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the

anticipatory
corpse

MEDICINE,
POWER, AND
THE CARE OF
THE DYING

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Prelude

One Sunday morning several years ago, Nancy met me after the early service at church. She walked up to me with the urgency of a determined woman. She said, “Jeff, I am yellow, and I need you to be my doctor.” I turned my eyes from engagement with Nancy to look carefully with the clinician’s gaze into her eyes. There it was: the ugly color of death—greenish yellow—looking straight back at me. I tried to contain my horror. Painless jaundice means one thing to a doctor—pancreatic adenocarcinoma, a cancer with few treatments and no cures. She noted that she was on a medication that could cause drug-induced hepatitis. With unrealistic hope, I focused on this medication as the probable culprit, reframing what she had read on the Internet about what being yellow means, telling her that the medication is possibly doing something to her liver. I told her not to take the medication that day and to meet me at the clinic first thing in the morning.

She arrived at 8 a.m. on Monday morning. I sent her immediately for blood work and fit her into my schedule. I then took a more thorough history, and after an examination, reassured her that nothing bad showed up on exam. After all, nothing really jumped out at me except for the painless jaundice; but then, I knew what this meant. I ordered an abdominal sonogram, and fortunately, the radiology department could perform the scan that morning. After I sent her to radiology, I pulled

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her lab results up; they showed a clear pattern of biliary obstruction. Something was blocking the main bile duct, preventing her body from clearing the bile, which resulted in her jaundice. The cause would most likely be a tumor of the pancreas. Then, the page from radiology came around noon, giving me the definitive news that I had not wanted to hear. I did not need to have specialized training in reading sonograms to see it. The tumor in the head of the pancreas was clearly visible. Thus began a long dance with death.

Nancy and her husband had adopted a newborn daughter when Nancy was 41 years of age and her husband, Tom, was 57. That fateful Sunday morning, Nancy was 49 and Tom was 65; their daughter was eight years old. We did have a few occasions for hope. What I thought was a pancreatic adenocarcinoma (a virtual death sentence) was in fact a neuroendocrine cancer of the pancreas (cause for a modicum of hope). On CT scans and other radiological studies for neuroendocrine tumors, the tumor appeared to be contained in the head of the pancreas. Nancy underwent a surgery called a Whipple procedure, which is a large, extensive surgery usually taking about fourteen hours. Fortunately, she was a runner and had the physiology of a 25-year-old. She flew through the surgery. After surgery, Nancy felt great, and she and her family believed, and her doctors hoped, that the tumor had been resected completely. Everything had gone according to plan; we were all very hopeful, and it appeared that the tumor was removed with her pancreas.

That optimism all came to an end with a three-month follow-up CT scan. The scan showed that the tumor had returned, and with a vengeance. There were flecks of tumor all over her liver—some very large ones, some rather small ones. It had already metastasized to her liver despite tests to the contrary before her surgery. I knew then, along with my surgical and oncological colleagues, that death was inevitable. We began to search for different therapies. At that time, I told her that there might come a time in which I would tell her that there were no other options and that she was going to die no matter what medicine had to offer. She was able to hear my warning, but she quickly made me promise only to speak of it again if she was actively dying and nothing could be done. We agreed never to talk of it, unless—in her mind, until in mine—that time came. Nancy would not remember that con-
versation. She wanted to remain positive; she had to live in order to raise her daughter.

Nancy’s eight-year-old daughter became the focus of Nancy’s approaching death. The motivation to stay alive for her daughter drove Nancy to pursue therapies that were to have little benefit. The will to live in order to see her daughter graduate from college, or perhaps just high school, drove her to pursue treatments that none of her regular doctors thought would work. Given her husband’s age, Nancy feared that if she died, no one would be around to raise their daughter. Nancy died at the age of 51, two days after her daughter left elementary school.

Pursuing these treatments meant time away from her daughter—time that could have been spent preparing her daughter for the inevitable. Yet death and its denial also gave Nancy a kind of purpose. Death threatened to take it all away, yet death also put the whole of her life into perspective, allowing her to understand fully how precious her daughter was to her and how desperately she wanted to be alive in order to raise her daughter. Death threatened Nancy’s life; it threatened the very things that she valued. And yet in the denial of her death she was able to find her purpose and to give her life meaning. The passing away of things, the fluidity and flux of life, brought into focus the value and importance not only of life, but also of a myriad of other factors and people in her life. Yet can medicine conceive of death with such paradoxes?

Medical science sees its role as providing therapeutic choices in the face of threats to life. On the one hand, medicine can attempt to manipulate, to “fix” the failing biology. On the other hand, medicine can attempt to “fix” the psychological wound, the sense of what is lost in death. Yet these are not horns of a dilemma. Contemporary medicine deploys both “fixes” simultaneously.

For a patient like Nancy, the technological “fix” was deployed to control the mechanism of her failing body after the tumor began to wreak its havoc. When oncologists and surgeons told her that no therapies were indicated now that her liver was chock-full of cancer, she underwent “experimental” radiation treatments at another academic institution in a distant city. However, she was not allowed to enroll in randomized controlled clinical trials (experiments) because the trials were designed for those in the last six months of their lives, for palliation.
Nancy liked the fact that she had more than six months but did not understand why a treatment that might help those in the extremity of life would not enroll her. At the same time, Nancy would not have wanted to be in a randomized trial; she wanted the experimental drug, not the placebo or the “usual” treatment. Thus, she pleaded with these doctors to give her the experimental drugs, even if she was not enrolled in an experiment, in a clinical trial.

The theory behind the radiation treatment seemed sound. The doctors would attach a radioactive isotope to a peptide (a short protein) that the tumor takes up in great quantity in order to deliver high doses of radiation directly to the metastasized tumors. A similar approach is used to treat certain forms of thyroid cancer. However, while the treatment seemed theoretically feasible, there were absolutely no data to support its use. The doctors gave these drugs to Nancy, yet there was no sign of improvement after a course of treatment with the experimental drugs.

When this failed, Nancy opted for forms of treatment directed at diminishing the blood supply to the tumors through interventional radiology. Radiologists would inject the blood vessels feeding these tumors with high doses of caustic materials to clot the blood vessel and thus starve the tumor of its blood supply. Even though this therapy can be directed only at the larger tumors, Nancy’s hope was to obliterate the smaller tumors as they got bigger—a hope not informed by medical science.

About twelve months into this ordeal, I could tell that Nancy knew subconsciously that we were in the mode of slowing down her death, though she persisted publicly in believing in cures. When these tumors were not destroyed and when the smaller ones got larger, she insisted on believing that the interventional radiologist could inject the arteries feeding these tumors, keeping her alive indefinitely, hopefully long enough to see her daughter through high school.

When the tumors grew too large despite interventional therapy, she began to have obstruction of the larger bile ducts both outside and inside her liver. She underwent more treatments, with stents being placed to keep the larger bile ducts open. Things got worse, and she even underwent treatments to drain the blocked bile, with tubes going from outside her body through her skin and directly into the bile ducts,
hopes of reducing her symptoms. Then she got ascending cholangitis (an infection deep in the bile ducts of her liver), despite these treatments. She also went into an altered mental state called hepatic encephalopathy. The toxins normally cleared by the liver and emptied into bile build up, causing mental confusion. Nancy received antibiotics and had the bile tubes replaced in order to treat the infection and to clear her confusion.

At the same time as it deploys all of these technologies, medicine treats patients like Nancy for their psychological grief. In other words, we can “fix” her psychologically by guiding her from denial to acceptance. We were able to provide good psychological support for her, as well as good social support through home health nursing. Nancy had wanted to be so positive that she would not entertain the possibility that our technological interventions would fail. After her third bout of ascending cholangitis and hepatic encephalopathy, and while she was lucid, I reminded her of the conversation, that there might come a time when I would tell her that death was inevitable. She did not remember that conversation about stopping aggressive therapeutic medicine, but subconsciously she must have, because she resigned herself to the idea of home hospice care without much of a fight. That is when full psychological, social, and spiritual support came into relief for her.

Nancy found the whole ordeal of psychosocial counseling extremely patronizing. She did not like people probing deeply into her psychological life, her life with her daughter, her life with her husband. She did not like the sense that everyone, including me, knew that she was going to die and that people kept pointing this out to her, even if only implicitly. She was a remarkably intelligent and educated woman. She would have known of Kübler-Ross; she knew that she would fall into a phase of grief known as denial. She did not like the fact that counselors were trying to move her along to acceptance. Even if this goal is not the stated goal of psychological counseling, it is the implicit one. After all, people who are dying are so much easier to face if they have accepted the fact that death is at hand. But acceptance meant she would not be able to raise her daughter; acceptance meant failure to reach this goal. She found the psychosocial support demeaning and patronizing, all along, but especially when she moved to hospice care. A chaplain for the home hospice company came by her house. Nancy found this demeaning and
outrageous because she was a faithful Christian and her own priest had been involved the whole time. This chaplain knew nothing of her, of her spiritual beliefs. She needed her priest, not the generic chaplain—the person who can minister to all faiths, and as such, the person of no faith. So the holistic care that was provided all along, even the holistic care that was provided in hospice care, could not assist Nancy, for her goal was elsewhere: living to raise her daughter.

Thus, death would threaten to take her away from her daughter; death would focus her on staying alive for her daughter. Death would take away all that was important to her, yet all that was important to her came into relief because death was on the immediate horizon. Can medicine with its “fixes” envision death as both destructive of meaning and conducive to it? Can medicine with its “fixes” really manage patients in a way that does not do violence to those things held most sacredly, values that come most clearly into relief in and through the clarity provided by the threat of death? Can a kinder, gentler medicine—a sensitive, caring, biopsychosocial medicine, even a spiritualized medicine (or is it a medicalized spirituality?)—act as a counterweight to the coldness of technological cures? Does the mere presence of a biopsychosocial medicine bring back the humanity that is lost when technologies are deployed? If we believe that such a medicine—call it a biopsychosociospiritual medicine—is possible, why is it that so often patients find themselves faced with a medicine striving to give them life, only to find it a demeaning experience in their deaths?

When medicine shifted to a biopsychosocial model from the biomedical model, the thought was that by not only introducing the biological features of life into medicine, but also by allowing the disciplines of psychology and sociology to contribute to medical care, one could more adequately address the whole person. Yet the question still remains: is the kinder, gentler medicine really kinder and gentler? Or is it a mask or a cloak for the cold ground of technological mastery of the living and dying body? Or is it a pall, a death shroud, covering over death, making it more palatable through palliation? Is the biopsychosocial medicine thereby more patronizing than ever, because it promises humanity but cannot deliver without making the patient an object of disciplinary power? Are the dying not more expertly controlled with the
psychologist, the social worker, the chaplain evaluating with their various tools of assessment, deploying their disciplinary expertises?

No doubt, psychologists who provide care for patients with cancer will think that somehow I failed as Nancy’s doctor, or that the psychological support was not as good as it could have been, or that something else could have been done to support Nancy. Social workers will no doubt think that Nancy’s support mechanism was not strong enough, despite the presence of her husband, mother, father, sister, brother-in-law, and numerous friends from her church. No doubt, palliative care experts will think that something more could have been done to assist Nancy to move from denial to acceptance. No doubt, chaplains will think that the pastoral care provided by her priest was not enough, or that he was not skilled in dealing with people who are dying. I say “no doubt” because I have heard all of these comments from colleagues either specifically about Nancy’s care, or about others like Nancy who will “not go gentle into that good night.”

I have even had these thoughts myself. After all, there is a strong belief in the efficiency and effectiveness—the two great metaphysical and moral principles of modernity—of medical interventions. Whether those interventions are technological or biopsychosocial, the belief is that they will work if carried out with proper technique. Shouldn’t we be able to manage such patients better? Are we not getting better at managing death? And why, when it is managed, perhaps even when managed well, is the whole process so dehumanizing? Or is it that death itself cannot be controlled, cannot be managed?

CULTURE OF LIFE VERSUS CULTURE OF DEATH

The ambiguous understanding of death that affects the lives of particular people, like Nancy, is also manifest at the level of society. Medicine is about preserving life, or making life a little easier, yet the coldness of medicine in its mechanical (technological) and disciplinary (psychosociospiritual) aspects results in a life that is often perceived to be worse than death. And when a life being lived is somehow perceived to be worse than death, there is the inevitable question about how death can be managed, either through the deployment of biopsychosociospiritual
medicine in the dress of palliative care, or through doctor-assisted suicide. This book is an attempt to explore how our social understandings of death come to structure medicine, and how medicine comes to construct for us our care of the dying. Scholars have examined how hospitals shape the end of life, but the thesis of this book is that our medical notions about death—notions informed by medicine’s philosophy—have shaped the way medicine cares for patients, and the way patients perceive their dying. In short, medicine’s epistemology and metaphysics can be seen in the way medicine cares for the dying. Not only do the practices surrounding death betray the social structure of medicine, but these practices and these social structures—deployed for the purposes of caring for the dying—betray something deeply held within the psyche of the Western world. In what follows, I shall claim that there is a return of the repression of death, which can be seen in the care of the dying, for death is at the center of medicine, at its core, and even at its cor (heart in Latin).

In part, it is the care offered—or not offered—to the dying that has caused so many people, such as Wesley J. Smith and Pope John Paul II, to recoil from certain medical practices. In a 1993 visit to the United States, the pope called for the faithful to usher in a culture of life. The call to action has been framed in oppositional, almost apocalyptic terms in John Paul’s encyclical letter Evangelium Vitae—the Gospel of Life. After all, it ends with a reflection on the book of Revelation. John Paul reads the image of the Blessed Virgin in the Apocalypse of John as the image of the mother of life. She is the mother of life in travail, in labor for humanity. She opposes the forces of the beast of tribulation, which represents the forces of death. While the encyclical’s theological framework is much broader than the apocalyptic and oppositional framing of life and death, John Paul’s call to action and his remedy for the culture of death is cultural agon (ἀγών, Greek), the cultural struggle to usher in a culture of life. The pope alludes to a much richer theology at play beneath and beyond the agon, oppositional struggle. After all, the death of Jesus, the God-man, is the central salvific act, and his resurrection is not just the reversal of death and return to life—opposing life to death—but the transformation of life and death themselves. But in the encyclical the pontiff never makes fully explicit the theological paradoxes and mysteries of life and death. As such, we are presented
with the oppositional struggle between the culture of life and the culture of death.

Likewise, in Wesley Smith's *Culture of Death*, the relationship of life and death is wholly oppositional. Smith claims that his book is meant to be a wake-up call to civilized society in order to draw attention to what has happened to medicine while we, as a culture, were sleeping. Like the moral, political, and cultural framing of John Paul's letter, Smith's work sees life merely as the opposite of death, and death as the opposite of life. For Smith, the struggle of life and death is out of balance, with those called to protect life — particularly, practitioners of health care, but also the law and the political structures of government — sidling too close to death. Smith sees the issue mainly in the shift from life as sacred to the idea that a certain quality of life is sacred; and that means that other lives with different, or lesser qualities, are dispensable.

In addition, Smith understands the struggle between the culture of life and the culture of death as oppositional in another way. He depicts a contemporary medicine that has lost its cultural heritage, in that it has lost its historical roots in the older, Hippocratic practice of medicine. On this view, our culture and the culture of medicine have shifted while we weren't looking. Society is in decay, for Smith. Of course, this view of the loss of an older, Hippocratic form of medicine has made itself known every few generations throughout the history of Western medicine. As pointed out by Dale C. Smith, whenever medicine feels under threat, a romantic longing for the old Hippocratic medicine rises up.12

This longing for the good life in the past does not in itself mean that Wesley Smith's version of the story is wrong. However, it is indeed odd to think that there has been real continuity between Hippocrates and the medicine of today. Medicine has forgotten the originary good at its core, or so the story goes, according to Smith. Yet, oddly enough, the oath itself prohibits the Hippocratic physician from treating with surgery, and if not the oath itself, certainly the Hippocratic writings advise the physician to leave, indeed to abandon, the patient when his services cannot help. Moreover, there is little evidence that doctors have taken the oath throughout the majority of time in the history of Western medicine.13

Thus, it seems to me that the underlying cause for Smith's fears, as well as John Paul's, lies elsewhere. Smith never fully gets at the heart
of the problem but merely documents what many perceive to be troubling. Yet this concern is no right-wing, conservative conspiracy theory, as it is often declared to be by those of a different political persuasion from that of John Paul or Wesley Smith. In fact, disability-rights scholars have been saying something very similar for years.14 Their resounding cry, which is also the name of the movement’s largest activist group, is “Not dead yet!”15 And their tactics are meant to be disruptive and to challenge the normalizing gaze of medicine and bioethics.16 Many have pointed out that new technologies, such as pre-implantation genetic testing and prenatal screening, have resulted in the termination of pregnancies merely for the reason that the fetus is likely to be disabled.17 The whole reason that these tests exist is to prevent people who cannot hear, or who will be disabled, or with a myriad of other conditions, from being born.18 Such policies of screening are structurally discriminatory, according to disability-rights scholars.19 Other scholars have pointed out that films such as Million Dollar Baby and Mar Adentro implicitly promote euthanasia for the disabled.20

The critiques emerging out of the disability-rights community are the most challenging to the heart of Western medicine, even more so than those articulated by the pontiff or by Smith, for they go to the heart of the power of medicine to name and then create the normal, and to obliterate its other.21 These scholars and activists are asking: why do we look to the body as the source of disability? All of our bodies are ‘broken’ in various ways,22 after all, but society has made it easy for some bodies to flourish, while oppressing other bodies and indeed destroying them through fetal abortion, legalized killing, or medically assisted death.23 Their point is that once society has made it easy to get around in a wheelchair, people who use wheelchairs will be seen in no different light from those who wear eyeglasses.24 Yet these voices are never fully heard or understood by medicine.25 Disability is truly medicine’s other.

The apprehension perceived by the disability community, the late pontiff, and Smith was made clear with the publication of Sharon Kaufman’s And a Time to Die. Kaufman’s thorough ethnographic description of how the hospital shapes death seems to confirm the suspicions of those who fear that medicine has come too close to death. Kaufman documents the final pathways of patients who are dying. With novel
insight, she uncovers the way in which Medicare, Medicaid, and private insurance funding structure the way people are cared for. Patients who are admitted to the hospital with acute problems and decide that they want to allow “nature to take its course” can be admitted for palliative care, and the financing of that care will be paid for. However, if a person is admitted with the very same set of problems but chooses an aggressive course of care and pursues this course of care for a number of days or weeks, and then decides to stop the antibiotics or fluids because of the extraordinary nature of these relative to the life she is living, it becomes very difficult to pay for it. Once the patient stabilizes in the hospital, “she can’t die here.” Thus, doctors, nurses, social workers, or case managers are compelled to begin to convince patients either to be aggressive so that the patient can be moved along through the social apparatus of the hospital, or to switch care to nontherapeutic care so that she can be moved home or to a nursing home for hospice/palliative care.

According to Kaufman, and I am in agreement with her, this desire to move patients along sets up the problematic of modern society described by Giorgio Agamben. The politics of life, or biopolitics, creates a no-man’s land between life and death, where the distinction between the two comes down to a decision. Kaufman names Agamben’s no-man’s land the gray zone of indistinction. As I have noted elsewhere, those in this zone have bare life and therefore deserve the protections normally afforded to the living, but they have no chance at the good life. The only thing that allows us to abandon a person’s life is the decision by her own sovereign will to abandon herself from the protections normally afforded the living. Death must be chosen, as Kaufman demonstrates in her empirical descriptions of the social apparatus of the dying, and it must be timed.

Further feeding the suspicions that medicine has sidled too close to death is this aspect of timing death. Kaufman notes that doctors, while terrible at prognosticating death, usually are able to accurately predict when someone is actively dying. Anyone who has worked in hospitals as a doctor, nurse, case manager, or social worker will recognize Kaufman’s description. Doctors, nurses, case managers, and social workers all know when the time for death has come. At that time, there is a family meeting in which families are eased (or not) into the
reality of the imminent death of the patient. Kaufman describes one of these in great detail, bringing into sharp relief all the ambiguities about death and decision, and the time of death in the space of the bureaucratic apparatus. She points to the ambiguities of the need to make decisions quickly and seemingly on the spur of the moment, and the necessary waiting between moments of decision, all structured by the social/bureaucratic apparatus of the hospital.

Kaufman describes two pathways to death. The first is the heroic measures pathway, in which the patient receives virtually every kind of medical intervention, from feeding tubes to ventilators to fluids to antibiotics, right up to within a few days of dying, when suddenly the mode of care changes. On the second pathway, the patient hits a revolving door. The patient is admitted and treated with a short hospital stay but never returns to his previous level of functioning. The patient goes home or to a nursing home, only to become sick again, requiring re-admission. This time the hospital stay is a bit longer, a little more difficult. The patient is again discharged, and the whole cycle is repeated again, each time the hospital stay becoming longer, the interval out of the hospital becoming shorter, until finally the patient, or the family, decides—after much prodding by the health-care team—to allow the patient to die.

As a medical doctor, and as someone who has acted in the capacity of the ethics consultant for a large university hospital, I have participated in many of these family meetings. Family have believed all along that the medical interventions to which they have agreed are working. Some families see successes where doctors and nurses do not. The family participates in decision after decision, all framed, as noted by Kaufman, by the social apparatus of the hospital and its warped sense of time and space. And the patient’s family reads this sudden change—although to the health-care team it is not sudden—when the doctors start to give very negative descriptions. Terms such as “quality of life” and “dignity” are bandied about. Notions such as “letting nature take its course” or “letting God decide” are used by the health-care team. Meanwhile, as Kaufman admirably describes, the patient’s family becomes more and more bewildered. In my own experience, coming into these situations as the ethics consultant, the family begins to think the patient’s health-care team is trying to usher him along to a quick death, or to “move things along,” as Kaufman puts it. It is no wonder, as Kaufman notes, that
families become confused about the finer distinctions between killing and letting die, or suicide and homicide; as we shall see, it is a confusion to which ethicists and doctors continue to add and in which they participate.

SUSPICIONS CONFIRMED

Kaufman’s account captures precisely the fears articulated by John Paul, Wesley Smith, and the disability-rights activists. In my opinion, they, along with other scholars, have picked up on something that should not be dismissed quickly. Their clarion calls should cause alarm—calls that perhaps have been too easily dismissed by the rest of society. There is indeed something rather odd about the fact that those who study human life in depth in its biological, social, and psychological aspects should become the ones who come very close to the zone of indistinction, when decisions about life and death are confused and the social apparatus of medicine comes to look as if it is promoting death. Even if society and modern medicine decide that active physician-assisted death is an acceptable practice, it is ironic that for much of its recent history, the motivation for modern medicine was just the opposite—to keep people alive. Was that motivation somehow wrong-headed? There is something unsettling about the power of medicine when it brings its expertise to implementing the norm, or normality, when medicine deploys an entire social apparatus to make people normal. Yet the oddness is perhaps even more acute when doctors take away a life that is perceived to be abnormal, or when it is perceived to have abnormal amounts of suffering, or when the patient’s predicament is outside the norm of human comforts. It is more than problematic for many practitioners of medicine when medicine engages in actions that, if placed in any other social context, would be appalling to us. What kind of political space has medicine carved out for itself? Kaufman notes the temporal aspect as well as the spatial, by drawing attention to the movement of the patient either to the pathway of heroic measures or the revolving door pathway. It is surely true that if the actions carried out within the political space of medicine were carried out in any other context, they would be beyond the pale.
The big moral questions about medicine and life and death are obvious. I propose to look more closely at other factors. Take the experience of an acquaintance of mine who was on a lung transplant list. She needed someone to die in order that she might live. Waiting (hoping?) for someone to die, so that she might live—perhaps even several people to live other than herself—was a surreal experience for her, fraught with guilt and hope. Or, take as an example Margaret Lock's description of her experience as she watched a certain patient being prepped for surgery. Like any other person about to go into surgery, he is on the breathing machine; he is asleep, or at least appears so; but he is really dead. His (its?) organs are to be removed. Sure, the person had been pronounced dead, legally speaking, but his beating heart and pink kidneys and fleshy liver do not betray a dead person.

Or take as an example the rite of passage of most medical students in Western countries. Is it not odd that their first patient is dead, literally patient beneath the dissecting knife? And to make it odder still, the first dead body that many medical students have ever seen is the cadaver, that anonymous person who has no social or psychological life, no family, no context. This patient is dead, and thus truly patient to the manipulations of medical knowledge. This dead body is the object from which medical students will learn in order to be of service to others whom they hope to keep alive. Oddly, the dead body does not appear anything like the living body; death obscures life after all, yet it is death that is first observed. So the medical study of life originates with a de-contextualized dead body; the body of the dead cadaver represents the bodies of the living.

There are other oddities that have become routine in the care of the dying. For example, there is a certain arrogance in medicine when it presumes to know the proper social or psychological response to the threat of death. There are actually diagnostic categories with criteria for normal and abnormal bereavement reactions in the *Diagnostic and Statistical Manual of Mental Disorders*. What is an appropriate grief reaction when someone is faced with death? What is a normal period of grief, and what is an abnormal grief? These are the sorts of questions that medicine and psychiatry attempt to answer empirically, or expertly. Once the questions are answered, the whole of the discipline's power—
disciplinary power, in Foucault’s sense of the phrase—can be brought to bear on the person who is grieving.

Our culture is more than willing to accept these medical practices that are subtly laden with power that in other contexts would be unsettling—when practitioners of medicine open dead bodies, or remove live organs from legally dead people, or define normal grief reactions. Why? Because they are done with good intention and in a proper social and political context. Is the alarm felt by John Paul, or Smith, or disability scholars and activists not merely due to the fact that life and death are opposed in an agonal cultural struggle? Or is it that at the heart of medicine, in the soul of medicine, there is a paradoxical relationship between life and death? After all, in a way, does medicine not need death as its motivator and as the ground on which its knowledge base stands? Is death not needed to educate, to transplant, and to research?

I shall argue that, contrary to Kaufman, it is not time and waiting that shape death, but space. The “pathways” that she describes go nowhere. They are abstract spaces created by International Classification of Disease tables and Medicare reimbursement tables. Kaufman notes how these features shape time, but it is precisely the abstract political space of tables used to codify disease—but interestingly not death—that distorts time; for one cannot die naturally, but only from disease according to the tables. The pathways described by Kaufman are not pathways so much as they are well-bounded spaces in which movement and therefore time are caught in the immanent chain of mechanized events—both social and bodily events—finally ending in stasis of the dead body. Thus, it is the spatialization of time that distorts our dying. It is in the dead body that the flux of time can be captured in the space of the body, and medicine and medical technology are built upon this truth. The denial of death that so many have noted is only one facet of the thesis of this book; another facet to which I shall draw attention is that it is death that is at the repressed core of medicine, and indeed much of contemporary society.

It is death, after all, that motivates medicine, as Daniel Callahan points out. Yet medicine is no simple and explicit quest for immortality, even if, structurally and politically, it seems to be on such a quest. The original discussion about quality of life was primarily about when
medical interventions went too far. Yet the perception today is that quality of life has become the sole focus of medicine. Yet if medicine is about quality of life, why are so many people so afraid to die and why do they demand technological cures over quality? Why are our intensive care units filled with those who have no hope of return to a meaningful life? Why does Smith claim that once medicine became focused on the quality of life, it ushered in the “culture of death”? At one level, practitioners of medicine have no doubt realized that their striving after life—an implicit and structural quest for immortality, even if not fully acknowledged as such by medicine—led them down the path to sustaining patients in states of life that were worse than death. Against the sentiment of a John Paul II or a Wesley J. Smith, isn’t a contemporary medicine that focuses on quality of life an acknowledgement by the medical establishment that the implicit quest for immortality is wrong-headed? Should medicine not acknowledge its finitude by acknowledging that human life is finite?

Surely, with medicine increasingly acknowledging its finitude, we can move away from the quest for immortality. So why is it that the new emphasis in medicine that has shifted away from the idea of prolonging life at all costs—relinquishing the implicit drive for immortality—is perceived by many as the primary sign that we live in a “culture of death”? Is it not also true that the “culture of life” as envisioned by technological medicine is in fact a culture of death, in that the technological imperative is a kind of quest for immortality? Are those who accuse today’s medicine of being a culture of death now demanding that medicine embrace the quest for immortality? Are these not the very people who hope for life eternal in a life beyond the grave?

And for those who would embrace death, due to a poor quality of life, is it not equally odd to think that death might be the proper means to achieve a quality of life, in ending it, or that the quality of a life might be so bad that the quality of death might be its counterpoint? In what sense can death be said to be better than a certain quality of life? And if we, as a culture of medicine and more broadly as a society, are so bent on improving the quality of life, why is it that patients still find themselves in intensive care units enduring lives worse than death, just as they did in the 1970s?
The great paradox in all of this, and the subject of this book, is that death serves as the cultural and political motivator for medicine. Indeed, one could claim that medicine—Western medicine, at least—is founded in a dream as old as humanity itself: to defer death. For death and the disease that is its harbinger are the most brutal reminders of the radical finitude of human existence. Death is the end of all meaning in and of (this) life. And because of this, humanity dreams the dream of eternal life, health, and youth—a dream that, as Plato points out, some of us attempt to realize by immortalizing ourselves in works of art or literature, others of us by erecting buildings that carry our names, and most of us by procreating in order to perpetuate our kind. Let us say, then, that the dream of eternal life in the face of death is what animates all civilization, all creation of meaning. If this claim is correct, then medicine is one part of the enterprise of human civilization, an enterprise that keeps aiming at eternity precisely because of the sting of death. From this point of view, death is not only destructive of meaning but—paradoxically—foundational to meaning as well. I will show that what modern medicine fails to recognize is that death not only represents the ever-receding frontier of medical progress, but also sits at the epistemological heart of medical science itself.

For Nancy, death threatened all that she knew as valuable and important, and at the same time, death also brought directly into focus the value and importance of living. Modern medicine, I submit, has failed to respond to this dialectics of life and death in an adequate manner, and its response leads to lives worse than death in the technological manipulation of the dying. In viewing death exclusively as the destruction of meaning, medicine has aimed to do more than alleviate suffering: without realizing it, medicine hides death with technology and dissolves death in discourses. In short, medicine seeks to remove death’s sting from the human community. Yet, like comedic heroes of literary tales, medicine comes along to stop suffering, to help, to bring a little relief, only to make things worse by begetting more and more dehumanization through its technological and psychosocial fixes.

On the one hand, the knowledge begotten by anatomy and physiology was motivated by the desire to stave off death and to relieve suffering; the practices of the 1960s in keeping people alive with technological
interventions yet without hope of meaningful living were an extreme expression of this motivation. On the other hand, the contemporary palliative care movement is a response of medicine to the suffering be-gotten by extreme care offered to those who are dying. Yet in medicine’s drive to alleviate the suffering caused by an over-technologized medicine, palliative care comes to attempt the control of death through discourses, demeaning the very idea that death might mean something, might frame the value of one’s life.

Dead anatomy begets physiology; physiology begets technology; technology — the replacing of a dead organ by a dead machine — begets a life worse than death. An over-technologized medicine begets a biopsychosocial medicine; a biopsychosocial medicine begets a biopsychosociospiritual medicine; a biopsychosociospiritual medicine begets holistic, palliative care medicine; but the holistic care of the dying comes to look totalizing, indeed, totalitarian. The word *palliate* comes to English from the Latin word *palliare*, which means “to mask or cloak, to mitigate.”\(^{39}\) Thus, today death is managed or controlled or cloaked through biomedical intervention, as well as a wide array of social, psychological, and even spiritual discourses. Do these practices prevent patients, their loved ones, their doctors, and even society at large from confronting death in its fundamental significance for human life? Is the drive to cloak death in technology and to master it in discourse merely covering the fact that death sits at the heart of medicine? And finally, is medicine not about the power of life and death? Thus, is medicine not also a form of politics?

Medicine needs death. For in its various techniques, from autopsy and dissection to organ transplantation, modern medicine “needs” death in order to create its own realm of theory and practice, but this death is a different kind of death from the one that allows someone to create existential or personal meaning. As noted by Kaufman in her anthropo-logical descriptions, by Foucault and Agamben in their philosophical treatises, and by medical practitioners every day in Western societies, the zone of indeterminacy, the no-man’s land between life and death, grows increasingly wider, and necessitates the decision of the one with the proper sovereignty to decide whether to live or die. Death is the radical other for Western society in general and medicine in particular, and as such it is our god. “Choose you this day whom ye will serve!”
Conscious choice is the central aspect of being human for those of us living in the West, and it is the deciding feature of the good death. In this book, I shall attempt to unpack medical notions about death, notions that are embedded in contemporary medical practices and result from the coincidence of medicine’s metaphysical, epistemological, and even political commitments.

OF GOODS AND PRACTICES

Medicine is a good in Western society. Those of us who are engaged in the practices of the good of medicine — especially in light of the status that medicine has achieved — think of ourselves as practicing a good that is virtually unqualified. So, when critiques come, we, the practitioners of medicine, tend to have one of two responses: either outright dismissal of the criticism or a quick attempt to resolve the problem. What follows in this book is another critique of medicine, particularly in its mode of caring for the dying. By “the dying,” I mean those who are in the ICU and in palliative care. I have no doubt that there will be those who will dismiss my critique outright. As for the second group, those who hear the critique and accept it as, at least in part, accurate, they will no doubt attempt a quick remedy, one that fixes the problems that affect a broken medicine. Those remedies will range from a call for better scientific data in order to know better how to care for the dying, to a call for a good dose of humanism in order to solve the problem. The former will emphasize the science of medicine; the latter will emphasize the art of medicine. The former will say that medicine needs better science in order to become, once again, humane; the latter will call for a therapeutic course of humanistic education, a humanities pill to fix what ails us. Yet it seems to me that we have been attempting both fixes for so long that we do not even know where the problem lies.

It is virtually impossible to think about how to solve any problem in medicine without our thinking becoming almost immediately mechanical and instrumental. We already live inside a way of thinking that prevents us from thinking differently; not that thinking differently is impossible, it is just difficult. If we are to prevent all practices in medicine from becoming thoughtless doing, we must once again turn to
how we think about what it is that we do. In order to achieve this, however, we must, paradoxically perhaps, realize that all thinking is also a kind of doing. The strict line between *theoria* and *praxis*, so prominent in the West, and the strict division between subject and object are, in a way, false ones, but they continue to flourish in our practices. These lines (theory vs. practice, subject vs. object) sit at the very heart of the West, if we are to believe thinkers such as Nietzsche and Heidegger; or perhaps these lines are just an aberration of late Western Scholasticism, or are lines drawn at the Enlightenment. If we accept Foucault’s position—which does not preclude accepting any one of these possible readings on the history of Western thought—we know that there are various kinds of practices implicit in all theoretical endeavors, and at the same time there are implicit theoretical stances in all that we do. Thus, we must think, once again, about what it is that we do by examining critically what we do.

Medicine as a discipline is mostly concerned with doing and with the effects it brings about in the world. Medicine concerns itself with how to pragmatically produce or cause those effects in the world. Or, as Carl Elliott points out, medicine collapses into an unthinking pragmatism, an inane “practice in order to be practical.” Medicine is a practice ordered toward and by its own practicality. Medical information is justified as medical knowledge if one can do something with it in the world. Medicine’s metaphysical stance, then, is a metaphysics of material and efficient causation, concerned with the empirical realm of matter, effects, and the rational working out of their causes for the purposes of finding ways to control the material of bodies; that is to say, medicine’s metaphysics of causation is one of material and efficient causation at the expense of final causes or purposes. Among Aristotle’s four causes, early modern science—including medical science—historically repudiated or, at the very least, minimized formal and final causation and elevated material and efficient causation. Efficient causality reigns supreme in all technological thinking, such that even matter comes to be thought of not so much as a cause, but as the stuff that stands in reserve of power, awaiting knowledge to mold it into what we desire it to be. On this view, matter—the body—has no integrity, except that it is driven by an automaticity and can be bent to our desires. At least since Bacon, it has been understood that knowledge is power gained to relieve
the human condition. That is to say, true knowledge can do things with the world. The purpose of knowing—the end of knowing—is to bring about desired effects in a world of immanent cause and effect.

Medicine gives no thought to its metaphysics; it might even deny having one. And it gives no thought to its practices, because medicine is about doing and not about thinking. For Western medicine, and perhaps for all of scientific and technological thinking, the important problem in the medical world is how to manipulate the body or the psyche in order to get the effects that we desire. Bodies have no purpose or meaning in themselves, except insofar as we direct those bodies according to our desires. In this sense Eric Krakauer has said that medicine is the standard-bearer of Western metaphysics. The world—the body—stands before us as a manipulable object, and all thinking about the world or the body becomes instrumental doing; thus, to do good we must manipulate the world and show our effects toward some measureable outcome.

In this book, I shall claim that the practices surrounding the care of the dying in our time are built upon this metaphysics of efficient causation, and that this metaphysics became possible precisely because medicine’s epistemology became grounded on the dead body, understood as an ideal-type. After all, life is in flux, and it is difficult to make truth claims about matter in motion, about bodies in flux. Thus, life is no foundation upon which to build a true science of medicine. The processes of living prevent the possibility of true knowledge about the body. Moreover, in the dead body, in the stasis of death, one can find a firm ground on which to make truth claims. Taking the dead body as epistemologically normative has metaphysical and ethical import, for in doing so, one highlights certain notions of causation over others and deploys practices that shape, direct, and enforce what we call care. The dead body, as the normative body, begets practices that efficiently manipulate bodies and psyches toward the “good” death.

I shall also argue that these practices of the care of the dying hide and mask their power and their force, even while they deploy that power and those forces. These forces both are possible and are deployed because of the implicit metaphysics already held by medicine; that is to say, medicine’s epistemology already holds the world and bodies to be objects that are primarily measureable, even before the measuring. The
dead body is the measure of medicine, creating the sense that life is primarily matter ordered to efficiently move within space, both within the space of the body itself but also within the space of the body politic. The dead body as the normative body in medicine creates the conditions for the possibility of the deployment of a metaphysics of efficient causation, a metaphysics of power and control of bodies and psyches. In short, the practices of care of the dying—both ICU care and palliative care—betray the cold ground of their origins.

I shall have to beg the reader's patience, first as I accumulate evidence for this claim, and second because it is no small thing to entertain the idea that our practices, which are designed to stave off death or to ensure a good death, have dark origins and deploy subtle (and not so subtle) forms of violence. It is no easy thing to turn to medicine's practices, which all along have been motivated by care and concern, and to acknowledge that the very structures of care and concern created to care for the dying (whether the person is in the ICU or the hospice) cloak death and, in so doing, betray a kind of coldness toward the dying. It will no doubt be hard for us to accept that our practices continue to repeat these violences—even in palliative care—precisely because there is something rotten at the heart of medicine.

It is in this sense that medicine has become thoughtless: medicine is primarily about pragmatic doing and efficient control, ordered to utilitarian maximization and its own practicality. In short, medicine's philosophies of life and death, its technologies of life, and its psychologies of death are founded first in an epistemological move to find a stable place to build its knowledge, namely, the dead body, and second in its deployment of a metaphysics of efficient causation for the mastery of living and dying bodies and psyches.

Medicine embraced the metaphysics of the modern natural sciences. Thus, with the rise of modern medicine, death is pulled out of communal contexts with various mythological, narrative, and liturgical meanings in order to become the ground of medical knowledge, and out of that ground, medicine is able to construct its knowledge. Modern medicine is continually struggling to master death, only to have death return with a vengeance. Death is thus shrouded in technology, hidden in discourse, and finally cloaked in palliative care. And in its return, medicine tries more exhaustively to name it, to shape it, to control its
uncontrollable features, only for it to flit away. In this sense, death is medicine’s other, an other at its very heart.

To make the claim that medicine has become a social apparatus for the control of the dying, I shall first have to lay down some philosophical groundwork and declare my own methodological commitments, because, after all, there is no view from nowhere. I take up a thesis articulated by Foucault, which I expand. The thesis, which I have already touched on above, is that in medicine the dead body is the epistemologically normative body, and medicine’s metaphysics is one dominated by efficient causation—the animation of dead matter. While I stand in the Foucauldian tradition of inquiry (if such a thing can be claimed), I do so with significant differences. So, I am not merely naming my sources or giving an account of my use of Foucault. Moreover, it should be noted that Foucault is a master diagnostician, but he is less helpful with therapy. However, Foucault’s insight into the role of space and time, now understood as political space and historical time, in medicine and other disciplines is potent for understanding why contemporary medicine is the way that it is.

STRUCTURING THE ARGUMENT

My first two chapters are primarily genealogical, that is, they critically examine the development of a medical philosophy of death. The first chapter is necessarily philosophical for several reasons. First, I disclose my philosophical and methodological stances, and I begin to unpack the philosophy that animates medicine. I take two notes from Michel Foucault: one is methodological, the other is a thesis. Foucault’s method is genealogical, a kind of historical project examining historical development in order to explain how we got to where we are. Foucault also calls his method archaeological in that he takes a good look around a particular historical moment in order to explain how different aspects of particular histories—of particular times—have different origins but work together to create the present. My method of engagement is both genealogical and archaeological; it deals with medicine’s history (time) and its politics (space). I explore political space and historical time, asking medicine how its practices came to be such that they betray its
coldness in the face of death. I pick up a thesis that Foucault articulates in *Birth of the Clinic*, namely, that within the space of the dead body, the flux of matter in motion is frozen; time stands still. I show how this understanding of the dead body becomes an ideal-type, a representation laid over the living body.

In chapter 2, I explore how the medical clinic matured. It seems clear that the science conducted especially within the laboratory, rather than the clinic, becomes the major site of innovation for medicine starting from the middle of the nineteenth century. Foucault notes that there is a tension in the clinic between those anatomists who would find scientific certainty in the dead body and those more clinically minded doctors who would see more certainty for medicine in the science of statistics. Given my thesis that the dead body is epistemologically normative for medicine, one might counter that this nonliving body is not what physiology studies, because physiology is about the living body. I explore the rise of physiology and statistical medicine and show the way in which they depend on an understanding of life as nonliving matter in motion. I also argue that the political space created by statistical theory gave medicine a platform to participate in the governance of the body politic. After all, as Foucault would claim, the task of good health is first a task of good government. I also explore how science must penetrate the body in order to know how to manipulate body and psyche, for their own good, no doubt, but also for the good of the body politic.

In chapter 3, I become more archaeological, in looking carefully at what contemporary medicine has at its disposal for the care of the dying. I trace the movement of the physiological laboratory back into the clinic/hospital, and of physiological science, which understands life as the series of functions that resist death, into the ICUs. Medicine intervenes on the prior cause, forcing dying matter to stay alive, and in so doing it too often demeans the patient’s understanding of the meaning and the purpose of life. Life is the series of functions, and as long as the matter is in motion, there is life. We are left with the perception that patients in the ICU are living lives worse than death.

In chapter 4, I explore medicine’s remedy to the problem of sustained mechanical life without hope of a good life. Because medicine understands life as function without purpose, then all that must be done
to remedy the problem is to stop doctors from forcing technology on the dying; doctors must take their dictates from decisions made by patients. Surely, this reversal of power is good, but it does not get at the heart of the question of medical violence. Rather than explore the meaning and purpose of life, medicine's response is to create the patient as the master of her own body. She must decide whether to embrace or to reject technology. Rather than addressing the very human questions of meaning and purpose, medicine simply changes who is in charge, who has the sovereignty to control life and death efficiently and effectively. This decision creates the space where euthanasia becomes a decision for the one in charge of his own subjectivity. Yet ensconcing physician-assisted death in the law only frames the decision for death as the most rational decision to be made by the sovereign. It is the individual's own-most decision, but only because it has been framed in that way by the social apparatus of medicine and law combined.

Chapters 5 through 7 deal with the question of brain death. Once the technologies of life are able to keep the dying alive, medicine is faced with a question of what to do with those who cannot come off the machines but whose physiology continues to be healthy. This attitude toward life as mechanical function also opens the possibility that life could be sustained indefinitely if the machine of the body could be sustained. Dead organs can be replaced by living organs. In chapter 5, I trace how the idea of brain death is constructed. In chapter 6, I trace how the drive to transplant organs leads to a series of conundrums and absurdities in practice, where the living bodies of the dead become the source of life for the dying bodies of the living. I also trace how brain death is increasingly being questioned as the definition of death, such that some are calling for the abandonment of the dead donor rule, thereby opening a space where death is embraced for the good of the body politic in need of organs.

In chapter 7, through the exploration of the cases of Terri Schiavo and Eluana Englaro, I explore how the abandonment of the dead donor rule moves life and death into the realm of decision. For political conservatives, bare life is deserving of the protections of the law even if the good life is not possible. For political liberals, the only lives deserving of protection are lives that can decide about the possibility of the good
life. Abandoning life, either in physician-assisted death or in abandon-
ing the lives of those in persistent vegetative states, becomes a decision
framed in terms of politics.

In chapter 8, I explore the biopsychosocial model of care, the rise
of Elizabeth Kübler-Ross, and the introduction of psychological and
sociological discourses into medical practice. This movement begins
with a shift from the biomedical model of medicine to a biopsychosocial
model. In this new model, medicine can be more sensitive to a person’s
psychological and social contexts. Through the use of statistics, medicine
creates assessments that give a scientific character to both psychology
and sociology. Total care — of body, psyche, and social relations — can
be managed because now they have achieved the status of science. Bio-
psychosocial medicine reaches its fruition in biopsychosociospiritual
medicine, where spirituality is allowed back in, but now as assessed
and measured. Each area — the biological, the psychological, the socio-
logical, and the spiritual — has an expert, and each expert creates tools
of assessment. These assessments are the means by which the expert
creates and defines his area of expertise. In short, these experts deploy
total(izing) care.

In chapter 9, I trace the beginning of the modern hospice movement
in the love and concern offered by a nurse and social worker, Cicely
Saunders. I show how it mutated into palliative care, which claims to
be “more than ‘tender loving care,’ a high level of sympathy, and time
and inclination to sit by the bedside holding a patient’s hand.” Palli-
ative care must achieve the level of a science, with instruments of as-
sessment, in order to be true care. Palliative care extends the reach of
the expert into the crevices of the patient’s psyche, into the fissures of
his social relations, into the caverns of his religious life. It extends be-
yond the grave into the familial space left empty by the patient’s death.
Medicine becomes at best totalizing, at worst totalitarian.

In my final chapter, “Anticipating Life,” I turn to explore, haltingly,
how medicine might be transformed. I approach, phenomenologically,
the nature of suffering and the ways in which life can be understood
only as flux, not as death. Life is in flux; it is by definition a suffering,
an undergoing of change. What if, instead of elevating efficient and ma-
terial causation in life, medicine understood that embodied life is also
the embodiment of formal and final causes? What if, instead of seeing

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only the loss of function in those who are suffering and dying, it also could see that human beings are losing meaning and purpose? What if, instead of highlighting function, it paid attention to purpose? What if, instead of thinking of life as the series of functions that resist death, medicine searches for its origins in the call of the suffering other? What if that call could only be heard and understood, not through a myriad of exhaustive social, psychological, and spiritual assessments, but from within a community of others? If medicine’s practitioners will but think back to their reception of a primordial call, will they not find that it was the call of a suffering other, a friend, a mother, a father, a sister, or brother, who called on them for assistance? Were they not called to be physicians by a suffering other? Would medicine deploy its technologies so readily or carelessly if it understood life as embodied purpose? Would its science and its practices look different? What if medicine took seriously its origins in community? What if medicine understood that life is inherently communal, with forms and purposes and not just material function? Would its understanding of life and death, or better, living and dying, be different?

For medicine to be other than it is, we must understand why it has become the way it is. My claim is that medicine has pulled the dead body out of community, stripped it of its communal significance, and found the ground of its knowledge in the dead, decontextualized, and ahistorical body. I shall argue that medicine has lost its way in the care of the dying—from ICU care to palliative care—because of how it understands death in the body.