a waste of resources. Yet without being able to communicate with Mr. Bennett in any way, the clinicians found it hard to decide to admit him to hospice, even if a bed at a public inpatient hospice facility, which served many uninsured patients, was vacated.

Two weeks later, Mr. Bennett was still in the hospital. Two palliative care nurses who tried to visit him agreed that 'he was clearly distressed just from our presence by his bed and was relieved when we left.' This prolonged hospitalization seemed torturing for him and was difficult for the staff. The problem of how to care for a severely ill patient who refused to convey any type of preference except for the unrealistic wish to be discharged home and be left alone seemed unsolvable. His social situation—having lived a long life in isolation and extreme poverty—made him almost uncommunicative: he hardly articulated himself, did not engage in conversation, and did not express any wish that clinicians could try to respect or follow. The medical staff began a long and slow process of conservatorship, which meant that a court-appointed person would take on the responsibility of representing him in medical decision-making.

Days later, however, the palliative care social worker reported at a team meeting that she found a distant relative of Mr. Bennett's. The team rejoiced:

> Physician: 'Did anyone see Mr. Bennett yesterday?'
>
> Chaplain: 'Yeah, he kicked me out of the room [laughs].'
>
> Social Worker: 'You know, I talked to a second cousin of his in Minnesota, [Physician: Really?] —and he described him as being very guarded, but a very nice human being and a quiet person. He told me a lot about him, that he likes walking in parks, and that he was born in this area. And the cousin is visiting California this week, for a family event, so he's going to come to the hospital.'
>
> Physician: 'Great! Ohh, wonderful! So we're going to have a meeting with him.'
>
> Social worker: 'I didn't get a sense that they were very close. They talked to each other a few times a year, and I started asking about what

> [Mr. Bennett] valued in his life, but I didn't get a sense that he had a good sense of it. But he did want to help, he sounds very nice.' [....]
>
> Physician: 'It's great, it's great. Such good news, really. I think what we're hoping from [the cousin] is not a ton. If he's visiting him – it's great. But I think that just, if we can have someone who can say… [Mr. Bennett] is in agreement with being discharged, but I think we're uncomfortable because he doesn't have an insight into his condition. The reality is that there's not a lot of options, it's just kind of [saying], this is what we're thinking. Does that sound okay to you and are you willing to sign him in and be an emergency contact for him if the doctors have any question? If he's cool with that then… Phew! We can get out of the conservatorship.'
>
> Nurse [to the social worker]: 'How did you manage to get a hold of [this cousin]? Do you have a private investigator or what?' […]
>
> Physician: 'You saved the county SO much money! You should get a little commission!'

Finding a distant cousin who could help make medical decisions for Mr. Bennett provided some moral relief. Although, as the physician noted, Mr. Bennett was clearly dying and there was not much to decide on anyway, clinicians were still somewhat 'uncomfortable because he doesn't have an insight into his condition.' A cousin who knew him, as distant as he was, could remedy this situation by giving his own consent to the transfer.

As the physician's last comment shows, this moral challenge had financial implications. Mr. Bennett was uninsured, and although the social worker applied for Medicaid coverage for him, this coverage would never meet the cost of his prolonged hospital stay. The solution that was found—relying on a second cousin's consent—was important organizationally: from the hospital's perspective, it facilitated a more efficient and less costly course of treatment. We can also see the strong moral motivation behind this solution. Mr. Bennett's ability to resist transfer was very limited—he was physically impaired and unlikely to sue. Doing detective work in order to find a relative on the other side of the country shows how important it was for the staff to find solutions that they felt were morally acceptable.

I have so far outlined the significance of what can be called *patients' own wishes* for medical practitioners working near the end of life. First, I showed that patients' own wishes provided moral validation to clinicians. Second, I showed that listening to patients and family members and considering their wishes had a practical importance: it helped consolidate care plans, which they were more likely to accept. Finally, I showed how patients and families who were expressive, reflective, and talkative—and whom clinicians deemed credible—were far easier to treat and manage. They voiced wishes, which clinicians could process and engage.

2. Subjectifying the Patient

The Subjective Ontology

Given the practical and moral significance of patients' wishes, much of clinicians' attention was directed at understanding whated patients want. Palliative care work, however, targeted a deeper and more fundamental personality layer than one's wishes. It sought to consolidate an intelligible and agreed-upon sense of what palliative care clinicians referred to as the patient's "goals and values," and what I call subjectivity.

Let me first outline the difference between three concepts: "wishes," "goals and values," and "subjectivity." Wishes are specific desires or expectations that patients or their family members voice. A patient may wish, for example, to die at home or in the hospital, to be given morphine, to be resuscitated if their heart stops, or to never be admitted to the ICU. Wishes may be realistic or unrealistic: a patient may wish to be cured from a cancer that is incurable, or to die in the hospital despite the fact that by her insurance company's standards, her condition and treatment make her ineligible for hospitalization. "Goals and values," on the other hand, pertain to one's more fundamental personality traits. As Charles Taylor observed, animals too have wishes and desires; in order "to be a person in the full sense you have to be an agent with a sense of yourself as an agent, a being which can thus make plans for your life, one who also holds values in virtue of which such different plans seem better or worse, and who is capable of choosing between them."[12]

Accordingly, palliative care clinicians did not seek to elicit specific requests or preferences from patients: they were interested in patients' selfhood or personality. A patient, for example, may value her independence, may value staying alive at all costs, or may value interacting with her family. Values cannot be deemed realistic or unrealistic: they are personal traits that are not measured against an objective reality. Clinicians may doubt that a patient's personality is well understood or represented, but cannot claim that a personality is invalid. Goals, on the other hand, can be deemed unrealistic, for example, when a patient has a life expectancy of days and has a goal of making it to his granddaughter's birth, although she is due in months. However, in palliative care vocabulary, the term "goals" usually refers to what the medical staff has already accepted as achievable wishes that represent the patient's values.

I use the term "subjectivity" to highlight an ontological assumption that underlies palliative care work: palliative care clinicians aimed their practices toward a selfhood that they assumed existed inside patients. They assumed the integrity and solidity of patients' personality, which included features that were inherent to the individual and characterized her or his existential entirety.[13] In their work, they tried to consolidate a sense of this ontology by talking to patients and families and mapping out their "goals and values." While assuming that there was a real subjectivity that existed inside the patient,[14] clinicians did not take this subjectivity as an inalterable

reality that they should passively and unquestionably accept. Interactions between clinicians, patients, and families were not a negotiation between separate actors that had pre-articulated goals and values. It was rather an interaction through which clinicians, patients, and families fleshed out patients' subjectivity and figured what patients' goals and values were. In Althusser's terms, it was an interaction that interpellated patients' subjectivity.[15] In Nicholas Rose's terms, it was an interaction that *subjectified* patients: made them subjects and at the same time *subjected* them to a patterned decision-making process.[16]

There are several practices and techniques through which palliative care clinicians subjectified: I discuss, first, how clinicians elicited patients' and families' illness experience and gained understanding of the patients' personhood; and second, how they used what I call "assistive conversational devices." Then, I focus on how clinicians intuited the "goals and values" of patients who were unconscious or uncommunicative: first, how they relied on written evidence—such as advance directives; and second, how they drew conclusions about patients' agency from patients' bodily gestures.

In search of patients' personhood

The first move in subjectifying patients was appealing to their *illness experience*. In Talcott Parsons's terms, illness is "a state of disturbance in the 'normal' functioning of the total human individual."[17] Parsons contrasted illness, which he considered to be medical sociology's main turf, to the purely physio-biological category of *disease*, which was medicine's traditional focus.[18] Palliative care clinicians deliberately appealed to patients' illness: they shifted clinical attention from the physical condition of the sick body to the subjective perceptions, feelings, and experiences of this condition. This is how one palliative care physician described his work:

> We just go to the patient, and we get to the subjective side of things immediately. So it's not, "Hey, Roi, Dr. X said this and that, and whether you know it or not – you're in heart failure and here's what you need to do." [If we do that,] you're almost like a player in your own life: we're telling you what [to do], it's devoid of your experiences, devoid of your personality, it's all based on your [physical] heart. [In palliative care] we go immediately to your experience: "Roi, tell us what it's like to live with a dysfunctional heart – it must be really hard. How do you cope with that?" [These are] questions that we use, so we get to the subjective immediately. [...] So you're not just a patient in a bed having shit done to you.

Put differently, palliative care clinicians worked to invest medical classifications—diagnoses, prognoses, and care plans—with patients' reflections on their illness experiences. They were ready to hear stories of suffering, pain, frustration, and

discomfort from illness, from the medical system, from the hospital, and also from the clinicians. In the process of inviting the patient to share their illness experience, palliative care clinicians also assessed patients' understanding of their *disease*. They evaluated whether and how much patients knew about the professional diagnosis of their condition, what information the medical staff had shared with them, and how patients understood and interpreted this information.

> Another question [that I ask when talking to patients] is "what do you understand about what's going on?" Your illness, or your disease, or whatever. You phrase open-ended questions, designed to elicit the person's understanding of what's wrong. And sometimes there are more probing questions: "Hmmm…. So, you told me what the doctor told you. What does it mean to *you*?" I'm trying to assess understanding.

Clinicians used answers to such questions in several ways. First, they treated them as signals for how careful they should be when talking to the patient: when patients mentioned that their condition was terminal, clinicians talked about death more directly and freely. Second, by asking patients to talk about their own condition, clinicians learned whether patients heard and understood the medical information given to them in earlier meetings. For example, a palliative care nurse from Public Hospital was happy to hear that a patient told me he was "terminal," since the day before he had had a long meeting with the physician, who informed him about this condition. Finally, patients' reflections on their illnesses were taken as indicating their medical literacy and even more strongly, their ability to contribute to decision-making. Recall how Dr. Nelson referred to a patient and a family as "medically sophisticated" when explaining why she trusted their decision-making capacity. Opposite cases existed too: the palliative care physician described Mr. Bennett as "lacking insight" into his condition. Even in less extreme cases, where patients and families who "lacked insight" were communicative and willing to participate in decision-making, their preferences were tempered with more of the clinicians' judgment.

Subjectification did not stop at evaluating patients' experiences and understanding. Palliative care clinicians tried to go deeper and gauge patients' very personality. They honed their conversational skills and worked on discerning opportunities to ask probing questions that would allow them to reach deeper into the patient's selfhood. They employed these skills regularly: when one patient told a Palliative Care Physician at Academic Hospital that she wanted to live, the physician asked what exactly she expected living to be like. The patient responded she would want to go back home and be independent, and the physician suggested this as the patient's definition of a life worth living, which could inform future medical decisions on prolonging her life.

When patients and families insisted they wanted to wait for a miracle and pursue more treatment in order to fully recover, the prescribed palliative care response,

which I found in all of the teams that I shadowed, was to acknowledge the hope that the patient would improve, and suggest that we should "hope for the best, prepare for the worst." (One physician was more careful in his phrasing and embraced the wording "hope for the best, prepare for everything.") This response typically directed the conversation toward the doctors' prognosis that the patient would indeed decline and die, and patients were then more likely to talk about more pessimistic scenarios.

Palliative care clinicians spoke of this effort to understand the patient's perspective as deriving from decades of humanist critiques of medicine, which rebuked modern medicine's objectification of patients and the reduction of patients' wholeness to body parts that clinicians manage technically.[19] They saw themselves as promoting a radical and non-conforming stance: against the tide of modernization and medicalization, they listened to patients and took account of patients' personalities when making medical decisions. As one physician said in an interview:

> Most people in the hospital feel alienated, feel homogenized, minimized. And I see how it happens: it ends up being cruel, but it's not intended cruelty. [In palliative care] we're here to kind of come, circle back and put it back into the formula of you as an individual, your subjective experience. I would never tell a patient what their experience is; I would always ask them. And then, in a sense, we meet people where they are.

Yet applying humanistic ideals of patient empowerment near the end of life was not an obvious task. The patients that the palliative care services followed were often debilitated from their disease, sedated from various pain medicines, and disoriented from long days of being bedbound in an unfamiliar environment. Severe illness is exhausting, and as genuine as clinicians' wish to understand who the patient was, the circumstances in which they acted were often unfavorable for deep existential reflections into one's inner life. The attempt to understand the patient as a person went beyond the person that clinicians saw in the hospital bed. It aimed at understanding the person that the patient was—or had been—ontologically, independent of the medical circumstances. Clinicians asked questions about the patient's past, and about how she was like when she was healthy and outside of the hospital.[20] A palliative care nurse said:

> I start [the conversation] with either, "the doctor asked me to see you, and before we get to the medical part, maybe you can tell me something about yourself, and who you are, and who you are when you're not a patient, and who your loved one is, not the sick person in bed, but [the person] you see and know."

Notice how the nurse moves quickly between the questions she asks patients and the questions she asks family members: "who you are when you're not a patient and who your loved one is, not the sick person in bed." Both conversations—with family

members and with the patient—help her sense the patient as a person. As people who have known the patient, family members are presumed to be in the best position to represent the patient's personhood. When an individual is too debilitated, disoriented or demented to perform and exhibit a coherent self, the family is expected to do it for her.

As numerous scholars and practitioners observed, participating in this process of subjectification is emotionally draining for family members.[21] I documented several cases in all hospitals where the families of patients in persistent vegetative states spent weeks hesitating about whether to disconnect them from life support. In three specific cases, the neurology teams involved were confident in saying that meaningful recovery was very unlikely—which still left the families hesitating. While in all three cases there were close family members who embraced the decision-maker role and did not want the medical staff to force them to withdraw life support, the burden of this role was nerve-wracking for them.

The palliative care clinicians involved in the cases recognized this and attempted to take some of the burden off the families. In two of the cases, they told the families that the surrogate decision-maker role was not to make decisions for the patient, but rather to provide the staff with information about what the patient would have wanted had they been able to speak. They suggested a division of labor between family and clinicians: the family would provide information about the patient's goals and values, and the clinicians would make the appropriate medical decision, given this information. "Did she ever say anything about what she would want if she were in this condition?" was a typical question that palliative care clinicians asked in such situations, which was at times followed by stories about the position the patient took when the family was grappling with another dying family member.

And still, for the family members involved in those cases, who knew that their answer could mean that the patient would be let die, this proposed division of labor did not make much difference. In all three cases, which occurred in three different hospitals and were managed by different medical teams, family members expressed the wish that the patient would wake up and instruct them what to do. This reveals the key paradox of subjectification: clinicians' efforts to empower patients and recognize them as subjects embodied an *expectation* that patients would be and act like subjects, express intelligible values and goals, and exhibit sufficiently clear personality traits, which would manifest through conversation. When patients were unconscious or uncommunicative, the expectation was that family members—or friends, when a person had no known family—would report on such consolidate qualities. Subjectification was an opportunity as well as an expectation, an invitation as well as a demand.

Cases where patients did not meet this expectation were extremely challenging for palliative care teams. Edwin Gentry, a man in his late 30s, who had been an alcoholic for much of his adulthood, was hospitalized in Academic Hospital with metastatic cancer. As his condition declined, he aspirated on his food and needed intubation, which was followed by several days in the ICU. When his condition stabilized, the medical team decided to feed him through a tube to avoid aspiration. Mr. Gentry, however, said he wanted to eat. The palliative care team had several long and intense meetings with him and his family. Having seen him survive several hospitalizations in which the doctors conveyed pessimistic prognoses, the family was suspicious of the doctors' insistence that his life expectancy was very short, and insisted that he remain Full Code. As one palliative care physician reflected at a team meeting, 'It's always so hard, there's a prototype, […] those guys are so seasoned. In some ways it's way harder for families and patients who have been through these episodes to accept that this time it's different.' The Gentry family wanted to continue prolonging Edwin's life: 'they definitely believe that any amount of time being alive is better than death,' a social worker said.

Mr. Gentry himself was hard to decipher. Several clinicians from the palliative care team had conversations with him and tried to understand his feelings about his condition, yet they could not consolidate a clear idea of what his "goals and values" were. An intern reported at a palliative care team meeting:

> I asked him what was important for him, and he said that he wanted to eat. I asked him, 'why do you think the doctors here don't let you eat,' and he said, 'because they don't understand how it feels to be a patient here.' So I said, 'Okay, you're probably right. But why do you think that they don't let you eat and do let others?' He says they think he would aspirate, and I asked him if he knows why they think so. He said, 'because I aspirated earlier, but it won't happen again.' And when I asked him what makes him think it won't happen again, he just said, 'It won't happen this time.' It's just like talking to a child. He doesn't have any decision-making capacity.

Edwin hung onto the *wish* to eat, but refused to reflect about its expected consequences—that he would aspirate and have to be taken to the ICU. He was not receptive to subjectification. Given how extreme the situation was, the palliative care team was open to the idea that he would eat, but wanted to ensure that he was aware of the consequences—life threatening aspiration—and hoped he would agree that if he aspirated, he would not be resuscitated and transferred to the ICU. A senior attending physician from the palliative care team told me that Mr. Gentry sometimes expressed a wish to die, but this wish did not seem credible enough to her. She thought that similarly to his wish to eat, it was impulsive and could not represent deeper and more stable goals and values that characterized him as a person.[22]

While devastation in the face of severe illness is very common,[23] how people converse with palliative care clinicians about feelings is sociologically variable. The bulk of palliative care work involves talking, communicating, and reflecting existentially on what one finds important in one's life, specifically near the end of life. These practices are sensitive to sociological factors: for one thing, patients who do not feel comfortable and confident interacting with doctors will find it harder to express themselves in palliative care meetings than those who feel at ease. Furthermore, quasi-psychotherapeutic existential reflections, while very common in certain classes, are not something that all people spontaneously embrace. A palliative care physician told me:

> We have a lot of people in this hospital who have not planned in advance for anything. Ever. And that's why they're in the situations that they're in. And they may have used substances, or things that are not healthy that they don't have access to now in the hospital to cope with them. I mean, someone who has been drunk, kind of perpetually, for years and years and years, who now is in the hospital, totally sober, and is facing down this decision... [Physicians] want to come in and say, "what do you want your final days to look like?" And [the patient is] just a total deer in the headlights. […] I think that we have some mechanisms to try to get at what's important to people.

One "mechanism" that I saw being used in several occasions was a card "game" called "Go-Wish," which *Coda Alliance*, a Silicon Valley nonprofit, run by people from "local hospices, hospitals, faith communities, universities, and elder care organizations," produced and distributed.[24] "Go-Wish" includes dozens of cards with printed statements that qualify as expressing "goals and values," and palliative care clinicians ask patients to sort these cards into three piles: "very important," "sort of important," and "not so important or unimportant to me." Afterwards, the patient may be instructed to choose the ten most important statements from the "very important" pile and rank them. Among other statements, the cards include: "to maintain my dignity," "to be kept clean", "to say goodbye to people in my life," "not dying alone," "to be mentally aware," "to have my family with me," "to be at home," and "not being connected to machines." These statements are based on a survey of patients, family members, and clinicians, which was reported in the Journal of the American Medical Association in 2000.[25] The game's outcomes—three piles that sort the various statements and a ranking of the most important statements—are treated as indications of the patient's goals and values. For example, this is how a nurse reported to a palliative care team on a Go-Wish conversation she had had with a patient:

> 'Being free of pain was clearly the number-one important thing for him, and he said he was okay with that even if it'd make him drowsy. He would be okay with being kept on machines, as long as he can speak with his mom. If he's in a situation in which he cannot speak with his

> mom, he wouldn't want to be kept on machines. He's been really reflective and pensive about his history with HIV; so the HIV unit would be a good place for him.'

In an interview, a palliative care physician told me:

> Things like this [the Go-Wish game] can spark ideas. You know, not everyone is really able to fully engage and do this, but we do this on a fairly regular basis. We sit down with people and try to go through these, and get a better sense...[26] A lot of times, it's not even just the sorting, it's the conversation that happens while they're reading it. You know, you just learn a lot more. And the nice thing is that they're at a fairly accessible level for different people. […] I actually have a printout of this. I put it on a piece of paper that you could leave with a patient, and then the patient can circle it to say what's important to them. Because sometimes this is a little bit overwhelming. […]
>
> There's a cancer support group here, at the hospital. So I did this game with them on a piece of paper, and they said, "well, this is actually a really great way for you to go to your family and say, 'hey, this is what we talked about in our group tonight.'" And that has been demonstrated in studies, that when people act as surrogate decision makers, the best way for there to be concordance between what the patient wants and what the surrogate thinks the patient wants is that they actually have the conversation about it.

The purpose of the Go-Wish activity is to start a conversation, spark a reflection, and when a family is involved, increase the chances that the patient would communicate this reflection to the family members who would later serve as surrogate decision makers. It incites patients to order intelligible statements on end-of-life care. When people do that, they at the same time articulate themselves as subject and subject themselves to clinical management: clinicians treat how they classified statements as reflective of their subjectivity. But while such an activity may be popular in support groups—among people who actively seek to process and verbalize their thoughts, feelings, and experiences—other patients found it less exciting. Go-Wish was far from solving any and every resistance to subjectification. In one case at Academic Hospital, I shadowed palliative care clinicians who visited an ICU patient, whose condition was improving and whom the medical staff hoped to discharge to a nursing home in a few days' time. A medical student who rounded with the palliative care team had had a "Go-Wish" conversation with him, in anticipation of a future decline in his condition.

> The med[ical] student asks him if he remembers that they played that card game together, about wishes, and says that she printed out his wishes. She shows him a few printed pages, and asks him if he would like her to put it here, maybe in his bag. He says that anything here

> would disappear, so maybe not. She suggests putting it in his bag, then says that she could always print out more copies, if he wants.

The medical student was, in fact, much more eager than the patient to have his "goals and values" printed, documented, and kept. She had them saved on her computer and could print out copies for him. Even as the most inexperienced member of the palliative care team, she internalized the importance that the team attributed to having a documented statement on the treatments that a patient would and would not want to have when his condition declined. It was not the patient who insisted on verbalizing and documenting his subjectivity; it was the medical student who initiated the Go-Wish conversation and tried to ensure that its outcomes would be documented and followed.

This dynamic was very common in cases of patients whose lucidity was compromised:

> Denise [Social Worker] and I go to do the Go-Wish together. Victoria [chaplain] prints it out in her office for us. As it turns out, Dr. Evans asked Denise to do it with the patient a few days ago, and she did—but then the patient lost it. […] As we walk, I tell Denise that I'm surprised she managed to do the Go-Wish with him. I saw the patient a few days earlier and he wasn't extremely communicative. She agrees and says, 'yes, I also think that he forgets a lot. It's possible that the Go-Wish form that we filled out together is in the trash. He doesn't really remember what he did with it.'
>
> We go to his room. [The patient] doesn't seem alert, hardly engages in conversation, and eventually Denise decides not to repeat the Go-Wish activity with him.

The Go-Wish activity was an example of a structured way to produce written records of patients' "goals and values." It induced patients to make explicit statements, which clinicians took as representing them as subjects and could inform decisions on their case. Clinicians were the ones who initiated Go-Wish: some patients did enjoy and identify with it, and yet Go-Wish was also used in cases of patients who did not actively seek self-expression. It was a method clinicians used to make the patient speak and by that make the dying subject: create written representations of patients' subjectivity.

Forms that (may) speak

When trying to gauge the subjectivity of unconscious patients, one of the first things palliative care clinicians did was inquiring if they had advance directives: questionnaires, which come in various formats, levels of detail, and lengths, and ask people about the treatment they would want to receive if they reached varying

degrees of physical and mental disability. The objective of advance directives is having people make medical decisions before their condition declines and they become uncommunicative. After a directive is filled out, the patient and two witnesses sign it, then the patient keeps it.[27] A 2000-2006 survey indicated that advance directives have become an extremely common toll in end-of-life care: 67.6 percent of the deceased patients, who required decision-making and lacked capacity to participate, had an advance directive.

The clinicians that I studied used advance directives as indicators of the "goals and values" of patients who became unconscious or were demented. They overall treated advance directives as anticipatory instructions, which the patient left when she or he was still communicative. Directives were supposed to speak for patients that disease had muted. In reality, however, there were many intervening factors and circumstances, which could weaken advance directives' credibility. First, in several cases, when patients' condition declined and they lost ability to express themselves, the advance directive form could not be found and used.

Second, even the advance directives that were found were often disputed. Family members questioned the circumstances in which the patient filled them out, suspected that patients did not fully understand the form and its meaning, and insinuated that the physicians who helped patients fill out the form misdirected and biased them. Ms. Chang, an elderly Chinese-American woman who was hit by a car on her way to the grocery store, was hospitalized unconscious and connected to the respirator in one of Public Hospital's ICUs. As one attending physician described it, nearly every bone in her body was broken. Her Primary Care Provider (PCP)* sent the hospital an advance directive she said she had filled out with Ms. Chang three years earlier. The form indicated Ms. Chang would not want to have her life sustained for longer than five days if she reached a similar condition, and clinicians involved in the case thought it clarified Ms. Chang's goals of care and were ready to extubate her.† Her daughters, however, who did not know about the advance directive, doubted its validity. They said Ms. Chang only spoke Mandarin, and it was impossible she could read the form, fill it out, and fully understand the consequences it would have for her care. Three years after the form was filled and signed, the PCP had no recollection of the exact situation in which she signed the form, and a significant shadow was cast on its validity.[28]

Third, people challenged advance directives over their temporality. Advance directives are filled out prior to patients' decline, at times years before being used.

* A Primary Care Provider is the physician who sees the patient on a regular basis outside the hospital. Many patients at Public Hospital did not have such a physician, since they had no insurance. Trauma patients, such as Ms. Chang, were common exceptions: Public Hospital had the only trauma room in the county, and it was therefore one channel through which insured patients sometimes got into the hospital.

† During extubation, clinicians remove the patient from the respirator.

But people evolve, and so do their views on end-of-life care. In many case, family members intuitively sensed changes in people's inclinations, in ways that were not represented in the short written texts and checked boxes.[29] The "disability paradox"—i.e. the fact that people with serious disabilities report experiencing high quality of life—further complicated the picture.[30] It was always possible that a person who did not want to be hospitalized when she was healthy would change her mind when her condition declined and hospitalization was needed.

Clinicians who unquestionably treated advance directives as genuine representations of patients' goals and values assumed that these goals and values were stable and consistent, and bracketed off the inherent changeability and unpredictability of human agency. The bureaucratic imperative to create consistent documentations of things as capricious and dynamic as human feelings, fears, and values created frequent gaps between people and the forms that were used to represent them.

Finally, it is practically impossible to follow advance directives verbatim. These forms outline hypothetical scenarios, and there are necessary differences between these scenarios and the actual condition of the patient.[31] A patient, for example, could check a box next to the statement:

> I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits.[32]

Even families who trusted such forms still had much to decide on: was the time left indeed "relatively short"? Has "a reasonable degree of medical certainty" that the patient would not regain consciousness been reached? And at what point could they confidently say that the "risks and burdens of treatment" outweighed the expected benefits? No checked box or written text can cover all possible disease trajectories and treatment possibilities. How advance directive forms played out in actual decision-making was circumstantial: it depended on how people interpreted these forms, how they bridged gaps that the forms' text left, and in what emotional state the surrogate decision-makers read them.

An advance directive "success story," which a palliative care social worker shared with me, illustrated this point. The patient, the social worker said, was an elderly woman with a very large family, who sustained a major stroke.[33] The palliative care team was consulted when the patient was in the ICU, and following a conversation with the several of the patients' children they decided to transfer her to comfort care. At that point, many other people from the family, who did not participate in the original conversation, "rushed down here" and said, as the social worker recounted, "she's a fighter, maybe we should start tube feeds, maybe we should start antibiotics

again." The social worker asked if she had an advance directive, and "they said, 'well, she is a really organized person, why don't we go and look.'"

At home, the family found a letter, where remarkably, the patient guessed that her relatives would characterize her as a "fighter" and would hesitate before transitioning her to comfort care. "It was two pages; it was the most beautiful document I've ever read," the social worker told me. In those two pages, the woman clarified that she would be fine living in a wheelchair, but she would want to be able to transfer to the wheelchair on her own, and be able to enjoy food, and have conversations with people. "But if it's not going to be like that," the social worker recalled her writing, "DO NOT give me tube feeds, DO NOT extend my life, DO NOT let me stay in the ICU more than five days. And it was all documented with each condition." "And so the family read this," the social worker said, "and they let her go. […] At the end of this b-e-a-u-t-i-f-u-l two-page document, she told them what she hoped for them. […] It was beautiful. That's what I'm talking about. That's thinking through your values ahead of time."

The social worker spelled out the intended moral of this story at its end: people should think through and document what they value. Between the lines, the story shows that the power of documents lies in the circumstances where families and clinicians open and read them: the exemplary success story that the social worker used to present the importance of advance directives to an interviewer—and which she told me she used as a teaching tool to her students—refers to a two-page letter that had little formal legal credence. The letter bore the patient's signature but there were no witnesses that guaranteed it was genuine. A Durable Power of Attorney could ignore it. The letter's power lied in its personal and non-standard character, which gave it maximum strength in the circumstances that developed: a family confronts an extremely difficult decision, they find a hidden letter, the letter successfully predicts how they would feel and react, and it ends with a touching note about what the woman wishes for her descendants. It may have been possible to challenge this letter on formal-legal grounds; it was impossible to challenge it in the social situation that developed.

More than everything, the letter, in its striking informality, left a clear impression of the patient's personality, values, and goals on the family and the clinical staff. Subjectification—in this case, the clinical effort to consolidate a sense of a mute patient's subjectivity—corresponded so smoothly to the patient's previous actions that it felt genuine. The success of subjectification, epitomized in the uncontested recognition of the patients' own values, led to a morally satisfying closure. The patient was transitioned to comfort care, extubated, and passed away shortly after.

It is unclear to what extent clinicians follow advance directives. In the 1990s, there was overwhelming evidence that advance directives and living wills had limited impact on how clinicians treated.[34] More recent surveys show that advance directives do have significant influence.[35] And still, given the inherent unpredictability of

courses of illness and the instability of people's "goals and values," deciding whether an advance directive form was followed or not is always open to interpretation. Recognizing these inherent uncertainties, Sudore and Fried have called to revise the traditional objective of advance directives—having "patients make treatment decisions in advance of serious illness." Instead, they suggest using advance directives to prepare patients and families for making decisions in real time, by starting a conversation on end-of-life care early.[36] Similarly, advocates of advance directive forms emphasize that filling out a form should only be the beginning of a conversation between the form's "owner" and the surrogate decision maker on how end-of-life decisions should be made.

These recommendations recognize that, in and of themselves, advance directive forms have limited influence. They become influential only when people recognize them as valid representations of the patient, or alternatively, when people use them similarly to Go-Wish cards, as an assistive tool in sparking a reflection on one's views on end-of-life care. When used in this way, forms provide scenarios that *train* people in thinking and reflecting, in preparation for the decision-making that awaits them in the future. They train people in achieving self-knowledge, in behaving as subjects, and in reflecting on the subjectivity of people whom they know.[37]

Advance directives are therefore important parts of the effort to subjectify patients: they epitomize an expectation that people would reflect and communicate about their views on end-of-life care, so that they can later present coherent and consistent goals and values to their clinicians. The expectation is that people will plan in advance, will be able to reflect on decisions, and will have opinions, preferences, and values. Ideally, they should prepare detailed orders, which explain exactly what type of care they would and would not want: they should talk to their family members and family doctor, explain their goals and values clearly and remain consistent about them. The fact that I didn't have an advance directive reflected very badly on me in the field, and when I casually mentioned it at one point, the response I received was a deafening silence: it made me appear irresponsible and uninformed. Like any person, I was one car accident away from coma, and without an advance direct I could find myself treated against my will.

The respect of patients' self-sovereignty is therefore not simply a respect for subjects, but respect for subjects with clearly ordered preferences and values. People's ability to rank their preferences and values in order and explain what they do and do not want is what defines them as subjects.

Bodies that (may) speak

Another way in which clinicians subjectified unconscious patients was relying on their bodily gestures. In many cases I observed, clinicians attributed agency to things patients did while they were unconscious. Most commonly, clinicians used

unconscious patients' facial expressions to conclude whether the patients were in pain or not. Deep wrinkles on an unconscious patient's forehead were signs that the patient was in pain; a patient who looked "peaceful" was presumed to be free of pain. Clinicians interpreted certain bodily postures, specifically the fetal position, as signals that the patient was in pain. When clinicians already felt ambivalent about a course of a treatment, identifying the patient as being in pain added to their doubt.

Another common interpretation of unconscious bodily gestures was in cases where patients pulled out IV lines or self-extubated. A former palliative care physician told me:

> Very seldom I've butted heads with families and patients, who demanded certain things that I thought were really not right. In particular, one was a young patient who had made it very, very, very clear—there's no question, he had verbalized it, he had indicated it, his actions had completely been consistent—that he did not want to be intubated. […] [After he became unconscious,] the family decided that they wanted him intubated, transferred to the ICU and all this, and I said no. This is not what he wants. […] This goes completely against his wishes. And in fact, when we compromised and decided to do something called CPAP,* he just ripped the mask off, because it was so uncomfortable. So I went to them and I said, do you get it now? Do you see that this is not what he wanted? And it was such a hard… Normally, it would be so easy to just give in and do it, but I knew so well that this guy… There was just no part of me that could accept that, because I knew SO well what he had wanted. […] This was kind of an idealistic decision that he would never be uncomfortable or whatever. He was in deep trouble, and he felt like crap, and he was barely gasping […], so he knew that he was progressing and dying. So for me, the decision that he had made was absolutely his decision. But his family was completely trying to reverse his decision, because they were having a tough time with him dying. […] [I think it was a cousin who said] "Oh, but I think that he's making a decision that he doesn't quite understand," and I said "he fully [understands]."

A palliative care social worker described a similar case, where she interpreted an unconscious self-extubation as validating a patient's previous statements on not wanting life-prolonging treatment:

> We got right now, in the ICU, an African American guy. A lot of drugs, alcohol, non-compliance. Family never came up to multiple

* CPAP (Continuous Positive Airway Pressure) is a mask that maintains the airway open with mild air pressure.

> hospitalizations. This guy defied, but v-e-r-y- c-l-e-a-r-l-y [in an] advance directive and [said] to his doctors who know him very well, please don't ever intubate me. Please don't ever give me a trach.* Please don't ever give me tube feeds. It's clearly documented, [there were] conversations. He's now in the ICU, can't make his own decisions, a son who hasn't been involved—a very dysfunctional family—has now showed up and said, I want everything done. [So now] he's intubated, he's on tube feeds. He's pulled the tube feeds out twice. They [the ICU staff] put them back in. He extubated himself – he pulled out his ventilator. He actually pulled it out. […] Unbelievable. But it tells you, you see, that in there, he still doesn't want this but he can't talk anymore.

Patients who pulled out IV lines, feeding tubes, or respirators were very difficult to watch. For one thing, their actions caused noticeable injuries, which involved bleeding and, one could imagine, much suffering to those unconscious patients who still felt pain. Moreover, it created a caregiving problem: patients who self-extubated still needed a respirator to survive; after the staff re-intubated them, there still remained a chance that the patient would self-extubate again. The only way to eliminate this risk was either to have a person sitting next to the patient at all times (a "sitter"), or to restrain the patient to the bed. Due to staffing constraints, the second solution was much more common in the three hospitals that I studied. Few situations created more moral qualms than having a severely ill patient restrained, while two nurses worked to re-insert IV lines he pulled out. In all of the cases that I documented, when such a situation persisted, unless the family agreed to not reinsert the IV lines or re-intubate the patient, a bioethics consultation was eventually called and the hospital staff confronted the family very directly.

The source of the moral distress in these cases is worth exploring. Would clinicians have been so distraught about reinserting IVs and re-intubating a patient had they not felt the patient was trying to communicate otherwise by pulling the IVs and the ventilator out? In one remarkable case, a patient who sustained a stroke and was hospitalized for several months in Public Hospital pulled out her trach twice. The internist who treated her said that the patient, who still had some limited capacity to communicate, responded affirmatively when her daughter asked her if she wanted to be Full Code and have the trach. There was a discrepancy between what the patient *said* and what the patient *did* unconsciously. Trachs and ventilators are after all physically uncomfortable, and even people who want their life prolonged can try to remove them when in delirium. In this case, the palliative care team was ready to call

* A trach is an airway opening in the neck (into the trachea), which physicians create in a surgical procedure—tracheostomy. In palliative care consults, the question of whether to perform or not to perform a tracheostomy often comes up when there is a possibility that a patient would be kept on a ventilator for a long period.

a bioethics consultation, but the physicians on the floor "felt comfortable" that the patient wanted the ventilator and called off the consultation.

In the more common cases, when patients who pulled out IV lines or self-extubated could not convey a sufficiently clear verbal message that they were actually interested in the treatments given to them, clinicians took their actions as statements against life prolongation—or at least as indications that they could not "appreciate" the treatment they received. Restraining them to bed felt like forcing something on them, as opposed to ensuring that they did not inadvertently interrupt a course of treatment that they wanted.

In sum, I outlined five subjectification practices, which palliative care clinicians used in their work. First, when a patient was communicative, palliative care clinicians worked to make them express sufficiently coherent goals and values, by talking with them about themselves, their lives, their understanding of the case, and their hopes. Second, palliative care clinicians used assistive conversational devices, such as Go-Wish cards and forms that summarized them, to spark conversations on these topics. Third, clinicians turned to families, as the people who have known the patient the best, and asked them to reflect and share who the patient was and what her "goals and values" were. Fourth, clinicians used forms such as advance directives as expressing the values of unconscious patients, and as voicing subjectivities that were mute. And finally, clinicians read preferences and inclinations in patients' bodies, and treated them as demonstrating the patient's wishes.

Subjectifying patients was a process of empowerment, in which patients' subjectivities—or selfhoods—were consolidated. By empowerment I do not mean that characteristics that had already existed in patients were given the faculty to surface and influence decision-making. Rather, I argue that power was applied on patients, families, and clinicians, and facilitated certain expressions and recognitions of patients' personalities. A successfully subjectified patient was one whose subjectivity was not in doubt. Family members, the patient, and the clinicians agreed on who the patient was, what they wanted, and what they would want. Ideally, they were also aware and accepting of each other's perspectives.

Achieving this agreement did not end medical decision-making, however. Once the patient's goals and values were established, clinicians connected them to concrete decisions on medical care.

3. Translating and Hooking

Clinicians made this connection through two practices, which I call "translation" and "hooking." Translation means restating a patient or a family member's statement and transforming it into a concrete medical goal.[38] "Hooking" means attaching the end-of-

life decision at stake to this goal. This section presents two cases to illustrate how palliative care clinicians employed these practices.

"My father loves life"

Mr. Becker was an 81-year-old white man, who lived about a two-hour drive from Academic Hospital. In the months that preceded his meeting with the palliative care team, he was hospitalized three times for recurrent pneumonia, and threatened to become a "revolving door" patient, who rotates in and out of the hospital, and whose hospitalizations gradually become longer and more intensive.[39] I met Mr. Becker during a particularly traumatic hospitalization: he got sick and became very short of breath, literally gasping for air, until his daughter Lynn decided to drive him to the hospital. Lynn later said she was not sure if they would make it to the hospital.

But they did. The ER physicians intubated Mr. Becker, put him on IV antibiotics, and transferred him to the ICU. Several days later, his pneumonia improved, the ICU physicians extubated him successfully; given his recurrent hospitalizations, they decided to call a palliative care consultation. I accompanied three members of the palliative care team—a palliative care fellow physician, a social worker, and a medical student who rotated with the team for two weeks as part of his training. The four of us walked into Mr. Becker's ICU alcove, where we found him sleeping in bed in front of a T.V. showing highlights from a recent LA Dodgers' game. Dr. Ashley, the palliative care fellow, touched his right arm and he immediately opened his eyes and smiled at her. We introduced ourselves, and when Dr. Ashley asked Mr. Becker how he was doing, he looked her in the eyes and said flirtatiously that he was always okay when he saw her.

A short conversation ensued, in which Dr. Ashley asked him if he was in pain (he said he wasn't) and 'what are you hoping for?' (he said he was hoping to get better). Mr. Becker said he had a bakery that he wanted to get back to, and then mumbled something I did not fully understand. After several minutes of small talk, Dr. Ashley said she enjoyed talking to him and would let him rest; she added she was going to meet with his daughter Lynn, and asked if it would be okay with that. "Of course," Mr. Becker answered. We shook hands and left for the conference room, where the ICU attending physician joined us. Lynn came in a few minutes later, apologizing for making us wait. Nick, the medical student who ran the meeting as part of his training said it was not a problem: 'we spend our days in our windowless office, so sitting in a sunlit conference room is always nice.' We introduced ourselves, one after the other, and then Nick began:

> Nick [medical student]: 'We just met your father, but wanted to start by learning more about him. So, could you tell us more about what he's like as a person when he's not here?'

> Lynn: 'My father loves life. He's always loved life, even though he has had a very difficult life. He was born in the same house where he's living today, and his brother was very sick when he was young and eventually died. He still talks about his death, says that it's such a shame he died when he was so young, such a loss. They had a family business, a bakery, which still exists. And it's been very difficult to keep it. We've been trying to convince him to sell it for a long time, but he has always insisted that as long as he is alive, the bakery will keep going.' […]
>
> Nick: 'And how has he been recently, in terms of health?'
>
> Lynn: 'Well, he's been getting short of breath when we were coming down to see the bakery, and you know, sometimes he gets upset about how things look like there, and then he gets more short of breath, so I've been trying not to do those trips too often.'
>
> Social worker: 'Tell me something, how is he when he's at home? How much time does he usually spend in bed or in his chair?'
>
> Lynn: 'I'd say that quite a lot, I think he spends most of his day in the chair, reading the paper.'
>
> [Conversation about how the daughter treats him at home and the mattress they bought in order to avoid bedsores.]

The meeting began with a general narrative about the patient's character and life story, which the medical student elicited from the daughter. Very talkative and friendly, the daughter responded in length and appeared to appreciate Nick's interest. The social worker, who was the most senior palliative care team member in the room, asked a more pointed question about the patient's medical condition and life at home. After some 15 minutes of conversation, the social worker turned the focus of the conversation to the daughter's feelings:

> Social worker: 'What would you like to ask him [the patient] right now?'
>
> Lynn [moved by the question, seems to be close to tears]: 'Mainly, I would really want to see him back in his house. This house has really been important for him, he's always been so connected to it, and all of his memories are from there.'
>
> [Lynn tells about financial problems they've been having with the bakery.]
>
> Social worker: 'And what worries you the most?'
>
> Lynn: 'Look, I know that at some point he can decline, and I'm just really worried about the moment we wouldn't be able to take him home and he wouldn't be able to live there. [People nod.] You know, it's

> not the first time that this happens: he had pneumonia in the past and was hospitalized, and he came back. And he spent some time in nursing homes after each hospitalization, and he really didn't like it.' [Talks about the experience of going to the hospital with her father this time]

Lynn's engagement in the conversation and emotional connection to her father were evident by her tears. She shared her worries about him and expressed their illness experiences articulately and with considerable detail. Mr. Becker's subjectivity were now on the table: Lynn did not list any concrete wish of his, yet spoke very clearly about his character and their fears from the future. At this point, the social worker started preparing the ground for hooking. At first, she summarized what Lynn told her, showing that she heard and understood what she said. Importantly, this summary was not a simple reiteration of what the Lynn said: the social worker *translated* Lynn's story into concrete and concise goals.

> Social worker: 'You know, *what I hear from you* [my emphasis – R.L.] is that he's not really a person who wants to be in a facility. He's not going to live well there - he's happy at home and this is where he'll be the happiest - sitting in his chair and reading his paper…' [People smile, Lynn nods and chuckles]

Once Lynn approved of the translation by nodding and chuckling, the ground was ready for hooking. The social worker mentioned the possibility of admitting Mr. Bennett to hospice and tried to connect it to the goals she just stated:

> Social worker: 'And if this is our goal—to bring him back home—it's important to remember that there is this thing called "hospice." I'm not even saying that this is a place where you are in right now, at this moment. But it's good to remember that this is a possibility for the future. We just want to put this idea out there, on the table.'
>
> Lynn: [Her tone of voice seems to change slightly] 'I don't know, my understanding has always been that hospice basically means not to treat him anymore, and in case he gets pneumonia and needs antibiotics, this will not be a great solution.'
>
> Social worker: 'So first of all, if you're on hospice and for any reason you're unhappy - you can always sign off and it's not a problem at all. And second, although in principle hospices are not going to give him IV antibiotics, you can also get him antibiotics in pills. He doesn't have trouble swallowing pills.'
>
> Lynn: 'So this is something that I didn't know.'
>
> Social worker: 'Again, it's not that I'm saying that you're there yet. But if you want to keep him at home, this is a type of support that will help you do that.' [Lynn nods.]

Like many other people, Mr. Becker's daughter recoiled at the mention of hospice. Indeed, Mr. Becker was not discharged to hospice at the end of this hospitalization. At the same time, the palliative care social worker successfully presented hospice services as something that matched Mr. Becker's goals of care, and in that way, increased the probably that his daughter would admit him to hospice at some point in the future. Throughout the exchange, the social worker maintained the focus of the conversation or Mr. Becker's goals of care as his daughter understood them. She did not tell the daughter that her father's medical condition means he should be admitted to hospice. Rather, she and the medical student elicited Mr. Becker's subjectivity from his daughter's stories and hooked hospice care to it. Consequently, if and when Mr. Becker would be admitted to hospice, it would not be because the social worker told him to do so, but because it matches *his* (or his daughter's) own will. Mr. Becker was successfully subjectified; his daughter, the main decision maker in the case, recognized and endorsed certain personality traits that represented him as matching hospice care in an economized way.

The related practice of *unhooking,* namely detaching a patient's subjectivity from a certain course of treatment, was done in a similar way: clinicians used certain details or themes in narratives on patients' subjectivity in order to highlight how certain treatments contradicted their goals of care. One patient's daughter, for example, told a palliative care team about her father's terrible experience at the nursing home where he lives. She explained that her father had been suffering from a lot of pain and that the nurses, who were badly understaffed, never managed to treat this pain properly. A palliative care physician responded:

> 'It sounds like *your* [my emphasis - R.L.] biggest concern right now is that your father has been through too much, and you want to make his life as peaceful and as comfortable as possible. So it's actually not a question of should he have surgery [or not], it's a question of does a surgery accomplish what his goals are.'

The possessive form "your" was of prime importance. The physician did not refer to his own medical opinion, but to the daughter's and the patient's subjectivity: it was the daughter who was concerned about her father's pain, and it was the daughter's own goal to make her father as comfortable as possible. The physician translated the daughter's experiences into a concrete goal of care, then *unhooked* a surgery from this goal. The logical outcome was that surgery did not correspond to the patient's goals of care.

These subjectification techniques allowed palliative care clinicians to navigate around more difficult questions. They asked families and patients about patients' character, life story, feelings, illness experience, and attitude toward medicine—not about whether to relinquish resuscitation, ICU admissions, and surgeries and succumb to death. No less important, these conversations were participatory: clinicians did not impose medical decisions on families and patients, but elicited patients' subjectivities

through the conversations, then hooked their care plans onto them. This process established patients' and families' *consent* to end-of-life decisions: it bridged between clinicians' inclination to respect patients' wishes and clinicians' own wish to avoid "aggressive" treatment and economize dying.

"Did he say NO?"

I did not have to know Mr. Emery's exact diagnosis to see that he was extremely sick. When I met him, a white man in his mid-50s, he was bedbound and suffered from multiple organ failures. Despite not having eaten for six months (the nurses fed him by TPN[*]), he was extremely overweight. He had been hospitalized for more than eight months, he had a tracheostomy opening in his neck, and he had just been transferred back from the ICU to a step-down unit, after having been "coded"—i.e. resuscitated and intubated. That morning, the palliative care attending physician seemed to have given up on his case; the team had had a conversation with Mr. Emery before he coded, but could not get him to consent to a less aggressive course of treatment. The team's nurse, social worker, and chaplain, however, thought there was still a chance that he would reconsider his position. In the team's morning meeting, the attending physician raised his arms in exasperation and conceded: 'I've been here only for one day, so I'm not really updated. If the team likes him, and you want to keep him on the service…' The chaplain, nurse, and social worker said they would go to see him together, and the chaplain declared that 'the doctors are released from this task.'

Hours later, outside Mr. Emery's room, the three of them, a medical student, and I congregated. Mr. Emery had two daughters who lived far away, did not come to see him, and were disengaged from the decision-making process. The consolidation of his goals and values and their translation into agreed courses of treatment involved him and the medical staff only. As we were waiting outside his room, Dr. Estefan, a young resident from the step-down unit who was in charge of Mr. Emery's case, joined us. Rebecca, the palliative care nurse, told him she did not think Mr. Emery should go to the ICU again if things got worse, and the resident, surrounded by the five of us, seemed to nod. "He [Dr. Estefan] doesn't argue back," I wrote in my notes, "doesn't express opinions that are different from theirs. Possibly because he agrees with them, but very likely because he doesn't have a clear opinion of his own."

Laura, the chaplain, said that her impression from their last conversation was that Mr. Emery tended to change the topic whenever it was inconvenient for him. When she asked him about DNR/DNI, he did not respond and instead asked her to bring him some ice. Rebecca laughed and said, 'then I'll bring some ice to the meeting and we can have it ready, right next to us.' A few minutes later she came back with a disposable plastic cup full of ice-cubes. When we walked into the room, two dialysis

[*] Total Parenteral Nutrition (TPN) provides nutrition through the bloodstream.

technicians covered a bloody dialysis machine and wheeled it out. Mr. Emery was lying on his side. Whenever he wanted to talk, Dr. Estefan had to remove a tube from his trach and replace it with a valve, which allowed air to flow in and pass back through his voice box. This allowed Mr. Emery to utter short sentences; after each one he had to stop for twenty seconds or so to catch his breath.

Rebecca, the palliative care nurse, was Mr. Emery's favorite. She had been treating him for four months, first for a pressure wound that refused to heal, then as a member of the palliative care team. "We brought you your favorite people here," Dr. Estefan started the conversation, "Rebecca and Laura." The rest of us introduced ourselves to him, then he signaled to Rebecca to come closer to him. "You're making me crazy," he whispered through the valve.[40] I felt uncomfortable, but Rebecca did not recoil: 'I like you too,' she responded. He said that the day before, one doctor came in and made him feel like he was on the "losers' club." 'Who was that?' Rebecca asked, but Mr. Emery could not remember. He apologized and said that he forgot to take his card, and we all laughed. Laura said 'it doesn't matter now. We shouldn't care about whatever he said. We came to talk about how *you* feel,' she told him, 'and what *you* want.' Laura asked him if he wanted some ice. He did, and she handed him the plastic cup. He took one ice cube from the cup and put it in his mouth.

> Dr. Estefan: 'We're here to talk about your goals, Adam. And we want to ask what are you goals? What are you expecting?' [places the valve on his trach]
>
> Mr. Emery [quietly, with some effort]: 'I want to go to Tennessee to live near my daughters.'
>
> Dr. Estefan: 'We made a big step forward when you got out of the ICU, you know. But right now your condition is not good enough to go to Tennessee. You would need a long-term acute care facility to stay in.'
>
> [Mr. Emery moves his hand, seems to signal that he wants to say something. Dr. Estefan puts the valve.]
>
> Mr. Emery: 'There's a facility right next to where my daughter lives.'
>
> Dr. Estefan: 'It's true, but it'll be difficult right now to move you there, because your condition is not good enough.'
>
> [Mr. Emery sobs voicelessly; tears roll down his cheeks.]
>
> Laura [to Dr. Estefan:] 'Just a second.'

One could say that Mr. Emery's wishes were clear: he wanted his condition to improve and to move to a facility near his daughters. Yet his doctor thought it was impossible to follow this plan. Mr. Emery had just returned from the ICU, and his condition was unstable. Transferring him from California to Tennessee was very risky, and since Mr. Emery was poor and only covered by Medicaid, he could not afford paying for an air ambulance. There was no way to follow his wish, given the

circumstances. His disappointment made him very emotional, which at least for me, was devastating.

Such situations, however, are the bread and butter of palliative care work. Mr. Emery was showing intense emotions, which could be used to further explore his experience of his suffering, and be *translated* into other goals of care.

> Laura [A few seconds later:] 'Adam, it's really difficult. You've had a really difficult time in the ICU, I know. And you've been here for a long time. Tell me something: what's keeping you through that? What makes you fight so hard?'
>
> [Dr. Estefan places the valve on the trach, so Mr. Emery can speak]
>
> Mr. Emery: 'My children. [mumbles something unclear] They're important for me.'
>
> Laura: 'I can see that.'
>
> Dr. Estefan: 'We're hoping that you will go there. Getting out of the ICU is a big step forward. You could go to a facility here, and then if your condition improves go to Tennessee. That would be a big step forward. And we're working hard with you to get you there. We know you've been working hard. Now, given all that, Adam, I want to ask you: if we see that you have to go to the ICU, and we know that this is a step backward, would you like to go back to the ICU?'
>
> [puts the valve back on the trach]
>
> Mr. Emery: 'If I know that there's no chance I'll get out of there… Then what for?'
>
> Dr. Estefan: 'So you're basically agreeing that if you go backward, the doctors here will decide what are the chances that you'll get out of the ICU?'
>
> [Mr. Emery twists his wrist several times, perhaps signaling "kind of" or "I'm not sure." Dr. Estefan puts back the valve.]
>
> Mr. Emery: 'More ice.'
>
> [Rebecca gives him another ice cube.]
>
> Laura: 'Let's talk about what we're understanding from you so far, Adam. Your main goal is to go to Tennessee and live in a long-term acute care facility by your daughters. Until then, if it's not possible we want to move you to an acute care center here, and hope that your condition will improve and you'll be able to move there. And if things go backward, and you have to go to the ICU, then you don't want that.'
>
> [Mr. Emery seems to nod]

Laura: 'Yes.'

Mr. Emery: [signals he wants to speak, and Dr. Estefan puts the valve on his trach] 'The ICU was really bad. They let me eat some fried chicken there and I didn't like that.'

Rebecca: [chuckles] 'That must have been a great dream… Tell me something, what can we do for you to make you feel better?'

Mr. Emery: 'Beer.'

[People chuckle]

Rebecca: 'You know, maybe it will be possible. We'll see. [Dr. Estefan seems to have a puzzled look on his face.] Maybe just a little bit of beer, just to feel the taste, especially since he swallows so well.' [he had a good swallowing test earlier in the day.]

[Dr. Estefan now nods]

Rebecca: 'What else would you like?'

Mr. Emery: 'Spaghetti.' [Says something unclear about how much he misses eating. He's very short of breath when he speaks]

Rebecca: [nods] 'You know, I feel it's been enough for today. We've probably made you tired. You've been through a lot, and you worked hard to get out of the ICU, which is great. And you know, it was your hard work—not ours.'

Mr. Emery: 'You think I didn't work hard?'

Rebecca: 'No, this is what I'm saying—that you did work harder than us.'

As the conversation went on, Mr. Emery's responses got shorter and shorter; he struggled to catch his breath when he spoke, and interaction became difficult. Before we left, however, he insisted on getting the valve again, thanked me and the medical student—the two observers who joined the meeting—for coming to see him, and wished us luck.

How did the palliative care clinicians consolidate Mr. Emery's goals and values? At first, Mr. Emery said that if he had no chance of getting out of the ICU, he would not want to be transferred there in the first place. In the rest of the conversation he voiced concrete wishes—e.g. drinking beer and eating spaghetti—both understandable wishes, coming from a man who has been fed intravenously for nearly six months and has not eaten anything over that period. Dr. Estefan tried to translate his words and suggested that "you're basically agreeing that if you go backward, the doctors here will decide what are the chances that you'll get out of the ICU." This translation emphasized the agency doctors would assume in determining the severity of his condition, and by consequence, whether his life would be

sustained. Yet Dr. Estefan did not get Mr. Emery's endorsement for this translation: Mr. Emery only made an unclear signal with his hand and asked for more ice.

Laura, the chaplain, made a second attempt. She translated Mr. Emery's words into a three-tiered map of his goals and values: first, moving to Tennessee; second, transferring to a nearby facility in California; and third, not being transferred to the ICU if his condition declines. This map was devoid of doctors' agency: Laura did not mention that doctors would determine whether his condition was irreversible, but simply mentioned that he would not be transferred to the ICU if his condition declined. Furthermore, this translation included Mr. Emery's original wish to live in proximity to his daughters and gave a more central expression to his agency. Whether or not Laura's translation received Mr. Emery's endorsement is open to interpretation: Mr. Emery appeared to nod, Laura said "yes," and he did not challenge her, but instead asked for ice, beer, and spaghetti. When the conversation ended, and the meeting's participants left the room, they had to decide what to make of it. Dr. Redcliff, a senior resident, joined them in the hallway:

> [Dr. Redcliff] is a tall man, acts and looks much more confident than Dr. Estefan. Rebecca says that we talked to Mr. Emery and he said he wouldn't want to go back to the ICU. Dr. Redcliff looks a bit doubtful, asks her a couple of times "did he say NO?" Laura says that he was very clear, and Dr. Estefan agrees with her. Dr. Redcliff says, 'what does it mean? I guess, DNI?' He chuckles, seems uncomfortable, looks at Dr. Estefan.
>
> Rebecca says 'I think you should feel totally comfortable making him DNI.' Dr. Estefan nods, says 'I think this is what I understood too.' Laura says, 'my impression was that he's much better, he knew what he was talking about, and he understood the decision.' Rebecca says 'he got his sarcasm back, which is important.' They talk about whether to give him beer and laugh about it together. 'I don't think it'll be a problem, since we're not talking about large quantities anyway. He could have half a cup a week or so. And since he keeps talking about eating, we could give him a little bit of food too.' Laura agrees with her, 'from a palliative care perspective, it's not a problem even if he aspirates and gets pneumonia.'

This conversation converted the rather ambivalent, inconsistent, and uncertain interaction between Mr. Emery, Dr. Estefan, Laura, and Rebecca into an unequivocal and formal order written on a standard printed piece of paper to not intubate Mr. Emery if he stopped breathing. The form did not capture much of the conversation that had taken place, nor did it reflect qualifiers that clinicians used before signing the form, such as 'my impression,' 'I think,' 'I guess.' The DNI form did not cite Mr. Emery's twist of his wrist, nor did it mention the ambivalence and equivocation that appeared throughout the conversation. Finally, the term "DNI" was not mentioned

even once in the original conversation; when talking to Mr. Emery, clinicians spoke of the "ICU," where he had difficult experiences, and not of a form that would mean he would not be intubated if he stopped breathing.

The next day, Mr. Emery stopped breathing. His doctors followed the DNI order, did not intubate him, and he passed away. About a month later, in an interview with Laura (the chaplain), she reflected on the moral difficulty that reaching this decision involved:

> I think [doctors] need to feel like, you know, a hundred percent certain that they're doing the right thing, which is often not a possibility. I think they need support. And that's why this collaborative decision-making model—it has many pitfalls—I think it's partly to serve, you know, the needs of the clinicians so that they don't feel guilt. You know, I think that the nurses who are actually doing the extubation, who are doing the administration of medicine, they think 'it's causing suffering,' and they also need a lot of support. But they're not in the decision-making level. Their distress is different. They have to do things that they maybe have moral compunctions about. But the doctors… I think they just often fight it off till the next one, because they don't want it hanging over them.
>
> [With Mr. Emery], […] you were there when he decided not to have the… And then the next day, he had this condition, the circumstance that led to him dying. […] Because he was saying no, he didn't go back to the ICU and he died. The doctors involved in that were like, "hmm. I hope he [Mr. Emery] made the right call." They would have been a lot happier if they had had some, there had been a few days that have gone by, where they could keep asking him, and he could keep telling them. It was virtually instantaneous after that conversation. And I felt like, ouch. That's a little heavy. You know? I don't know. If it could have been: "this is gonna happen, we know this is gonna happen, are you sure?" Because every time in the past when it had happened, he had wanted to go [to the ICU]. You know? You just don't know. You don't know. And I actually wrote that doc [Dr. Estefan] [an email], 'how 'ya doing?' Are you doing okay? And he wrote back and said, 'I'm doing okay, yeah.'

Laura acknowledged the moral difficulty in reaching decisions to let patients die. She argued that in practice, physicians were the ones who made these decisions, and that collaborative decision-making—i.e. involving patients and families in making end-of-life decisions—satisfied doctors' moral needs, since it took some burden off of them. The way she reflected on Mr. Emery's case was indeed an illustration of this very mechanism: Laura completely eliminated her agency from the decision-making process. At no point did she mention how central she was in the conversation with

Mr. Emery; she kept referring to the decision to not be intubated as a decision that Mr. Emery himself made.

At first blush, Laura's reflection seems paradoxical: if Mr. Emery was the one who made the decision against ICU transfer, why should the clinicians feel responsible for it? Yet after observing the entire working process in which clinicians elicited goals and values, translated, and hooked, this paradox clarifies: patients' subjectivity is invested in the agency of clinicians. While clinicians did not construct patients' subjectivity singlehandedly, and while clinicians could not read anything they wanted into what patients told them, they were the ones who carried out subjectification, and by consequence, they had much impact on what they eventually documented as patients' goals and values.

Conclusion

Few professionals face moral dilemmas of the same intensity that clinicians who work near the end of life face. Medical decisions such as stopping artificial nutrition, withholding ventilation, and forgoing future hospitalizations encapsulate some of the most acute ethical predicaments that modern medicine raises. In many cases, these decisions have morally unsettling outcomes; they involve hesitation before they are made, and doubts after. Even when not made explicitly, end-of-life decisions are made implicitly; to paraphrase Sartre, people make choices even when they ignore, deny, and avoid them.[41]

Reflecting on her fieldwork on end-of-life care, Sharon Kaufman noted how she began her research "holding the common, negative opinion about 'being attached to machines'" and against "artificially prolonged death." After two years in the field, however, she wrote: "I *think* I know what I would want or what I would do, how long I would ask for life-sustaining procedures, and how long I would maintain hope—but I learned that I cannot be sure" [my emphasis].[42] Equivocation replaced her certainty. In this realm of perpetual equivocation, I show that subjectification provided an important moral anchor.

This chapter illuminates three dimensions of subjectification: first, a moral dimension, which highlights the moral importance that clinicians attributed to taking patients' personalities into account in end-of-life decisions. Second, a Foucauldian dimension, highlighting how subjectification at the same time empowered and controlled patients. And third, a stratifying dimension, which exposed how patients of different social backgrounds connected to palliative care's subjectification techniques in varying ways.

I began and ended this chapter by showing how central subjectification was to clinicians' intuitive moral sense. As Laura remarked, involving patients in decision-making satisfied the moral and emotional needs of clinicians. As Dr. Nelson reflected,

knowing that a patient wanted aggressive treatment provided staff with some moral relief, which was particularly important given how ambivalent staff were about the benefits of the care they were giving. At the same time, we can also see that what patients wanted—and more strongly, who patients *were*—was often an outcome of the decision-making process rather than its point of departure. Only some patients presented to palliative care conversations as consolidated subjects who bore clear and articulate goals and values, which they explained to clinicians. The core of palliative care work was dealing with the rest of the patients, whose "goals and values" were still in flux, and consolidating their subjectivity—i.e. *subjectifying* them.

Parts of this subjectification began prior to hospitalization. Years before people reached the hour of their death, they were encouraged to fill out advance directives and have conversations on their goals and values with their potential surrogate decision-makers. Through advance directive forms—and later on, through the conversational techniques that palliative care clinicians employed—patients were induced to be *subjects* with personality traits and consistent "goals and values." In Foucault's terms, the practices of self-reflection and self-knowledge that palliative care clinicians employed were constitutive of patients' subjectivity. Patient empowerment definitely existed here: clinicians tried to understand who their patients were and make decisions based on this understanding. Yet the rules and patterns through which self-knowledge was attained were at the same time disciplining factors that structure subjectivities in particular ways.[43] Subjectification was an expectation: clinicians expected the dying to be subjects with intelligible and consistent personality traits, values, and inclinations that they could translate into medical decisions and hook onto care plans.

We saw how some patients, who did not assert themselves as opinionated subjects, and were not receptive to subjectification, left clinicians uncertain, morally frustrated, and unsure about what to do next. This category of unsubjectifiable patients dovetails Bourdieu's category of unopinionated people, who respond "I don't know" when asked questions in social surveys. As Bourdieu argues, "I don't know" answers result from various social circumstances: self-censorship (i.e. reluctance or discomfort engaging a certain question); social perception of incompetence (feeling unable to formulate an opinion on a certain topic); and lack of interest.[44] All of these causes are unequally distributed, in a way that applies to end-of-life care as well.

Similarly important are the social circumstances in which opinions—and non-opinions—are produced. In survey interviews as in palliative care practice, "opinions are made to exist which did not pre-exist the questions, and which otherwise would not have been expressed."[45] The clinical interview fabricates subjectivities through its demand that people stop and reflect on who they or their loved one is. The subjectivities that are ultimately consolidated are sensitive to the particular character of the subjectification practices—what Bourdieu calls "the modes of production" of personal opinions. Subjectivities would have been quite different were other practices and techniques employed, and in any event, these subjectivities would have

"had little chance of being formulated spontaneously,"[46] without clinicians' intervention. Indeed, the often-stated reason for calling palliative care consults was that they 'know how to talk to patients' and bring them to agreement with courses of treatment that clinicians deem feasible.

By consequence, interaction with palliative care clinicians was more rewarding to those people who self-reflect in the mode that palliative care teams encourage. In this sense, even when social inequalities did not influence the content of end-of-life decisions directly, they had much impact on people's experience of their illness, on their understanding of their illness, and on their clinicians' understanding of them. When I asked a former palliative care physician from Academic Hospital about the difference in outcomes of consulting patients who were "intellectually curious" and with whom he had a good connection, and those patients with whom "it's difficult," he answered:

> I don't know about a quantifiable difference, in terms of survival benefit or something like that. In terms of their experience, in terms of their acceptance of what happens to them - it's much better. [People with whom I have good connection] will generally have a better experience with their disease no matter how good or how bad the outcome is. […] They'll have, generally, a better death, if there's such a thing.

The "better experiences" of people who have good interactions with the clinical staff reflect the inequality structured into subjectification. The correlation between one's social predisposition and the subjectification techniques that palliative care clinicians employ are cardinal to the probability that one would experience what one could define "a good death."

Chapter 5: Tricks of the Trade

Some two years after I finished fieldwork, I attended a physician continuing education conference, where a palliative care physician that I knew spoke. I walked quickly past the elegant entrance to the convention center, determined to avoid the $700 registration fee, which far exceeded what a sociology graduate student could afford. At the lobby, I found myself surrounded by promotion tables of physician and hospital networks offering "career opportunities," academic publishers selling overpriced books, and pharmaceutical company representatives eager to "provide information" about their most recently FDA-approved drugs. A meticulously dressed middle-aged white woman planted a flyer in my hand and said: 'We're organizing a dinner tonight with a panel about hepatic encephalopathy. You should reserve a spot in advance because there aren't many seats left!' From the flyer I learned that the dinner—at an expensive restaurant a few blocks away—was courtesy of Salix Pharmaceutical Inc., which "cordially" invited me to eat and hear about their newly marketed drug, XIFAXAN® (rifaximin) 550mg.

But I came to hear a lecture, which was about to begin in the nearby auditorium. Some 600 physicians filled the large space. In their day-to-day work, the grand majority of them focused on curing or slowing down disease with drugs that pharmaceutical company representatives promoted over expensive dinners. Now they were about to hear Sean, the palliative care physician I knew, talk about economized dying. Charismatic as always, he began with a joke:

> So this guy went on a vacation, and he leaves his cat with his brother. A couple of days into his vacation he calls his brother, and they're chatting on the phone. "So, by the way, how's my cat?", and the brother says, "Oh, God, your cat… I'm so sorry. Your cat died." He says, "what do you mean my cat died?" The brother says "yes, it just… died. I'm sorry." "But you can't just say that! You can't just tell somebody, just like that, that their cat died." The brother says, "what do you want me to do?"—and he says "well, you know, you can call me the first day and tell me that the cat is on the roof and you can't get it down. A couple of days after, I'll call back and you'll say, 'I called the fire department and they can't get the cat off the roof.' Then a couple of days after-- *then* you say the cat died." The brother says, "well, alright. If you think that'll make things better, then okay."
>
> A few days later they're talking on the phone, and the brother says "how's your vacation?" The guy says "yeah, I'm having a great time. I'm still sorry about the cat, but I'm doing alright." So after a while, they're still chatting and he says "Oh, by the way, how's mom?", and the brother says: "Oh, mom's on the roof and we can't get her down."

I must have been the only one who knew the joke already, because the entire auditorium burst out laughing. Sean said he liked the story because it reminded him that there were many ways to communicate bad news. The question was *how* to communicate effectively with people who are seriously ill. '70 percent of the healthcare providers,' he said, 'report having conflicts and misunderstandings with patients and families. Research found PTSD symptoms in about one-third of the providers.' 'We can mitigate stress among patients, staff, and physicians with good communication,' Sean promised, and in the next forty minutes he explained *how* to talk to severely ill patients and their families, *what* to say, and perhaps most importantly—what *not* to say.

Sean knew "how to talk to people" and could also instruct others on how to do that. This dimension in palliative care was something that many non-palliative clinicians acknowledged: when I asked what they thought was the added value palliative care brought to medicine, clinicians often invoked palliative care clinicians' superior communication skills. Chapter 4 focused on how palliative care clinicians garnered a sense of who patients were from patients, families, written documents, and bodily gestures. This chapter focuses on what palliative care clinicians *said to* patients and families—the "tricks of the trade," which they applied in their work. As Sean implied, many of these "tricks" were conversational: they involved the wording of questions, the careful reaction to what patients and families said, the framing of conversation, and the way they conveyed news.

These palliative care techniques had to address a key paradox. On the one hand, palliative care had a relatively clear medical agenda—economizing dying, questioning the necessity of life-prolonging treatments, and moderating the use of curative treatment when people approached the end of their lives. On the other hand, palliative care clinicians aspired to be patient-centered and empower patients and the people who were close to them to participate in medical decisions. Many of the clinicians I interviewed were very conscious of the influence they had on patients, some to the point of doubting it was honest to speak about patient participation in medical decisions. 'Every physician goes to the bedside and lets the patient drive decisions,' told me Andy, an organ transplant surgeon. 'But patients [depend] […] on the presentation that you give them.' Physicians, according to Andy, could sway patients' wishes in any direction they wanted:

> 'You can drive them to the fountain: I can say, "Mrs. Smith, grandma is 85 and it'll only make her suffer if we operate on her, and it's not going to cure her." Or I can say, "Mrs. Johnson, you know, I think I can get the cancer out of you." And what do you think they'll want to do? Of course that if I tell her that I can cure her, she'll go with me, no matter what other people are telling her. As a doctor, you come to talk to patients with your biases: if your experience is that you've done transplants in 80 year olds and they turned out fine, then you're biased toward that.'

Scholars of medical practice have called this dynamic "the illusion of choice": medical discourse may hail patient autonomy rhetorically, but in reality, professionals (e.g. physicians) and institutions (e.g. hospitals and insurance companies) heavily constrain and control patients.[1] If a physician or a hospital does not present a patient with the possibility of having a surgery (or conversely, transitioning to hospice care), this possibility will most likely remain outside of the patient's realm of choice.[2]

At the same time, I found quite a few physicians, who like Andy, recognized and reflected on the influence they had on patients. Notice that Andy talked about his "bias" as a transplant surgeon—not unlike Scott, the palliative care physician, who, as I mentioned in chapter 1, said that he "[drew] the line" before other physicians and recommended withholding life-sustaining treatments earlier than them. Clinicians were aware of their power and thought about it critically: the impact they had on patients as experts was inevitable, and they thought about how to use it methodically, so that they would not empty the idea of *autonomy* of all meaning. Palliative care techniques therefore walked a very fine line: while clinicians deliberately influenced patients and families, they did not want to manipulate, completely dominate, or dictate their decisions.

The chapter's first section outlines the chief "don'ts" of palliative care: common patterns in doctor-patient interactions that palliative care clinicians criticized. In the second section, I summarize several examples of practices that palliative care practitioners encouraged and advocated. The third and last section examines how palliative care clinicians dealt with situations in which despite their best efforts, patients and families resisted economizing dying and insisted on continuing life prolonging treatment. In these cases as in others, the effort to economize dying and influence the patient (or family) was methodical: clinicians clearly controlled and constrained patients, but avoided dominating them completely.

1. The Don'ts

Disfavored formulae: "do everything" and "laundry lists"

Nick was an attending nephrologist, a senior kidney specialist, who worked as a partner in a private practice and saw patients at Private Hospital. As a nephrologist, he regularly consulted on the treatment of ICU patients, whose kidney function declined. One intervention that he and his colleagues frequently offered was dialysis. Yet the acute condition of many of his ICU patients made him doubt the appropriateness of dialysis in their cases. When I interviewed him, he criticized interns and residents who worked in the ICU and blamed them for not interacting with families properly:

> Nothing irritates me more than when I'm called onto a case and the house doctors* say, "Well, we asked the patient if they wanted everything"—"everything" is the term they usually use […]—and [the patient] said "Yes." Or, we asked the wife, "Do you want us to do everything?" and she said yes. […] I don't think that's an appropriate question or appropriate wording. [Q: why?] […] It puts family members and decision makers in a real uncomfortable and precarious place, where they feel pressured to say, "what do we want […] to do? Of course, we want them to be healthy, we want them to be alive, we want them to regain their health, so of course—do everything, because that's the only way we're going to achieve that."

Vocabulary matters. In end-of-life care, the intuitive phrase "do everything" has become a red flag, since it prompts very particular reactions from patients and families. Textbooks and seminars on end-of-life care present the use of "do everything" as a common mistake that clinicians make in family meetings, which can and should be corrected. Pediatricians Chris Feudtner and Wynne Morrison cited several circumstances in which "do everything" comes up at the bedside:

> The physician may offer this up as a pledge: "We are going to do everything." Or asks the question: "Do you want us to do everything?" Alternatively, a family member may utter the phrase as a request or demand: "We want you to do everything." Heads nod in silent agreement. We will do everything.[3]

Feudtner and Morrison argued that the term "do everything" is misleading. First, it is logically impossible to do everything, since any treatment necessarily come at the expense of something else: one cannot "hold a loved one's hand while they are dying at the same moment that a code team yells 'clear' and attempts to defibrillate the patient's heart." Second, by "do everything," families and clinicians may mean different things: a family's demand to do everything may be a simple cry for help and support, while clinicians typically perceive it as a concrete request for aggressive medical interventions.[4] Finally, "do everything" confronts families, patients, and clinicians with a binary choice: it is either that *everything is done* or that *not everything is done*. This fosters "an adversarial air in conversation": families and patients "may be more likely to fear that care is being rationed for some reason other than the patient's best interests." The "do everything" phrase is therefore "dangerous nonsense. A moratorium is warranted, halting all medical personnel from further casual utterances of 'do everything.'"[5]

The palliative care clinicians that I studied criticized the "do everything" phrase on lexical as well as indexical grounds: they not only took issue with the phrase's

* "House doctors" included interns and residents—physicians in their first three years after medical school.

dictionary meaning, but also with the effect it had on interactions at the bedside. Other phrases and expressions, which had similar effects, attracted similar criticisms. Laura, a palliative care chaplain, who clinicians widely recognized as an excellent communicator, told me:

> If you ask people "do you want to live?" – 99.9 percent of them are gonna say "yeah, I want to live." If you ask them "what do you hope for?" – 99.9 percent of them are going to say. "I hope to live." When you ask a question – you influence the answer. […] [You ask:] "what are your goals?", [and they answer:] "my goal is cure." It's sort of a formulaic question, "what are your goals."

As I described in chapter 4, the term "goals" has a very central place in palliative care jargon. But as Laura says, when clinicians use it to ask a patient or a family a direct question about their wishes, it becomes an invitation to request more curative treatments. A palliative care social worker said that the wording of some advance directive forms had a similarly problematic effect:

> If somebody, at some point in their life, doesn't want to be in an ICU intubated – that can be recorded in [an] advance directive. [But only] in a really good advance directive – not these crappy pieces of shit that we have here. I don't know if you've seen them, but it's awful. They say, "do you want to be intubated?" – of course you're gonna say "yes." You don't know what that means, you could have pneumonia and you'd be intubated for five days and recover and go back to your life. They're just very black-and-white and they're very… It says, "do you want to prolong your life?" – of course people would want to prolong their life! Why would people say no?

We can notice several palliative care don'ts: first, the "do everything" phrase; second, general open-ended questions about patients' "hopes" or "goals," which are likely to elicit unequivocal "I want to be cured and live" answers; and finally, any phrasing of yes-or-no questions about the use of specific medical procedures. Similarly to "everything done," asking patients and families whether they do or do not want to be intubated, resuscitated, or transferred to the ICU if their condition declines is far too narrow, too "black-and-white" to capture the unpredictability of scenarios and the nuanced preferences that patients and families may have. Making the term "everything done" more concrete by listing all of the medical procedures in discussion does not solve the problem: pointed yes-or-no questions still set families to respond "yes" to any medical procedure that clinicians mention.

Learning these conversational skills is a slow process, and new palliative care clinicians are bound to make mistakes. A nurse who began working with Public Hospital's palliative care service joined the rest of the team to meet the family of a

severely ill elderly woman. The morning after the meeting, the team sat to debrief, and the nurse learned she had made a conversational mistake:

> Physician: It was a tough meeting yesterday.
>
> Nurse [smiles]: Yes, it was.
>
> Physician: The [medicine] doctor there was frustrated that the family couldn't understand that we can't fix [the patient's] aspiration. Just to keep you in the loop [talks to another nurse, who wasn't in the meeting], she had a brain stem stroke […] and she was at [a nursing home] where she kept getting fever from infections […], because she's having problems with aspiration. The family is very medically focused, they're constantly talking about the small details. […]
>
> Chaplain: I actually felt that they were a little bit open to talking about the situation in general. They were clear in saying that they have to say "yes" to everything, but at the same time the sister said that she didn't want [the patient] to suffer.
>
> Nurse: Right, and I did notice this small crack open, when the sister said she wanted to do everything, but at the same time she didn't want [the patient] to suffer, so I immediately tried to jump in and try to open this little crack… I'm sorry.
>
> [Physician nods without saying anything]
>
> Nurse: ...And I asked her what does she mean when she says she doesn't want [the patient] to suffer – would she want [the patient] to be intubated? And she said yes. Would she want [the patient] to be admitted to the ICU? And she again said, yes. And then at the same time she says that she doesn't want [the patient] to suffer…

The nurse's brief apology ("I'm sorry"), followed by the physician's silent nod, signified a shared recognition of a mistake. The nurse was right to recognize a "little crack," but wrong in how she tried to "open" it—asking yes-or-no questions about specific interventions, which triggered unequivocal affirmative answers. Asking such questions would be mistaken in any conversation with any family, let alone with a family that, as the chaplain mentioned, was "clear in saying that they [would] have to say 'yes' to everything." Palliative care clinicians, as the chaplain implied, prefer to keep the conversation on the "general" level. As a general statement, the family's stance was still pliable to interpretation and could still be negotiated. In another hospital, for example, a palliative care social worker, who talked to the children of a severely ill patient, interpreted a similar request differently: she said that when saying "we'll have to say 'yes' to everything," the children implicitly requested that doctors would *not* ask them what life-prolonging treatments to provide, because they felt obliged to say "yes" even to procedures that made their mother suffer. Public Hospital's nurse, by contrast, made the family specify all of the concrete life-

sustaining interventions they would "have to say 'yes' to." The general statement quickly solidified into a set of demands and expectations from the medical team. While these demands could still be discussed and changed, this would probably require much work.

The nurse acknowledged that she made a mistake. Many non-palliative care clinicians, however, felt they could not comfortably withhold life-sustaining treatment without hearing an explicit request from the patient (or family). Presenting direct questions to them was the most intuitive thing to do—what could be more straight-forward than asking one whether or not they would want a certain procedure done? Mike, a palliative care physician, criticized this tendency to me:

> [These doctors] reason in a way that […] pisses me off. Everything that is not prohibited is mandatory. […] It's the idea of a medical provider […] being a cafeteria worker throwing stuff on people's plates [and asking]: "would you like some pressors* with that?" Seriously—no! […] The incentive for the team for the moment is to say, 'do you want prunes?' It's easier for them to give [patients and families] choice...

On one of the days I shadowed him, Mike took the opportunity to engage a resident who rotated with him. The two of them debriefed after a meeting with the son of a 98-year-old woman, who had terminal metastatic cancer. In previous conversations with the medicine unit's physicians, the son was very eager to prolong his mother's life in any way possible, hence the medicine physicians decided to call the palliative care team. But during the meeting, the son consented to Do Not Resuscitate and Do Not Intubate orders very quickly. Mike was happy, but had some reservations about how the medicine physician interacted with the son. 'You did great, thank you,' he told the physician, but then added: 'feel comfortable not to check off all that laundry list of interventions when you talk to families.'[6] After the medicine physician left, Mike turned to the resident (Kara):

> Mike: 'So what did you think about how the code status conversation went? I think we saw the pattern, the laundry list that they went through.'
>
> Kara: 'I think it was already established when [the son] said, "don't do chest compressions, and I don't want to intubate her." You didn't necessarily need to ask him again.'
>
> Mike: [nods] 'Well, it's all a personal call, right? It all depends on the physician's confidence. What would you, as a physician, need to hear to feel comfortable putting that order in. So it can range all the way from,

* Pressors are an intensive care measure, used to sustain blood pressure when it drops.

"listen, dude, I'm not gonna code* a 98-year-old with metastatic cancer—I'm not asking you." You can say it nicely, but you *can* say it. I don't *need* [the son] to tell me that in order to do that. […] Or I might say: "let me propose this to you: we're going to treat her urinary tract infection, in hope that she improve enough to eat and drink. If she does not, and there are signs that she is dying, we will *not* do things to her that will only hurt her. By which I mean: we will not put her on life support, we will not put her on dialysis, we will not give her a ventilator, or do CPR." […] Do you need to spell that out? Or do you need to be comfortable just with the general concept, and not go through the laundry list […], just say, "we will do the things that will help, and not do things that have no chance of helping her, or will only hurt her." There are all sorts of ways to approach it. The question is, Kara, what do *you* need to get in order to put that order in.'

Kara: 'I thought what the son said was enough.'

Mike: 'But let's take it from the specific case to the general case. How would you handle that, if the son hadn't said it that explicitly? What would you have done?

Kara: [hesitates, smiles uncomfortably]

Mike: 'Do you need hear it spelled out? [Kara still quiet] "No, I don't want dialysis; no, I don't want a ventilator?" Do you *need* to hear those words in order to put that order in? Or do you just need to hear the general concept? Or do you not even need to hear that?'

[Silence. I start feeling awkward myself]

Kara: 'I think… The general concept. I think… given the fact that he doesn't have medical background, most people, if you put too many details of possible scenarios… I think it's confusing…'

Mike: 'I agree with you. But, that means that you're comfortable describing a general concept, meaning, as soon as they say things like, "I don't really want them to go through a lot of interventions" – [you will sign a DNR/DNI]?". […]

[Kara quiet again]

Mike: 'Because I think it's going to come up a lot, especially if you want to be a hospitalist, eh? You're going to have to figure out what you need to hear to feel okay putting in an order?

[She smiles, nods, but doesn't say anything]

* The verb "to code" means performing CPR.

Mike: 'It's not my usual approach, but [what] I want to first clarify, beyond the goals, is the general understanding. Then on the more specific level of what to do—some of these are doctor decisions, not family decisions. One of the things that [I try] to avoid is that laundry list: […] "yeah, have a little bit of dialysis, maybe a ventilator, hold the pressors and the CPR"—these mixed plans don't make any sense, right? [Kara nods, smiles silently] That's how that happens. Because if you, as a physician, need to have a written contract with every potential intervention ruled out… […] I remember one time - I'll never forget it: a really good resident told me about his patient 'he didn't say no to blood transfusions!' And I remember saying 'is everything not prohibited mandatory?' Think about this for a second: if a patient doesn't specifically say "don't do it"—then you're obliged to do it? In other words, let's say we check her hemoglobin and it went down to 8 or 9. Will you have to transfuse her, because we didn't talk about it in that conversation?"

[Kara hesitates. A few seconds of silence ensue, Mike continues looking at her, waiting for an answer]

Kara: I feel like the son would want it.

Mike: Um-hm. There isn't a right or wrong answer. But I think that one of our struggles is this idea that every single decision is turned over to a family, and then our critical thinking [as physicians] disappears. So this is a case where I would feel very comfortable saying that we can't do this. We're not going to put hemoglobin. We'll do our best, but we're not going to do things that would hurt her. Just so you know, as a physician, me, personally, I feel comfortable to say "no." You need to develop your own style and the level of comfort you need [in order] to do what is medically right. And my recommendation to you is not to go through a laundry list, but to elicit a general understanding of the medical situation and the goals of care […]. Because you know what will happen [in this case] - right? She'll get either dehydrated or infected, because that's what happens when people have terminal cancer. […] Does that make sense? How do you feel about that?"

[Kara nods, still with an awkward smile].

Mike presented to Kara his method: he avoided asking pointed questions about specific treatments, and instead focused on the general gist—"the general concept"—of what patients and families told him. When economizing dying by relying on such a gist, clinicians could interpret general statements much more flexibly than specific requests for pressors, ventilation, antibiotics, or dialysis.

In general, palliative care clinicians flagged certain vocabulary and interaction patterns as flawed and sought to eliminate them from interactions with families and

patients. When clinicians made such "mistakes" in meetings, palliative care people approached them after meetings ended and explained why avoiding these words and phrases was preferable. They defined variants of the "everything done" phrase as overly vague and prone to create conflicts and misunderstandings, and they criticized yes-or-no questions—"would you like us to readmit her to the ICU?", "would like him to be resuscitated?", or "would you like her to be intubated?"—as presenting families and patients with counter-productive "laundry lists."

What patients (and families) did and did not want was of prime interest to palliative care clinicians. Yet they pursued this interest through very particular methods. They did not take patients' subjectivities as unalterable: knowing that how they asked questions impacted people's answers, palliative care clinicians chose their words and phrased questions very carefully. In this way, while maintaining the focus on the patient, they controlled and contained the range of possible reactions and preferences, which patients and families could expressed: they *tamed* patients' and families' agencies.

Futile interactions: manipulations and altercations

In part, palliative care clinicians criticized "do everything" and "laundry list" formulae because they passed too much responsibility to patients and family members. The opposite tendency—of completely opposing patients' and families' preferences and trying to dictate what they should do—drew much criticism as well. Knowing how to back off and let patients and families say the last word, even if it completely contradicted clinicians' medical and moral intuitions was an important skill, which many clinicians found very hard to practice in real time.

The palliative care team at Academic Hospital met to talk about a meeting they had a day earlier, which Dr. Robbins, one of the hospital's most accomplished physicians, managed. Perhaps because of Dr. Robbins's status, the team's younger physicians enjoyed parodying his somewhat limited conversational skills:

> Fellow: 'Dr. Robbins—he was the attending—kept telling [the family] that CPR is "violent." He always says this word, "violent," I don't know why…'
>
> [Another member of the team emulates how Dr. Robbins presented CPR to the family, improvising aggressive chest-compressions. People laugh loudly]
>
> Fellow: 'He kept asking them if we should do this "violent" thing to [the patient], and the family kept saying "yes." So he asked again and again, and there was this back and forth for a while: "are you sure you want us to do this violent thing?" [emulates chest compressions, pushing an

> invisible chest down with both hands] - "yes" - "are you sure?" - "yes" – "but are you?" – "yes."'

Dr. Robbins made a mistake—asking a direct yes-and-no question—and at he same time refused to accept the answer he did not want to hear. The team found it grotesque and clumsy, if not outright manipulative. For one thing, Dr. Robbins exposed the fact that he already held a clear opinion about the case and left the impression that his interest in the families' and patients' opinions was a mere attempt to validate his own inclinations with an appearance of shared decision-making.[7] For another, he led to a very awkward exchange, where he asked the same question and received the same answer several times. A month later, the teams' clinicians confronted a very similar challenge, when they consulted on the case of a 72 year old woman who suffered a major stroke and lied unconscious in the ICU in a steady condition. The neurology team was very pessimistic about her chances of regaining meaningful cognitive abilities, but her husband, a religious Christian, was reluctant to disconnect her from the ventilator.

> [During a staff meeting:] Nancy [nurse] talks about the patient, says that it's a Catholic family, and they are not willing to disconnect [the patient] from the respirator. One of the sons also has severe medical problems, and the experience with him has made them somewhat less willing to go in this direction. She says that Sarah [palliative care fellow physician] had a conversation with them last week. […] The husband did say […] that [the patient] wouldn't want to be in a vegetative state, but at the same time he felt that taking her off the respirator would be murder [I was present in that meeting, and heard him use the word "sin"]. Sarah also talked to the son, who said that he understood that 'a decision has to be made.' […]
>
> Anna [palliative care fellow physician] asks if there was any discussion about the fact that there is no real choice here, since [the patient] is never going to be able to live out of the ICU. She *has* to be disconnected from the respirator.
>
> John [attending physician] agrees: he thinks that it's really a false decision. We know that we have to disconnect her from the respirator, and this is a *medical* decision. He says that maybe we should just inform the family that we have reached this medical decision, and it will take the burden off of them. He says that he talked about it a lot with Sarah [palliative care fellow] and Dan [the ICU physician treating the patient], and this was what he told them: although they were talking about a family making a decision, from his point of view, this was just a false choice.
>
> Anna says she talked to the son, who seemed to be more in line with the palliative care team's approach. The son said that knowing his father,

> he's the type of person who would become a lot tougher if you told him that extubating her was your own professional decision. But if you let him feel that this was a decision that he was making, he would be more likely to agree.
>
> John says that he's concerned about what would happen if he […] asked the husband what he would want to do, and the husband said he wanted to make a trach* and keep her in the ICU. In this situation, John says, he'd have to tell the husband, 'well, no, actually this is not really your decision, and we have decided to take her off the respirator.'

By emphasizing that the team should ask questions only when it is willing to hear several different answers, John substantiated families' agency and acknowledged that he did not fully control what they said. Discussions with families should not be a manipulative effort to affect people's answers, but a genuine invitation to participate in conversation and influence medical decisions. When a clinician knows s/he would not be able to accept certain requests, she should not present them as possibilities. Taking patients' and families' agency seriously necessitated constraining it.

Similar cases of unconscious and ventilator-dependent patients regularly occurred in ICUs and often led to complex decision-making processes. In some circumstances, medical teams presented continued ventilation and artificial nutrition as possibilities; in others, they refused to offer them and gave families the time to look for other institutions that would. Confronting families directly was, however, something that palliative care clinicians tried to avoid. Similarly to manipulations, they regarded outright altercations with families as futile—and criticized the physicians involved in them:

> Around 1pm, I see two big men in suits and ties near the [ICU] nurse station, and in the meanwhile—a heated exchange between Carol [palliative care nurse] and one of the ICU residents. The ICU resident tells Carol, 'It was written in the chart,' and Carol, more than a foot shorter than him, looks up straight into his eyes and asks a rhetorical question assertively: 'So what do you want to do?' I learn from the ICU social worker that […] the son of Mr. Levinsky, a ventilator dependent ICU patient, told somebody on the phone, 'somebody will get hurt here,' so security were called, apparently by protocol. The social worker says that the son is now on his way, and 'it's going to be a mess.'
>
> By the time the son arrives, only one security guard stands at the ICU entrance. He is probably about 6'7 and 240lb. [...] But the son turns out to be far less intimidating than he apparently sounded on the phone—

* Respirator-dependent patients are at high risk of developing pneumonia. After a certain period, usually 14 days, physicians have to decide whether to extubate them or ventilate them through a trach.

> he's maybe 5'7—and seems very shy. The senior resident, a tall and assertive young man does everything short of yelling at him. He speaks loudly, dramatically, asking him pointed questions bluntly: 'would you do anything like that to yourself?' 'You can see how he's doing. Would he want to be like that? Do you want him to suffer?'
>
> The son answers in a much lower tone of voice, with a strong Russian accent. He says that *he* [his father] is not suffering anymore. 'It's we, the people who are here that are suffering.'

A few days later, when I asked Carol how the case turned out, she answered in a sarcastic tone, "yes, Trach n' PEG!"—referring to the two surgical procedures required to keep ventilator-dependent patients on life support for the long term. An outright confrontation, which involved a security guard and a direct and aggressive series of questions from an emotional ICU physician made the son dig in his hills and keep his father ventilator-dependent and artificially nourished in a long term acute care facility.

The *don'ts* of question phrasing—employing disfavored vocabulary, phrasing yes-or-not questions, manipulating, and confronting patients—were not avoided by all practitioners at all times. Yet they marked out a general approach to communication. Looking at this approach, we can see that, first, palliative care clinicians valued the opinions of patients and families and relied on them when engaging end-of-life decisions. Second, clinicians were aware that how they asked questions—the vocabulary they used, the formulae they employed, and their general approach to interaction—had much influence on the wishes and preferences that patients and families voiced. Third, palliative care clinicians encouraged their colleagues to methodically control how they phrased questions and what vocabulary they used. And fourth, neither palliative care clinicians nor their colleagues saw patients and families as completely amenable to how they phrased questions. The irreducibility of families and patients' wishes to clinicians' speech acts was what validated and substantiated their impact on medical decision-making.

2. Embedded Agency

Having discussed the vocabulary and formulae that palliative care clinicians criticized, we should look at the conversational techniques that they practiced. I focus on three techniques: first, phrasing questions; second, presenting palliative care as an active way of caring; and third, contextualizing and interpreting the disease and the medical treatments provided. All of these techniques signified a view that patients' agency was embedded in clinicians' agency.

Phrasing questions the palliative care way

On my first day in Academic Hospital, I shadowed Ben—a medical resident who rotated with the palliative care team as part of his training. Ben was highly regarded by the palliative care staff, who appreciated his efforts to learn from them, his interest in palliative care, and his general sensitivity and insightfulness. (Three years later, he decided to specialize in palliative care and did a fellowship as a hospice and palliative care physician). Abigail, a medical student in her fourth year, was also shadowing the palliative care team, yet being at an earlier stage of her training, she was not working as independently as Ben.

> Ben and I walk into the office, Abigail is there too, writing [medical] notes. They talk about the experience of rotating [with the palliative care team]. Ben says that he actually feels he misses a lot this month, because since he's a resident, they sort of tell him, "okay, you're a resident, go do your thing," [i.e. talk to patients and families and manage cases on your own]. But he feels that he gets the most from shadowing [the palliative care staff], because then he can see people from the palliative care team like Hanna, or Laura, or Zach in action. He asks me if I know Laura, and I say that I have seen her once; he says, […] she just speaks really well to patients. [Also,] the other day [Ben says he] borrowed Zach to do a family conference for him, and he learned so much from him. [I ask him what he learned, and he says], things such as how to word questions are really important.

About a week into his tenure with the palliative care team, Ben noticed that the wording of questions impacted how patients and families answered them. He wished to follow experienced palliative care clinicians more closely in order to learn the intricacies of their question wording skills.

> [Ben:] 'For example, I used to ask, "if your heart stops, would you want us to bring you back to life?" – and of course people would say yes. It's as if you're inviting them to say "yes," regardless of what their goals of care are. But when Zach had the code conversation[8] with them, he asked it, "when your time comes, would you like to die peacefully and naturally?" And this was what made the difference.'
>
> Abigail agrees with him, says that you usually go [to family meetings] and you say, 'that was a good conversation.' But then you see one [done by palliative care] and say, 'Wow, they *really* did it amazing.'

When Ben asked patients if they wanted to be brought back to life, he tended to get affirmative answers; when Zach phrased the question differently, and emphasized that signing a Do Not Resuscitate (DNR) / Do Not Intubate (DNI) form would lead to "natural" and "peaceful" death, patients and families were more willing to sign it. This was one central lesson that Ben learned as a trainee: how to use language in a

deliberate and premeditated manner in conversations with patients and families, knowing that he could influence their stated wishes. Palliative care clinicians worked as conversation analysis practitioners:[9] they controlled their wording in effort to elicit desired reflections—and at times responses—from patients and their families.

Zach's question phrasing style was common. Other palliative care practitioners that I observed used different words, but the principle of contrasting a natural and peaceful death to a different and presumably less favorable dying trajectory repeated in almost all cases. For example, a Private Hospital palliative care physician asked a patient: "If your heart were to stop, would you like us to let you progress naturally, in what I call a 'peaceful, soft landing,' or would you want us to attempt to resuscitate you and connect you to machines?" This formula has been so common that researchers tested its effectiveness in a laboratory setting. Using an online simulation, Barnato and Arnold asked 256 adults to imagine their parent or spouse was admitted to an ICU and put on life-sustaining treatment for "pneumonia, severe sepsis, and acute lung injury." Respondents then watched an interactive video, in which an actor playing an ICU physician answered their questions and provided information about the patient's condition, prognosis, and planned treatment. At the end of the video, the actor informed the respondents that their family member had a 10 percent chance of "survival to discharge in the event of cardiac arrest requiring CPR" and asked them to decide whether or not they wanted to forgo CPR. When the actor described the alternative to CPR as "allowing natural death," 49 percent of the respondents requested CPR; when the actor presented the alternative as "Do Not Resuscitate," 61 percent of them requested it.[10]

It would be wrong to dismiss this deliberate choice of words as a simple manipulation. If a clinician is aware that phrasing questions influences answers, she can be blamed for manipulation regardless of how she phrases her questions. Asking "would you want to be resuscitated?" influences families' and patients' answers no less than offering them choice between "a natural and peaceful death" and "being connected to machines." Any phrasing of any question would tilt answers in one direction or another. Palliative care practitioners' choice of words leaned toward economized dying; being self-aware meant acknowledging that there was no way to phrase a question neutrally and choosing the best non-neutral way to do so.

Framing economization as an active form of care

Discussing economized dying on the more general level required just as much attention as asking questions. Ultimately, forgoing, discontinuing, or limiting life-prolonging interventions collided with the intuitions of many families, who thought of these interventions as essential to caring. When talking to such families, palliative care clinicians made sure to frame economization as an active form of care. They presented economization not as a negative agenda—the withdrawal of unnecessary

care—but as a positive one—the provision of appropriate care, which matched the patients needs.

Take, for example, how Scott approached one of the cases he was called to consult:

> [Scott and I walk] to the step-down unit. […] [He] picks one of the big folders—the patient's chart—from the shelf [at the nurse station]. He opens the chart and says "Oh, he's 97!" He tells me that he just read somewhere that 30 percent of the children born today will make it to a hundred—'of course, if we don't reach complete nuclear annihilation by then.' 'Would you believe that?' He asks me. 'How old do you think people should be today to have a 30 percent chance to make it to a hundred?' I hesitate, and he encourages me, 'guess!' 'Probably very old,' I say. He says '96!'

Scott made two implicit statements in this exchange. First, he pointed out that the mortality rate of people in their late 90s is very high; a patient's old age (in this case 97) already signaled that his life expectancy was very short. The second statement was more subtle: Scott referenced the fact that life expectancy in the U.S. was rising and that in the next decades, such hospitalizations of severely ill elderly people will become even more common.

> Two numbers [in the chart] especially draw Scott's attention. 'His abdomen is very low,' he says and points at a lab test result, 'and his INR* is really high. With this INR I don't think he'll make it to a hundred, unfortunately.' He starts reading notes [that were written] since [the patient's] admission. They're all handwritten […] [and] pretty long. At some point [Scott] says, 'wow! All of this from today?' and adds that based on his numbers he can say it's either hepatorenal syndrome† or ATN.‡ 'I know [the patient] doesn't urinate,' he says, 'but then—how can I know whether it's because he doesn't produce urine, or perhaps he has an obstruction?' He looks at me, silently. 'But right now it doesn't matter, because his INR is so high that I wouldn't be surprised if it'll be a matter of days for him.' Then he flips to the last page of the chart, and there's a note from about an hour ago.
>
> The note says that [the patient's primary care physician] talked to the family, and they have reached a decision to discharge [the patient] to hospice at home. Scott skims it, then says, 'so I guess they've made the decision. I don't have much to do here.'

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* INR (International Normalized Ratio) is a measure of blood clotting.

† Hepatorenal syndrome involves liver failure, followed by kidney failure.

‡ Acute Tubular Necrosis is a medical condition involving the death of cells in the kidneys, which is one of the most common causes of Acute Kidney Injuries.

Before seeing patients, palliative care clinicians "gathered information" from their chart. Based on the patient's age, medical history, symptoms (e.g. the cessation of urination), and two lab-results that significantly deviated from normality, Scott made his opinion about the patient's prognosis: he was convinced that the patient's life expectancy was very short ("a matter of days"). His declaration that he was not really needed in the case, which he made upon learning that the patient's family and personal physician decided to transfer the patient to home hospice, showed that he saw his role in this case as garnering the patient and family's consent to hospice.

Scott walked into the patient's room and found him unconscious. He conducted a physical examination and talked briefly to the patient's hired caregiver, who was sitting there. He then walked out and called the patient's primary care physician on the phone. Like several other patients at Private Hospital, this patient was wealthy and had a concierge physician: a doctor, who for annual fees that sometimes reached $20,000 served as the patient's personal physician and committed to being available on-call for anything the patient needed. After the phone conversation, Scott and I walked to a nearby room to write a note in the patient's electronic chart.

> Scott logs into the computer. He says that the patient should have been admitted to hospice much earlier, that this hospital admission was unnecessary, and they should have let him stay at home. 'That's what I don't like [about] his doctor,' he says. 'He could have put him on hospice a long, long time ago. And when I ask him [on the phone] why he didn't, he tells me that it's because the son was not ready for that, [he said:] "you know – orthopedists."'

Trying to build a common language with a palliative care physician, the primary care physician mentioned that the patient's son was an orthopedist and offered implicit criticism of the son's support of more life-prolonging care. The primary care physician placed himself on Scott's camp, implying that like Scott, he thought the son was being unreasonable. Scott did not confront the physician on the phone, but when talking to me later, he sounded very critical:

> 'It's not the son who is disagreeing with [hospice],' Scott [tells me], 'it's the doctor who didn't know how to frame it for the son. Because when you ask [the son], 'would you like to withdraw care and send him to hospice' – of course he will say 'no.' But if you talk with him about how we can come up with a plan that would be the most appropriate for [your father's] age and condition right now – he'll be much more open to the idea of hospice. As much as I hated all of this humanities talk about rhetoric when I was in college – it really, really matters.'

Scott's view of the son's agency in medical decision-making was complex. On the one hand, similarly to the primary care physician, Scott recognized the son as a legitimate decision-maker: at no point did he challenge the son's right to participate in medical

decisions for his father. On the other hand, Scott knew he could influence the son's decisions by framing what hospice meant: suggesting that hospice was *not* "withdrawal of care," but rather a form of care that "would be most appropriate to your father's age and condition."[11]

When training younger medical staff, senior palliative care clinicians repeatedly emphasized this need to frame economization as an active form of care. At Academic Hospital, a palliative care fellow, who gave a class to medical students and interns, told them: "don't say 'there's nothing else that we can do,' and don't say 'withdrawal of care.' I really don't like these two phrases." Ryan, an attending physician from the same service, added that "withdrawal of care" was a very misleading description of, say, disconnecting a patient from a ventilator (i.e. extubating). In contrast to popular imagery, which often portrays extubation as a simple act of "pulling the plug" or turning a switch off, extubating was a methodical procedure, which required much preparation and skill: preparing the right morphine doses ahead of time, so that the patient would not appear in respiratory distress (which may traumatize family members); administrating the medications properly and on time; pulling the tube out correctly, so that it does not injure the patient and cause bleeding; etc. Rather than a cessation of care, extubation was a very meticulous and attentive form of care.

In Public Hospital, I observed Linda, a palliative care physician, using a similar framing at the bedside when talking to a patient's Spanish-speaking daughter (Anna, a medical resident, served as a translator):

> [Linda and Anna] put their stethoscopes on the patient's chest and listen for about 20 seconds. They touch her arms and then roll down the blanket. They touch and feel her legs, then lift and bend them slowly, each from one side of the bed. [This physical exam] takes a couple of minutes, then Linda turns to the daughter and says 'there are many things I think we can do.' Anna translates, and the daughter's eyes light up: "Si???" she says.
>
> Linda says that 'first, we can give her some more pain med[ication]s, to make sure she's totally comfortable.' Anna translates, and the daughter nods. 'Second,' Linda says, 'we can see if we can move her to Unit D, so you can have more privacy. Or if this is not possible, we can move the other patient in the room somewhere else, so you can have your own space here.' Anna translates and the daughter nods again. 'And then another thing is the oxygen mask,' Linda says. 'Usually, after a while, patients don't feel comfortable with the oxygen mask on their face. So one thing that we can do is to remove the mask and put a fan right next to them, which will move the air near her face. There are studies that show that it makes them more comfortable,' Linda says, and adds that 'still, there are some families that don't like this idea and prefer to keep the mask on the patient's face.' After Anna translates, Linda asks the

> daughter what she would want. Anna translates that the daughter would be totally fine with removing the mask.

Even when at first, a daughter seemed to identify "things that we can do" as life-sustaining, or even life-saving, interventions, Linda hung onto her framing. By framing the removal of life-sustaining and life-prolonging interventions as active measures of caregiving—as opposed to withdrawal of care, Linda facilitated the daughter's consent to economization.

Contextualizing

A third interactional technique that palliative care clinicians encouraged was contextualizing: communicating to patients and families general information about the disease process. In the beginning of a typical meeting with family, clinicians summarized the patient's medical condition and the events that led to it. Recapping the disease process and describing the patient's present situation were interpretive acts: clinicians controlled the case's presentation and could specify what decisions were on the table.

In one family conference at Public Hospital, members of the palliative care and medicine team met with the family of a young patient who suffered from hepatorenal syndrome. Like many families of young patients, this family was eager to pursue every possible life-prolonging treatment. At the beginning of the meeting, the chief medicine resident provided the family with background on the patient's condition and the disease's progress:

> The chief resident says that […] the results of the biopsy are that it seems like [the patient's] liver condition is not due to an autoimmune disease, namely, it's not that the body is attacking her liver for some reason, and that it is probably a liver-failure due to alcohol use. [I see the husband nodding silently]. The resident says that we were hoping that her liver would recover a bit and that following that, her kidneys might regain function. But this hasn't happened. Right now she is totally dependent on dialysis and her liver is not functioning, so she will most likely need a liver transplant to survive.
>
> The dialysis she's getting is not something that will help recover her kidneys, the resident says. It's something that replaces her kidneys. Sometimes the kidneys restart after a while, and then the dialysis can be stopped, but in any case, it functions instead of the kidneys rather than improving their function. Linda [palliative care physician] says that another way to frame it is that dialysis is not a treatment for kidney failure, but a treatment that comes instead of kidney function, in cases where the kidneys don't work.

By contextualizing, i.e. representing the patient's overall medical condition, the resident and the palliative care physician gained more control over the discussion. They not only presented the most recent medical conclusions—that the cause of the illness was alcohol and not an autoimmune disease—but also mentioned the previous hopes that they had for liver and kidney recovery, which did not materialize. They emphasized that the patient was in decline and also clarified (twice) that dialysis would not be a long-term solution. Several days later, when the patient's blood pressure dropped and did not allow dialyzing her, the family experienced this as an expected progression of the disease and the patient died shortly after.

Take another example for a contextualization that changed family members' initial intuitions. Mr. Lipset, a white man in his 70s, suffered from Congestive Heart Failure. I first saw him when I accompanied Carol (a palliative care nurse) to a meeting with him, his son, and his wife. We walked into Mr. Lipset's room and after introducing ourselves, Carol said we could either hold the meeting in the room or find another location.

> The son, looking a bit angry—or perhaps he's just anxious?—says that his take on the whole thing is that his father simply needs rehab. 'We've already been in this situation,' he says. 'A cardiologist told [my father] that he had six months! And that was two years ago! But then he went to rehab and his physical condition really improved. He came back home and he was extremely energetic, in great condition. But then, you know, he didn't do much with himself, and he stayed home all day, in his armchair, watching T.V and being lazy—and his condition [declined] again. So if we only get him rehab and improve his condition again – this will change everything.'
>
> Mr. Lipset is lying in bed, appearing rather thin. He looks at his son and Carol, seems to nod silently as the son says he should go to rehab.
>
> Carol responds in a very calm tone of voice—quite a sharp contrast to how the son speaks. She says, 'I will answer your question, but I suggest that we move to another room where we can all sit, if this is okay. The social worker will join us there.'

Mr. Lipset's son had a very clear view on what led to his father's condition, and Carol had to respond to it in some way. Leaving Mr. Lipset in his bed, the son, wife, Carol, and I went to the conference room down the hallway. Two residents from the medicine unit joined us, both appeared tired and one nearly fell asleep as Carol, the son, and the wife talked. Carol introduced herself again and asked about Mr. Lipset's living situation and his life story. She then talked about what the son had said when they were still standing in Mr. Lipset's room, still characterizing it as a "question":

> 'Now I want to answer your question. You are talking about how your dad was two years ago. And two years ago, with rehab, he was able to

> gain back some of his function. But this is not the case now. Because according to the tests that we did, his heart is very weak. His disease has progressed, and he is not in the same condition he was two years ago. And you can see it by the fact that he doesn't eat well and that he's lost so much weight. Usually you can see a lot by just looking at people; you can see much more than you would see in a medical test: he is so thin because his heart cannot pump blood to both his kidneys and his brain.'
>
> The son and wife listen quietly, and Carol continues: 'In his condition right now,' she says, 'he is not going to benefit from rehab.'

Carol set the context for the discussion that followed: she confronted Mr. Lipset's family with her diagnosis and presented it as a hard medical fact. This contextualization conditioned the rest of the interaction: from that point on, the conversation was about what they should do given the fact that Mr. Lipset's condition would not improve. Contextualizing was a technique, which tamed the son's agency: it did not fully determine his position on Mr. Lipset's care, but it did put certain limits on it.

Practices of question phrasing, framing, and contextualizing mark out an implicit approach to what agency is. According to this approach, human agency is circumstantial: it does not only depend on patients' and families' characteristics, but also on the interaction between them and the clinicians. Clinicians knew they could influence patients and families and deliberately used their influence to construct patients' and families' agency.

3. Handling "No"s

Seeking the communicator

I have so far used a clumsy phrase—"patients-and-families"—to refer to all the people who discussed decisions with the medical staff. There were many cases, however, in which families disagreed among themselves, which made economization—and conversation in general—very difficult: different family members presented different views about the patients and how they would want to be treated. I heard numerous stories on cases where a palliative care team and a family reached agreement on how to treat a certain patient, just to confront a "new" opinionated daughter, son, or sibling who flew in from the other side of the country and opposed all of the decisions that they had reached. Even when all family members participated in family meetings from the beginning, they could see things very differently. Frustrations, tensions, and angers from time immemorial tended to surface when families faced such a difficult decision, making conversations extremely difficult.

The most basic strategy palliative care teams adopted in such cases was to identify a single key family member, who they thought was closest to the patient or most authoritative, and ask her (or him) to be the family representative. They reduced a plethora of potentially contradictory opinions of multiple people to the voice of one person and encouraged families to discuss things and settle internal disagreements before meeting with the medical staff. This was an important dimension of taming patients' and families' agency: by designating one representative to each family, palliative care clinicians made families' agency more consistent, coherent, and manageable.

Take the counter-intuitive example of Carol's conversation with Mr. Lipset's son. Carol chose to talk to Mr. Lipset's son and wife without Mr. Lipset, although Mr. Lipset was clear enough to participate in a conversation and stayed in a private and sufficiently large room. Recall that initially, Carol mentioned they could hold the meeting in his room: "[Carol] says that we can do [the meeting] here or see if there's a family room where we can meet." But after the son said he wanted to send Mr. Lipset to rehabilitation, she suggested that 'we move to another room where we can all sit, if this is okay. The social worker will join us there.'

> 'Would that be okay with you?' [Carol] asks Mr. Lipset, who looks a bit confused from the fast exchange [between Carol and his son]. I personally feel a bit confused too. This is a pretty intense beginning of conversation [the son looking anxious and insisting that his father should go to rehab], which I didn't really expect. Mr. Lipset seems to nod and says, 'it's okay if they meet with you.' Carol says, I promise that you'll hear everything that we'll talk about here.' The son nods, and the wife appears to defer to him. We all leave the room.

Most of the conversation during the meeting was between Carol and the son, and the wife was far less involved. At the end of the meeting, after they reached a decision to transfer Mr. Lipset to an inpatient hospice, the son asked Carol about whether and how to communicate the decision to his father:

> [Son] says he's worried about what exactly we're going to tell [Mr. Lipset]. […] 'I don't want to make him feel […] that he's going to die soon. So maybe we can tell him that we're moving him to a rehab facility, which is true, because he could get physical therapy there.' Carol hesitates […]. She says that we can tell him that we're moving him to an inpatient facility where they'll take a good care of him—which is true—and that if he gets better he'll be able to go back home, which is also true. Carol mentions things that they will stop doing [at the hospice]: they're not going to check his blood sugar so frequently—she says [that] since he's at the end of his life, it's not that important to monitor his sugar right now. The son says he's surprised that they have [done that], because he eats so little that he hardly ever needs insulin.

> Carol mentions a few other medications that they're going to take him off of.
>
> [Back in Mr. Lipset's room], the son is telling Mr. Lipset that they'll try to find him a place where he can do some physical therapy and improve his condition, because he can't go home the way he is now. Nathalie [resident] and Carol walk [in] together […]. [Carol] shakes Mr. Lipset's hand and tells him that he has a great family. He nods and smiles. Carol says, 'I don't know what you did right with these guys, but apparently you did something right. They really want your best interest,' she says, […] 'we were talking about how to give you the best care that we can for your condition, and we will now work on finding a place where we can do that.' He nods.

Carol did not choose to talk to the son because he had a more favorable opinion on hospice. At least initially, he seemed adamant to pursue more rehabilitative and curative care, in order to bring his father back to his previous condition. But in this situation, when a "no" appeared to have been uttered, she decided to confront the son with his father's diagnosis in a separate room. Statements such as, "he's at the end of his life" were easier to make when the subject of the conversation was not around. Ultimately, it was Mr. Lipset that she bypassed: Carol and the son sought ways to tell him a truth without telling all the truth, and did not say "hospice" or "dying" next to him. They enacted a Goffmanian boundary between the backstage—the conference room behind a closed door—and the front-stage—Mr. Lipset's room. The conference room was an area where Carol and the son prepared for their performance in Mr. Lipset's room.[12]

I documented several opposite cases, in which palliative care clinicians insisted on empowering *patients* to speak in order to bypass the agency of their family members.[13] Ms. Ju, a quadriplegic woman in her 80s, was hospitalized at Private Hospital for aspiration pneumonia. After 48 hours in the ICU her condition improved, and she was transferred to the step-down unit. Yet the clinical staff was confident about how the rest of her life would look: she was likely to suffer from repeated incidents of aspiration pneumonia, which her weakening immune system would be unable to control; she would be hospitalized more frequently for longer and longer periods.

A day after a meeting with Ms. Ju and her three children, the palliative care team discussed its outcomes:

> Resident: We tried to have [Ms. Ju] participate. She [responded] with her eyes. One blink is yes, two blinks are no, and she also tries to talk.
>
> Attending [interrupts her]: The first part of the meeting was futzing with the ventilator, which was clear the son really enjoyed. That was much better for him that we were messing with the vent.

> Resident: We couldn't get from the son exactly what he wanted—when we asked him, he said that he didn't prepare a statement for this occasion. [people laugh] 'I haven't prepared anything, so I have nothing to say'—it was really strange.
>
> Attending: The daughter was nicer—I hate to put it in normative terms—[…] but she gave me a little bit of information. […] I think what's happening is that with old patients who end up being incredibly medically dependent but are not totally impaired [i.e. are able to participate in medical decision making], we tend to notice the really grey line between encouragement and coercion. You know, […] I gave [the patient] ample opportunity to say "I'm done here", and she can't quite say it. It's clear […] she can't say "I've had enough" before the family accepts that.

Several other people in the room agreed with the attending that Ms. Ju probably wanted to transition to comfort care and her children (her son in particular) pressured her not to. (These opinions, however, were not independent of the attending's—since he left a note in her medical chart, which they read.) The attending decided to visit Ms. Ju's room when her children were not around to hear what she genuinely thought. A few hours later, I observed their interaction: the attending said that the doctors were "totally fine" with the plan to treat her pneumonia, but that he still thought that 'you didn't get the space to talk about what you wanted yourself.' And still, when he asked her 'is that true, do you feel this way?' Ms. Ju blinked twice, signaling that she disagreed.

> Outside Ms. Ju's room, I wonder how [the attending] would interpret what she just signaled him. As far as I could judge, she completely refuted his suspicion that the son didn't allow her the space to make her own decision. A small circle emerges by the nurse station—the social worker, the case manager, the resident, and the palliative care attending. The attending says that there is also a matter of altered agency here. […] The son influences her a lot, and she doesn't have enough space to say that she's actually had enough. […] [I] just talked to her when she was alone, but she still doesn't feel comfortable to say it.

While the attempt to talk to the patient alone did not lead to a different conclusion than the one reached in the family meeting, it illustrates a method that palliative care teams use: bypassing one communicator's outright resistance. When a family member said "no," there was a possibility to talk to another family member—or to the patient herself. When the patient said "no," it was possible to approach them through family members or other supportive parties. Regardless of what a patient said, it was almost always possible to maintain that she or he was unfairly influenced by others.

At the same time, it is not that palliative care clinicians listened to the party that was most open to economized dying. They were, quite simply, likely to engage with those

patients and family members who were most open to engagement. Mr. Lipset's son, for example, at first seemed resistant, yet Carol identified him as a potential person with whom she could communicate. By contrast, Ms. Ju's son was "really strange" and hence a disfavored communicator. Yet when palliative care conversations did develop, their outcome usually pushed decisions toward economized dying. By consequence, the people who engaged in these conversations were more likely to be the parties who would lead the transition from curative to comfort care.

Revisiting and validating

Another technique to deal with resistance was treating it as one phase in a long and still ongoing conversation. Refusals to sign Do Not Resuscitate forms, for example, were not taken as final words in a discussion, but as positions that could change as time passed, the discussion developed, and the patient's medical condition persisted or declined. When families did not decide to withhold some life-sustaining treatments on the first meeting, second, third, and fourth meetings could be called, and the topic could be revisited. Take, for example, the case of Mr. Richards, who was hospitalized, minimally conscious, after suffering a series of strokes. By the time the palliative care team began consulting on his case, he started having seizures. He was nourished through a PEG tube,[*] which a surgeon had inserted several weeks earlier, but in his delirium, kept hitting and pulling it out. The alternative to removing the tube and stopping artificial nutrition was restraining him to bed, which the medical team was reluctant to do. At a meeting with the family, the medicine unit's attending physician, Dr. Wright, insisted that they needed to transition Mr. Richards to comfort care. The day after, at a staff meeting of the palliative care team, I saw that many disagreed with his approach.

> Nurse: So we had a family meeting with Dr. Wright yesterday, he was the attending physician [on the floor]. They [the family] really insisted that they wanted [Mr. Richards] to be full code.
>
> Social worker: You know, I actually appreciated their position there. Wright was there for half an hour, and he came from the place of "okay, this is my agenda, this is what I think we have to do." And he talked for most of the time, and didn't really listen to them. […] I got the impression that this family was very well educated and very thoughtful, and that they've given it a lot of thought. Wright just didn't listen to them, he was talking all the time and there was no conversation for about half an hour, until he left. […] We should keep talking to this family, this conversation is just not over yet.

[*] PEGs tubes are inserted surgically into the stomach and provide artificial nutrition directly to the digestive system. This is a common way to provide long-term artificial nutrition to patients who cannot eat.

The family's insistence on keeping Mr. Richards full code despite Dr. Wright's recommendation did not lead the palliative care team to withdraw from the case. Two elements were particularly important: first, the social worker's impression that the family was "very well educated and very thoughtful." Within palliative care practice, thoughtfulness was a highly valued cultural capital: unlike Ms. Ju's son, who palliative care clinicians thought was "strange," the Richards family was appreciated. Second, the palliative care team sensed that the attending physician did not handle the conversation well, did not listen to the family, and did not let family members express themselves. Seemingly, the palliative care team appreciated the family more than it appreciated Dr. Wright. The statement that "the conversation is just not over yet" and the decision to continue meeting the family were illustrative palliative care moves: even when a family or a patient insisted on continuing certain life-prolonging interventions, palliative care teams could continue talking to them and revisit their refusals.

However, when patients consented to economization, palliative care teams did not revisit their decisions, but validated them. For example, when a daughter of a cancer patient gradually consented to forgo curative and life-prolonging treatments, the palliative care fellow endorsed each of her decisions and emphasized they were "very good":

> The daughter asks about antibiotics; she has a UTI, do you think we should not give more antibiotics and fluids to her? Sarah [palliative care fellow] says she doesn't think we should, because it wouldn't really help her at this point. The daughter nods. 'Do you think I'm making good decisions?' she asks Sarah. Sarah nods and says quickly, 'I think you're making very good decisions. Very good decisions.'

In another case, a palliative care social worker validated the decision of another woman, who explicitly mentioned that her family was critical of her choice to transition her father to hospice care:

> [The daughter] tears a bit, but still manages to control herself. She asks Hanna several times if she thinks she's doing the right thing, and Hanna says she does. The daughter says, 'this is not really accepted where I come from; my cousins were telling me that I'm killing him, and that I need to wait until God helps him, but I understand that going to hospice will be better for him.' Hanna nods in affirmation.

All end-of-life decisions are difficult. Prolonging life may lead people to question whether this life is worth living. Economizing dying may involve much guilt and remorse. The professional predisposition of palliative care clinicians is to promote economization: from the perspective of palliative care, signing a DNR/DNI form, transitioning to comfort care, and forgoing hospitalizations or other forms of escalation of care are actions that end and seal decision-making. In many cases,

however, the rejection of economization is treated as an ad-hoc position, which invites further discussion.

Lubricating and trialing

Two additional palliative care techniques were *lubricating* and *trialing*. Clinicians "lubricated" in cases where a family was generally open to economize dying, but wanted certain procedures done first. For example, the family of Ms. Hauser, a patient with a brain tumor whose ability to participate in conversation declined very fast, leaned toward accepting a care plan of hospice and no further escalation of care. Yet during a palliative care consult they said they wanted to do an MRI before transitioning her to hospice:

> The daughter […] asks if it won't make sense to do an MRI, just to know if the tumor has grown and how much. [Palliative care physician] nods, says, 'I wouldn't recommend on it, and I'll tell you why. We do MRIs when we think that the result that we'll get can change our decisions on a certain case. And in this case, if the MRI says that the tumor has grown, it's not going to change our plan for her. So I wouldn't *recommend* [emphasizes] on an MRI in this case. But, I actually just had a conversation about when to do an MRI in such cases. [Sometimes] families need it for reassurance, and this is something that I can understand. Is it important for you?' He asks the daughter.
>
> The daughter says that she thought that if they just knew whether the tumor has grown by 8% or 2%, it would give them a sense of what's going on, how the disease is progressing. [Physician] nods, says that he can understand that, if it's important to her, he's open to the possibility.

MRIs are expensive procedures, and insurance companies do not pay for them unless a doctor confirms that they are necessary. The daughter said she needed the MRI to satisfy some general curiosity the family had about the disease's progression—a reason that an insurance company was unlikely to accept.

> The daughter asks if the insurance would cover that, […] tells [the palliative care physician] about [Ms. Hauser's] coverage. […] [He says,] 'usually we don't have problems with this company, I think they'll approve it, we'll just have to think how to justify it to them. The other thing is whether it's worth it for the patient, because the MRI is a really intense experience: it's lying down on the table there, and it's noisy. It's not pleasant. And I see that you're feeling better today, he tells [Ms. Hauser], which is great, but is it going to be okay with you?' She doesn't answer, and the son says, 'she'll be fine with that - she's a fighter.' Physician says, 'okay, I can write this order.' Thinking loudly, he says,

> 'we can tell them [the insurance company] that if the tumor has grown significantly, we would still want to get an oncology consult, perhaps to resect it, and if not - then we'll proceed with the hospice plan.' He says quietly, 'I can order the MRI, we should just think about how to bill for it.' And then adds instantly: 'I mean, not bill-bill. Just how to present it to the insurance company.'

Especially in Private Hospital, where physicians needed to bill directly (since most were not salaried), lubricating involved massaging orders. Lubrication helped smoothen and expedite the decision-making process and was particularly helpful in giving families a "final push" before they endorsed economization: in this case as in many others, it was a way to give families the peace of mind required to economize.

> […] Outside, [physician] tells the resident: 'it's such a pleasure to talk to these people. Every one out of ten patients that I see - I just have to have families like that, otherwise the conservative republican comes out of me, and you can ask Roi that it can happen.' We laugh and she [the resident] smiles politely. […] He tells [the resident] that he prefers to do this MRI: 'maybe I'm biased because I've just made a similar decision with another patient, which was a different case [but a similar decision because in both cases he decided to do an MRI although he didn't consider it medically necessary– R.L.]. But I think it makes sense here. It's a short hospitalization, overall, and if what I need to do to make sure that [the patient] gets discharged on time is to get this MRI - it sounds like a reasonable decision.'

Studying sales interactions, sociologist Asaf Darr analyzed the role gifts play in finalizing transactions. The salespeople that Darr studied offered "closing gifts" when buyers were close to making their final decisions, for example, by adding a software package as a gift to a customer who considered buying a computer. Darr also observed "post-sale gifts," which sellers gave buyers *after* they completed transactions. "The best explanation for the post-sale gifting," Darr wrote, "is socio-psychological in nature. The seller wants to express gratitude for an easy and large sale and to reward the buyer for playing her social role as a buyer to perfection."[14]

"Lubricants" were located somewhere between pre- and post-sale gifts: the palliative care physician agreed to order an MRI scan as Ms. Hauser's family was accepting hospice as a care plan. The physician's reasoning for lubricating the decision with an MRI dovetailed Darr's interpretation: first, 'it was a pleasure to work with these people,' i.e. they have fulfilled an exemplary role as family members of a patient and reached a decision that he thought was responsible, reasonable, and feasible—all in a timely manner. Second, ordering the MRI was legitimate since it saved money by expediting decision-making: it helped streamline medical decisions and ultimately, discharge.

Similarly to lubricants, *trials* facilitated economization. The key difference between them was that *lubricants* were about limiting the *number* of cure-oriented medical procedures that physicians approved, while *trials* were about limiting the *time period* physicians would provide such procedures. When setting a trial, clinicians could determine, for example, that they would wait several additional days before transitioning a patient to comfort care. As a palliative care physician put it in an interview:

> One of the tricks of a palliative care doc is what's called "a trial of therapy." If you're not gonna win the argument—not that it's a win or loss thing—but if you're not gonna, you know, for lack of better words, get your way, set a limit [on] when we are going to reevaluate what we're doing.

Becky, a palliative care physician in Public Hospital, suggested using a trial in the case of Mr. Su, an elderly Vietnamese-American man who was ventilator-dependent in the ICU. In a staff meeting of the palliative care team, she said:

> It's hard, because he's intubated, so he can't speak. You can't really communicate directly with him […], so getting at what he wants is really hard in this situation, even though he's awake. He was really out of it for me, and I don't even know how to say hello in Vietnamese. I should ask my friends. So my hope is to coach the [ICU] team […], to suggest that they frame this as a time-limited trial. […] He's really dependent on the ventilator, and what this might mean is that he'll go to a Long-Term Acute Care facility, and […] I don't even know what will cover the Long-Term Acute Care [LTAC]. [Maybe it] means that he's gonna go to another state somewhere to be on an LTAC. […] There are only several facilities that take medical patients for Long-Term Acute Care. It's a handful of beds, and way more people waiting for them than there are beds.

Becky hesitated to transfer Mr. Su to a Long-Term Acute Care facility for several reasons. First, she was unsure who would pay for the facility (although generally, Medicaid covered it). Second, she suspected that the patient would have to move far away from his family, since there were not enough LTAC beds in the area. And finally, she was generally reluctant to destine Mr. Su to a long ventilator-dependent life, without knowing what he wanted. She suggested the trial as a compromise: keeping Mr. Su on the ventilator for an agreed-upon period, which would allow him some time to improve, and if improvement did not occur—extubating him. Such trials were negotiation tools that palliative care clinicians used with families, as well as with other clinicians: by stipulating a date in which everybody will review their past decisions and evaluate whether the curative treatment they offered proved itself, they increased the probability that people would ultimately embrace economization:

> [In a palliative care staff meeting:] [Physician] says that she made a recommendation to the primary team to increase Ms. Andrews' IV dose of pain meds, and that it will be helpful to meet with the team and define the concept of time limited trial in TPN.[*] She [Ms. Andrews] has just started getting a TPN, which is not unreasonable, but we should decide now how long we're going to try this course.

Trials were particularly significant in cases where, in principle, the treatment provided could continue indefinitely. By setting time limits on this treatment, palliative care clinicians tried to create agreement among families and clinicians over what would count as a sufficient medical improvement to continue life-prolonging efforts and by what date this improvement should show. The construction of such trials facilitated a smoother decision to withdraw life-sustaining measures: trials ensured that everybody involved in the case agreed about what future developments would count as proof that a patient's condition was indeed irreversible and the time to economize dying has come.

Two forms of withdrawal

In several cases when families or patients insisted on life-prolonging treatment, the palliative care team conceded that there was little it could do to make them change their mind. There were two main ways palliative care teams withdrew from cases. First were complete withdrawals, in which palliative care teams accepted that a certain patient would "go down with all guns blazing," as one physician put it.

> Hospice Liaison: Mr. Abel died yesterday.
>
> […]
>
> Physician: Without being fully coded?
>
> Nurse: Nancy dealt with [the case], so I suspect that the ICU got called [about Mr. Abel's code]. [Smiles:] you can't save every starfish, and that one was gonna go down with drama, because his wife was creepy.
>
> Physician: He crashed on Sunday [two days earlier]. Hard.

The nurse's starfish comment referenced a popular motivational story, which was adapted from Loren Eiseley's essay *The Star Thrower*.[†] As a palliative care nurse, she

[*] TPN is Total Parenteral Nutrition—a form of intravenous nutrition.

[†] "A man was jogging down the beach after a major storm had just come through the area. He was dismayed by the huge number of starfish that the storm had washed up on the beach. He thought that there was nothing he could do because of the immense numbers. As he continued down the beach he saw an old man throw something into the water. As he got closer, he saw the old man walk a little farther down the beach, bend over, pick up a starfish and throw it back into the water. As the jogger approached, the old man stopped

was surrounded with cases of patients dying painful and terrible deaths, but could not save all of them. She accepted that every once in a while, despite her best efforts—and for reasons that she could not control (e.g. a "creepy" wife)—she failed to "save" patients.

In some cases, palliative care teams withdrew their involvement completely and removed the patients from their list. In others, teams continued consulting on the case, but restricted their interventions to technicalities such as sympthom management. Ms. Davis, who had terminal cancer, enrolled in a phase-one clinical trial. (Phase-one trials involve testing drugs' side-effects and determining their safe dosage—which for one thing, means immense suffering, and for another, is almost certain to provide no life-prolongation.)

> Pharmacist: Ms. Davis is now on a clinical trial, phase one experimental chemo. […]
>
> Fellow: [looks at her chart] I see she has nausea, and maybe we can treat her for the nausea and then step back.
>
> Attending: [laughing] Treat her nausea—and then that's it—she's palliated!"

The palliative care team took Ms. Davis's enrollment in the trial as a sign that she was completely dedicated to pursuing the most extreme and aggressive treatment in existence. For them, this was the ultimate and most unequivocal rejection of economization, and they restricted their interventions to technical symptom management, without talking to her and her family about "goals of care."

The second form of withdrawal was what I term *engaged withdrawal*: palliative care clinicians still remain involved in the case, even though they did not fully influence decision-making. Take a particularly illustrative case:

> Hanna [palliative care social worker] says that Mr. Chang's family has been really, really difficult. 'They take a wonderful care of him, but everything goes very hard with them: in meetings there are sometimes 10 different people in the room, some of them children, and all of them have questions to ask. […] They [prepare] flashcards with questions, and they have some system, they take turns asking questions from the flashcards.' "Like, what questions?" I ask her. They ask about this blister that suddenly appeared on his pinky! She says. 'What should we do

---

again, bent over, picked up another starfish and was about to throw it into the water. The jogger stopped and asked 'Why are you doing that? There are thousands of starfish on the beach. You can't possibly make a difference.' The old man looked at the starfish, threw it back into the water, then replied, 'I made a difference to that one, didn't I?'"
I quote this version of the story from the website of George Mason University's IT department. http://mason.gmu.edu/~ctemple/Portfolio/documents/starfish.pdf [last accessed April 25, 2016].

> with that? And then when you actually look at it you see that it has already disappeared,' she laughs.
>
> [Later] in the office, with Sarah [fellow] and Kathy [resident], I hear more details about the last meeting they had with the family, which Hanna apparently felt uncomfortable sharing in the hallway. Sarah says that during that meeting, she kept [saying], "let's look at the big picture", [but] they asked her to look at the blister that popped up on [the patient's] penis. Sarah laughs, 'I had to look at the blister and tell them that it's okay.' Hanna says that they even insisted that she look at it too, and she closed her eyes, leaned forward, tried not to burst out laughing, and said 'I think it's good, I think it looks really good!'
>
> Hanna says that the hepatology team stopped passing there in rounds—they're avoiding the family as much as they can. The family looks through the door, waiting for them to come as they walk down the hallway, and then the team just sneaks by the room, without entering it.

The palliative care team classified the family as "detail-oriented"—and while this case was an extreme example, they referred to many other families and individuals similarly. Such families insisted on discussing specific problems rather than talking about the patient's overall condition or disease trajectory, and consequently, it was hard to talk to them about dying. But Hanna stayed in touch with the family even when it was clear she had little ability to influence them:

> 'And the family asks me, "are they skipping us on rounds?" And I say, "Oh no, what makes you think so? Of course they're not passing over you!"' 'Nobody can bear them,' Hanna says, 'but I actually like them.'
>
> 'How can you handle them?' Sarah asks her. 'They just fascinate me,' Hanna replies, 'their system of who speaks when and asks what questions is just incredible.'

Hanna found the family intriguing and entertaining, which made her continue seeing them. But this was idiosyncratic: other clinicians "couldn't bear them." In another case at another hospital, a palliative care nurse continued seeing an ICU patient who battled multiple organ failures, and used his dialysis catheter to inject heroine. Just like Hanna, she felt personally attached to him, even though she did not believe she would convince him to embrace economization.

Knowing how and when to withdraw was no less important than knowing how to talk to people. In his lecture at the continuing education conference, Sean emphasized that in cases where clinicians felt very strongly about economization, they needed to know how to step back:

> 'It's common to become frustrated. A doctor came and told me, "I'm having a family meeting every day and we're not getting anywhere." So I tell him, 'Stop. Take a step back. All cases resolve, eventually. Even Mrs. Jones will die eventually. Take a step back, relax, stop having family meetings if they're not going anywhere.' Sometimes disengagement will help you.

Disengagement did not only allow clinicians to relax and recuperate, but also gave families and patients some time in which they did not have to push back against economization. It eased tensions and gave everyone an opportunity to put down their defenses and think independently. Ultimately, this could also serve the purpose of economizing dying.

Conclusion

From a palliative care perspective, treating patients' and families' wishes objectively did not mean abstaining from influencing them. Clinicians recognized their role in constructing patients' and families' agencies and saw influencing them as part of their job. In the process, they avoided using certain vocabulary and formulae, deliberately employed other vocabulary and formulae, controlled the medical information they provided about the patient's condition and treatment, chose which party in the family to talk to, revisited decisions to escalate care, and used *lubricants* and *trials* to smoothen the decision-making process.

These practices did not suppress families' and patients' agency. For one thing, confrontations were strongly discouraged, and when they did happen, they were seen as mistakes. Furthermore, the acknowledgement that one could not "save every starfish"—and multiple instances where palliative care clinicians withdrew from cases—reflected patients' and families' relative autonomy from clinicians. At the same time, clinicians heavily influenced this autonomy. The consent achieved in clinician-family-patient interactions was circumstantial: what people thought and wanted partly depended on how clinicians approached them, how they phrased questions, what interpretations they shared, and what medical options they presented. Consent was not a voluntary endorsement that autonomous patients and families gave to certain plans of care; it was rather a recursive negotiation process in which statements that patients made could gradually be transformed into a consent to die. Family meetings were sites where agencies consolidated, and clinicians had much impact on this consolidation process.

A comparison of the different cases that this chapter presents reveals the social inequalities structured into such construction processes. Palliative care practice is mostly verbal: the bulk of palliative care work consists of talking. Conversational skills, friendliness, reason, intuitive understanding, and ability to control and express one's emotions are all socially variable qualities, which some people have and others

do not. Expressing oneself in a way that makes sense to clinicians, and does not manifest itself as “strange” or “creepy,” in the medical setting is not obvious, especially for people who deal with situations as difficult as the death of a loved one. This puts families and patients who feel comfortable talking, expressing themselves, and showing emotion at an advantaged social position. Not only are they able to articulate themselves better and reach better and more consolidate sense of who they are and what they want, they also enjoy the acknowledgement and respect of the medical staff.

Conclusion

> Consider modern medicine, a practical technology which is highly developed scientifically. The general 'presupposition' of the medical enterprise is stated trivially in the assertion that medical science has the task of maintaining life as such and of diminishing suffering as such to the greatest possible degree. Yet this is problematical. By his means the medical man preserves the life of the mortally ill man, even if the patient implores us to relieve him of life, even if his relatives, to whom his life is worthless and to whom the costs of maintaining his worthless life grow unbearable, grant his redemption from suffering. […] Yet the presupposition of medicine, and the penal code, prevent the physician from relinquishing his therapeutic efforts. Whether life is worthwhile living and when—this question is not asked by medicine. Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside, or assumes for its purposes, whether we should and do wish to master life technically and whether it ultimately makes sense to do so.
>
> Max Weber, *Science as a Vocation*[1]

These poignant words, which Weber included in his famous 1918 lecture, testify that the challenge of economizing dying far predated the U.S. movement for hospice and palliative care. Beyond any specific discussion on death and medicine, the economization of dying touched upon fundamental modern quandaries: how far scientific progress can go, what issues it can and cannot solve, and what relationships develop between science and human values. Weber argued that science could *not* answer moral questions, and by consequence, modern medicine could not determine "whether life is worthwhile living and when" and "whether we should and do wish to master life technically." The moral values that physicians and other "men of science" followed did not derive from scientific reason, but from a "presupposition," which originated elsewhere, that life should always be prolonged and death should always be postponed.

One thing that has changed since Weber's lecture is that some fractions within the medical profession have embraced new moral presuppositions, which contradict the old one. The movement for hospice and palliative care has spread the idea that when it comes to end-of-life care, treating less is oftentimes treating better, and "the task of maintaining life as such" is no longer the single and ultimate moral principle that underlies medical practice. There are today several groups of medical specialties,

each pursues different moral ends rationally while making others account for their own presuppositions.

Seemingly, this corresponds to the liberal political framework, which Weber advocated.[2] Yet other things that have changed since the early twentieth century complicate this picture both empirically and analytically. These changes mark out the new moral economy of death that has developed in the U.S. and help understand a new relationship that has emerged between science, morality, and economy in late capitalist societies.

From oikos to economy

The moral concerns that Weber discussed were financially embedded. This embeddedness, however, was on the level of *private* household finance. Weber described families' struggle to pay the "costs [of] maintaining [a] worthless life" as an absurd situation, which medical progress created and could not solve without extra-scientific moral guidance. Decades later, economization became a macro problem. The chief economic concern of advanced capitalist societies is not how to create more wealth, but how to manage, control, and allocate the wealth they have already created.[3] In medicine as in other areas, policymakers confront the challenge of governing progress: controlling industrial development and making it environmentally sustainable; moderating the consequent rise in inequality and easing boom-and-bust cycles; taming healthcare progress and mitigating the growth in medical utilization and spending. Advanced economies face an endemic problem of *excess*;[4] in the domain of healthcare, this problem assumes the form of too much care, which is being given to too sick people for too long periods.

Countries with centralized healthcare systems have orchestrated economization through central planning. The UK's National Health Service (NHS), for example, adopted a comprehensive metric—the Quality Adjusted Life Years (QALY). It administers surveys where people rank how they value life in severe illness and disability, calculates the QALY that various treatments add on average, and estimates the costs of these treatments. Based on these calculations, NHS rules which treatments are cost-efficient and should be funded and which treatments do not justify their cost.[5] The state, through centralized means, counteracts the unsustainable tendencies of the market.[6] The U.S. healthcare system, by contrast, is highly decentralized: it comprises a myriad of insurance companies, hospitals, nursing homes, and physician networks, each has different policies and standards for cost-efficiency. Healthcare costs in the country are the highest in the world, partly because they are extremely hard to follow and control.

In this context, where economization through central planning seems impossible (and has indeed failed several times), an economizing medical specialty, which imbues hospitals, medical schools, insurance companies, and the common sense of many

patients and families in the country may have an enormous power. Beyond its potential ability to control the rise in healthcare spending, hospice and palliative care moralizes economization, presenting it as a moral as well as a fiscal imperative.

Ironically, there is evidence indicating that this potential is not being fulfilled. Joan Teno and colleagues showed that in 2000-2009, utilization of palliative care and curative care rose in tandem. On the one hand, rates of *hospital* deaths *declined* from 32.6 to 24.6 percent, while *hospice* deaths *climbed* from 21.6 to 42.2 percent. Yet on the other hand, more hospice patients were transferred to hospice in the last three days of their life (4.6 percent in 2000, 9.8 percent in 2009); people were more likely to be hospitalized in the last three months of their lives (62.9 percent in 2000, 69.3 percent in 2009); more patients received ICU care in the 30 days before their death (24.3 percent in 2000, 29.2 percent in 2009); and cancer patients were more likely to receive mechanical ventilation in the last month of life (5.9 percent in 2000, 6.7 percent in 2009).[7]

The new moral economy of death has so far not *replaced* the old one, but developed next to it. Clinicians continue treating severely ill patients curatively—by some measures, even more invasively and aggressively than in the past—and when this treatment fails, pass patients to hospice.[8] The common dying trajectory in early twenty-first century U.S. is of a patient who receives much invasive curative care at a hospital, then passes on to receive much hospice and palliative care. The healthcare system provides more of everything: patients quite naturally move from a curative moral economy of intensive care technologies, chemotherapies, and surgeries to a palliative moral economy of hospice and comfort care. Both economies extract financial value from the process, and both rely on elaborate moral reasoning to justify their clinical practice.

A moralizing specialty

What is the role science and specialists play in the new moral economy of death? As Weber contended, scientific thinking, rational professional thinking, and rational thinking in general cannot answer moral questions. At the same time, this book shows that the essence of hospice and palliative work is addressing moral questions through professional means. Even if palliative care clinicians cannot answer moral questions rationally, there is much moral work that they do: first, they configure a homologous relationship between moral values and a financial program. The hospice and palliative care agenda led to a situation where organizations, clinicians, and patients do not have to choose between moral values and financial efficiency: economization is financially efficient as much as it is moral and pursuing one means pursuing the other. Second, palliative care clinicians facilitate moral reflections among patients, families, and clinicians, which increase the probability that they would embrace economization. They bridge between the general moral economic

logic of economization and people's personal views and experiences. The techniques that I outlined did not always succeed to make people embrace economization. Sometimes, economizing dying failed. At the same time, on average, palliative care clinicians did manage to tilt patients' subjectivity in more economized directions. Had they not been able to do so—hospital administrations would not have hired them.

The new moral economy of dying that hospice and palliative care created is particularly intriguing sociologically, since it developed in a realm of moral indefiniteness. As the clinicians that I studied said multiple times, there are often no clear and categorical rights and wrongs in end-of-life care. Palliative care clinicians tried to do what they thought was moral in situations that oftentimes did not have clear solutions. To a great extent, they were damned if they did and damned if they didn't: when prolonging the life of a seriously ill patient—they could be blamed for torturing her and serving the profit-driven medical-industrial complex. When they allowed a seriously ill patient to pass away—they could be rebuked for managing a death panel, which possibly served their hospital's financial interest.

At the same time, by bridging between economized dying and people's intuitive moral sense, palliative care clinicians cut through this Gordian knot of end-of-life care. Talking to patients in ways that tended to elicit preferences for more moderate medical interventions meant that palliative care clinicians not only economized dying, but also facilitated people's *consent* to economization. This was not "consent" in the superficial formal legal sense, used to described standard "consent forms" that hospitals and clinicians require patients to sign before they provide treatment. It is rather a deeper sociological consent,[9] which is anchored in people's sense of self: their emotions, their hopes, and their fears. A successful palliative care consult ended not with palliative care clinicians making the patient economize dying, but with the patient and their families willingly adopting an economized dying trajectory, because they realized that this is what they genuinely wanted.

The power of palliative care can very well be characterized as a Foucauldian technology of self: it does not oppress people – but acts through the ways they define and think of themselves. In Nikolas Rose's words, it is not a power that coerces norms and behavioral patterns upon people, but a power that conducts people's conduct.[10] Palliative care handles a plethora of intuitions, inclinations, hopes, and caprices that patients and families may have: on the one hand, it tames them by taking potential possible courses of treatment out of patients' realm of choice. On the other hand, it walks them through the process of coming to terms with severe illness and deciding how to handle it. It sets people on a course of articulating clear values that define them as people, documenting these values in formal forms, and by that locking and cementing them, making patients' and families' agency more solid and consistent. In this process, people come to articulate to themselves and to others who they are and what they want. Palliative care clinicians very much inform this articulation: it confronts people with the expectation that they reflect on themselves, formulate opinions that represent them, make choices, and plan ahead so that they can follow

these choices. The power of palliative care clinicians lies in the deeply empathetic and loving way in which they pursue this productive governance of subjects: this is what transforms this form of governance from an external constraint on human agency to an internal constitutive project, in which subjects are made.

This power, however, impacts different people differently. Hospice and palliative care had very particular social origins: the people who promoted it were largely white, highly educated, and from middle and upper class backgrounds. The specialty's quasi-psychotherapeutic quality reflects these people's cultural tastes, which still underlie much of palliative care's professional logic. Consequently, there are very particular social groups whose intuitions resonate with palliative care, and who feel "at home" when talking to palliative care clinicians. The people whose cultural and social capital matches the expectation to reflect existentially, who feel they need to articulate and voice an inner self, which they feel they have, and who feel comfortable talking with clinicians about themselves will act and communicate in the hospice and palliative care way and feel comfortable. People who are unclear about their wishes; people who do not trust the medical establishment and whom medicine discredits; people who do not have family members or friends who know them well and feel comfortable representing them when they lose consciousness; and people who live their life from day to day, who for any reason do not plan ahead and refrain from endorsing any future commitment are less likely to articulate themselves and have their voices heard and be validated in the decision making process.

Paradoxically, it is exactly the people with valued cultural and social capital that palliative care can more easily conduct and control. Social privilege makes one more pliable to palliative care's management, hence more likely to economize dying. Obviously, from a certain moral perspective, being more pliable to palliative care and to economized death is advantageous: the alternative to economized death is a wild, untamed and unrestrained dying trajectory—so different from the ideals of good death that the hospice and palliative care movement promoted. Economized dying is therefore a very tempting trajectory in an otherwise indefinite moral realm. It provides at least a partial answer to the questions that Max Weber raised.

Notes

Introduction

[1] Palin, Sarah. 2009. "Obama and the Bureaucratization of Healthcare." *The Wall Street Journal*. September 8, 2009.

[2] 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.

[3] NPR, August 12, 2009.

[4] The prize was given by Politifact.com.

[5] Institute of Medicine (2014), p. ix

[6] 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).

[7] This very much connects to what Michel Foucault termed "state-phobia," which characterizes the neoliberal condition: "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).

[8] See, for example, the title (and content) of the aforementioned Institute of Medicine report—"Improving Quality and Honoring Individual Preferences Near the End of Life." Institute of Medicine (2014).

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

[10] While the GOP attacked the Affordable Care Act on many fronts, it is hard to think of a debate as memorable as the death-panels controversy. As I show in the next chapters, with several notable exceptions, such as the Terry Schiavo case, controversies over end-of-life care remained fairly apolitical. Historically, the promotion of hospice and palliative care was a bipartisan effort, very different from other morally charged areas, such as abortions and stem-cell research.

[11] Ariès (1981).

[12] I borrow the term "sociology of expertise" from Gil Eyal. Eyal (2013); see also Eyal and Buchholz (2010).

[13] Gender was an interest that I had, but palliative care clinicians did not seem to talk about much. Many palliative care clinicians were interested in how "culture" affects interaction—using the concept in a manner far too popularized and general for me to endorse.

[14] Geertz (1973)

[15] The specialty's ability to absorb social critiques of medicine and apply them in revised and refined medical practice is indeed impressive.

[16] See Bourdieu (1993)
[17] This is how historian David Clark (2013) defined his position in a book he wrote on palliative care in the U.S. The book was commissioned by the Open Society Institute's *Project on Death in America* (see chapter 1.)
[18] Robbins (1945, p. 16).
[19] See Kierkegaard (1993).
[20] Kübler-Ross (1969).
[21] A more elaborate account of this observation appears in chapter 3.
[22] Sociologists have long challenged the death denial thesis. See for example, Kellehear (1984); Seale (1998); Zimmermann and Rodin (2004); Lavi (2005);
[23] For example, Zelizer (2005); Fourcade and Healy (2007).
[24] 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).
[25] See, Livne (2014).
[26] Becker (1986: P. 147-9).
[27] See, Armstrong (1998). Armstrong and Becker both discuss the moral entrepreneur as socially privileged. The story of hospice and palliative care is more complex, however, since as I show in chapter one, the movement was relatively marginal to U.S. medicine.
[28] As Paul Starr wrote, doctors "serve as intermediaries between science and private experience." Starr (1982, p. 4).
[29] One can think of this tension as characteristic of situations where a general rational logic needs to be applied to individual cases. What seems an unquestionable and necessary measure on the macro-policy level—treating patients less aggressively when their medical condition seems hopeless—may be difficult to implement at the bedside. In the words of physician Gregg Bloche:

> I teach and write about health policy. I've cared for patients and advised public officials on what to do about soaring medical costs. […] I helped to formulate President Obama's healthcare reform plan. So I'm

> painfully aware that our medical spending habits are unsustainable. The numbers are scary – the fiscal equivalent of global warming. Within twenty-five years, if we keep on the current track, we'll be spending nearly a third of our income on medical care, unless we learn to say no to pricey treatments that produce tiny benefits. But don't tell that to me when it's my mother's life that's at stake.

Bloche (2011, p. 1-2)

[30] Steinfels (1974)

[31] Kübler-Ross (1969: 36)

[32] Filene (1998, p. 49). As Steinfels recognized, arguments about denial "cannot be made today without betraying a distressing insensitivity to the climate of our society." Steinfels (1974: p. 1)

[33] Steinfels and Veatch (1974)

[34] Marx (1972)[1845]; Marx and Engels (2001)[1932]

[35] See Kaufman (2005).

[36] Bloche (2011, P. 2).

[37] For example, Gawande (2014).

[38] Peterson (2004, Ch. 3).

[39] On the social construction of social problems see, for example, Jerolmack (2008); Murphy (2012).

[40] Berger and Luckman (1967).

[41] See, Hacking (1999).

[42] For one thing, this use of social constructivism is limited to human agency: it assumes that people unquestionably accept categories such as gender and race as real because they collectively perceive and act on them as such. This approach stops short of grasping the reality of non-human factors, which is particularly important when one studies a phenomenon as absolute as death. Cancer deaths, for example, are clearly objects of cultural interpretation and human practice: the imagery of malignant tumors as unruly foreign tissues that permeate the human body is immersed in cultural meanings and informs medical practice. At the same time, the deadly effects of cancers are independent of human agency and will often play out regardless of how people perceive and react to them.

[43] Latour (1999).

[44] See, Latour (2005).

[45] For a particularly convincing use of this approach to constructivism see Eyal et al. (2010).

[46] Bourdieu (1990).

[47] In Ian Hacking's terms, I am referring to the historical, ironic, and unmasking senses of constructivism. See, Hacking (1990)

[48] Freidson (1970).

[49] Starr (1982: p. 9-13).

[50] Conrad (2007).
[51] This critique resonated with much of the critical scholarship in the social sciences during that period, and most famously, Marcuse (1964).
[52] American Humanist Association (1973).
[53] I borrow the expression from the Institute of Medicine (1997, P. 47).
[54] Payer (1988: p. 124-5); Sontag (1978). On the comparatively aggressive character of U.S. healthcare see, for example: Bunker (1970); Notzon et al. (1987).
[55] Rosenberg (1987).
[56] Zussman (1992: P. 21)
[57] On the gap between the public image of CPR and its actual effectiveness see Timmermans (1999).
[58] Agamben (1998)
[59] We can find such critiques as early as the progressive era (Rosenberg, 1987), yet as I explain below, they did not institutionalize professionally, organizationally, and politically before the 1960s-1980s.
[60] As mentioned above, 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.
[61] This very much resonated with the 1960s mobilization for de-institutionalization, which reverberated in many other medical domains. See, Eyal et al. (2010)
[62] 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).
[63] 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, 2006).
[64] Epstein (1994, p. 103).
[65] For a programmatic discussion of the co-emergence of disciplines and their objects of analysis, see Latour (1994).
[66] This terminology is very specific to the U.S. In other countries, such as France, palliative care and hospice care are used interchangeably.
[67] See, Starr (1982: 347-378).
[68] Rodwin (2011: 102, 110)
[69] Welch et al. (2011)

[70] Starr (1984: 381-8); Schmidt (1999)
[71] Rodwin (2011: 142-3)
[72] Kaufman (2006: 131-146)
[73] Glaser and Strauss (1968: 148-178)
[74] Kaufman (2006: 89-91)
[75] These figures are for Medicare fee-for-service only. CDC data show that in 1989-2007, hospital deaths declined from 48.6 to 36 percent of all deaths. Teno et al. (2013); National Center for Health Statistics (2011: P. 105)
[76] Belah et. al (2008[1985], P. xiv).
[77] Rose (1998).
[78] Arney and Bergen (1984)
[79] Foucault (1975, P. xviii).
[80] Arney and (1984, P. 46).
[81] See Fox and Swazey (2008).
[82] 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).
[83] Arney and Bergen (1984)
[84] It is emblematic that this quintessential attempt to advance *patient autonomy* could only be countered by a lie-of-the-year allegation that the Affordable Care Act was in fact violating *patient autonomy*.
[85] Heimer and Petty (2010); Rothman (1991); Jonsen (1988).
[86] See, Burawoy (1979).
[87] Cf. Foucault (2007).
[88] Althusser (2001, P. 115-120); see also Lahir (2011).
[89] Rose (1998, P. 2)
[90] Heimer and Staffen (1998); Timmermans and Buchbinder (2010).
[91] 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.
[92] See Foucault (1991); Rose (1990); Rose and Miller (1992).
[93] Livne (2014)
[94] Interestingly, Cicely Saunders made a very similar point about 50 years earlier, when reflecting on her pioneering work at London's Saint Christopher's Hospice. (Saunders 1969).

[95] Glaser and Strauss (1965); Sudnow (1969).
[96] Zussman (1992)
[97] Anspach (1993)
[98] Timmermans (1996).
[99] Kaufman (2006). Kaufman conducted her ethnography in the late 1990s; she mentioned that at the end of her fieldwork, one of the hospitals that she studied recruited a palliative care specialist. Historically speaking, this book begins where Kaufman's ended.
[100] A similar methodological approach was adopted in Reich (2014). Reich, however, found stark differences between the three hospitals that he studied, while I emphasize professional consistency, which survives the socio-economic and organizational differences that do exist.
[101] Cf. Dohan (2002).
[102] In the state of California, as in several other states, it is illegal for non-academic hospitals to employ their physicians directly. The formal logic behind this regulation is that it decouples physicians medical decisions from hospitals' financial interests. Yet obviously, since this regulation ultimately sends physicians to work independently or in networks, it in ultimately mingles medical work with a different set of incentives. See Rodwin (2011)
[103] Goffman (1959)
[104] On the use of in-depth interviews in multi-site ethnographies see Ho (2009).
[105] Cf. Bosk (1979).

Chapter 1
[1] NHPCO (2012).
[2] Clark (2005, P. 7).
[3] On the declared promises of medicine in the post-WWII decades, see Kaufman (2015).
[4] McGehee and Bordley (1976)
[5] These patients were admitted after hospital physicians or their family physicians diagnosed them as having three months or less to live. See, Saunders (1965)
[6] Clark (2005).
[7] Weber (2002, P. 121.)
[8] Saunders (1969) P. 57, 58).
[9] Saunders (1969)
[10] Saunders (1965)
[11] Saunders (1969)
[12] This challenging of hierarchies stood in interesting contrast to the fact that Saunders held enormous executive powers at Saint Christopher's: she was not only an ultimate professional authority, but also a powerful manager who determined policy almost singlehandedly. See Buck (2005)
[13] Buck (2005)

[14] Saunders (1965).
[15] Saunders, (1969, P. 57, 58).
[16] Saint Christopher's was located in London, and the mention of Ireland is a clear reference to a peripheral and less worldly geographical area.
[17] Worchester (1940).
[18] Worchester (1940, p. 14). Compare, for example, to Gawande (2014); Welch et al., (2011); Bloche (2011 [story about patient who had a tumor but eventually died of something else].
[19] Worchester (1940, P. 18).
[20] Worchester (1940, P. 44).
[21] Baszanger (2012).
[22] Clark (1998, 2001).
[23] Saunders (1960).
[24] Poe (1972).
[25] Zuelzer (1974). This article too was quoted in a Congressional hearing. Medical Ethics: The Right to Survival. Hearing Before the Subcommittee on Health of the Committee on Labor and Public Welfare. U.S. Senate, 93rd Congress, 2nd session on examination fo the moral and ethical problems faced with the agonizing decisions of life and death. June 11, 1974.
[26] Raymond S. Duff. "On Choosing Death," Presentation before the Senate Health Subcommittee, June 11, 1974. Duff was one of the physicians who participated in the hospice pilot program in New Haven (see below).
[27] Filene (1998, Chapter 3).
[28] Buck (2009).
[29] Bourdieu and Wacquant (1992).
[30] On the professional and economic devaluation of feminized care work see England (2005).
[31] See Wald and Leonard (1964); Wald (1966).
[32] This group included Morris Wessel and Raymond Duff (pediatricians), Edward Dobihal (chaplain), Jeanne Quint (a nurse researcher), Claire O'Neil (director of nursing at Yale-New Haven Hospital), and Donna Diers (nursing faculty); Max Pepper (physician and MPH), Olivia Vlahos (anthropologist), and Kathy Klaus (nurse) joined a few months later.
[33] Buck (2005: p. 119).
[34] Buck (2005: p. 124).
[35] Buck (2005: p. 138).
[36] Buck (2005: p. 155).
[37] Buck (2005: p. 161).
[38] Wald and Dobihal appeared at the Foundation of Thanatology conference, the New York City Presbytery Symposiums, and the Conference on Death and Dying organized in New Jersey (Buck 2005: p. 166). Similarly, when the American Journal of Nursing

printed a programmatic article on hospice care, Wald and Craven (a nurse at Hospice Inc.) were its authors. (Wald and Craven 1975).
[39] Buck (2005: p. 167).
[40] Buck (2009).
[41] Buck (2007).
[42] Buck (2009).
[43] Glaser and Strauss (1965, 1968, 1970)
[44] Duff and Hollingshead (1968).
[45] Saunders (1999).
[46] Kübler-Ross (1969).
[47] Filene (1998).
[48] Cf. Abbott (1988).
[49] Buck (2005: p. 168).
[50] "Death with Dignity: An Inquiry into Related Public Issues." Hearing Before the Special Committee on Aging, United States Senate, 92nd Congress, second session. August 7, 1972.
[51] Baszanger (2012).
[52] Holleb (1974), quoted in Baszanger (2012).
[53] Krakoff (1979), quoted in Baszanger 2012).
[54] Buck (2009).
[55] Among these services were "nursing care," "physical or occupational therapy or speech-language pathology," "medical social services," "services of a home health aide who has successfully completed a training program," "medical supplies," "physicians services," "short-term inpatient care," and "counseling […] with respect to care of the terminally ill individual and adjustment to his death."
[56] See P.L. 97-248-SEPT. 3, 1982: 96 STAT. 359-363
[57] OSI is known today as the Open Society Foundation; I am using the organization's name during the discussed period.
[58] Most central among the other funders were the Nathan Cummings Foundation, the Emily Davie and Joseph S. Kornfeld Foundation, The United Hospital Fund, the Fetzer Foundation, the Millbank memorial Fund, the Commonwealth Fund, and the Fan Fox and Leslie R. Samuels Foundation. See, OSI (2004).
[59] Patrizi, Thompson, and Spector (2011).
[60] Lynn (1997).
[61] SUPPORT Principal Investigators (1995).
[62] RWJF first funded SUPPORT in 1986 and continued through 1994. (Patrizi et al. 2011: P. 6).
[63] There were 55 hospitals that applied to participate. (Schroeder 1999).
[64] SUPPORT Principle investigators (1995, p. 1594).
[65] As one of SUPPORT's principle investigators reflected, "At that time, the expert consensus was that uncertainty over determining patients' prognoses and inadequate

understanding of patients' wishes were the key barriers to improving end-of-life care." (Schroeder 1999).
[66] SUPPORT Principle Investigators, (1995: p. 1595-6)
[67] 68-69 percent of families and patients said the care they received was "excellent" or "very good." Ibid.
[68] SUPPORT (1995: p. 1591)
[69] SUPPORT, (1995: p. 1596)
[70] I quote this sentence from the article's abstract. Interestingly, the authors phrased the statement more softly in their concluding remarks: "success will require reexamination of our individual and collective commitment to these goals, more creative effort at shaping the treatment process, and, perhaps, more proactive and forceful attempts at change."
[71] Patrizi et al. (2011: p. 6).
[72] Schroeder (1999).
[73] Soros (1998).
[74] Clark (2013: p. 13).
[75] OSI (2003: p. 18).
[76] Patrizi et al. (1011: p. 11-12).
[77] Aurlino and Foley (2001).
[78] OSI (2003: P. 35).
[79] OSI (2003: P. 55).
[80] PDIA fellow Diane Meier similarly argued that "there's no hope of changing care at the bedside without trained medical faculty in the medical schools—not just scientific content, but also the attitudes, the way of being. If doctors don't learn it from experts in palliative medicine, they won't learn it." (OSI 2003: P. 19).
[81] OSI (2003: P. 44).
[82] OSI (2003: P. 44).
[83] IoM (1997).
[84] Clark (2013: P. 167-8).
[85] These were *Improving Palliative Care for Cancer* (2001), *Describing Death in America: What We Need to Know* (2003), and *When Children Die: Improving Palliative Care and End-of-Life Care for Children and Their Families* (2003).
[86] I counted Gerri Frager, who held both Registered Nurse and Medical Doctor degrees, as a physician.
[87] Clark (2013, P. 14). In addition, only 6% of the fellows were African American and 3% were Asian, although this hardly signified a change from the hospice movement's early days.
[88] Clark (2013: P. 191-3).
[89] OSI (2003: P. 36-8).
[90] A notable figure was Betty Ferrell, who had received a PDIA grant to advance palliative care in nursing homes. This was the HOPE program; see, Clark (2013: P. 94-5).

[91] Laporte, Sherman, and Matzo (2001); Ferrell and Coyle (2001). See Clark (2013).
[92] See Clark (2013: P. 193-4).
[93] Altilio and Otis-Green (2011). See, Clark (2013: P. 239).
[94] Clark (2013: P. 192).
[95] Clark (2013: p. 17).
[96] OSI (2003: P. 27).
[97] Connor (2007-8).
[98] Morrison and Meier (2015). The number has been in constant increase: a 2008 research found that 52.8 percent of the hospitals it surveyed had palliative care services; 72.2 percent of hospitals with over 249 beds had palliative care services and 84 percent of the medical schools were associated with at least on hospital that had a palliative care service.
[99] Morrison and Meier (2015). Grades were awarded according to the percentage of hospitals with over 50 beds that reported a palliative care service in each: A - over 80% of the hospitals reported a palliative care service, B (61-80%), C (41-60%), D (21-40%), F (20% or less).
[100] CAPC gave a D grade to Alabama, Alaska, Arkansas, Mississipi, Oklahoma, and Wyoming. West Virginia, Tennessee, Kentaky, Georgia, South Carolina, Kensas, Texas received Cs.
[101] OSI (2003: P. 65).
[102] Weisfeld, Miller, Gibson and Schroeder (2000). Also, Patrizi et al. (2011).
[103] Clark (2013: P. 71).
[104] Golodetz (1997). I thank Cindy Bruzzese, executive director of the Vermont Ethics Network, for providing me the report.
[105] OSI (2013: P. 49)
[106] OSI (2013: P. 20)
[107] OSI (2013: P. 60)
[108] Aulino and Foley (2001).
[109] Clark (2013: p. 36-7).
[110] OSI (2013: p. 59-60).
[111] Clark (2013: p. 73-4).
[112] In Sartre's terms, hospice expanded "the field of possibilities" toward which an individual such as Soros could act (Sartre 1968: P. 93).
[113] Relmand (1980).
[114] Timmermans and Berg (2003: p. 86).
[115] Kaufman (2015: p. 8-9).
[116] OSI (2003: P. 29).
[117] After the American Board of Medical Specialties recognized Hospice and Palliative Care as a medical subspecialty, physicians who wanted to specialize in the field were required to spend a year as "fellows," which they split between various institutions and teams, and then pass a board examination. Their medical training therefore typically consists of four years in medical school, a year of internship, two years of

residency, and a year of fellowship that they spend in the hospice and palliative care area.

[118] See, Chambliss (1996).

[119] Alex Smith, a physician who co-edited the widely-read palliative care blog GeriPal, reacted to JAMA's 2016 special issue on "death, dying, and end of life:" "we've put in hard work in palliative care to change the frame from 'death, dying and end of life' to 'living well with serious illness.' Wouldn't it be nice to see a theme issue about promoting quality of life for people with serious illness and their caregivers?". Alex Smith, "Reaction to JAMA Theme Issue on Death, Dying, and End of Life." *Geripal*, January 21, 2016. The Center for the Advancement of Palliative Care has done research on how to best present or "brand" the palliative care sub-specialty to people without embracing the label of the death harbingers.

[120] Goffman (1961).

[121] Featherstone, Hepworth, and Turner (1991).

[122] Eva's Jewish identity and my own Jewish name probably led her to make this reference.

[123] Jerolmack and Khan (2014).

[124] In 2010-2011, the center for the Advancement of Palliative Care launched a project entitled Improving Pallaitive Care (IPAL), which aims to intergrate palliative care in a variety of professional settings. As of 2016, the project focuses on three such settings: intensive care, emergency medicine, and outpatient care. See http://www.capc.org/ipal [last accessed April 11, 2016]

Chapter 2

[1] Callahan (2011).

[2] Economic problems, as Çalişkan and Callon put it, are outcomes of economization processes, through which "behaviours, organizations, institutions and, more generally, objects are constituted as being 'economic.'" (Çalişkan and Callon 2009, 2010).

[3] I rely on Bruno Latour's concept, *matter of concern* here. See Latour (2004).

[4] Kübler-Ross (1969).

[5] Kübler-Ross (1969: P. 30).

[6] Kübler-Ross did, however, implicitly expressed such stance in a later Congressional hearing: "Death with Dignity: An Inquiry into Related Public Issues." Hearing Before the Special Committee on Aging, U.S. Senate, 92nd Congress, 2nd Session. August 7-9, 1972. P. 6. For later, contemporary counter-examples, see Mahar (2006); Welch et al. (2011).

[7] "Death with Dignity: An Inquiry into Related Public Issues." Hearing Before the Special Committee on Aging, U.S. Senate, 92nd Congress, 2nd Session. August 7-9, 1972.

[8] "Death with Dignity", *Hearing*, August 7. P. 3.

[9] Ibid. 16-7.

[10] Kübler-Ross (1977), quoted in Cohen (1979: p. 85).

[11] Feifel (1959, 1977)
[12] Kalish (1977).
[13] An interesting exception is Jessica Mittford's (1963) classical account "The American Way of Death," whose witty criticism of how death's mystique in the U.S. led to exorbitant prices in the funeral industry. See also, Vanderlyn and Phillips (1970).
[14] Connor (1996).
[15] Wald (1988), cited in Buck (2011).
[16] For example, McNulty and Holderby (1983: p. 166): "community-based, all volunteer programs that do not have to fit into an organizational structure provide, perhaps, the purest form of hospice care."
[17] Comptroller General (1979: p. i).
[18] In 1978, in a speech to the Association of Community Cancer Centers, Peter Bourne, assistant to the president for Health Affairs, noted "we are aware than an excess of Federal zeal has been known to provide the kiss of death to many perfectly viable efforts, through over-regulation and bureaucratization. Therefore, we are working with the Committee and with the Congress to determine what the appropriate Federal role should be" (Congressional Record- House 10: 1978-0512, P. 13554).
[19] See for example, Glenn (1970).
[20] Comptroller General (1979, P. 21).
[21] This hospice's salaried staff included only two part-time nurses and one part-time secretary, and it reported on $190,000 worth of professional services donated to it. It is likely that 40 other hospices, which were mentioned by the Comptroller General but did not send it financial data, relied on donations and volunteer work as well. Kavanagh (1983).
[22] Cohen (1979); Osterweis and Szmuszkovicz Champagne (1978); Wentzel (1981, P. 107); Davidson (1978, p. 51); Statement of Dennis Rezendes, Executive Secretary, National Hospice Organization. Subcommittee on Health, Committee on Ways and Means, House of Representatives, 6/18, 27/1979. P. 407.
[23] Davidson (1978: P 54-5).
[24] Stoddard (1978: P. 188).
[25] Buck (2011).
[26] Buck (2007).
[27] Buck (2007).
[28] Buck (2007).
[29] Beresford (2007). See also, U.S. Senate. 1978. *A Report of the Special Committee on Aging: Developments in Aging: 1978*. P. 113.
[30] Beresford (2007).
[31] Beresford (2007).
[32] Beresford (2007). One indication for the chasm that began emerging in the hospice movement was Florence Wald's decision to leave Hospice Inc. in 1978. See, Buck (2009).

[33] Beresford (2007).
[34] Beresford (2007).
[35] Carolyn Cassin, founder of a hospice in Battle Creek, Michigan, quoted in Beresford (2007).
[36] For example, Garrett (1978); Wentzel (1981: P. 12); Rosman (1977: P. 205-8). Also, Rep. Robert N. Giaimo, Testimony of Members of Congress at the Departments of Labor and Health, Education, and Welfare, 4/6/1977, P. 595. Hoffman (2012).
[37] Osterweis and Szmuszkoviz Champagne (1978).
[38] Hospices during the period operated in many forms—as inpatient and outpatient services, and as independent and hospital-affiliated organizations—but in general, they leaned towards making home hospice their principle model of care, as part of the effort to demedicalize and deinstitutionalize death and shift the primary site of death from hospitals to patients' homes.
[39] Comptroller General (1979: P. 29).
[40] Hospice Project Task Force (1980). At the same time, the report recommended to update the home health agency authorization guidelines, make them more suitable for the number of RN home visits required for terminal cancer patients, and encourage hospices "to obtain authorization for appropriate services and bill the MediCal program. It also recommended to establish standards for hospice certification.
[41] Statement of Dennis Rezendes, Subcommittee on Health, Committee on Ways and Means, House of Representatives, 6/18, 27/1979: P. 409. Also, Amado, Cronk, and Mileo (1979).
[42] Mor and Barnbaum (1983).
[43] Mor and Barnbaum (1983: P. 81).
[44] Beresford (2007).
[45] Beresford (2007).
[46] U.S. Congress. 1983. Medicare in Florida: Looking to the Future. Hearing Before the Select Committee on Aging, House of Representatives. 98th Congress, 1st Session December 28, 1983. P. 77.
[47] Mor and Barnbaum (1983).
[48] "Death with Dignity." *Hearing*, P. 17.
[49] Wentzel (1980: P. 105).
[50] IHHD (1978: p. 32).
[51] NHPCO (2008-2012).
[52] Whether hospice is indeed cheaper than conventional care is still unclear, and depends on the type of hospice care provided, hospice patients' length of stay, and how costs are defined. See, for example, Mor and Kidder (1985); Emanuel and Emanuel (1994).
[53] DHEW (1971).
[54] Zussman (1993).
[55] Riley and Lubitz (2010).

[56] Piro and Lutins (1973).
[57] Civetta (1973).
[58] Civetta (1973: P. 267-8).
[59] Civetta (1973: P. 268-9).
[60] Cullen, Civetta, Briggs, and Ferrara (1974).
[61] Cullen, Ferrara, Briggs, Walker, and Gilbert (1976).
[62] Cullen et al. (1976: P. 986).
[63] Cullen et al. (1976: P. 986-7).
[64] Turnbull, Carlon, Baron, Sichel, Young, and Howland (1979).
[65] Turnbull et al (1979: P. 20).
[66] Turnbull et al (1979: P. 20).
[67] Turnbull et al (1979: P. 20).
[68] See, for example, Thibault, Mulley, Barneet, Golstein, Reder, Sherman, and Skinner (1980)
[69] Christkis (1999).
[70] Scitovsky (1984).
[71] Scitovsky (1984: P. 605).
[72] Scitovsky (1984: P. 602, 603).
[73] Scitovski (1994).
[74] Scitovsky (1984)
[75] IOM (1997: P. 184).
[76] For example, Lubitz and Prihoda (1984); Lubitz and Riley. (1993).
[77] Long, Gibbs, Crozier, Cooper, Newman, Larsen (1984).
[78] McCall (1984).
[79] Callahan (1987: P. 15-18).
[80] Callahan (1987: P. 171).
[81] See, Callahan (1998).
[82] Lamm (1984), quoted in Scitovski (1994).
[83] Riley, Lubitz, Prihoda, and Rabey (1987).
[84] Scitovsky (1988).
[85] Scitovsky (1988: P. 656).
[86] Bayer et al. (1983).
[87] Bayer et al. (1983).
[88] Rodwin (2011: P. 112).
[89] Ashmore, Mulkay, and Pinch (1989).
[90] Schmidt (1999).
[91] HMOs that benefited from such grants varied in type: some employed their medical staff directly, and others contracted groups of self-employed physicians (Independent Practice Associations, henceforth IPAs); some of them were for-profit, and others were not-for-profit. See Scott, Ruef, Mendel, and Caronna (1999).
[92] Mayes (2007).
[93] Rodwin (2011: P. 111).

[94] Rodwin (2011: P. 112).
[95] Hoffman (2011: P. 130)
[96] Hoffman (2011: P. 182).
[97] Hoffman (2011: Ch. 8).
[98] Rodwin (2011: P. 124).
[99] Hoffman (2011).
[100] Mayes (2007).
[101] Hoffman (2011: P. 175).
[102] Hoffman (2011: P. 175).
[103] "CMS to Cut Reimbursement Rates by up to 2% for about 2K Hospitals." August 5, 2013.
[104] Gawande (2011: P. 347).
[105] Fligstein (1990).
[106] For a comprehensive review see, Bazzoli et al. (2004).
[107] Burns and Pault (2002).
[108] U.S. Census Bureau. 2010. *Income, Poverty and Health Insurance Coverage in the United States, 2009.*
[109] Rodwin (2011: P. 122-3).
[110] Rodwin (2011: P. 123-4).
[111] Rodwin (2011: P. 129-130).
[112] Rodwin (2011: P. 128).
[113] Pantilat el al. (2007: p. 3).
[114] Pantilat el al. (2007: P. 3-4).
[115] Pantilat el al. (2007: P. 4).
[116] Pantilat el al. (2007: P. 5).
[117] Pantilat el al. (2007: P. 6).
[118] Pantilat el al. (2007: P. 7).
[119] Pantilat el al. (2007: P. 9).
[120] Pantilat el al. (2007: P. 14).
[121] Callon (1998).
[122] Callon (1998).
[123] See for example, CAPC and NBGH (2014).
[124] These explanations rely on Robbin's classical definition of economic situations as cases where actors are forced to make choices under conditions of scarcity. Robbins (1945: P. 4).
[125] Fligtein (1996).

Chapter 3
[1] Katz (1984: P. viii-ix).
[2] Kübler-Ross (1969: P. 209-210).

[3] This was a fundamentally different role from the one organized medicine assigned to patients in the 19th and early 20th centuries. The only clause of the American Medical Association's ethical code, which encouraged physicians to take their patients' wishes into account, dismissed those wishes as irrational: "Reasonable indulgence should be granted to the mental imbecility and caprices of the sick." AMA (1847). The 1903 code omitted the former group, referring only to "the caprices of the sick."
[4] Fox and Swazey (2008).
[5] Fox and Swazey (2008: P. 153)
[6] Messikomer, Fox, and Swazey (2001: P. 491); Fox and Swazey (2008: P. 154-5); Katz (1984). Orentlicher (1992).
[7] Rothman (1991)
[8] Heimer and Petty (2010).
[9] See Evans (2002, 2012).
[10] Kaufman (2006: 28)
[11] Schneider (1998: P. xii).
[12] For example Dworkin (1993); Dworkin (1998).
[13] Halpern (2001: p. 201).
[14] U.S. Congress, *Hearing on Death With Dignity Part III*, P. 100.
[15] The Hasting Center Report also printed Alfred Morgan's letter to the editor, which could very well be what led to his invitation to the hearing. Morgan (1971).
[16] Morgan (1971).
[17] U.S. Congress, 1972. *Hearing on Death With Dignity Part I*, P. 7, 9.
[18] U.S. Congress, 1972. *Hearing on Death With Dignity Part III*, P. 100.
[19] U.S. Congress, 1972. *Hearing on Death With Dignity part III.* P. 104-5.
[20] This number was quoted in the Washington Star article. U.S. Congress, 1972. *Hearing on Death With Dignity part III.* Appendix C.
[21] U.S. Congress, 1972. *Hearing on Death With Dignity part III*. Appendix A.
[22] U.S. Congress, 1978. *Hearing on Home Care for the Elderly*. P. 12-13, 19.
[23] U.S. Congress, 1972. *Hearing on Death With Dignity Part I*, P. 10. Added emphases are mine.
[24] U.S. Congress. 1984. *Hearing on Administration's Proposed Payment for Hospice Care*. P. 31.
[25] U.S. Congress. 1984. *Hearing on Administration's Proposed Payment for Hospice Care*. P. 44.
[26] Cf. Latour (1987).
[27] Kübler-Ross (1969). *On Death and Dying*. New York: Scribner.
[28] U.S. Congress, 1972. *Hearing on Death with Dignity Part I*, P.2-3. The quote is from Kübler-Ross (1969: P. 22-3).
[29] Kübler-Ross (1969: 249, 251).
[30] Kübler-Ross (1969: 250).
[31] Kübler-Ross (1969: 251).

[32] Kübler-Ross (1969: 252, 254).
[33] Kübler-Ross (1969: 256).
[34] Kübler-Ross (1969: 259).
[35] Kübler-Ross (1969: Ch. 3.
[36] Lo, McLeod, and Saika (1986).
[37] IoM (1997) P. 45.
[38] See Dartmouth Atlas Project. Undated. "Inpatient Days per Decedent Duroing the Last Six Months of Lif, by Gender and Level of Care Intensity." http://www.dartmouthatlas.org/data/topic/topic.aspx?cat=18 [Last Accessed: March 29, 2016]. Carina Storrs. "Hospice: What is it and when is it for you?" CNN, July 26, 2015. http://www.cnn.com/2015/06/29/health/hospice-fast-facts/ [Last Accessed: March 29, 2016].
[39] Cicourel (1964).
[40] See chapter 1.
[41] Patrick et al. (1997).
[42] Danis et al. (1996).
[43] For example, Hofmann et al. (1997); Teno et al. (2009).
[44] Paris, Crone, and Readon (1990).
[45] Paris et al. (1999).
[46] S. 1766, 101st Congress, 1st Session. October 17, 1989.
[47] H.R. 4449, 101st Congress (1989-1990).
[48] See Levi-Strauss (1963).
[49] These were the words of the palliative care physician who consulted on the case.
[50] I had heard other clinicians talking about Russian families as particularly resistant to economized dying in previous interviews. Given my own Ashkenazi Jewish background, which my Hebrew accent and last name often betray, I felt I needed to explicitly invite this physician to talk about this group.
[51] Belluck, Pam. 2005. "Even as Doctors Say Enough, Families Flight to Prolong Life." New York Times. March 27, 2005.
[52] Pew Research Center. 2013. *Views on End-of-Life Medical Treatments*. http://www.pewforum.org/files/2013/11/end-of-life-survey-report-full-pdf.pdf [Last Accessed: March 10, 2016]
[53] Previous research found similar patterns. Compared to White people, African Americans were found to be less likely to discuss treatment preferences before they died, complete a living will, designate a Durable Power of Attorney for Health Care, embrace care limitation in certain situations, and withhold treatment before death. Hopp and Duffy (2000).
[54] For a comprehensive review, see IoM (2013: P. 3-26-29).
[55] Pew Research Center. 2013. *Views on End of Life Medical Treatments.* P. 55.
[56] Pew Research Center. 2013. *Views on End of Life Medical Treatments.* 84-5.
[57] Kaufman (2015: P. 4, 25).
[58] Prendergast and Luce (1997).

[59] Prendergast, Claessens, and Luce (1998).
[60] Day (2015).

Chapter 4

[1] See Lee Romney. "Hospital Says Conditions Must be Met for Jahi McMath's Transfer." *Los Angeles Times* 12.30.2013.

[2] These two meanings add to a third one, which the first two chapters discussed: *subject* also means *a topic*. This chapter is about medical practitioners who *make "dying" a subject* by applying professional practices that center on dying people.

[3] See Friedman (1990). As Bellah and his co-authors put it, people in the U.S. *choose* the values in which they believe, pursue them, and achieve self-fulfillment based on their success or failure in this pursuit. "American cultural traditions define personality, achievement an the purpose of human life in ways that leave the individual suspended in glorious, but terrifying, isolation." Bellah et al. (2008: p. 7). In the U.S., the individual subject is a principle component of what Abend called *the moral background*: it is an elementary category, which informs how people think and judge themselves and others. Abend (2015).

[4] See Abramson (2015).

[5] The modern subject, Foucault argued, co-emerged with modern techniques of governance: people became subjects at the same historical moment that they were *subjected* to these techniques.[5] This idea was rooted in Althusser's analysis of self-identification as an act in which one *subjects* to external powers. When embracing an identity—i.e. defining themselves as individual subjects—people *subject* themselves to their identity. (For example, identifying as a woman, man, or gender non-conforming, American or anti-American, and capitalist or working-class is an act of self-definition *and* subjection to social and political categories.) Foucault (2007); Althusser (2001).

[6] In Nicholas Rose's words, subjectivity is an abstraction—an assumption that people possess "a natural locus of beliefs and desires," which are the origin of their "actions and decisions." People are supposed to have an inside—personality traits, which represent them, guide their behavior, and summarize their entirety as human beings. This inside should be at least somewhat consistent and coherent—it can be worked on, actualized, processed, and improved, through conversation and guided reflection. Rose (1998: 22); Lahire (2011).

[7] This is what Nicholas Rose called "the psys." Rose (1998).

[8] With some exceptions, hospices usually require that their patients relinquish hospital care if their condition declines. By consequence, a patient who wants to be admitted to hospital almost always needs to sign off of hospice.

[9] "Mortality itself," as Timmermans observed, "cannot be avoided, but individual *causes of death can be determined,* and then manipulated and postponed." Timmermans (2006: 11). See also, Zussman (1993); Kaufman (2006).

[10] Still, litigations pose public relations risk to hospitals, and financial burden to doctors, who may face higher insurance rates if patients file charges against them. The legal risk does not necessarily involve losing a case in court, but rather having to deal with a case.
[11] In many medical settings, clinical staff's dependence on the families members, who care for the patient after the hospital discharge, is a structural factor that makes clinicians take into account families' and patients' opinions. See, Heimer and Staffen (1996). Anspach (1993).
[12] Taylor (1985: p. 257).
[13] This is in line with the modern development of what Mauss described as the person as a "psychological being": "The mentality of our ancestors is obsessed with the question of knowing whether the individual soul is substance, or supposed by a substance: whether it is the nature of man, or whether it is only one of the two natures of man; whether it is one and indivisible, or divisible and separable; whether it is free, the absolute source of all action, or whether it is determined, fettered by other destinies, by predestination." Mauss (1985).
[14] See Rose (1998: P. 22).
[15] Althusser (2001).
[16] Foucault (2005).
[17] Parsons (1951: P. 431).
[18] Timmermans and Haas (2008).
[19] See, Chambliss (1996).
[20] Put differently, since, as Goffman observed, institutions strip people of their personality, the effort to rehumanize patients draws on who they are outside the hospital Goffman, Erving (1962).
[21] See discussion in chapter 3.
[22] For a discussion of this concern, see Halpern (2001).
[23] I came across several similar cases, of clinicians who doubted whether patients' death wishes represented these patients' goals and values—as opposed to a momentary lapse of reason or emotional crisis that could be overcome. Kubller-Ross identified "depression" as one of the psychological phases of the dying process. Kubller-Ross, *On Death and Dying*.
[24] http://www.gowish.org (Last Accessed: May 8, 2014)
[25] Steinhauser, et al. (2000).
[26] The pronoun "we" is a misleading: in all of the cases that I observed, the Go-Wish activity was carried out by nurses, social workers, or lower ranked doctors and medical students.
[27] Some integrated care systems, such as Kaiser Permanente, can keep electronic documentation of such forms on their records. The hospitals that I studied, however, were not integrated care systems, and Advance Directive forms were carried by the patient, not by the hospital.

[28] Generally, surrogate decision makers' instructions had priority over advance directives. Even in cases of patients who filled out very explicit advance directives forms, family members could trump it once the patient lost her or his decision-making capacity. When the clinical staff agreed that the family's concerns might have some validity, advance directives were particularly weakened.
[29] There is much research showing that patients' views and treatment preferences change when their medical condition declines, specifically near the end of life (Fried et al., 2006; Fried el al., 2007).
[30] Sudore and Fried (2010). Ubel PA et al. 2005. "Misimagining the unimaginable: the disability paradox and health care decision making." *Health Psychology* 24: S56-62.
[31] Sudore and Fried (2010); Reilly, Teasdale, and McCullough (1994).
[32] California Advance Health Care Directive. 2005. http://www.caringinfo.org/files/public/ad/california.pdf [Last Accessed: May 5, 2016]
[33] In palliative care stories, references to "large families" function as Chekhov's gun: they appear on the first act and fire on the second, usually when the multiple family members pressure the medical team in multiple different directions.
[34] See, Smedira et al. (1990); Schneiderman et al. (1992); Teno et al. (1994); Lo et al. (1985); Goodman et al (1998); Danis et al (1991).
[35] Silveira et al. (2010).
[36] Sudore and Fried (2010).
[37] Foucault (2005).
[38] Cf. Latour (1999: ch. 2).
[39] Kaufman (2006).
[40] The two cases of Mr. Becker and Mr. Emery show how regularly women clinicians encounter sexual insinuation when treating men patients.
[41] Jean-Paul Sartre (1973).
[42] Kaufman (2006: 17-8).
[43] Foucault (2005: P. 332).
[44] Bourdieu (1984: P. 401-411).
[45] Bourdieu (1984: P. 413).
[46] Ibid.

Chapter 5

[1] Kaufman (2005: 47-50); Margolin (1997).
[2] Margolin (1997).
[3] Feudtner and Morrison (2012).
[4] Notice how in line with what I described in chapter 3, the authors here assume that families and patients are leaning toward economized dying more than clinicians. This assumption is particularly interesting since the article reflects the authors strong support in economization.

[5] Feudtner and Morrison (2012). One palliative care physician radicalized this conclusion further: "I prefer a 'ban' to a 'moratorium', as a moratorium is temporary, and I don't see any reason for a second life for this particular phrase." Alex Smith, "Ban the Phrase 'Do Everything': It's Dangerous Nonsense." *Geripal*, 9.7.2012. http://www.geripal.org/2012/09/ban-phrase-do-everything-its-dangerous.html
[6] This attending physician was young and new to the hospital, hence Mike felt comfortable instructing him in this way.
[7] Margolin (1997).
[8] The term "code conversation" refers to conversations about whether or not to resuscitate and / or intubate patients.
[9] For a review see Goodwin and Heritage (1990).
[10] Barnato and Arnold (2013).
[11] Scott was also happy to show me that the patient could have been discharged to hospice from his previous admission to Private Hospital:

> Scott says that we can look back in the chart, and he bets the patient was hospice eligible five months ago. A few clicks and he reaches the screen he was looking for. "See?" he shows me [the patient's] low abdomen number and high INR - I could have totally admitted him to hospice when he was admitted last time. But his doctor didn't consult me then, so we couldn't have a plan in place.
> I ask him if the fact that the patient had a concierge physician influenced anything. Scott says that these physicians try to do everything that would satisfy their patients, which oftentimes means that they wouldn't call him, "until shit hits the fan." […] He says that the patient being in the hospital might be really bad for him anyway. Yes, he's on antibiotics, and maybe it helped his infections somehow. But what do I know? Maybe by bringing him to the hospital and putting him on IV antibiotics I've just caused him C. diff, and then he's going to spend the last days of his life with horrible diarrhea?

[12] See Goffman (1959).
[13] Virtually all of the palliative care practitioners that I interviewed told me that patients were more likely to embrace economized dying than their families.
[14] Darr (forthcoming); Darr and Pinch (2013).

Conclusion
[1] Weber (1946a).
[2] Weber, Max. 1946b [1919]. "Politics as a Vocation," pp. 77-128 in Hans H. Gerth and C. Wright Mills, *From Max Weber: Essays in Sociology*. New York: Oxford University Press.
[3] Galbraith (1958).
[4] Cf. Karl Marx's (1992) analysis of overproduction.

[5] Ashmore et al. (1989).
[6] Cf. Polanyi (2001).
[7] Relative to other diagnoses, cancer deaths are predictable and can easily be classified as economization-worthy, so this rise reflects a significant backlash to economization. Two issues complicate this finding. First, Teno el al. studied Medicare fee-for-service patients. It is very likely that hospitalization rates of managed care patients did not grow as much, since unlike in fee-for-service, the financial incentive of their provider is reducing utilization. Second, Teno et al. found different patterns in different diagnoses: the 90-day hospitalization rate for COPD (Chronic Obstructive Pulmonary Disease) patients rose very moderately, from 81.6 to 82.8 percent; in Dementia patients the rate dropped from 69.9 to 65.5 percent; while in cancer patients it rose from 75 percent to 80.3 percent. (Teno et al. 2013).
[8] In 2009, 14.2 percent of the patients transitioned between healthcare institutions in the last three days of their life, compared to 10.3 percent in 2000. Teno et al. 2013.
[9] Cf. Burawoy (1979); Gramsci (2010).
[10] Foucault (2008). Rose (1998, 1990).

References

Abbott, Andrew D. 1988. *The System of Professions: An Essay on the Division of Expert Labor*. Chicago: University of Chicago Press.

Abend, Gabriel. 2015. *The Moral Background: An Inquiry into the History of Business Ethics*. Princeton: Princeton University Press.

Abramson, Corey M. 2015. *The End Game: How Inequality Shapes Our Final Years.* Cambridge, Mass.: Harvard University Press.

Agamben, Giorgio. 1998. *Homo Sacer: Sovereign Power and Bare Life*. Stanford: Stanford university Press.

Althusser, Louis. 2001[1971]. *Lenin and Philosophy and Other Essays*. New York: Monthly Review Press.

Altilio, T. and S. Otis-Green (eds.). 2011. *Oxford Textbook of Palliative Social Work*. New York: Oxford University Press.

AMA (American Medical Association). 1847. *Code of Medical Ethics of the American Medical Association*. Chicago: AMA Press.

Amado, Anthony, Beatrice A. Cronk, and Mileo Rich. 1979. *Cost of Terminal Care: Home Hospice Vs. Hospital*. Nursing Outlook 27(8): 522-26.

American Humanist Association. 1973. *The Humanist Manifesto II*. http://goo.gl/xi8Gp6 [Last Accessed May 3, 2016]

Anspach, Renee. 1993. *Deciding who Lives: Fateful Choices in the Intensive-Care Nursery*. Berkeley, CA: University of California Press.

Ariès, Phillip 1981. *The Hour of Our Death*. New York: Knopf.

Armstrong, Elizabeth M. 1998. "Diagnosing Moral Disorder: The Discovery and Evolution of Fetal Alcohol Syndrome. *Social Science and Medicine* 47(12): 2025-2042.

Arney, William R. and Bernard J. Bergen. 1984. *Medicine and the Management of Living: Taming the Last Great Beast*. Chicago: University of Chicago Press.

Ashmore, Malcolm, Michael J. Mulkay and Trevor J. Pinch. 1989. *Health and Efficiency: A Sociology of Health Economics*. Philadelphia: Open University Press.

Aurlino, Felicity and Kathleen Foley. 2001. "The Project on Death in America." *Journal of the Royal Society of Medicine* 94: 492-5.

Barnato, Amberg E. and Robert M. Arnold. 2013. "The Effect of Emotion and Physician Communication Behaviors on Surrogates' Life Sustaining Treatment Decisions: A Randomized Simulation Experiment. *Critical Care Medicine* 41(7): 1686-1691.

Baszanger, Isabelle. 2012. "One More Chemo or One Too Many? Defining the Limits of Treatment and Innovation in Medical Oncology." *Social Science and Medicine* 75: 864-872.

Bayer, Ronald, Daniel Callahan, John Fletcher, Thomas Hodgson, Bruce Jennings, David Monsees, Steven Sieverts and Robert Veatch. 1983. "The Care of the Terminally Ill: Morality and Economics." *The New England Journal of Medicine* 309(24): 1490-4.

Bazzoli, Gloria J., Linda Dynan, Lawton R. Burns and Clarence Yap. 2004. "Two Decades of Organizational Change in Health Care: What Have We Learned? *Medical Care Research and Review* 61: 247-331.

Becker, Howard S.. 1986. *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press. P. 147-9.

Belah, Robert N., Richard Madesen, Wiliam Sullivan, Ann Swidler, and Steven Tipton. 2008 (1985). *Habits of the Heart*. Berkeley, CA: University of California Press.

Beresford, Larry. 2007. "The Legacy of the Medicare Hospice Benefit." *Newsline* 18(3): 8-16. http://goo.gl/kLvm3Y [last accessed: May 4, 2016]

Berger, Peter L. and Thomas Luckmann. 1967. *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Garden City, NY: Doubleday.

Bernard Lo, Gary A. McLeod, Glenn Saika. 1986. "Patient Attitudes to Discussing Life-Sustaining Treatment." Archives of Internal Medicine 146: 1613-5.

Bloche, M. Gregg. 2011. *The Hippocratic Myth: Why Doctors are under Pressure to Ration Care, Practice Politics, and Compromise their Promise to Heal.* New York: Palgrave MacMaillan

Borgstrom, Erica, Stephen Barclay and Simon Cohn. 2013. "Constructing Denial as a Disease Object: Accounts by Medical Students Meeting Dying patients." *The Sociology of Health and Illness* 35(3): 391-404.

Bosk, Charles L. 1979. *Forgive and Remember: Managing Medical Failure*. Chicago: University of Chicago Press.

Bourdieu, Pierre and Loïc J. D. Wacquant. 1992. *An Invitation to Reflexive Sociology*. Chicago: University of Chicago Press.

Bourdieu, Pierre. 1984. *Distinction: A Social Critique of the Judgement of Taste*. Harvard: Harvard University Press.

Bourdieu, Pierre. 1990. *The Logic of Practice.* Stanford: Stanford University Press.

Bourdieu, Pierre. 1993. *Sociology in Question*. Thousand Oaks, CA: Sage.

Buck, Joy. 2005. *Rights of Passage: Reforming Care of the Dying 1965-1986*. Ph.d Dissertation, University of Virginia.

Buck, Joy. 2007. "Netting the hospice butterfly: politics, policy, and translation of an ideal." *Home Healthcare* Now 25(9): 566-571.

Buck, Joy. 2009. "'I am Willing to Take the Risk': Politics, Policy, and the Translation of the Hospice Ideal." *Journal of Clinical Nursing* 18: 2703.

Buck, Joy. 2011. "Nursing the Borderlands of Life: Hospice and the Politics of Health Care Reform." Pp. 203-220 in "History as Evidence: Nursing Interventions Through Time", edited by Patricia D'Antonio and Sandra B. Lewenson. New York: Springer.

Bunker, JP. 1970. Surgical Manpower: A Comparison of Operations and Surgeons in the United States and in England and Wales. *New England Journal of Medicine* 282: 135-144.

Burawoy, Michael. 1979. *Manufacturing Consent: Changes in the Labor Process Under Monopoly Capitalism*. Chicago: University of Chicago Press.

Burns, Lawton and Mark V. Pault. 2002. "Integrated Delivery Networks: A Detour on the Road to Integrated Health Care?". *Health Affairs* 21(4): 128-143.

Çalişkan, Koray and Michel Callon. 2009. "Economization, Part 1: Shifting Attention from the Economy Towards Processes of Economization." *Economy and Society* 38(3): 369-398.

Çalişkan, Koray and Michel Callon. 2010. "Economization, Part 2: A Research Programme for the Study of Markets." *Economy of Society* 39(1): 1-32.

Callahan, Daniel. 1987. *Setting Limits: Medical Goals in an Aging Society*. New York: Simon and Schuster. P. 15-18.

Callahan, Daniel. 1998. *False Hopes: What America's Quest for Perfect Health is a Recipe for Failure*. New York: Simon and Schuster.

Callahan, Daniel. 2011. "Rationing: Theory, Politics, and Passions." *Hasting Center Report* 41(2): 23-7.

Callon, Michel. 1998. "Introduction", in Michel Callon (ed.), *The Laws of the Market*. London: Blackwell.

CAPC (Center for the Advancement of Palliative care) and NBGH (National Business Group on Health). 2014. *Improving Care for People with Serious Illness Through Innovative Payer-Provider Partnership.* https://goo.gl/2J0MSl [last accessed: May 4, 2016]

Chambliss, Daniel F. 1996. *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics*. Chicago: University of Chicago Press.

Christakis, Nicholas. 1999. *Death Foretold*. *Prophecy and Prognosis in Medical Care*. Chicago: University of Chicago Press.

Cicourel, Aaron V. 1964. *Method and Measurement in Sociology*. New York: Free Press.

Civetta, Joseph M. 1973. "The Inverse Relationship Between Cost and Survival." *Journal of Surgical Research* 14: 265-269.

Clark, David (ed.). 2005. *Cicely Saunders – Founder of the Hospice Movement: Selected Letters 1959-1999*. Oxford: Oxford University Press.

Clark, David. 1998. “Originating a Movement: Cicely Suanders and the Development of Saint Christopher’s Hospice, 1957-1967.” *Mortality* 3: 43-63.

Clark, David. 2001. “A Special Relationship: Cicely Saunders, the United States, and the early Foundations of the Modern Hospice Movement.” *Illness, Crisis, and Loss* 9:15-31.

Clark, David. 2013. *Transforming the Culture of Dying: The Work of the Project on Death in America*. Oxford: Oxford University Press.

Cohen, Kenneth P. 1979. *Hospice Prescription for Terminal Care*. Rockville, MD: Aspen.

Comptroller General. 1979. *Hospice Care, A Growing Concept in the United States: Report to Congress*. Washington: U.S. General Accounting Office.

Connor, Stepehn R. 2007-8. “Hospice and Palliative Care in the United States.” *OMEGA* 56(1): 89-99.

Connor, Stephen R. 1996. *Hospice: Practice, Pitfalls, and Promise.* Bristol, PA: Taylor and Francis.

Conrad, Peter. 2007. *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore: Johns Hopkins University Press.

Cullen, David J., Linda C. Ferrara, Burton A. Briggs, Peter F. Walker, and John Gilbert. 1976. “Survival, Hospitalization Charges and Follow-up Results in Critically Ill Patients.” *New England Journal of Medicine* 294(18): 982-7.

Cullen, David, Joseph Civetta, Burton Briggs, and Linda Ferrara. 1974. “Therapeutic Intervention Scoring System: A Method for Quantitative Comparison of Patient Care.” *Critical Care Medicine* 2(2): 57-60.

Danis, Marion, Elizabeth Murtran, Garrett Joanne, Sally Stearns, Rebecca Slifkin, Laura Hanson, Jude Williams, Larry Churchill. 1996. “A Prospective Study of the Impact of Patient Preferences on Life-Sustaining Treatment and Hospital Cost.” *Critical Care Medicine* 24(11): 1811-17.

Danis, Marion, Leslie I. Southerland, Joanne M. Garrett, Janet L. Smith, Frank Hielema, C. Glenn Pickard, David M. Enger, and Donald L. Patrick. 1991. “A Prospective Study of Advance Directives for Life-Sustaining Care.” *New England Journal of Medicine*. 324: 882-8.

Darr, Asaf and Trevor Pinch. 2013. “Performing Sales: Material Scripts and the Social Organization of Obligation. *Organization Studies* 34(11): 1601-16023.

Darr, Asaf. Forthcoming. “Gift Giving in Mass Consumption.” Forthcoming in *Current Sociology*.

Davidson. 1978. *Hospice: Development and Administration*. Hemisphere.

Day, Adrienne. 2015. “Ends and Means.” *Stanford Social Innovation Review* 13(2): 66-7.

Department of Health and Human Services, CMS. 2016. "Advance Care Planning (ACP) as an Optional Element of an Annual Wellness Visit (AWV). https://goo.gl/QdROQw [last accessed: May 3, 2016]

DHEW (U.S. Department of Health, Education and Welfare). 1971. *Health Insurance Coverage of Adults who Died in 1964 or 1965*. National Center for Health Statistics, 22(10)

Dohan, Daniel. 2002. "Managing Indigent Care: A Case Study of a Safety-Net Emergency Department. *Health Services Research* 37(2): 361-376.

Duff, Ray and August Hollingshead. 1968. *Sickness and Society*. New York: Harper & Row.

Dworkin, Gerald. 1988. *The Theory and Practice of Autonomy.* Cambridge: Cambridge University Press.

Dworkin, Ronald. 1993. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books.

Emanuel, Ezekiel J. and Linda Emanuel. 1994. "The Economics of Dying: The Illusion of Cost Saving at the End of Life." *The New England Journal of Medicine* 330(8): 540-544.

England, Paula. 2005. "Emerging Theories of Care Work." *Annual Review of Sociology* 31: 381-399.

Epstein, Steven. 1994. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, CA: University of California Press.

Evans, John H. 2002. *Playing God? Human Genetic Engineering and the Rationalization of Public Bioethical Debate.* Chicago: University of Chicago Press.

Evans, John H. 2012. *The History and Future of Bioethics: A Sociological View.* Oxford: Oxford University Press.

Eyal, Gil and Larissa Buchholz. 2010. "From the Sociology of Intellectuals to the Sociology of Interventions." *Annual Review of Sociology* 36: 117-137.

Eyal, Gil et al. 2010. *The Autism Matrix: The Social Origins of the Autism Epidemic*. Cambridge, UK: Polity.

Eyal, Gil. 2013. "For a Sociology of Expertise: The Social Origins of the Autism Epidemic." *American Journal of Sociology* 118(4): 863-907.

Featherstone, Mike, Mike Hepworth and Bryan S. Turner (eds.). 1991. *The Body: Social Process and Cultural Theory*. Newbury Park, CA: Sage.

Feifel, Herman (ed.). 1959. *The Meaning of Death*. New York: McGraw-Hill

Feifel, Herman (ed.). 1977. *New Meanings of Death*. New York: McGraw-Hill.

Ferrell, B.R. and N. Coyle (eds.). 2001. *Textbook of Palliative Nursing.* Oxford: Oxford University Press.

Feudtner, Chris and Wynne Morrison. 2012. "The Darkening Veil of 'Do Everything'." *Archives of Pediatric and Adolescent Medicine* 166(8): 694-5.

Filene, Peter. 1998. *In the Arms of Others: A Cultural History of the Right-to-Die Movement in America.* Chicago: Dee.

Fligstein, Neil. 1990. *The Transformation of Corporate Control*. Cambridge, Mass.: Harvard University Press.

Fligstein, Neil. 1996. "Markets as Politics: A Political-Cultural Approach to Market Institutions." *American Sociological Review* 61(4): 656-673.

Florence, Wald. 1988. "In Search of the Spiritual Component of Hospice Care," in *In Quest of the Spiritual Component of Care for the Terminally Ill: Proceedings of a Colloquium,* edited by F. Wald. New Haven: CT: Yale University School of Nursing.

Foucault, Michel. 1975. *The Birth of the Clinic: An Archaeology of Medical Perception*. New York: Vintage Books.

Foucault, Michel. 1991. Governmentality. Pp. 87-104 in G. Burchell, C. Gordo, and P. Miller (eds.). *The Foucault Effect: Studies in Governmental Rationality*. Hemel Hempstead: Harvester Wheatsheaf.

Foucault, Michel. 2005. *The Hermeneutics of the Subject. Lectures at the Collège de France 1981-1982*. New York: Picador.

Foucault, Michel. 2007. *Security, Territory, Population: Lectures at the Collège de France 1977-1978.* New York: MacMillan.

Foucault, Michel. 2008. *The Birth of Biopolitics: Lectures at the Collège de France 1978-1979*. New York: Palgrave McMillan.

Fourcade, Marion and Kieran Healy. 2007. "Moral Views of the Market Society." *Annual Review of Sociology* 33: 285-311

Fourcade, Marion. 2006. *Economists and Societies: Discipline and Profession in the United States, Britain, and France, 1890s to 1990s*. Princeton, NJ: Princeton University Press.

Fox, Renée and Judith Swazey. 2008. *Observing Bioethics*. Oxford: Oxford University Press.

Freidson, Eliot. 1970. *Professionalization of Medicine*. New York: Harper & Row.

Fried, Terri R., Amy L. Byers, William T. Gallo, Peter H. Van Ness, Virginia R. Towle, John R. O'Leary, Joel A. Dubin. 2006. "Prospective study of health status preferences and changes in preferences over time in older adults." *Archives of Internal Medicine* 166: 890-5.

Fried, Terri R., John O'Leary, Peter Van Ness, and Liana Fraenkel. 2007. "Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *Journal of the American Geriatric Society* 55: 1007-14.

Galbraith, John Kenneth. 1958. *The Affluent Society*. London: Hamish Hamilton.

Garrett, Dorothy M. 1978. "Needs of the Seriously ill and Their Families: the Haen Concept." *Aging* 289/290: 12-15

Gawande, Atul. 2011. "The Cost Conundrum." In, *The Sociology of Health and Illness (5th edition),* edited by Peter Conrad and Valerie Leiter. P. 347.

Gawande, Atul. 2014. *Being Mortal: Medicine and What Matters in the End.* New York: Metropolitan.

Geertz, Clifford. 1973. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.

Glaser, Barney G. and Anselm L. Strauss. 1968. *Time for Dying*. Chicago: Aldine.

Glaser, Burney G. and Anselm L. Strauss. 1965. *Awareness of Dying*. Chicago: Aldine.

Glaser, Burney G. and Anselm L. Strauss. 1970. *Anguish: A Case History of a Dying Trajectory*. Mill Valley, CA: Sociology Press.

Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. New York: Anchor Books.

Goffman, Erving. 1962. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Chicago: Aldine.

Golodetz, Arnold et al. 1997. *Vermont Voices on Care of the Dying: A Report from the Vermont Ethics Network*. Montpelier, VT: Vermont Ethics Network.

Goodman, Martin D., Michael Tarnoff, and Gus J. Slotman. 1998. "Effect of Advance Directives on the Management of Elderly Critically ill Patients." *Critical Care Medicine* 26:701-4.

Goodwin, Charles and John Heritage. 1990. "Conversation Analysis." *Annual Review of Anthropology* 19: 283-307

Gramsci, Antonio. 2010. *Prison Notebooks*. New York: Columbia University Press.

Hacking, Ian. 1999. *The Social Construction of What?*. Cambridge, Mass.: Harvard University Press.

Halpern, Jodi. 2001. *From Detached Concern to Empathy: Humanizing Medical Practice*. New York: Oxford University Press.

Heimer, Carol A. and JuLeigh Petty. 2010. "Bureaucratic Ethics: IRBs and the Legal Regulation of Human Subjects Research." *Annual Review of Law and Social Science* 6: 601-626.

Heimer, Carol A. and Lisa R. Staffen. 1998. *For the Sake of the Children: The Social Organization of Responsibility in the Hospital and the Home.* Chicago: University of Chicago Press.

Ho, Karen. 2009. *Liquidated: An Ethnography of Wall Street*. Durham, NC: Duke University Press.

Hoffman, Beatrix. 2012. *Healthcare for Some: Rights and Rationing in the United States since 1930*. Chicago: The University of Chicago Press.

Hofmann, Jan C., Neil S. Wenger, Roger B. Davis, Joan Teno, Alfred F. Connors, Norman Desbiens, Joanne Lynn, and Russell S. Phillips. 1997. "Patient Preferences for Communication with Physicians about End-of-Life Decisions." *Annals of Internal Medicine* 127(1): 1-12.

Holleb, Arthur I. 1974. "A patient's right to die... The easy way out?" *CA: A Cancer Journal for Clinicians* 24(4): 256.

Hopp, Faith P. and Sonia A. Duffy. 2000. "Racial Variations in End-of-Life Care." *Journal of the American Geriatric Society* 48(6): 658-663.

Hospice Project Task Force. 1980. *Report to the 1980 California Legislature on the Hospice Project*. Berkeley, CA: California State Department of Health.

IHHD (Institute on Health and Healthcare Delivery). 1978. *The Hospice as a Social Health Care Institution.* Los Angeles, CA: Hillhaven Foundation. P. 32.

IoM (Institute of Medicine). 1997. *Approaching Death: Improving Care at the End of Life*. Washington D.C.: National Academy Press.

IoM (Institute of Medicine). 2014. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington DC: National Academic Press.

Jerolmack, Colin and Shamus Khan. 2014. "Talk is Cheap: Ethnography and the Attitudinal Fallacy." *Sociological methods Research* 43(2): 178-209

Jerolmack, Colin. 2008. "How Pigeons Became Rats: The Cultural-Spatial Logic of Problem Animals." *Social Problems* 55(1): 72-94.

Jonsen, Albert R. 1988. *The Abuse of Casuistry: A History of Moral Reasoning*. Berkeley, CA: University of California Press.

Kalish, Richard K. 1977. "Dying and Preparing for Death: A View of Families." Pp. 216-232 in *New Meanings of Death,* edited by Feifel. New York: McGraw-Hill.

Katz, Jay. 1984. *The Silent World of Doctor and Patient*. New York: Free Press.

Kaufman, Sharon. 2006. *…And a Time to Die: How American Hospitals Shape the End of Life*. New York: Scribner.

Kaufman, Sharon. 2015. *Ordinary Medicine: Extraordinary Treatments, Longer Lives, and Where to Draw the Lines*. Durham: Duke University Press.

Kavanagh, Even. 1983. "Volunteers in Hospice," Pp. 210-212 in *Hospice Care: Principles and* Practice, edited by Charles A. Corr and Donna M. Corr. New York: Springer.

Kellehear A. 1984. "Are We a Death-Denying Society? A Sociological Review." *Social Science and Medicine* 18: 713-23.

Kierkegaard, Søren. 1993. "At a Graveside," Pp. 71-102 in *Three Discourses on Imagined Occasions*. Princeton: Princeton University Press.

Krakoff, Irwin H. 1979. "The case for active treatment in patients with advanced cancer: not everyone needs a hospice." *CA: A Cancer Journal for Clinicians* 29(2): 108-111.

Kübler-Ross, Elisabeth. 1969. *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy, and Their Own Families*. New York: Scribner.

Lahire, Bernard. 2011. *The Plural Actor*. Cambridge, UK: Polity Press.

Laporte, M., D.W. Sherman, M.K. Matzo (eds.) 2001. *Palliative Care Nursing: Quality Care to the End of Life*. New York: Springer.

Latour, Bruno. 1987. *Science in Action: How to Follow Scientists and Engineers through Society*. Cambridge, Mass.: Harvard University Press.

Latour, Bruno. 1994. *We Have Never Been Modern*. Cambridge, Mass.: Harvard University Press.

Latour, Bruno. 1999. *Pandora's Hope: Essays on the Reality of Science Studies*. Cambridge, Mass.: Harvard University Press.

Latour, Bruno. 2004. "Why Has Critique Run Out of Steam? From Matters of Fact to Matters of Concern." *Critical Inquiry* 30(2): 225-248.

Latour, Bruno. 2005. *Reassembling the Social: An Introduction to Actor-Network-Theory.* Oxford: Oxford University Press.

Lavi, Shai. 2005. The Modern Art of Dying: A History of Euthanasia in the United States. Princeton: Princeton University Press.

Lawrence M. Friedman. 1990. *The Republic of Choice: Law, Authority, and Culture*. Cambridge, Mass.: Harvard University Press.

Levi-Strauss, Claude. 1963. "History and Anthropology," in *Structural Anthropology*. New York: Basic Books.

Livne, Roi. 2014. "Economies of Dying: The Moralization of Economic Scarcity in U.S. Hospice Care." *American Sociological Review* 79(5): 888-911

Lo, Bernard, Glenn Saika, William Strull, Elizabeth Thomas, and Jonathan Showstack. 1985. "'Do not resuscitate' decisions: a prospective study at three teaching hospitals." *Archives of Internal Medicine* 145: 1115-6.

Long, Stephen H., James O. Gibbs, Jay P. Crozier, David I. Cooper, John F. Newman, Arne M. Larsen. 1984. "Medical Expenditures of Terminal Cancer Patients During the Last Year of Life." *Inquiry* 21(4): 315-327.

Long, Stephen H., James O. Gibbs, Jay P. Crozier, David I. Cooper, John F. Newman, Arne M. Larsen. 1984. "Medical Expenditures of Terminal Cancer Patients During the Last Year of Life." *Inquiry* 21(4): 315-327.

Lubitz, J.D. and G.F. Riley. 1993. "Trends in Medicare Payments in the Last Year of Life." *New England Journal of Medicine*. 328: 1092-6.

Lubitz, J.D. and R. Prihoda. 1984. "The Use and Costs of Medicare Services in the Last 2 Years of Life." *Healthcare Financing Review* 5: 117-31.

Lucy Griscom Morgan. 1971. "On Drinking the Hemlock," *The Hasting Center Report* 1(3): 4-5.

Lynn, Joanne. 1997. "Unexpected Returns: Insights from SUPPORT." In *To Improve Health and Health Care*, edited by Stephen L. Isaacs and James R. Knickman. San Francisco, CA: Robert Wood Johnson Foundation.

Mahar, Maggie. 2006. *Money-Driven Medicine: The Real Reason Health Care Costs so Much*. New York: HarperCollins.

Marcuse, Herbert. 1964. *One-Dimensional Man: Studies in the Ideology of Advanced Industrial Society*. Boston: Beacon Press.

Margolin, Leslie. 1997. *Under the Cover of Kindness: The Invention of Social Work*. Charlottesville, VA: University Press of Virginia.

Marx, Karl and Frederick Engels. 2001[1932]. *The German Ideology. Part One.* London: Electric book Co.

Marx, Karl. 1972[1845]. "Theses On Fueurbach." Pp. 143-145, in *The Marx-Engels Reader,* edited by Robert C. Tucker. New York: W. W. Norton.

Marx, Karl. 1992[1867]. *Capital: Volume 1: A Critique of Political Economy.* New York: Penguin.

Mauss, Marcell. 1985. "A Category of the Human Mind: The Notion of Person; The Notion of Self." In *The Category of the Person: Anthropology, Philosophy, History*, edited by Michael Currithers, Steven Collins, and Steven Lukes. Cambridge: Cambridge University Press.

Mayes, Rick. 2007. "The Origins, Development, and Passage of Medicare's Revolutionary Prospective Payment System." *Journal of the History of Medicine and Allied Sciences* 62(1): 21-55.

McCall, Nelda. 1984. "Utilization and Costs of Medicare Services by Beneficiaries in Their Last Year of Life." 22(4): 329-342.

McGehee, Harvey and James Bordley. 1976. *Two Centuries of American Medicine*. Philadelphia: Saunders.

McNulty, Elizabeth G and Robert A. Holderby. 1983. "Hospice: A Caring Challenge." Springfield, Ill.: C.C. Thomas.

Messikomer, Carla M., Renee C. Fox, and Judith P. Swazey. 2001. "The Presence and Influence of Religion in American Bioethics." *Perspectives in Biology and Medicine* 44(4): 485-508.

Mitchell, Timothy. 2002. *Rule of Experts: Egypt, Techno-Politics, Modernity*. Berkeley, CA: University of California Press.

Mitford, Jessica. 1963. *The American Way of Death*. New York: Simon and Schuster.

Mor, Vincent and David Kidder. 1985. "Cost Savings in Hospice: Final Results of the National Hospice Survey." *Health Service Research* 20(4): 407-420

Mor, Vincent and Howard Barnbaum. 1983. "Medicare Legislation for Hospice Care: Implications of National Hospice Study Data." *Health Affairs* 2(2): 80-90.

Morrison, Sean S. and Diane E. Meier. 2015. *America's Care of Serious Illness.* New York: Center to Advance Palliative Care.

Murphy, Alexandra K. 2012. "Litterers:' How Objects of Physical Disorder are used to Construct Subjects of Social Disorder in a Poor Suburb." *Annals of the American Academy of Political and Social Science* 642(1): 210-227.

National Center for Health Statistics. 2011. *Health, United States, 2010: With Special Feature on Death and Dying*. Hyattsville, MD: U.S. Government Printing Office.

NHPCO (National Hospice and Palliative Care Organization). 2012-2014. *Facts and Figures*. http://goo.gl/i4S97L [last accessed May 3, 2016]

Notzon et al. 1987. Comparisons of National Cesarean Section Rates. *New England Journal of Medicine* 316: 386-89.

Orentlicher, David. 1992. "The Illusion of Patient Choice in End-of-Life Decisions." JAMA 267(15): 2101-2104.

OSI (Open Society Institute). 2004. *Transforming the Culture of Dying: The Project on Death in America*. New York: Open Society Institute. https://goo.gl/i9fklE [last accessed May 4, 2016]

Osterweis, Marian and Daphne Szmuszkovicz Champagne. 1978. "U.S. Hospice Movement: Issues in Development." *American Journal of Public Health* 69(5): 492-6.

Pantilat, Steven Z., Michael W. Rabow, Kathleen M. Kerr, and Amy J. Markowitz. 2007. *Palliative Care in California: The Business Case for Hospital-Based Programs.* Oakland, CA: California HealthCare Foundation.

Paris, John J. Robert K. Crone, and Frank Readon. 1990. "Physicians' Refusal of Requested Treatment: The Case of Baby L." *The New England Journal of Medicine.* 322(14): 1012-1014.

Paris, John J., Edwin H. Cassem, G. William Dec, and Frank E. Reardon. 1999. "Use of DNR Order Over Family Objections: The Case of Gilgunn v MGH. *Journal of Intensive Care Medicine* 14(1): 41-45.

Parsons, Talcott. 1951. *The Social System*. New York: Free Press.

Patrick, Donald L., Robert A. Pearlman, Helene E. Starks, Kevin C. Cain, William G. Cole, and Richard F. Uhlmann. 1997. "Validation of Preferences for Life-

Sustaining Treatment: Implications for Advance Care Planning." *Annals of Internal Medicine* 127:509-17.

Patrizi, Patricia, Elizabeth Thompson, and Abby Spector. 2011. *Improving Care at the End of Life: How the Robert Wood Johnson Foundation and Its Grantees Built the Field*. RWJF Retrospective Series, Robert Wood Johnson Foundation. http://goo.gl/rw9Q8v [last accessed May 4, 2016]

Payer, Lynn. 1988. *Medicine and Culture*. New York: Owl Books.

Peterson, Peter G. 2004. *Running on Empty*. New York: Picador.

Piro, Paula A. and Theodore Lutins. 1973. "Utilization and Reimbursements Under Medicare for 1967 and 1968 Decedents." *Social Security Bulletin* 74-11702.

Poe, William D. 1972. "Marantology, a Needed Specialty." *The New England Journal of Medicine* 286: 102-103.

Polanyi, Karl. 2001[1944]. *The Great Transformation: The Political and Economic Origins of Our Time.* Boston, MA: Beacon Press.

Prendergast, Thomas J. and John M. Luce. 1997. "Increasing Incidence of Withholding and Withdrawal of Life Support from the Critically Ill." *American Journal of Respiratory and Critical Care Medicine* 55(1): 15-20.

Prendergast, Thomas J., Michael T. Claessens, and John M. Luce. 1998. "A National Survey of End-of-Life Care for Critically Ill Patients." *American Journal of Respiratory and Critical Care Medicine* 158(4): 1163-7.

Reich, Adam. 2014. *Selling Our Souls: The Commodification of Hospital Care in the United States*. Princeton: Princeton University Press.

Reilly, Rebecca B., Thomas A. Teasdale, and Laurence B. McCullough. 1994. "Projecting patients' preferences from living wills: An invalid strategy for management of dementia with life-threatening illness." *Journal of the American Geriatrics Society* 42: 997-1003.

Relmand, Arnold. 1980. "The New Medical-Industrial Complex." *The New England Journal of Medicine* 303(17): 962-70.

Riley, Gerald and James Lubitz. 2010. "Long-Term Trends in Medicare Payment in the Last Year of Life." *Healthy Service Research* 45: 565-576.

Riley, Gerald., James. Lubitz, R. Prihoda, and E. Rabey. 1987. "The Use and Costs of Medicare Services by Cause of Death. *Inquiry* 24: 233-43.

Robbins, Lionel. 1945. *An Essay on the Nature and Significance of Economic* Science. London: MacMillan. P. 16

Rodwin, Marc A. 2011. *Conflicts of Interest and the Future of Medicine: The United States, France and Japan.* Oxford: Oxford University Press.

Rose, Nicholas and Peter Miller. 1992. "Political Power Beyond the State: Problematics of Government." *British Journal of Sociology* 43(2): 172-205.

Rose, Nicholas. 1990. *Governing the Soul: The Shaping of the Private Self*. London: Routeldge.

Rose, Nicholas. 1998. *Inventing Our Selves: Psychology, Power, and Personhood.* Cambridge: Cambridge University Press.

Rosenberg, Charles E. 1987. *The Care of Strangers: The Rise of America's Hospital System*. New York: Basic Books.

Rosman, Parker. 1977. *Hospice: Creating New Models of Care for the* Terminally. New York: Association Press.

Rothman, David J. 1991. *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making*. New York: Basic Books.

Sartre, Jean-Paul. 1968. *Search for a Method.* New York: Random House. P. 93.

Sartre, Jean-Paul. 1973. *Existentialism and Humanism.* London: Eyre Methuen.

Saunders, Cicely. 1960. "The Management of Patients in the terminal stage," Pp. 403-17 in *Cancer* Volume 6, edited by R. Raven. London: Butterworth.

Saunders, Cicely. 1965. "Last Stages of Life." *American Journal of Nursing* 65(3): 70-5.

Saunders, Cicely. 1969. "The Moment of Truth: Care of the Dying Person. Pp. 49-78 in *Death and Dying: Current Issue in the Treatment of the Dying Person*, edited by Leonard Pearson. Cleveland: Case Western Reserve University

Saunders, Cicely. 1999. "Origins: International Perspectives, then and now". *Hospice Journal* 14(3/4): 1-7

Schmidt, Laura Anne. 1999. *The Corporate Transformation of American Health Care: A Study in Institution Building*. Ph.d Dissertation, University of California, Berkeley.

Schneider, Carl E. 1998. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. Oxford: Oxford University Press.

Schneiderman, Lawrence J., Richard Kronick, Robert M. Kaplan, John P. Anderson, and Robert D. Langer. 1992. "Effects of offering advance directives on medical treatments and costs." *Annals of Internal Medicine.* 117(7): 599-606.

Schroeder, Steven A. 1999. "The Legacy of SUPPORT." *Annals of Internal Medicine* 131(10) 780-2.

Scitovski, Anne A. 1994. "'The High Cost of Dying' Revisited." *The Milibank Quarterly* 72(4): 561-591.

Scitovsky, Anne A. 1984. "'The High Cost of Dying': What Do the Data Show?" *Milibank Memorial Fund Quarterly/Health and Society* 62(4): 591-608.

Scitovsky, Anne. 1988. "Medical Care in the Last Twelve Months of Life: The Relation Between Age, Functional Status, and Medical Care Expenditures." *Milibank Quarterly* 66: 640-60.

Scott, W. Richard, Martin Ruef, Peter J. Mendel and Carol A. Caronna. 1999. *Institutional Change and Healthcare Organizations: From Professional Dominance to Managed Care*. Chicago: Chicago University Press.

Seale, Clive. 1998. Constructing Death: The Sociology of Dying and Bereavement. Cambridge: Cambridge University Press.

Shapiro, Susan. 2012. "Advance Directives: The Illusive Goal of Haivng the Last Word." NAELA Journal 8(2): 205-232.

Silveira, Maria J., Scott Y.H. Kim, and Kenneth M. Langa. 2010. "Advance Directives and Outcomes of Surrogate Decision Making Before Death." *New England Journal of Medicine* 362: 1211-1218.

Smedira Nicholas G., Bradley H. Evans, Linda S. Grais, Neal H. Cohen, Bernard Lo, Molly Cooke, William P. Schecter, Carol Fink, Eve Epstein-Jaffe, Christine May, and John M. Luce. 1990. "Withholding and Withdrawal of life support from the critically ill." *New England Journal of Medicine* 322: 309-15.

Sontag, Susan. 1978. *Illness as Metaphor.* New York: Farrar, Strauss, and Giroux.

Soros, George. 1998. "Reflections on Death in America," in *Project on Death in America, July 1994-December 1997*. New York: Open Society Institute.

Starr, Paul. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.

Steinfels, Peter and Robert M. Veatch. 1974. *Death Inside Out: The Hastings Center Report*." New York: Harper & Row Publishers.

Steinfels, Peter. 1974. "Introduction," in *Death Inside Out*, Edited by Peter Steinfels and Robert M. Veatch. New York: Harper & Row Publishers.

Steinhauser, Karen E., Nicholas A. Christakis, Elizabeth C. Clipp, Maya McNeilly, Lauren McIntyre, James A. Tulsky. 2000. "Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*. JAMA* 284: 2476-2482.

Stoddard, Sandol. 1978. *The Hospice Movement: A Better Way of Caring for the Dying.* Briarcliff Manor, N.Y.: Stein and Day.

Sudnow, David. 1967. *Passing On*. Englewood Cliffs, NJ: Prentice-Hall.

Sudore, Rebecca and Terri Fried. 2010. "Redefining the 'planning' in Advance Care Planning: Preparing for End-of-Life Decision Makong." *Annals of Internal Medicine* 153: 256-262.

SUPPORT Principal Investigators. 1995. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)." *JAMA* 274(20): 1591-8.

Taylor, Charles. 1985. "The Person." In *The Category of the Person: Anthropology, Philosophy, History*, edited by Michael Currithers, Steven Collins, and Steven Lukes. Cambridge: Cambridge University Press.

Teno, Joan et al. 2013. "Changes in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *JAMA* 309(5): 470-7.

Teno, Joan M., Joanne Lynn, Russell S. Phillips, Donald J. Murphy, Stuart Youngner, Paul Bellamy, Alfred F. Connors Jr., Norman A. Desbiens, William Fulkerson, William Knaus. 1994. "Do Formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients?" *Journal of Clinical Ethics* 5(1): 23-30.

Teno, Joan M., Pedro L. Gozalo, Julie P.W. Bynum, Natalie E. Leland, Susan C. Miller, Nancy E. Morden, Thomas Scupp, David C. Goodman, Vincent Mor. 2009. "Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *JAMA* 309(5): 470-477.

Teno, Joan M., Pedro L. Gozalo, Julie P.W. Bynum, Natalie E. Leland, Susan C. Miller, Nancy E. Morden, Thomas Scupp, David C. Goodman, Vincent Mor. 2013. "Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009." *JAMA* 309(5): 470-477.

Thibault, George E., Albert G. Mulley, G. Octo Barneet, Richard L. Golstein, Victoria A. Reder, Ellen, L. Sherman, and Erik R. Skinner. 1980. "Medical Intensive Care: Indications, Interventions, and Outcomes." *New England Journal of Medicine* 302(17): 938-942.

Timmermans, Stefan and Mara Buchbinder. 2010. "Patients-in-Waiting: Living Between Sickness and Health in the Genomics Era." *Journal of Health and Social Behavior* 51(4): 408-423.

Timmermans, Stefan and Marc Berg. 2003. *The Goal Standard: The Challenge of Evidence Based Medicine and Standardization in Health Care*. Philadelphia: Temple University Press.

Timmermans, Stefan and Steven Haas. 2008. "Toward a Sociology of Disease." *Sociology of Health and Illness* 30(5): 659-676.

Timmermans, Stefan. 1999. *Sudden Death and the Myth of CPR.* Philadelphia: Temple University Press.

Timmermans, Stefan. 2006. *Postmortem: How Medical Examiners Explain Suspicious Deaths.* Chicago: University of Chicago Press.

Turnbull, Alan D., Graziano Carlon, Robinson Baron, William Sichel, Charles Young, and William Howland. 1979. "The Inverse Relationship between Cost and Survival in the Critically Ill Cancer Patient." *Critical Care Medicine* 7(1): 20-23.

Ubel Peter A., George Lowenstein, Norbert Schwarz, and Dylan Smith. 2005. "Misimagining the unimaginable: the disability paradox and health care decision making." *Health Psychology* 24: S56-62.

Vanderlyn, Pine R. and Derek L. Phillips. 1970. "The Cost of Dying: A Sociological Analysis of Funeral Expenditures." *Social Problems* 17(3): 405-417.

Vernon, Glenn. 1970. *The Sociology of Death*. New York: Ronald.

Wald, Florence S. 1966. "Emerging Nursing Practice." *American Journal of Public Health and the Nations Health* 56(8): 1252-1260

Wald, Florence S. and Joan Craven. 1975. "Hospice Care for Dying Patients." *The American Journal of Nursing* 75(10): 1816-22.

Wald, Florence S. and Robert C. Leonard. 1964. "Towards Development of Nursing Practice Theory." *Nursing Research* 13(4): 309-313.

Weber, Max. 1946a [1919]. "Science as a Vocation," pp. 129-156 in Hans H. Gerth and C. Wright Mills, *From Max Weber: Essays in Sociology*. New York: Oxford University Press.

Weber, Max. 1946b [1919]. "Politics as a Vocation," pp. 77-128 in Hans H. Gerth and C. Wright Mills, *From Max Weber: Essays in Sociology*. New York: Oxford University Press.

Weber. 2002. *The Protestant Ethic and Spirit of Capitalism.* London: Penguin. P. 121.

Weisfeld V, D. Miller, R Gibson and S. Schroeder. 2000. "Improving Care at the End of Life: What Does it Take?" *Health Affairs* Grant Watch 19(6): 278.

Welch, Gilbert H., Lisa M. Schwartz, and Steven Woloshin. 2011. *Overdiagnosed: Making People Sick in the Pursuit of Health*. Boston, Mass.: Beacon Press.

Wentzel, Kenneth B. 1981. *To Those who Need it Most Hospice Means Hope*. Charles River Books.

Worchester, Alfred. 1961[1940]. *The Care of the Aged, the Dying, and the Dead*. Springfield, IL: Charles Thomas.

Zelizer, Viviana. 2005. *The Purchase of Intimacy.* Princeton: Princeton University Press.

Zimmermann, Camilla and Gary Rodin. 2004. "The Denial of Death Thesis: Sociological Critique and Implications for Palliative Care." *Palliative Medicine* 18: 121-8.

Zuelzer, Wolf W. 1974. "Medicine and Ethics: Part III," News and Comment, American Academy of Pediatrics 25(3).

Zussman, Robert. 1992. *Intensive Care: Medical Ethics and the Medical Profession*. Chicago: University of Chicago Press.