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Death and Resurrection in US Hospice Care:
Disability and Bioethics at the End-of-Life

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Abstract Cover Page

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An abstract of
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Abstract

Death and Resurrection in US Hospice Care: Disability and Bioethics at the End-of-Life

By Harold Braswell

Death and Resurrection in US Hospice Care: Disability and Bioethics at the End-of-Life is a rethinking of the concept of "death" in US bioethics. Rather than defining death as an isolated biological endpoint, this dissertation attempts to reorient bioethics around an understanding of death as a dynamic social process. Such a definition requires examining the unique ways in which death is defined in both particular clinical situations and broader structures of health policy. The result is an understanding of death that is both more intellectually robust and clinically practical than current bioethical definitions of death.

I demonstrate the utility of this approach through a historical and ethnographic study of how death is defined in US hospice care. Through a historical study I argue that the modern US hospice movement developed a definition of death that was explicitly non-medical. In this non-medical conception, death was a matter of private kinship; its meaning was constituted by kinship relations in the private sphere. This definition of death led hospice care to be based on an outpatient treatment model, in which the patient's long-term care needs were to be met by his or her family. Through an ethnographic study of a "Amberview Hospice—a contemporary "modern" hospice organization—I argue that this model creates systemic problems in the treatment of patients who lack sufficient kinship support to sustain hospice care. As an alternative to this arrangement of treatment, I conduct an ethnographic examination of Our Lady of Perpetual Help Home, a charitable end-of-life care facility. "Our Lady" provides both long-term and hospice care to those patients who have been excluded from the health care system. This unique treatment modality is, in turn, based in the home's particularly Catholic conception of death. I argue that Our Lady's synthesis of hospice and long-term care is a model for the reorganization of US end-of-life care.

I conclude by arguing, based on my rethinking of the definition of death, that the reform of US hospice care should be considered a bioethical project.

Cover Page

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Much of this dissertation was written under or immediately following a period of intense emotional and financial distress. This distress was spurred, largely, by the death of my two mothers: Estelle Sechster and Andrea Braswell. It was intensified by a brutal lawsuit that nearly bankrupted me both financially and emotionally. I would not have gotten through this period without the support of my friends—who quite suddenly saw themselves thrust into roles that were not unlike those of family. They have my gratitude for accepting these roles so readily and handling them with such skill and care.

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This dissertation is the product of extensive archival research and ethnographic fieldwork. This work would not have been possible without the cooperation and, truly, collaboration, of a number of individuals affiliated with the organization I describe as "Amberview Hospice," as well as the sisters, staff, and patients of Our Lady of Perpetual Help Home. For me, the work being done by end-of-life providers, and the bravery and strength of terminally ill patients was a subject of more than academic interest. It became my lifeline. I am grateful for all those who helped me with this work.

Most importantly, I am grateful for my family: my cats Teddy and Flash, who were constant companions throughout this process; my wife, Nikki Karalekas, who made the time for me to finish this, who made me want to write it, and who made me believe that I *could* write it. I love you.

Last, but certainly not least, I want to thank my daughter, Estelle Inez Braswell-Karalekas, for smiling at me when I came home and for giving me something beautiful to think about while I was away. I dedicate this dissertation to her.

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Introduction

Bioethics, Disability Studies, and the Question of Death

This dissertation is an intervention into two scholarly fields: bioethics and disability studies. Bioethics is the field charged with the deliberation of ethical dilemmas in science and medicine. Disability studies is a field that examines disability from an interdisciplinary perspective based primarily in the humanities and social sciences. As many prominent bioethical issues directly involve disability, there is a substantial overlap between the concerns of bioethicists and disability studies scholars. But this overlap has, traditionally, not been harmonious: On the contrary, disability studies scholars have charged that, under the seemingly inoffensive guise of "ethics," bioethicists consistently promote violent discrimination against the disabled. Bioethicists, in turn, have dismissed disability scholars as failing to fully engage the complexities of contemporary medicine.[1] By taking the concerns of both bioethicists and disability scholars seriously, this dissertation attempts to synthesize and, in the process, enrich both fields.

It does so through an exploration of a topic that is contentiously debated both within and between these fields: end-of-life decision making. In this "Introduction," I will outline the general terms of this debate. Bioethicists largely understand such decision making through the concept of "end-of-life autonomy," which I define as the individual's legally protected and medically enacted right to die in response to an incurable medical

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[1] Additional texts exploring the contentious intersection of bioethics and disability studies include Alicia Ouellette, *Bioethics and Disability: Toward a Disability-Conscious Bioethics* (New York: Cambridge University Press, 2011) and Jackie Leach Scully, *Disability Bioethics: Moral Bodies, Moral Difference*, (Lanham: Rowman & Littlefield Publishers, 2008).

condition. Though bioethicists continue to debate both the means through which such "autonomy" can be realized, as well as the population to which it might reasonably be applied, the field generally supports the ability of incurable patients to end their lives as an act of personal choice. Disability studies scholars have contested this framing of end-of-life decision making. Such scholars have argued that the choice of individuals to die at the end-of-life is not "autonomous," but rather a response to discriminatory social circumstances; by framing such decisions as matters of person choice, the concept of "end-of-life autonomy" both obscures and reinforces violent discrimination against the very populations it purports to protect.

Nevertheless, while disability studies scholars are uniformly opposed to the application of "end-of-life autonomy" to persons with incurable disabilities, the field is divided about whether the concept can be applied to the terminally ill. Some disability studies scholars argue that terminal illness is constitutively different from disability and that terminally ill individuals should therefore be able to receive medical assistance in ending their lives. Others claim that, in reality, "end-of-life autonomy" discriminates against the terminally ill in a manner that is not fundamentally distinct from disability discrimination. Consequently, they unequivocally oppose the very concept of "end-of-life autonomy," whether it is applied to the chronically disabled or the terminally ill. The result is an impasse, within disability studies, about the bioethical regulation of disability at the end-of-life.

I argue that this impasse is rooted in the epistemological structure of the field of disability studies; in particular, it is based in the manner in which disability studies scholars have understood the relationship between disability and death. These scholars have consistently argued that the relationship between disability and death is not *natural*, but rather *social*. In general, the cause of death among disabled populations is not disability itself, but rather by both overt and systemic discrimination against the disabled. By highlighting the social character of this relationship, disability studies scholars seek to minimize and, to the extent possible, eliminate this violent discrimination—thus protecting disabled populations from death.

But this model of understanding death makes it impossible for disability studies scholars to consider those disabilities that are the result of terminal disease. Such disabilities are linked to death, not by social discrimination, but rather a natural disease process. As these disabilities are manifestations of an intrinsic link between disability and death, disability studies scholars either directly or indirectly exclude them from the category of "disability" itself. This exclusion is, I claim, the root of the current impasse in disability studies regarding the validity of end-of-life autonomy for the terminally ill.

Overcoming this impasse entails designing a disability studies approach to a question that might not, at first, seem of direct importance to the field: What is death? I argue that it is only by addressing the question of death that disability studies scholars can develop an account of which deaths occur as the result of violent discrimination and which are the result of natural disease processes. Such an account is, in turn, necessary to develop a nuanced disability studies perspective on the distinctions between chronic disability, terminal illness, and other seemingly ambiguous bioethical categories, such as brain death and vegetative states. Without an appreciation of such distinctions, it will be impossible for the field to not only address the particular issue of end-of-life autonomy, but also larger questions about the constitution of bioethics as a field. Consequently, by not addressing death, disability studies scholars inadvertently support the very bioethical project that, by their own account, is harmful to disabled populations throughout the lifespan.

In the final section of this introductory chapter, I outline a dissertation project that develops a disability studies approach to the bioethical definition of death. I will begin by describing the guiding epistemological frameworks of, first, bioethics, and, then, disability studies.

Bioethics: Informing Patients, Protecting Autonomy[2]

Bioethics is a field dedicated to the mediation of medicine and science by professional ethicists; these ethicists are tasked with bringing medical and scientific practice in line with external legal protection.[3] According to David Rothman's history of bioethics, this regulation began in the 1970s, in response to a lack of trust between doctors and patients, scientists and subjects.[4] In this context of mistrust, the regulation of medicine and science was necessary in order to protect patients from abuse. Bioethicists arose to design and propose suggestions that could allow safe and ethical medical and scientific practice to continue.

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[2] This section was previously published, in a slightly modified form, in Harold Braswell "Taking Representation Seriously: Rethinking Bioethics through Clint Eastwood's Million Dollar Baby," *Journal of Medical Humanities* 32 (2011): 1-11.

[3] For histories of the field that confirm this definition, see: Albert R. Jonsen, *The Birth of Bioethics*, (New York: Oxford University Press, 2003); Helga Kuhse and Peter Singer, "Introduction," in *Bioethics: An Anthology*, ed. Helga Kuhse and Peter Singer (Oxford: Blackwell Pub., 2006), 1-8.; David J. Rothman, *Strangers at the Bedside : A History of How Law and Bioethics Transformed Medical Decision Making* (New Brunswick [N.J.]: Aldine Transaction, 2008).

[4] Rothman, *Strangers at the Bedside*, 4-10.

A central concept in this regulation was “patient autonomy.”[5] While there are many definitions of “patient autonomy” in bioethics, the term generally applied to the individual’s freedom to make decisions about his or her medical treatment options.[6] These decisions must be judged “rational,” but rationality is not only assessed according to a medical criteria, but also according to the coherence of an individual’s decision with his or her long-held values.[7] From a bioethical perspective, the individual could only make such decisions in cognizance of the relevant scientific and medical information. Consequently, “informed consent,” in which doctors and scientists inform patients about the scientific and medical aspects of their situation, became the precondition of “autonomy.”[8] “Patient autonomy” was contrasted with “paternalism,” which is “the interference of a state or an individual with another person, against their will, and defended or motivated by a claim that the person interfered with will be better off or protected from harm.”[9] “Patient autonomy,” “paternalism,” and “informed consent” reinforced each other to form a coherent model of the individual subject. The central goal

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[5] On the centrality of “autonomy” to bioethics see Onora O’Neill, *Autonomy and Trust in Bioethics* (Cambridge; New York: Cambridge University Press, 2002).

[6] Ibid., 37: “What is rather grandly called ‘patient autonomy’ often amounts simply to a right to choose or refuse treatments on offer, and the corresponding obligations of practitioners not to proceed without the patient’s consent.”

[7] James L. Werth, “Introduction to the Issue of Rational Suicide,” in *Contemporary Perspectives on Rational Suicide*, ed. James L. Werth, (New York: Routledge, 1998), 5.

[8] Ibid., 3: ““What passes for patient autonomy in medical practice is operationalised by practices of informed consent.”

[9] Gerald Dworkin, “Paternalism,” in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, (Summer 2010 Edition), http://plato.stanford.edu/archives/sum2010/entries/paternalism/

of bioethicists was to protect such patient autonomy. But while the goal of providing patients with the ability to make their own decisions in an informed manner might seem relatively unproblematic, it is challenged at a basic level by the field of disability studies.

Disability Studies: Through the Lens of the Social Model

The field of disability studies emerged, in the 1980s, in opposition to what its proponents term the "medical model" of disability.[10] The medical model of disability understands disability as an isolated biological condition. Within this model, disability is considered to be inherently negative, as it is assessed according to the normative understanding of health dominant in medical practice. From this perspective, a disability is qualitatively worse than an ability, much as sickness is worse than health. This qualitative inferiority is inherent to the constitution of disability as an entity that is *biological*. Disability, in this view, is not a social issue, and while proponents of the medical model may acknowledge some disability discrimination, the presence or absence of such discrimination has limited bearing on the fundamental negativity of disability itself. As this negativity is biological, it can only be alleviated via a "curative" medical intervention that eliminates the disability from an individual's body. Should such an intervention not exist in medical practice, the person with a disability will be condemned to a biologically inferior quality of life.

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[10] For more extensive analysis of the medical and the social model of disability see Dimitris Anastasiou and James M Kauffman, "The Social Model of Disability: Dichotomy between Impairment and Disability," *Journal of Medicine and Philosophy* 38, no. 4 (2013): 441-59; Tom Shakespeare, "The Social Model of Disability," in *The Disability Studies Reader*, ed. Lennard J. Davis, (New York, NY: Routledge, 2013): 214-21.

Disability studies scholars reject this medical understanding of disability in favor of what they call “the social model of disability.” This model differentiates between an individual’s “impairment” and his or her “disability.” The “impairment” is the individual’s isolated biological malady. The “disability,” in contrast, is the meaning ascribed to this malady in a social setting. While the impairment is morally neutral, “disability” can have either a positive or negative value, depending on the setting. Nevertheless, as dominant institutions in US and, to a significant extent, Western society are premised on the medical model of disability, it generally has a *negative* meaning. This meaning is not inherent to the biological constitution of disability. Rather, it is the result of the organization of society. Society is, from a disability studies perspective, predominantly organized to be *inaccessible* to persons with disabilities. This inaccessibility is multi-layered, containing components that are alternatively—and often simultaneously—architectural, economic, educational, political, and even medical. This inaccessibility—not the underlying medical condition—is both the cause and, to an extent, the product of the negative meaning ascribed to “disability” in Western social settings. Consequently, disability studies scholars do not advocate for “curative” medical interventions to eliminate disability; instead, they favor socio-political interventions that change the meaning of disability through the promotion of accessible institutional structures. Such interventions are logical outgrowths of understanding disability through the “social model.”

Such political interventions are not, for disability studies scholars, matters of “personal” choice. Indeed, understanding disability as a matter of individual experience mystifies the underlying social conditions that both create and limit this experience to begin with. Disability, in this view, is an inherently communal category and disability politics require a communal perspective. In this sense, the disability studies rethinking of medical epistemology necessarily entails a new conception of the political subject as a socially-constituted, collective being.

World Turned Upside Down: The Disability Studies Challenge to Bioethics

This rethinking of medicine and politics is a powerful challenge to the key bioethical principles of "patient autonomy" and "informed consent."[11] Disability studies scholars are critical of the conception of individual choice enshrined in the bioethical principle of "patient autonomy." This conception, they claim, ignores the underlying social determinants of individual behavior, particularly with regard to disability. In a context of pervasive ableist discrimination, the "individual choice" advocated by bioethicists is not liberating, but rather can be a manifestation of and response to oppressive social norms and institutional structures. The concept of "paternalism" provides no barrier to such coercive forces; on the contrary, its individualistic focus obscures their functioning. Thus, disability studies scholars generally oppose the

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[11] For critiques in this vein see Carol Gill, "The False Autonomy of Forced Choice: Rationalizing Suicide for Persons with Disabilities," in *Contemporary Perspectives on Rational Suicide*, ed. James L. Werth, (New York: Routledge, 1998), 171-80; Adrienne Asche, "Disability, Bioethics, and Human Rights," in *Handbook of Disability Studies*, ed. Gary L. Albrecht, Katherine D. Seelman and Michael Bury, (Thousand Oaks, Calif.: Sage Publications, 2001), 297-326; Tom Shakespeare, "Disability, Genetics and Global Justice," *Social Policy and Society* 4, no. 01 (2005): 87-95; Christopher Newell, "Disability, Bioethics, and Rejected Knowledge," *Journal of Medicine and Philosophy* 31, no. 3 (2006): 269-83; Ron Amundson and Shari Tresky, "Bioethics and Disability Rights: Conflicting Values and Perspectives," *Journal of Bioethical Inquiry* 5, no. 2-3 (2008): 111-23; and Rosemarie Garland-Thomson, "The Case for Conserving Disability," *Journal of Bioethical Inquiry* 9, no. 3 (2012), 339-55.

autonomy/paternalism dichotomy in bioethics. This opposition is not categorical, but rather based on the particular manner in which these concepts function with regard to larger social structures and, more particularly, the conception of medical epistemology enshrined in “informed consent.”

From a disability studies perspective, “informed consent” guarantees that “personal autonomy” will be a vehicle for disability discrimination. In bioethics, the information communicated in “informed consent” is *medical* information. It is selected and delivered by doctors and other medical professionals, and based on the “medical model of disability;” it does not contain information about the socio-political context that gives disability its meaning, nor does it offer alternatives to the negative attitudes of disability prevalent in US medicine and society. Under the pretense of scientific objectivity, it masks an agenda that is intrinsically and devastatingly discriminatory against the disabled. Worse, it provides patients with this agenda under the false claim that, by accepting it, disabled populations will protect their “patient autonomy.” In this sense, “informed consent,” is disability discrimination cloaked in the seeming neutrality of clinical medicine.

The problem with informed consent is deeper than simply the *content* of its “information;” it is the belief, inherent to dominant models of bioethical thought, that “information” itself is sufficient to protect “patient autonomy.” While disability studies scholars support more socially-situated informed consent protocols, even the most thoughtfully designed consent protocol will be insufficient if it is not accompanied by social changes that promote accessibility. In this sense, from a disability studies perspective, a bioethics that takes “patient autonomy” seriously must also be dedicated to changing existing social structures so that they can be more inclusive of persons with disabilities. Only through this social change can the realization of the bioethical goal of "patient autonomy" be possible.

In this sense, the disability studies challenge to bioethics is characterized by the accusation that bioethicists betray the very ideals they claim to uphold. Dominant bioethical narratives claim that the patient autonomy protects patient choice; in fact, from a disability studies perspective, it provides patients with practically no protection from the oppressive social structures that dictate their choice for them. Dominant bioethical narratives claim that informed consent provides patients with relevant medical information; in fact, from a disability studies perspective, it obscures the information truly relevant to patient decision making. Dominant bioethical narratives claim that bioethics is a field that follows in the tradition of 1960s liberatory movements like the civil rights and women's rights movements[12]; in fact, bioethics, with its focus on individual decision making, works against the forms of collective politics epitomized by those struggles. And, most damningly, bioethicists claim that the rise of bioethics was a blow to medical authority; in fact, informed consent removes medical knowledge from critical scrutiny, while patient autonomy enacts an individualistic model of decision making that allows doctors to largely maintain control over the distribution, practice, and definition of medical care. In short, from a disability studies perspective, the field of "bioethics" is the world that bioethicists purport to defend turned upside down.

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[12] The clearest argument for such a view of bioethics is Rothman, *Strangers at the Bedside*.

Disability studies scholars are not alone in such a critique. On the contrary, scholars from a broad range of fields and areas of study have criticized bioethics for its general inattention to the social constitution of reality and, more specifically, the functioning of it own key principals to reinforce dominant power relations of race, gender, socio-economic status, and nationality.[13] But though it is quite compatible with these other critiques of bioethics, the disability studies critique is unique in that it provides, in the social model, an alternative epistemology of medicine around which to organize bioethical research and practice. The result is a critique of bioethics that, at least in its implications, is totalizing—requiring a complete rethinking of the basic categories of bioethical thought.

Nevertheless, there is a contradiction within this disability studies critique of bioethics. Disability studies scholars apply the social model of disability to *disability*. Nevertheless, though many bioethical issues involve disability, many do not. The result is what I would call the "paradox of the disability studies critique of bioethics": The disability studies critique of bioethics is a *totalizing* critique in that it provides an alternative medical epistemology that, in theory, could apply to any issue; and yet, disability studies scholars have only applied this totalizing critique to a *particular*—and,

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[13] For some examples of such critiques of bioethics, see Oonagh Corrigan, "Empty Ethics: The Problem with Informed Consent." *Sociology of Health and Illness* 25, no. 7 (2003): 768-92; Paul Farmer, "New Malaise: Medical Ethics and Social Rights in the Global Era," in *Pathologies of Power: Health, Human Rights, and the New War on the Poor*, (Berkeley: University of California Press, 2003), 196-212. Catherine Myser, "Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States," *American Journal of Bioethics* 3, no. 2 (2003): 1-11; Mary C. Rawlinson, "The Concept of a Feminist Bioethics," *Journal of Medicine and Philosophy* 26, no. 4 (2001): 405-16.

in fact—particularly small set of issues that directly involve conditions labeled as "disabilities." Such issues include, mainly, selective abortion for fetuses found to have disabilities, cochlear implants for deaf patients, and euthanasia and/or assisted suicide for persons with disabilities.[14] Though all of these issues are important, they constitute only a small range of bioethical topics.

More troublingly, a disability studies approach, with its focus on "disability," is only able to address a limited aspect of these issues. For example, disability studies scholars may apply the social model of disability to "selective abortion," but have been extremely reticent to do so to the larger question of abortion itself. The result is a limitation of the social model's challenge to bioethical epistemology. Such a limitation, though questionable in itself, is especially troubling in that it leads to conflict within disability studies when scholars in the field attempt to apply the social model outside of the "appropriate" context of disability. Such conflict splinters the field, leading to the overall weakening of a disability studies approach to not only bioethics, but also those very issues that specifically involve disability. There is no better example of the troubling consequences of such conflicts than the debate, within disability studies, about the bioethical regulation of patient autonomy at the end-of-life. But, before I can examine this conflict within disability studies, I must first elucidate the framework in which bioethicists have discussed the exercise of "end-of-life autonomy."

Fatal Autonomy: Bioethics at the End-of-Life[15]

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[14] See Ouellette, *Bioethics and Disability* and Scully, *Disability Bioethics*, for more comprehensive surveys of disability studies literature on these issues.

[15] This section is taken, with some modifications, from Harold Braswell, "Can There Be a Disability Studies Theory of 'End-of-Life Autonomy?'", *Disability Studies Quarterly* 31,

Since the inception of bioethics, the field's members have debated how the bioethical conception of "patient autonomy" could be applied to the murky area known as the "end-of-life." The expression "end-of-life" can include a range of medical conditions, such as chronic diseases, terminal diseases, "severe" disabilities, vegetative states, and brain death.[16] There is debate about which conditions the category includes, but commentators agree that non-medical and transitive conditions do not place one at the " "end-of-life," no matter how severely the individual may experience them; thus, the temporary depression incurred by the loss of a loved one would not be considered an "end-of-life" condition, even if the individual felt that his or her life had effectively ended.[17] Similarly, commentators are unified in considering whatever medical condition they do classify as "end-of-life" to be of a "serious" or "severe" nature, even if, amongst themselves, they might disagree on the specific conditions to which these expressions of emphasis should apply. Consequently, in spite of the seeming confusion in defining the "end-of-life," the conditions discussed under the category's rubric are united by their being incurable medical conditions considered to be severe by both the individual and the society of which he or she forms part.

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no. 4 (2011).

[16] For examples in each case see Felicia Ackerman, "Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard," in *Physician-Assisted Suicide: Expanding the Debate*, ed. Margaret Pabst Battin, Rosamond Rhodes, and Francis Silver, (New York: Routledge, 1998),149-63; Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*, (New York: Vintage Books, 1994); Gill, "The False Autonomy."

[17] Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, T.M. Scanlon, and Judith Jarvis Thomson, "Assisted Suicide: the Philosophers' Brief," *The New York Review of Books,* 44, no. 5 (1997: 41-47).

Debates about defining the "end-of-life" are particularly impassioned because of the actions that "end-of-life autonomy" legitimizes: "End-of-life autonomy" allows individuals to terminate their lives. Bioethicists have heatedly debated the permissible limits of such actions: Some bioethicists support voluntary *active* euthanasia (VAE), in which the patient requests that the medical provider ends his or her life via the administration of a fatal injection.[18] Other bioethicists favor physician-assisted suicide (PAS), in which the physician can prescribe—but not administer—the fatal substance, which the patient then administers him or herself.[19] Finally, some bioethicists advocate for voluntary passive euthanasia (VPE)—also known as the refusal of life-sustaining treatment or, colloquially, "pulling the plug"—in which, upon a patient's request, the physician removes the medical technology that had been sustaining the patient's life.[20] Though I will, in the conclusion of this dissertation, examine the underlying rationale for these positions, I here want to highlight that all three positions are united in conceptualizing the "decision" conferred by end-of-life autonomy as a decision to die.

Given these debates about what actions "end-of-life autonomy" authorizes, as well as what constitutes the "end-of-life" itself, it would seem impossible to provide a

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[18] James Rachels, "Killing and Starving to Death," *Philosophy* 54, no. 208 (1979): 159-71; Peter Singer, "Voluntary Euthanasia: A Utilitarian Perspective," *Bioethics* 17, no. 5, (2003): 526-41.

[19] Charles H. Baron, Clyde Bergstresser, Dan W. Brock, Garrick F. Cole, Nancy S. Dorfman, Judith A. Johnson, Lowell E. Schnipper, James Vorenberg, and Sidney H. Wanzer, "A Model State Act to Authorize and Regulate Physician-Assisted Suicide," *Harvard Journal on Legislation* 33 (1996): 1-36; Judith Jarvis Thomson, "Physician-Assisted Suicide: Two Moral Arguments." *Ethics* 109, no. 3 (1999): 497-518.

[20] Daniel Callahan, *The Troubled Dream of Life: In Search of Peaceful Death* (New York: Simon & Schuster, 1993); Leon Kass, *Life, Liberty and the Defense of Dignity: The Challenge for Bioethics* (New York: Encounter Books, 2004).

general definition of the term. Nevertheless, as I have demonstrated above, in spite of the different definitions of "end-of-life autonomy," these definitions all ascribe to a common general formula: "End-of-life autonomy" is *an individual's legally protected and medically enacted decision about whether to die in response to a serious incurable medical condition*. This general formula constitutes the common consensus that underlies—and makes possible—existing bioethical debates about both the category of the "end-of-life" and the actions authorized by "end-of-life autonomy." The debate within disability studies about end-of-life autonomy is a debate about whether the field should accept certain articulations of this consensus, or reject it altogether.

Not *Dying* Yet? The Disability Studies Debate about End-of-Life Autonomy

Within the disabled community, various commentators have taken issue with the application of "end-of-life autonomy" to persons with disabilities. Disability studies scholars such as Carol Gill, Paul Longmore, and William Peace have argued that, when end-of-life autonomy is applied to persons with disabilities, it becomes a vehicle for social oppression.[21] These scholars consider the application of "end-of-life autonomy" to persons with disabilities to be a double standard: Suicide is universally pathologized in US medicine, *except* when the suicidal individual has a disability.[22] This double standard indicates the presence of discrimination against the disabled. This discrimination—not

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[21] Carol J. Gill, "No, We Don't Think Our Doctors Are out to Get Us: Responding to the Straw Man Distortions of Disability Rights Arguments against Assisted Suicide," *Disability and Health Journal* 3, no. 1 (2010): 31-38; Paul K. Longmore, "Medical Decision Making and People with Disabilities: A Clash of Cultures," *The Journal of Law, Medicine & Ethics* 23, no. 1 (1995): 82-87; William J. Peace, "Comfort Care as Denial of Personhood," *Hastings Center Report* 42, no. 4 (2012): 14-17.

[22] Gill, "The False Autonomy of Forced Choice," 171.

the biological impairment—is the reason why persons with disabilities desire to end their lives. As a result, the application of "end-of-life autonomy" to the disabled epitomizes the very oppression that it ignores[23]

Nevertheless, though the majority of the disability studies community shares these scholars' concerns about the application of "end-of-life autonomy" to persons with disabilities, many disability studies scholars support the application of "end-of-life autonomy" to the terminally ill. Most prominently, in 2005, the Society for Disability Studies (SDS) was divided on whether to support a legal brief opposing the state of Oregon's assisted suicide law.[24] While SDS's decision to withdraw its initial support from the brief was influenced largely by procedural concerns, the dispute spotlighted members of the disability studies community in favor of "end-of-life autonomy." Prominent disability studies scholars and advocates, including Hugh Gallagher, Drew Batavia, and Lennard Davis voiced support for the Oregon law and, more generally, for attempts to legalize physician-assisted suicide for the terminally ill.[25] For such disability studies scholars, the solution to debates about the place of "end-of-life autonomy" in disability studies is to separate the "disabled" from the "terminally ill," while maintaining the basic concept of "end-of-life autonomy" itself.

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[23] Ibid., 172.

[24] Scott Jaschik, "Rift in Disability Studies," *Inside Higher Ed*., October 5, 2005, http://www.insidehighered.com/news/2005/10/05/disability.

[25] Drew Batavia and Hugh Gregory Gallagher, "Gallagher and Batavia on Physician-Assisted Suicide: An Open-Letter to People with Disabilities," *Independent Living Institute*, 1999, http://www.independentliving.org/docs1/gallbat.html; Jaschik, "Rift in Disability Studies."

Philosopher Felicia Ackerman has been particularly critical of such attempts by disability scholars to make a sharp distinction between disability and terminal illness.[26] She argues that, while seemingly more benign than arguments in favor of legalizing euthanasia for the disabled, claims that the "terminally ill" should be medically assisted in ending their lives follow the same discriminatory logic. By narrowing the "end-of-life" to terminal illness, disability rights advocates create their own double standard between the "terminally ill" and the other members of the population.[27] This double-standard gives the terminally ill the impression that their lives are less valuable than those of others in society; as such, it is coercive, potentially inciting the terminally ill to take their own lives. The implication of Ackerman's argument is that the very concept of "end-of-life autonomy" is an oxymoron: By singling out certain groups as the recipients of "autonomy," their autonomy to decide freely is compromised.

But this logic has been countered by legal scholar Alicia Ouellette. In her book *Bioethics and Disability: Toward a Disability-Conscious Bioethics*, Ouellette examines the cases of individuals whose bodies are actively harmed by life-sustaining medication.[28] She gives the example of a female patient whose body could no longer process protein. Because she was given tube feeding, the patient's life was extended, but, as she could not incorporate protein, her body began to consume itself. For Ouellette, removing life-sustaining treatment from such a patient is not a form of anti-disability prejudice. She

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[26] Ackerman, "Assisted Suicide, Terminal Illness, Severe Disability, and the Double Standard."

[27] Ibid., 149.

[28] Ouellette, *Bioethics and Disability*, 312-314.

argues that disability studies scholars should support the exercise of certain limited forms of end-of-life autonomy among the terminally ill as, in such cases, the real ableist violence lay in continuing to provide care that is just as harmful as the premature removal of life sustaining treatment. For Ouellette, this case demonstrates how the inability of disability studies scholars to conceive of situations in which such interventions might be removed is itself a form of violence against the disabled. Consequently, her work raises the question of how to conceptualize end-of-life autonomy in a way that addresses the concerns of disability studies scholars about anti-discrimination, as well as the specificity of terminal illness.

This debate within disability studies about end-of-life autonomy is a reflection of the field's larger ambivalence about the social model of disability itself. Scholars like Gill and Longmore advocate for a broad application of the social model to the category of "end-of-life autonomy" itself. But other scholars argue that the social model should solely be applied to those instances of "end-of-life autonomy" that directly concern populations with disabilities. This debate about the limits of the social model is, in turn, a debate about the extent of the disability studies critique of bioethics—and, indeed, the validity of the bioethical enterprise itself. Advocates for the more expansive conception of the social model adopt a totalizing critique of bioethics that includes such key concepts as autonomy and informed consent; advocates for a more limited conception support patient autonomy and informed consent in a general sense, while opposing their limited application to disabled populations on certain issues. The result is an impasse about both the particular topic of end-of-life autonomy and the broader field of bioethics itself. I will now argue that this impasse reveals a larger problem within disability studies: the exclusion of terminally ill patients from the category of "disability." This exclusion is a product of the limited way in which disability studies scholars have explored the topic of death.

Exiling Death, Excluding the Dying: Inadvertent Discrimination in the Social Model

Though there have not been, at present, any studies that examine death from a disability studies perspective, death appears continually in the works of disability studies scholars. Such appearances can be grouped into two categories: First, disability studies scholars criticize representations portraying disability as a form of death-in-life and/or a harbinger of death.[29] Second, disability studies authors have examined the causes of the disproportionately high rates of violent death among disabled populations.[30]

These categories are, in disability studies scholarship, linked in a manner that is at once intrinsic and causal: Representations of disability as a form of death-in-life both justify and lead to violence against disabled populations. This violence can be both direct and indirect. Indirectly, the representation of disability as a form of death-in-life has historically obscured the underlying social structures that truly make life a kind of living death for disabled populations. Directly, this representation justifies either homicidal

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[29] Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (New York: Verso, 1995); , Leslie A. Fiedler, "Pity and Fear: Images of the Disabled in Literature and the Popular Arts," *Salmagundi*, no. 57 (1982): 57-69; Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, (Columbia University Press, 1997).

[30] Nirmala Erevelles, *Disability and Difference in Global Contexts: Enabling a Transformative Body Politic*, (New York: Palgrave Macmillan, 2011); Hugh Gallagher, "What the 'Nazi Euthanasia Program' Can Tell Us About Disability Oppression." *Journal of Disability Policy Studies* 12, no. 2 (2001): 96-99. Mark Sherry, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?*, (Farnham: Ashgate Publishing, Ltd., 2010).

violence against or suicidal violence among disabled populations, who are either considered vectors of contamination to the body politic, or, alternatively, to be so intrinsically miserable that their lives are "unworthy of living." Representations of disability *as* death themselves *cause* death among disabled populations.

Disability studies scholars have contested these representations by drawing on the social model of disability. They argue that there is no intrinsic link between death and disability. To the extent that disability and death are related, their relationship is the product of an ableist society. This society, not the disabled body, is the true bringer of death and, as this death disproportionately impacts disabled populations, they are its victims. Making society more accessible to the disabled will, in turn, diminish any link between disability and death. In this sense, by contesting the representational link between disability and death, disability studies scholars aim to decrease the propensity of existing social structures to cause death among disabled populations. Thus, while there may be no works that directly address death from a disability studies perspective, the field of disability studies has historically been oriented around a powerful argument about the relationship of disability and death: Disability is not a form of death-in-life and when death occurs among disabled populations, it is not *natural* but rather *social.*

While this argument has been extremely generative for the field of disability studies, it contains a key omission: the status of disability at the end-of-life. Terminally ill patients generally have a range of disabilities.[31] Some of these disabilities are the result of

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[31] Jennifer King, Lindsey Yourman, Cyrus Ahalt, Catherine Eng, Sara J. Knight, Eliseo J. Pérez-Stable, and Alexander K. Smith, "Quality of Life in Late-Life Disability: 'I Don't Feel Bitter Because I Am in a Wheelchair,'" *Journal of the American Geriatrics Society* 60, no. 3 (2012): 569-76; Alexander K. Smith, Louise C. Walter, Miao Yinghui, W. John Boscardin, and Kenneth E. Covinsky, "Disability During the Last Two Years of Life,"

medical conditions that, most likely, will cause death. In this sense, terminal illness raises the very specter that disability studies scholars have been trying to dispel: Terminal illness links disability to death in a manner that is both inextricable and *natural*. Disability at the end-of-life is thus a kind of “other” to the constitutively non-fatal disabilities that have been the central subjects of disability studies scholarship. Disability studies scholars have generally responded to this “other” with neglect: No major introductory disabilities reader or textbook contains a discussion of disability at the end-of-life.[32] This avoidance of terminal illness is a direct result the dominant understanding of death in disability studies: By arguing that the link between death and disability is entirely social, disability studies scholars constitutively exclude those disabilities that are, naturally, biologically, linked to—and even causative of—death.

This exclusion can be explained in the terms of the social model of disability. The relationship of terminal illness to death is not a social product, but rather part of its very biological constitution. As such, terminal illness is not a “disability,” but an “impairment.” No amount of social change, with the exception of a curative medical intervention, will uncouple terminal illness and death. Consequently, there is no “social model of terminal illness.” Terminal illness is a medical problem. Indeed, the status of terminal illness as a medical problem is itself one of the chief conditions for

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JAMA Internal Medicine 173, no. 16 (2013): 1506.

[32] Lennard J. Davis, *The Disability Studies Reader*, 4th ed. (New York, NY: Routledge, 2013); Dan Goodley, *Disability Studies: An Interdisciplinary Introduction*, (Los Angeles, Calif ; London: SAGE, 2011); Rod Michalko and Tanya Titchkosky, eds. *Rethinking Normalcy: A Disability Studies Reader*: (Toronto: Canadian Scholars Press, 2009).

understanding disability as a social problem. The social model of disability can thus only be applicable to the extent that it excludes the terminally ill from its analytical framework, and, indeed, from the category of "disability" itself.

This exclusion is the underlying epistemological basis for the acceptance, by some disability studies scholars, of the application of "end-of-life autonomy" to the terminally ill. Such scholars understand terminal illness as a largely medical problem. As a result, they argue that there is a qualitative difference between terminal illness and disability. This qualitative difference makes it acceptable for them to support end-of-life autonomy for the former, while rejecting it for the latter. In the process, these scholars enact a coercive double-standard, even as they gloss over structural discrimination against the terminally ill that, as Ackerman notes, is not, in many ways qualitatively different from that experienced by disabled populations.[33] In this sense, the exclusion of the terminally ill from disability studies leads some disability studies scholars to advocate for violence against them that, from a disability studies perspective, might not seem altogether different from that which they condemn amongst the disabled.

Nevertheless, Ouellette's argument shows that the question is not that simple.[34] Scholars who conflate disability and terminal illness are correct in identifying a double-standard in treatment, just as they are in noting the presence of discrimination in the care of the terminally ill. But these same scholars, though correct in noting the commonalities between disability and terminal illness, fail to recognize the specificity of terminal illness. They consequently advocate for treatments that, though appropriate in the context of

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[33] Ackerman, "Assisted Suicide."

[34] Ouellette, *Bioethics and Disability*.

chronically disabled populations, are themselves violent against the terminally ill. In this sense, Ouellette shows that, while it is necessary to develop a social model of terminal illness, it is not possible to do so in the exact same terms as the social model of disability. The specificity of terminal illness—its uncomfortable blending of biological and social elements—must be respected.

Understanding this specificity entails examining a question that disability studies scholars have addressed only indirectly: What is death? Disability studies scholars have, in their critical accounts of anti-disability violence, theorized death as the product of oppressive social structures. But they have yet to develop an account of death that considers the possibility that it can be the result of a natural disease process. Most importantly, they have not considered the complex interaction of medical and social factors in the constitution of any particular death. This failure to theorize death has led to the exclusion of the terminally ill from disability studies, and the field's concurrent impasse regarding the issue of "end-of-life autonomy." Overcoming this impasse is crucial not only to respond to the specific issue of terminal illness, but also to the broader question of how to reformulate bioethics in a manner that is compatible with the social model of disability. Consequently, developing a disability studies approach to death will resolve the internal impasse within disability studies and demonstrate the power of disability studies to reformulate the methodology and epistemology of bioethics itself.

This dissertation develops such a disability studies approach to the question of death. More specifically, it examines, from a disability studies perspective, how death has been defined in bioethics. As disability studies scholars have traditionally excluded "death" from the constitution of "disability," this examination will necessarily address literature that has been considered external to the disability studies cannon. Nevertheless, its general methodology might be described as an attempt to apply the "social model of disability" to death." As the "social model" has been the epistemological basis for the exclusion of death from disability studies, such an application will necessarily entail rethinking the social model itself. But such a rethinking is, as I hope to have shown, a disability studies project of urgent importance. I will now describe the methodology and chapter structure through which I will attempt to examine the question: What is death?

Methodology and Chapter Outline

This dissertation examines the definition of death in bioethics through two predominant methodological approaches: the history of medicine and medical anthropology. History and anthropology are ideal tools because they examine how medical categories emerge and are sustained both over time and in contemporary practice. At the same time, they understand such categories not as neutral windows into reality, but rather as contingent social formations capable of both sustaining and subverting dominant power relations. While this dissertation is not quantitative, it produces a series of new questions, categories, and problems that, as I will argue in my conclusion, lend themselves to future quantitative study. But, before such quantitative questions regarding death can be entertained, it is necessary to define death itself. I develop such a definition over the course of four chapters.

In Chapter 1, "Death: A New Definition," I examine longstanding debates about the definition of brain death in bioethics. I argue that these debates are rooted in a larger shift in the meaning of death that occurred in the mid-late 19th century West. In this shift, death went from being defined as a dynamic social process to being considered an isolated biological event. I argue that this understanding of death obscures the social nature of death as a category at the intersection of power dynamics and cultural difference. To develop a more nuanced understanding of death, I explore existing literature on the topic of "social death." This literature provides a model of death that remedies the problems inherent to dominant bioethical debates about death. But it also raises a problem: If death is a social process, then it cannot be studied in the abstract. It must be examined in the context of social institutions. The result is a new methodological model for bioethics as a field that draws on the humanities and social sciences to examine how death is redefined in particular medical settings. I develop such a model through a historical and ethnographic study of the dominant form of end-of-life care in the United States: hospice. Hospice, I claim, provides an ideal site for such a study because of the modern US hospice movement's own ambivalence about the bioethical definition of death.

In Chapter 2, "A Faithful Betrayal: Technology, Humanism, and the Medicalization of Death in the Modern US Hospice Movement, 1970-1980," I examine how death was defined in the formative decade of the so-called "modern" US hospice movement. Contrary to critics who claim that the hospice movement's conception of death became increasingly "medicalized" over this period, I argue that hospice leaders steadfastly opposed the "medicalization" of death. Instead, they adopted a "humanistic" conception of death, which, while supported by medicine, was also defined by its constitutive exclusion from medical technology. I argue that this humanistic conception of death limited the ability of the modern hospice movement to protect its own non-medical interventions within the broader ambit of US health care. The hospice movement's humanistic conception of death was displaced by a bioethical understanding of death that achieved institutional hegemony because of its explicitly medical character. I conclude this chapter by arguing, contrary to dominant historical literature on hospice, that the medicalization of death did not lead to a "betrayal" of the modern hospice movement's ideals. On the contrary, the movement's limitation was the result of its failure to adequately engage the epistemology of death in US medicine. This argument provides a transition to an exploration of the epistemology of death in contemporary US hospice care.

In Chapter 3, "A Gap in the System: Patients with Limited Kinship Support under the Medicare Hospice Benefit," I examine how the understanding of death in the federal regulation of US hospice care impacts patient care in an Atlanta-area hospice. US hospice care is designed according to a neoliberal economic model in which death is considered to be a matter of private kinship. This model is ensconced in the Medicare Hospice Benefit, with defines hospice primarily as an outpatient treatment modality that supports the unpaid care of the dying by their local kinship network. Though this model is sufficient for most patients, I claim that it leads to the routine mistreatment of patients who lack sufficient kinship support. Such patients are either abandoned at home or they are sent to a nursing home. As nursing homes are not designed to care for the terminally ill, these patients must continue to receive hospice care on an outpatient basis. But the conflicting organizational cultures and economic incentives of hospice and nursing home providers hinder the provision of such care. As a result, these patients are fragmented between two opposing medical providers. I conclude by arguing that this movement from abandonment to fragmentation is implicit in the way that the Medicare Hospice Benefit defines the “interdisciplinary” care of the dying.

Chapter 4, “Death and Resurrection in Our Lady of Perpetual Help Home: The Dying God, The Eucharistic Enactment, and the Totality of Catholic End-of-Life Care,” is an examination of Our Lady of Perpetual Help Home, a Catholic end-of-life care facility in Atlanta, Georgia. “Our Lady”—as it is known to locals—provides both long-term and end-of-life care to terminally ill patients whose lack of sufficient kinship support leads to their exclusion from the US hospice system. Our Lady’s ability to provide this synthesis is due to the home’s unique payment structure: It is a charitable institution, operating only on donations. As it does not depend on governmental revenue, it is able to provide both long-term and end-of-life care in a way that is otherwise foreclosed by the regulations of the US health care system. I argue that Our Lady’s synthesis of long-term and end-of-life care leads to vastly improved patient outcomes over the coordination of nursing home and hospice care in the current Medicare system. This unique treatment modality is based in the home’s underlying definition of death. This definition is based on the death and resurrection of Jesus Christ. Christ’s body becomes the fulcrum for an understanding of death not as an isolated malady pertaining only to terminally ill patients—but as constitutive of the living matter of all human beings. By redefining death, Our Lady’s sisters make possible a new form of end-of-life care.

In my conclusion, I draw on this research to propose a new model for the category of “natural death” in US bioethics. I argue that a “natural death” must occur in the context of the provision of adequate end-of-life care. Based on my fieldwork, I suggest revisions to the actual practice of hospice care in the US so that it can provide such care to those patients who remain abandoned due to their lack of kinship support. In this sense, my bioethical redefinition of death in Chapter 1 thus leads to a series of proposals for the reform of US end-of-life care. I argue that this movement from category constitution to medico-political reform provides a model for a disability studies approach to bioethics. I will now begin this movement with an exploration of the definition of death in Western bioethics.

Chapter 1

Death: A New Definition

Introduction

Since its emergence in the early 1970s, the field of bioethics charged itself with the task of defining death. The field's proponents claimed that the development of new medical technologies in preceding decades had changed death from an unambiguous medical event to a complex negotiation between patients, families, and providers. As a result of this shift, it was necessary to define death in a manner that protected patients, while incorporating the psychological, spiritual, and legal dimensions of the deathbed. Bioethicists would fill this need, designing policy and arbitrating clinical decision-making. Bioethicists thus justified their field's creation based on their ability to answer a question that, while age-old, was somehow brand new: What is death?[35]

This chapter is an intervention in the bioethical debate about how to best answer this question. This debate has been structured by a key dichotomy: the difference between the death of the person and the death of the organism. Advocates for an organism-centered definition identify death within the functioning of the "whole brain"—which they association with the brain stem and cerebral cortex—and consider it to be a biological phenomenon. Advocates for a personhood standard favor a "higher brain" criteria—associated with the cerebral cortex—and define death by standards that are psychological, theological, and socio-cultural.

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[35] For general overviews of the history of bioethics that follow this trajectory, see Jonsen, *The Birth of Bioethics*; Rothman, *Strangers at the Bedside;* and Helga Kuhse and Peter Singer, "Introduction."

In this chapter, I question the neurological and philosophical claims underlying both positions in the bioethical debate about brain death. Supporters of an organism-centered standard fail to provide adequate neurological evidence to justify their contention that essential brain activity has ceased. Supporters of personhood standards, though claiming to present pluralistic accounts, define personhood in terms that are neurologically monolithic. Consequently, neither side in the bioethical debate provides a standard of death that is philosophically consistent with their neurological framework. Such inconsistencies are based in a shared exclusion, by proponents of both organism and personhood standards, of the social dynamics of death. This exclusion, in turn, has reinforced a split between bioethical deliberation and clinical decision making. There is consequently a need for an integrated definition of death, even as such a definition must rethink the terms in which bioethicists have debated the topic for more than forty years.

I begin such a rethinking by examining the work of historian Gary Belkin.[36] Belkin argues that a new starting point for bioethical deliberations on death can be found in the seminal 1968 Report of the Ad Hoc Committee of the Harvard Medical School. For the authors of the Report, brain death was not an attempt to provide a philosophically reasoned conception of death, but rather to provide an appropriate response to the new clinical problems generated by mechanical ventilation. For the Harvard Committee, then, death was not an essential category, but was rather based in—and responsive to—the

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[36] The chapter will focus particularly on Gary S. Belkin. "Brain Death and the Historical Understanding of Bioethics," *Journal of the history of medicine and allied sciences* 58, no. 3 (2003): 325-6; and Gary S. Belkin, *Death before Dying: History, Medicine, and Brain Death*, (Oxford: Oxford University Press, 2014).

contingencies of the clinic. Belkin argues that this clinically contingent understanding of death is more useful and accurate than bioethical attempts to develop a philosophical account of death that, however consistent, does not address the circumstances of clinical care. I claim that Belkin's work provides a new foundation for justifying an organismic standard of death: Such a foundation lies not in the abstract consistency of a neuro-philosophical framework, but rather in the responsiveness of such a framework to what is clinically possible. This rethinking of the biological organism as a clinical entity necessitates a consideration of the questions of socio-cultural meaning and power that have been central to advocates of a personhood standard.

Via an engagement with the work of Foucauldian philosopher Jeffrey P. Bishop, I extend Belkin's conception of the contingency of death to the category of personhood.[37] Bishop argues, contrary to dominant narratives within bioethics, that the problems with existing definitions of brain death lie not in the advent of mechanical ventilation in the 1960s, but rather in the rise of clinical medicine in early 19th century France. He claims that the French clinic redefined death as an isolated biological endpoint of life; in the process, it excluded metaphysical conceptions of personhood from medicine. This exclusion is the origin of the existing bioethical split between the person and the organism. While Bishop argues that medicine must reintegrate metaphysics, I emphasize, by situating Bishop's work in the historiography of death and dying in the US, that it must also consider how the concept of "personhood" is intertwined with existing social

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[37] Jeffrey P. Bishop, *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*, (Notre Dame, Ind.: University of Notre Dame Press, 2011).

power relations. Considering the mid-nineteenth century redefinition of death, then, makes it necessary to develop a new criterion for the death of the person.

I develop such a criterion by drawing on scholarship on the concept of "social death." Such scholarship argues that the death of the person is not a static biological event but rather a dynamic social process. This process continues even after the person's death as an organism, when, through practices of mourning, the individual can be reintegrated into the community. Consequently, the death of the person is not determined by the cessation of higher brain functioning, but rather by the cessation of mourning and the resurrection of the person—albeit in a changed role—through practices of memorialization. Such a death, though social, is no less biological than the death of the organism. But the biology of the death of the person is not the biology of higher brain functioning, but rather the biology of attachment, loss, and mourning. Consequently, the dichotomy between the organism and the person is not a question of whether death is biological or social; death is always both social and biological. For the organism, it is a static endpoint. For the person it is a moment in a larger process of death and resurrection.

Building on this analysis, I propose an integrated definition of death around which to orient bioethics as a field. Bioethicists must be attentive to both the death of the person and the death of the organism. The organismic conception of death can provide a necessary starting point and boundary for bioethical deliberations of death; but this death must be understood in the significantly broader context of the death of the person. In this sense, bioethicists must thus stake out a position "between" the two deaths: mediating between the needs of human being as both a person and an organism. How to accomplish such mediation cannot be postulated in advance, but rather must be worked through in actual social situations. Death, then, must be understood as a necessarily contingent concept, and bioethicists must embrace this contingency, constantly redefining death as appropriate to certain situations. Embracing this contingency entails rethinking the field's methods and purpose.

Though such a contingent conception of death might seem impractical, I demonstrate, through an extended case study, that it provides a more effective death criteria for dying individuals, their loved ones, and medical providers. Implementing such a criteria involves redefining bioethics as a field prepared to explore how death is defined not only within isolated clinical situations, but also within particular medical institutions and the US healthcare system more broadly. I conclude with by outlining a bioethics research project on death in US hospice care. I begin by tracing the emergence of the bioethical conception of death.

Brain Death and the "Birth" of Bioethics

In August 1968, the Ad Hoc Committee of the Harvard Medical School published a report in the *Journal of the American Medical Association*.[38] Though titled "A Definition of Irreversible Coma," the Report's purpose—as indicated in its first sentence—was not simply to define irreversible coma, but rather to establish irreversible coma as a "new criterion for death."[39] The report's authors claimed that this new criterion was due to the advent of mechanical ventilation that could sustain respiration and

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[38] Ad Hoc Committee of the Harvard Medical School, "A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," *Jama* 205, no. 6 (1968): 85-8.

[39] Ibid., 85.

heartbeat in irreversibly comatose individuals, even after clinical tests determined that all brain functioning had ceased. While previously, such individuals would have died due to their ailments, they were now being maintained corporeally living, even as all brain functioning had ceased. There were no medical means through which their brains could resume functioning; at the same time, there was no protocol through which treatment could be withdrawn. The result was a confusion that harmed patients and family members, while limiting the viability of organ donation and draining hospital resources.[40]

In response to this confusion, the Committee proposed to classify these patients as "brain dead." Such a classification would make it possible to justify removing them from medically futile life-sustaining treatment; it would also make them eligible for organ donation.[41] Nevertheless, though the Harvard Committee claimed to be establishing a new criterion for death, it did not pretend to have redefined death; rather, its members insisted that death had always been characterized by the loss of cerebral functioning.[42] Prior to the advent of mechanical ventilation, such loss had coincided with the loss of cardiopulmonary functioning. As cardiopulmonary loss had been easier to detect, it had been the standard criterion for determining death. But the advent of ventilation changed this, making it possible for machines to maintain cardiopulmonary life in the absence of brain functioning; the result was a need to develop criterion to identify such "brain dead"

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[40] Ibid., 85.

[41] Ibid., 87.

[42] Ibid.

patients as dead.[43] Such a criterion was both accurate and necessary given the lack of a clear clinical protocol for treating irreversibly comatose patients.

The Harvard Committee's criterion for determining brain death was based on three clinical signs: unresponsiveness to external stimuli, lack of breathing, and no discernible reflexes. Such clinical signs—which, when possible, could be confirmed by EEG testing—identified that the individual's brain was no longer functioning.[44] If such criteria were met, the Committee argued, it was appropriate to declare the patients to be "dead." Such a declaration would be followed by the removal of mechanical ventilation, which would lead to the cessation of cardiopulmonary functioning.[45] The Harvard Committee thus advocated for both the need to situate death in the brain, a criterion for testing for it, a definition of which parts of the brain were essential for life, and a protocol for treating such "brain dead" patients. The Report had an immediate impact, and by 1981, twenty-seven states had included the Ad Hoc Committee's criterion in their brain death statutes.[46]

Nevertheless, in spite of its political success, the Ad Hoc Report met with immediate criticism on various fronts. Some critics argued that the Report's definition of brain death was philosophically inconsistent due to its excessive reliance on clinical

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[43] Ibid.

[44] Ibid., 85-6.

[45] Ibid, 86.

[46] D. Alan Shewmon, "Brain Death: Can It Be Resuscitated?" *Hastings Center Report* 39, no. 2 (2009): 18.

findings, rather than putatively objective laboratory brain scans.[47] Others claimed that the medical approach taken by the Report's authors was insufficient to account for the psychological, cultural, and theological complexities of death.[48] From such a perspective, the Ad Hoc Report could seem like a way for physicians to protect their own waning authority in the wake of the patient's rights movement.[49] More damningly, critics accused the committee of establishing the new death criterion for the sole purpose of garnering more organs for transplantation.[50] As a result of these concerns, critics argued that brain death required medicine to be regulated by a new breed of professional trained in the philosophical, theological, and legal complexities of death.[51]

This new professional was the bioethicist. Bioethicists would develop standardized protocols for the definition of death, as well as for how to address the needs of patients who were engaged in conflicts with doctors that, bioethicists claimed, had been created by the advent of new medical technologies. Mediating these conflict entailed the use of philosophical, legal, and theological methods that were extrinsic to

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[47] Belkin, *Death before Dying*, 273-311; Robert M. Veatch, "The Impending Collapse of the Whole-Brain Definition of Death," in *Defining the Beginning and End of Life: Readings on Personal Identity and Bioethics*, ed. John P Lizza (Baltimore: Johns Hopkins University Press, 2009), 484.

[48] Belkin, *Death Before Dying*, 273-311

[49] Martin S. Pernick, "Brain Death in a Cultural Context: The Reconstruction of Death," in *The Definition of Death: Contemporary Controversies*, ed. Stuart J. Youngner, Robert M. Arnold and Renie Schapiro, (Baltimore: Johns Hopkins Press, 2002), 20-1.

[50] Hans Jonas, "Against the Stream: Comments on the Definition and Redefinition of Death," in *Defining the Beginning and End of Life*, ed. John P. Lizza (Baltimore: Johns Hopkins University Press, 2009), 498-506. Jonas' essay was originally published in Hans Jonas, *Philosophical Essays: From Ancient Creed to Technological Man*, Englewood Cliffs, N.J.,: Prentice-Hall, 1974), 132-40.

[51] Pernick, "Brain Death," 17-24; Rothman, *Strangers at the Bedside*, 1-14.

medicine. It also entailed developing principles and protocols—such as "patient autonomy" and "informed consent"—to ensure that the final authority over medical decision making lay not with doctors, but with patients and their families. Finally, in response to the Harvard Report's lack of philosophical justification for brain death criterion, bioethicists endeavored to develop a conceptually consistent criterion for determining brain death.[52] Nevertheless, though the field's advocates generally concurred that there needed to be a concept of brain death, the debate about how to define brain death split the field.

Person or Organism? The Emergence of a Bioethical Agreement to Disagree

In his overview of what he terms the "reconstruction of death," Martin Pernick argues that, in the period from 1968 to 1981, new medical technologies and various challenges to physician authority led to the emergence of a broad consensus, within US bioethics, that death was located, not in the heart, but in the brain. Nevertheless, bioethicists disagreed about where in the brain death was located. Two competing definitions emerged: "whole brain" death and "higher" brain death.[53] Here, I will broadly outline these two positions, and will tie them to what D. Alan Shewmon has identified as the philosophical distinction underlying the bioethical debate about brain death: the distinction between the organism and the person.[54]

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[52] Ibid.; Belkin, *Death before Dying*, 205-250.

[53] Martin S. Pernick, "Brain Death,"19-20.

[54] D. Alan Shewmon, "Constructing the Death Elephant: A Synthetic Paradigm Shift for the Definition, Criteria, and Tests for Death," *Journal of Medicine and Philosophy* 35, no. 3 (2010): 256-98.

Advocates of whole brain death argue that, in the brain, death occurs with the permanent cessation of functioning in both the cerebral cortex and the brain stem. This permanent cessation makes it impossible for the individual to both breathe without mechanical ventilation and experience conscious life. Only in the absence of both brainstem and cortical functioning could the individual be declared dead. Such absence would be detected via clinical signs, although laboratory tests—such as electroencephalography—can be used for confirmation; in response to this absence, the patient would be termed dead and ventilation would be turned off.[55]

Nevertheless, unlike the Harvard Committee—whose chief concern was responding to clinical problems generated by mechanical ventilation—bioethicists justify this criterion via a larger philosophical account of the nature of death. Due to the influential works of Bernard Gert, Charles Culver, and—most prominently—James Bernat, the whole brain criterion has come to be justified on the claim that death is a biological event.[56] In Bernat's understanding, "biology" is defined in diametrical opposition to society, spirituality, and metaphysics. This split is incarnated in the distinction between the "person" and the "organism." The "person" is a social, spiritual, and metaphysical entity. The "organism" is, in contrast, biological.[57] As a result of this

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[55] James L. Bernat. "The Biophilosophical Basis of Whole-Brain Death," in *Defining the Beginning and End of Life: Readings on Personal Identity and Bioethics*, ed. John P. Lizza, (Baltimore: Johns Hopkins University Press, 2009), 533-50. See also James L. Bernat, Charles M. Culver, and Bernard Gert, "On the Definition and Criterion of Death," *Annals of Internal Medicine* 94, no. 3 (1981): 389-94.

[56] Bernat, "The Biophilosophical," 414. See also James L. Bernat, Charles M. Culver, and Bernard Gert, "On the Definition and Criterion of Death," *Annals of Internal Medicine* 94, no. 3 (1981): 389-94.

[57] Ibid.," 416.

distinction, “people” cannot die. Rather, only organisms can die.[58] Such deaths are not social, but biological. As biological events, they are uniform across cultures and historical periods.

As an event, the death of the organism is characterized by the irreversible cessation of functioning in the bodily organ that integrates and maintains the unity of the organism’s parts. This organ is the brain. Without the brain, Bernat argues, the organism “as a whole cannot function.”[59] Its parts may still function: hair may still grow and, with ventilation, the heart and lungs may continue to pump. Nevertheless, these parts of the body are non-essential. The brain, in contrast, is the “critical system” of the body, regulating consciousness, motor function, and physical and emotional sensitivity. These functions are distributed throughout the brain, including the cerebral cortex, thalamus, hypothalamus, and brain stem.[60] Consequently, brain death can only be defined as “whole brain” death.

Both this whole brain criterion and its justification in an account of the human as a biological organism were enshrined in policy in the 1981 Report of the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. [61] The President’s commission created a model statute—the

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[58] Ibid.,” 417.

[59] Ibid., 421.

[60] Ibid., 423.

[61] President's Commission for the Study of Ethical Problems in Biomedical Medicine and Biomedical and Behavioral Research, *Defining Death: A Report on the Medical, Legal, and Ethical Issues in the Determination of Death*, (Washington, DC: US Government Printing Office, 1981).

Uniform Determination of Death Act (UDDA)—which established the validity of both whole-brain and cardiopulmonary criterion for determining death.[62] The UDDA criterion has been adopted by all fifty states, and is the standard used for the "Dead Donor Rule," which establishes that organ donors must be dead prior to donation.[63] Consequently, whole brain death, and its philosophical justification in a conception of the human as a biological organism, have become standardized in US policy.

Nevertheless, in spite of its dominance in policy, the organism standard has been consistently questioned by bioethicists who advocate for what they term a "personhood" standard of death.[64] In bioethical discourse about death, the "person" is contrasted with the "organism"; while the latter is a biological entity, the former is "metaphysical, moral, and cultural."[65] Nevertheless, though personhood is socio-cultural, it is contingent on the biological capacity for "psychophysical integration, where *psycho* refers to a capacity or potential for conscious experience of the world."[66] Personhood advocates locate such

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[62] Ibid. 73; Shewmon, "Brain Death," 18.

[63] Shewmon, "Brain Death," 18.

[64] Michael B. Green and Daniel Wikler. "Brain Death and Personal Identity," in *Defining the Beginning and End of Life: Readings on Personal Identity and Bioethics*, ed. John P Lizza, (Baltimore: Johns Hopkins University Press, 2009), 507-32; John P Lizza, "On the Definition of Death." In *Defining the Beginning and End of Life: Readings on Personal Identity and Bioethics*, ed. John P Lizza (Baltimore: Johns Hopkins University Press, 2009), 533-50; James Rachels, *The End of Life: Euthanesia and Morality* (Oxford Oxfordshire ; New York: Oxford University Press, 1986); Peter Singer, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* (New York: Macmillan, 1996); Robert M Veatch, "The Impending Collapse."

[65] Lizza, "On the Definition," 545.

[66] Ibid., 535.

potential in the regions of the “higher” brain, specifically the cerebral cortex. They thus consider the permanent loss of higher brain functioning—as displayed by patients in persistent vegetative states—to be equivalent to death.[67]

Though the higher brain criterion for determining death is biologically rooted, it depends on a philosophical account of the human being as a social entity. Its advocates have thus been open to a pluralistic understanding of death through their advocacy for “conscience clauses.”[68] Such clauses give individuals the option of choosing how and according to what criteria they should be defined as dead. Through such clauses, personhood advocates situate themselves as simultaneously extending the definition of death to the higher brain, even as they are more open to differing conceptions of death. In theory, these two positions are linked: An openness to higher brain death, by expanding the range of death definitions, also allows for a more pluralistic understanding of death. Thus, by advocating higher brain death, “personhood” advocates contrast their position with an organism standard that they consider biologically monolithic.

Over the past forty years, the bioethical debate about death has been dominated by these two positions on brain death. Such positions are based in putatively opposing conceptions of the neurological and philosophical nature of death: Organism advocates consider death to be a biological phenomenon that is rooted in the functioning of the brain as an integrated system; personhood advocates consider death to be a socio-cultural entity localizable to the higher brain. Nevertheless, in spite of the seeming intractability

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[67] Green and Wilker, “Brain Death,” 522; Lizza, “On the Definition,” 543; Rachels, 60-87; Singer, *Rethinking*, 67.

[68] Veatch, “The Impending Collapse,” 491.

of these positions, I will now argue that both are inconsistent according to their own premises.

Not *Exactly* Dead Yet: The Unsteady Foundations of a Stalemated Debate

Advocates for an organismic standard for death have claimed that death is a biological phenomenon. Nevertheless, though they have defined biology in isolation from society, their criterion of brain death is biologically inconsistent. D. Alan Shewmon has pointed out various integral aspects of the body that continue to function after the cessation of whole brain functioning.[69] Other bioethicists have argued that whole-brain advocates do not establish a convincing biological distinction between those areas of the brain deemed essential and those considered inessential. For example, patients diagnosed as "brain dead" have been found to have continued electrical activity in the majority of their neurons.[70] Though whole-brain advocates have dismissed such activity as inessential to maintaining the organism's integrated functioning, critics have argued that their criterion for doing so is highly selective. Such selection is made not according to putatively asocial "biological" standards; rather, it is highly social, the product of deliberations by private individuals with limited public input. This social aspect of the decision-making process invalidates the consistency of organism-based arguments, which base their authority on the claim that their definition is purely biological. Consequently, the organismic standard is unfeasible on its own terms.[71]

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[69] Shewmon, "Constructing," 258-60.

[70] J. L. Bernat. "How Much of the Brain Must Die in Brain Death?" *The Journal of clinical ethics* 3, no. 1 (1992): 24-5; Veatch, "The Impending Collapse," 484.

[71] Franklin G. Miller and Robert D Truog. *Death, Dying, and Organ Transplantation: Reconstructing Medical Ethics at the End of Life* (Oxford University Press, 2011), 52-79;

Arguments for a personhood standard suffer from a structurally similar—though seemingly opposed—mismatch between neurological and philosophical criterion. Personhood advocates claim that death is socio-culturally pluralistic. Nevertheless, their neurological criterion of higher brain functioning is monolithic. This is, in part, an empirical problem, as individuals without consciousness would be considered alive in the vast majority of the world's cultures.[72] But this empirical problem underscores the inconsistency inherent in advocating for a conception of death that is simultaneously culturally pluralistic and determined by a uniform standard of brain functioning. A culturally pluralistic understanding of death would require a similarly pluralistic account of the *neurology* of death. Such a neurology could not be uniform; rather, it would need to be context specific, as the very content of "death" as an entity would be determined by its cultural setting. And yet, by defining death in terms of higher brain functioning, advocates of a personhood standard propose a conception of the neuroscience of death that is both static and putatively universal. In the process, they extend—and even radicalize—the biologization of death that is advocated by proponents of an organism standard. The personhood standard thus fails according to its own stated goal of forming a conception of death as a social, metaphysical, and moral event.

Consequently, both sides in the bioethical debate about brain death fail to adhere to their own premises. These inconsistences, in turn, are products of a shared orientation, among both personhood and organism advocates, to excise any robust consideration of social dynamics from the definition of death. In the case of organism advocates, this

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Shewmon, "Constructing," 258-60; Veatch, "The Impending Collapse," 484-5.

[72] Shewmon, "The Biophilosophical," 424.

orientation is fully expressed in their conception of biology. Though personhood supporters claim to integrate socio-cultural logics into death, their conceptions of its underlying neurology is both individualistic and universalistic. This places their neurological account at odds with their philosophical support for socio-cultural difference. In this sense, though theoretically opposed, personhood and organism advocates both understand death as a fundamentally asocial event.

This shared premise has led to a debate that is not only stalemated, but also removed from clinical practice, which has remained governed by a whole-brain criterion for the past forty years.[73] This persistence of such stalemated conceptual debates with minimal clinical impact has been so persistent that one bioethicist has declared that he is "dead tired of repetitious debates about death criteria."[74] Such persistence indicates the need to rethink both the conceptual and practical bases of the bioethical discussion of brain death. I will now undertake this rethinking by examining the historical origins of this debate. To do so, I will turn to the work of Gary Belkin.

A Bioethics of Contingency: Gary Belkin's Rethinking of the Origins of "Brain Death"

In **"**Brain Death and the Historical Understanding of Bioethics," Gary Belkin reexamines the history of the 1968 Report of the Ad Hoc Committee of the Harvard Medical School.[75] He argues that "brain death" was a category borne of clinical

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[73] Pernick, "Brain Death," 20.

[74] James M. DuBois, "Dead Tired of Repetitious Debates About Death Criteria," *The American Journal of Bioethics* 11, no. 8 (2011): 45-47.

[75] Belkin, "Brain Death."

necessity. The continued ventilation of individuals in irreversible comas was medically futile and potentially harmful. Nevertheless, though such individuals should have, from a clinical perspective, been disconnected, family members and medical providers might fear that such a procedure would induce the patient's death. Situating "death" in the brain—not the body—would absolve family members of such guilt, even as it also cleared medical personnel of accusations of homicide. Thus "brain death" was not an attempt to provide "an explicit, worked-out theory of consciousness," but rather a "response to a real need to sort out the implications of caring for patients with severe coma."[76] Belkin studies this focus on clinical utility in the Report's two primary sections: "Characteristics of Irreversible Coma" and "Comment."

Written by neurologist Robert Schwab, "Characteristics of Irreversible Coma" established a clinical criterion for diagnosing irreversible coma. Schwab, Belkin argues, did not believe that a laboratory-based criterion for brain death was in itself a sufficient basis for such a clinical criterion[77] He thus defined irreversible coma via a "triad" of clinical signs: unresponsiveness, apnea, and absence of reflexes.[78] The connection of these signs of irreversible coma to a prognosis of corporeal death following the withdrawal of ventilation justified the creation of "brain death." While Schwab still viewed the laboratory criterion as a key part of determining brain death, his expansion of

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[76] Ibid., 343.

[77] Ibid., 334-351.

[78] Ibid 331.

this criterion to include clinical signs highlighted his recognition of the need to account for the contingency of the clinic.[79]

In the "Comment," anesthesiologist and Ad Hoc Committee Chair Henry K. Beecher attempted to provide an ethical framework to address such contingent clinical dilemmas. He did so by elaborating a situational medical ethics that sought to balance the contingency of clinical practice with a standardized policy framework[80] This framework was what Beecher would later refer to as the patient's "right to be let alone."[81] Patients with irreversible comas should not, Beecher argued, be subjected to medically futile treatments. Such treatments were equivalent to the "unethical experimentation" that he had condemned in his historic expose of unethical scientific research, published two years prior in the *New England Journal of Medicine*.[82] Protecting the patient from harm was Beecher's primary goal; this goal justified both the diagnosis of "brain death" and the removal of the patient from medically futile treatment. Thus, Beecher's ethics were based on the need to attend to the perceived and potential suffering of irreversibly comatose patients.

Nevertheless, Beecher acknowledged that the calculus of how to treat patients with brain death might shift in cases of organ donation[83]. In normal circumstances, maintaining an irreversibly comatose patient alive via "intrusive" techniques could not be

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[79] Ibid., 334-351.

[80] Ibid., 351.

[81] Ibid., 356.

[82] Ibid.

[83] Ibid., 357.

justified; transplantation, however, justified such intrusive care because it would provide other individuals with much needed organs. It thus changed the calculus of medical futility. However, while facilitating transplantation, brain death was not a response a need for transplantation. Rather, transplantation was a justification of the intrusive application of therapeutic practices for purposes that were not, for the patient, therapeutic. Beecher's ethics of brain death was thus first oriented toward the patient—and only indirectly toward the potential organ recipient.

Taken together, Beecher and Schwab's contributions to the Report link the ethics and epistemology of death. Rather than propose a standardized solution to the questions raised by irreversibly comatose patients, they sought a framework that would allow medical professionals to work through the ambiguities of clinical care. The virtue of this framework was its openness toward contingency; its radicality was its extension of this contingency to the very category of death. And yet, Belkin argues, the virtue and radicality of the Brain Death Report would be marginalized by the rise of bioethics.

Following the Report's publication, studies emerged that attested to the accuracy of "brain death" in predicting cardiovascular nonsurvivability.[84] Nevertheless, in spite of this practical success, a number of researchers were displeased with the conceptual underpinnings of brain death.[85] Critics called for the brain death criteria to be based in tests of brain stem functionality. Though not better predictors of nonsurvivability, such tests cohered with emerging neuroscientific models that named the brainstem as the seat of consciousness. This adoption of clinically useless criteria marked a shift in the purpose

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[84] Belkin, *Death before Dying*, 208.

[85] Ibid., 211.

of "brain death": While initially valued because of its practical impact, now conceptual fidelity would provide the rationale for the brain death diagnosis.[86]

Nevertheless, the difficulties that bioethicists encountered in establishing a conceptually consistent definition of brain death led them to turn to principles such as "autonomy" and "informed consent" to provide guidelines for clinical decision-making. For Belkin, this has simplified the framework developed in the Harvard Report.[87] While Beecher considered informed consent to be a starting point for an ethical relationship between patient and provider, bioethicists viewed it as an end-in-itself. At the same time, they advocated for a distinction between medicine and ethics that Beecher rejected, considering brain death to be a concept at once ethical and clinical.[88] Thus, Belkin argues, Beecher's situational definition of brain death raises the question of whether it is even necessary for bioethics to exist as a field dedicated to the exploration of ethical dilemmas emerging in clinical practice.

The *Whole* Brain: Clinical Foundations of the Biological Organism

Belkin's work provides a new basis for theorizing the whole-brain standard of death. At present, this standard is predominantly argued in terms that not only fail to be biologically consistent, but that also define biology in opposition to society. This division between biology and society is the methodological foundation for the organism criterion. Nevertheless, as I have previously argued, it is impossible to mark a "biological" cut-off point for whole brain death without involving social value judgments; these judgments

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[86] Ibid., 213.

[87] Ibid., 219-235.

[88] Ibid.

may be made by medical personnel, but that does not mean that they are less social. Attempts to base a whole brain definition on an asocial understanding of the organism will necessarily fail.

Belkin's work provides a different justification for the whole brain criterion. Rather than argue for an understanding of whole-brain death that is made in isolation of the contingency of the clinic, Belkin argues that whole-brain death can only be understood and justified in a clinical context. In this sense, it is—and, in the Harvard Committee's initial formulation, was—a rethinking of how the knowledge generated in the laboratory might be made useful in responding to the contingent problems that manifest in the dynamic context of the clinic. Brain death was designed specifically to address this dynamic context. In this sense, the definition does not, nor should it, be conceptually consistent in isolation from this context. Whole-brain death is an inherently and intrinsically clinical entity.

In this sense, Belkin's work provides a resource for reimagining what it means to be a biological organism *for the purposes of acting medically*. Contrary to the current conception of organism that dominates bioethical thought, this definition of the organism cannot be separated from the clinical context of what is medically possible. The definition of an organism, then, is context dependent. Advocates of an organism standard must explore this context, and base their arguments on an analysis of the immanent logic of contingent clinical situations. Doing so can assist in minimizing the split that has developed, within bioethics, between existing clinical protocols and philosophical debates within bioethical literature. The lack of impact that such debates have on clinical practice should in part be attributed to the choice, by bioethicists, to craft their definitions of brain death in opposition to the contingency of the clinic. By embracing this contingency as central to the biological organism, bioethicists can promote a more profound and fluid dialog between clinicians and bioethicists.

This rethinking of the organism provides the possibility of reconceiving the relationship between the organism and the person. Social scientists and medical humanists have highlighted how clinical calculi are influenced by implicit social value judgments and metaphysical conceptions.[89] In this sense, to be an organism is not only clinically contingent, but also a *socially* contingent. Such an understanding of the organism entails considering the questions of metaphysical and socio-cultural meaning that have, within bioethics, been considered central to the category of "personhood." The personhood standard is thus not distinct from the organism standard because of its "social" nature. On the contrary, as the organism standard is itself inherently social—as well as biological—it logically entails valorizations of social, cultural, and metaphysical worth. Thus, Belkin's analysis of brain death provides the foundation for thinking of the organism and the person as entities that are not opposed, but inherently interrelated.

Developing this foundation entails situating brain death in the history of death in Western medicine. However, this history does not begin with the advent of mechanical ventilation in the mid-twentieth century, but rather with the rise of clinical medicine itself in early 19th century France. To explore this history, I now turn to Jeffrey P. Bishop's work *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*.

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[89] For some examples of such critiques see Jonathan M. Metzl and Anna Rutherford Kirkland. *Against Health: How Health Became the New Morality* (New York: NYU Press, 2010).

Death Without Meaning: Jeffrey P. Bishop's *The Anticipatory Corpse* and the 19th Century Origins of Bioethics

In *The Anticipatory Corpse*, Bishop draws on Michel Foucault's *Birth of the Clinic* to argue that the rise of clinical medicine in early 19th century France redefined death. Physicians came to perceive the dead body as a static entity existing outside of historical time; the living body, in contrast, was dynamic and in flux.[90] And yet, because it was always changing, the living body could not provide a stable ground in which to base medical science. It was only through studies of the dead body that it was possible to examine life.[91] This was true of anatomical studies based in dissection, as well as physiological studies that, through vivisection, provoked death to understand life. These studies redefined the dead body as at once transcendental and immanent to medicine. Medical science became the study of life from the vantage point of death.[92]

This redefinition of death profoundly impacted medical practice. Clinicians defined "life" and "death" in terms of motion: Life was motion, while death was the cessation of movement. The result grounded medicine in *physics*, the science of matter in motion; *metaphysics*, the study of meaning and purpose, would become the domain of religion. Its basis in physics defined medicine as an objective science: While metaphysical claims might vary according to the individual or group, physics would remain uniform regardless of context. But while the exclusion of metaphysics standardized medicine, it also changed its purpose. Medicine now studied the functioning

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[90] Bishop, *Anticipatory*, 351.

[91] Ibid., 21.

[92] Ibid., 90.

of life so as to more efficiently manipulate it. Consequently, medicine's basis in the dead body redefined it as a instrumentalist field, in which the control of matter was considered an end-in-itself.[93]

This framework had gruesome implications for those patients that medicine could not control: the dying. Building on the work of Giorgio Agamben and Sharon Kaufman, Bishop argues that, within Western medicine, the dying began to exist in a "zone of indistinction" between life and death.[94] They could not be returned to a physical functionality, and yet they continued to require medical care. They confronted metaphysical questions of the meaning of life. And yet, medicine either had no response to those questions or, worse, ignored them in the service of physical cures that would, at best, be ineffective and, at worst, provoke harm. This therapeutic ineffectiveness led doctors to punish the dying: alternatively abandoning them, subjecting them to harmful interventions, or even killing them.

While Bishop acknowledges important medical advances since the early 19th century, he considers these to be largely technical. Medicine can more effectively control living matter, but it maintains the same underlying conception of life and death. In this sense, medicine today remains based on the "anticipatory corpse": the anticipation of a dead body that exists as a transcendental object, outside of historical time and social

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[93] Ibid., 71.

[94] Ibid., 11; Giorgio Agamben, *Homo Sacer: Sovereign Power and Bare Life*, trans. by Daniel Heller-Roazen, Meridian, (Stanford, Calif.: Stanford University Press, 1998); Sharon R. Kaufman, *--and a Time to Die : How American Hospitals Shape the End of Life*, (Chicago: University of Chicago Press, 2006).

context.[95] Bishop's book examines the presence of this conception of death in a variety of contemporary modalities of end-of-life care, including the ICU, hospice and palliative care, and interventions for individuals in persistent vegetative states.[96] In each of these cases, their status as medical failures condemns dying patients to varying forms of death-in-life. This mistreatment of the dying is rooted in the early 19th century redefinition of death.

Relevant historical scholarship substantiates Bishop's claim about this redefinition, while providing a deeper understanding of how the advent of the French clinic influenced US understandings of death. Historian and physician Jason Szabo's *Incurable and Intolerable: Chronic Disease and Slow Death in Nineteenth-Century France* confirms Bishop's Foucauldian reading of the French clinic.[97] Szabo argues that the rise of the clinic "enhanced and systematized" the exclusion of France's incurably ill.[98] Though diagnosing such individuals as incurable, emerging medical institutions abandoned them because of their medical futility. Thus, the incurably ill were not "medicalized"; rather, they were denied medicalization when they most needed it.[99]

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[95] Bishop, *Anticipatory*, 278.

[96] Ibid., 96-285.

[97] Jason Szabo, *Incurable and Intolerable : Chronic Disease and Slow Death in Nineteenth-Century France*, (New Brunswick, N.J.: Rutgers University Press, 2009).

[98] Ibid., 180.

[99] Ibid., 6, 180.

Szabo thus argues that end-of-life dilemmas that bioethicists claim originated in the mid-twentieth century in fact date back to the rise of the clinic in 19th century France.[100]

In *Against the Spirit of System: The French Impulse in Nineteenth-Century American Medicine*, historian John Harley Warner examines the impact of the French clinic on nineteenth-century US medicine.[101] While US doctors accepted the French rejection of metaphysical systems, they also modified what they perceived as the coldness of French empiricism with a concern for the broader well-being of the patient.[102] Nevertheless, though this humanized interpretation of French empiricism dominated US medicine through the mid-nineteenth century, by the late 19th century it was superseded by the American incorporation of the German medicine. In contrast to their French counterparts, German doctors emphasized systematic thinking based on laboratory science. While they shared in the French rejection of metaphysics, they claimed that French medicine's emphasis on clinical observation was unscientific. Medicine was to be grounded in the laws of science, as dictated by the laboratory.[103] The dominance of the German laboratory tradition within US medicine led to a rejection of both metaphysical systems and French clinical empiricism.

Emily Abel's *The Inevitable Hour: A History of Caring for Dying Patients in America* examines the impact of German medicine on the US care of the dying. Prior to

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[100] Ibid., 2.

[101] John Harley Warner, *Against the Spirit of System : The French Impulse in Nineteenth-Century American Medicine*, (Princeton, N.J.: Princeton University Press, 1998).

[102] Ibid., 10.

[103] Ibid., 334.

the laboratory revolution, “disease was assumed to arise from the particular interaction of individuals with their environment.”[104] Doctors considered “universalistic knowledge of physiological processes [to be] less important than personal knowledge of patients and the contexts of their lives.”[105] German bacteriology eclipsed this understanding of medicine. Considering dying to be an isolated biological process, hospitals separated the terminally ill from the familial environment that, previously, had been considered central to their care. Nevertheless, the resistance of the dying to the insights of the lab led hospitals to frequently abandon them. For Abel, this systematic abandonment of the dying in the late nineteenth and early twentieth century was the root of many of the problems that would subsequently be attributed to the technologies of the 1960s: “[L]ong before the advent of defibrillators, feeding tubes, and respirators, dying in a hospital was an extremely dehumanizing experience.”[106]

The work of Warner and Abel deepens, but slightly revises, Bishop’s understanding of the 19th century redefinition of death. These authors locate the key moment of this transition not in the early nineteenth century rise of the French clinic, but rather in the late nineteenth century emergence of German bacteriology, and the subsequent dominance of this laboratory perspective within US medicine. But in spite of this disagreement, Bishop, Abel, and Warner concur that the 19th rise of medical authority led to a redefinition of death as biological event that was isolated from broader social questions of meaning and purpose. This division provides a new context to

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[104] Emily K. Abel,*The Inevitable Hour : A History of Caring for Dying Patients in America*, (Baltimore, Md.: Johns Hopkins University Press, 2013).

[105] Ibid., 24.

[106] Ibid., 3.

understand existing debates about brain death, as well as the larger critiques that have been leveled at the field of bioethics itself.

Personhood, Pluralism, and the Definition*s* of Death

This split between an understanding of death as an isolated biological event and a dynamic social process provides a new context in which to understand current debates between advocates of organism and personhood standards of death. Such debates are not mere extensions of this 19th century split. Rather, as I have argued above, although advocates of a personhood-centered conception of death claim to be pluralistic in their openness to socio-cultural difference, their neurological account of death is monolithic: Death is the loss of higher brain functioning. In this sense, though seemingly opposed to the organism standard, conceptions of the death of the "person" in fact extend it from the whole brain to the "higher" brain. The bioethical debate about brain death is predicated on a shared acceptance of death as an isolated and seemingly universal biological event.

This acceptance is itself based on a shared historical narrative. This narrative locates the emergence of the bioethical debate about death in the advent of new medical technologies in the 1960s. But such technologies were introduced long after death had been defined, within US medicine, as an isolated biological event. By taking the 1960s as a starting point, personhood advocates accept a conception of death that is itself the key source of the lack of a pluralistic understanding of death in Western medicine. Though they claim to provide an entry into the socio-cultural logic of death, their very definition of death as a biological and historical entity precludes such an exploration. By focusing on the 19th century redefinition of death, Bishop's account makes it possible to consider the socio-cultural aspects of personhood that bioethicists have excluded from their debates.

In this sense, there is no conception of the "person" within bioethics. Rather, the "person" is considered to be an extension of the organism. But, while I have drawn on the Report of the Ad Hoc Committee provides a new expectation for considering the organism, the Committee's work does not extend to the death of the person. Though the Committee's clinical conception of brain death rejected prevailing understandings of death based in the laboratory, it delineated the boundaries of the clinic in a way that excluded the questions of socio-cultural meaning that had characterized pre-nineteenth century understandings of death.[107] This conception of the clinic as an autonomous, yet contingent space marks the Ad Hoc Report as an inheritor of French clinical empiricism. Bioethicists responded to this definition by reasserting the centrality of the laboratory in determining death. Nevertheless, in spite of their differences, both the Harvard Committee and its critics defined death in isolation of social processes.

The exclusion of a dynamic social understanding of death has proven highly damaging to bioethics. Not only does it prevent an understanding of the social nature of death, but, as death forms the basis of medical epistemology, this understanding of death also forms the basis of bioethical conceptions of "autonomy" and "informed consent." Such conceptions are, in theory, attempts to reintroduce the "person" into medicine, but they are based on a standardized understanding of bioethical protocols and medical epistemology that essentializes the late 19th century definition of death as an isolated

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[107] Pernick, "Brain Death, 13-17.

biological event. Thus, the very attempts of bioethicists to "personalize" medicine only entrench the lack of an understanding of the "person" as a social entity.[108]

In addition to helping to explain the flaws of autonomy and informed consent, this historical understanding of bioethics provides a deeper understanding of the persistence of these concepts within bioethics. While numerous scholars have criticized both autonomy and informed consent for their mystification of the social dynamics underlying clinical decision-making, these critiques have yet to transfer to substantive changes in bioethical protocols.[109] Though the persistence of these concepts is based largely in the powerful political and economic interests maintaining them, it can also be attributed to a failure, on the part of critics, to understand that these very concepts are themselves insufficient responses to the excision of society from the medical definition of death in the 19th century.[110] Critiques that challenge these concepts, without rethinking death, leave their foundation intact. Consequently, rectifying longstanding problems within bioethics entails orienting the field around a definition of death that reintroduces the social content that was excluded via the rise of the laboratory paradigm of death. I will now develop such a definition via an engagement with scholarship on "social death."

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[108] See Bishop's similar critique in *Anticipatory* and Jeffrey P. Bishop, "Rejecting Medical Humanism: Medical Humanities and the Metaphysics of Medicine," *Journal of Medical Humanities* 29, no. 1 (2008): 15-25.

[109] Corrigan, "Empty Ethics"; Farmer, "New Malaise: Medical Ethics and Social Rights in the Global Era."

[110] On ties of bioethics to dominant political and economic interests see: Gary S. Belkin, "The Technocratic Wish: Making Sense and Finding Power in the 'Managed' Medical Marketplace," *Journal of Health Politics, Policy and Law* 22, no. 2 (1997): 509-32; Roger Cooter, "The Resistible Rise of Medical Ethics," *Social History of Medicine* 8, no. 2 (1995): 257-70; Paul Root Wolpe, "The Triumph of Autonomy in American Bioethics: A Sociological View," in *Bioethics and Society: Constructing the Ethical Enterprise*, ed. Raymond; Subedi DeVries, Gregory, (Upper Saddle, NJ: Prentice Hall, 1998), 38-59.

Death, Mourning, Resurrection: Foundations for a Theory of Social Death

A starting point for a conception of social death is the work of French sociologist Robert Hertz. In his essay "The Collective Representation of Death," Hertz argues that death destroys both the individual's "visible bodily life" and "social being."[111] This destruction leads the individual's community to enter a "mortuary state" analogous to the individual's own.[112] Through mourning, the community separates the individual's social essence from his or her physical form. In the process, the individual is able to transition, in a disembodied form, to the afterlife, while the community members are able to "make their rightful re-entry into the world of the living."[113] Death is thus not an isolated biological event, but rather a social process that ends with the resurrection of both the individual and the community. The death of the person thus must be understood as a fluid concept that is based in social practices of recognition.

Though, for Hertz, death is social, it is not egalitarian. He claims that "the emotion aroused by death varies extremely in intensity according to the social status of the deceased."[114] While a chief may be mourned, "the death of a stranger, a slave, or a child will go almost unnoticed."[115] Though these individuals may die physically, they lack the "social being" necessary for their deaths to be mourned. As a result, their

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[111] Robert Hertz, *Death and the Right Hand*, trans. Rodney Needham and Claudia Needham (Aberdeen: Cohen & West, 1960), 77.

[112] Ibid., 78.

[113] Ibid., 75.

[114] Ibid., 76.

[115] Ibid.

physical deaths are final; they are denied resurrection through mourning. Thus, in a paradox, the only ones who can truly die in Hertz's account are those whose lives have so little value that they are beyond death.

Hertz does not use the term "social death" in his essay. Rather, his central point is that death *is* social. Nevertheless, the power differentials he observes in the deaths of individuals of different social status provide an early template for the concept: "Social death" refers to a phenomenon in which individuals are not socially recognized as living. They are excluded from the dominant conception of "personhood" in a given society. Such individuals can be biologically alive or dead. But their life, from a social perspective, is not recognized. Thus, for Hertz, the key marker of death is not the individual's biological state, but rather the status of her social being. Consequently, the inegalitarian nature of death attests to its *social* character. While Hertz focused on non-Western societies, subsequent scholars would argue for the relevance of "social death" in Western societies and, in particular, the modern United States.

In US social science scholarship, the term "social death" first emerged in a series of sociological writings about end-of-life care. These writings argued that terminally and chronically ill individuals were considered to be socially dead by the medical staff treating them.[116] Nevertheless, the term's use extends beyond the incurably and terminally ill. Orlando Patterson, in his famous study, *Slavery and Social Death*, argued

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[116] David Sudnow, *Passing On: The Social Organization of Death*, (Englewoods Cliff, Nj: Prentice Hall1967); Stefan Timmermans, "Social Death as Self-Fulfiling Prophecy: David Sudnow's *Passing on* Revisited." *The Sociological Quarterly* 39, no. 3 (1998): 453-72.

that the experience of slavery was defined by social death.[117] More recently, authors have applied the category of "social death" to individuals in a multiplicity of settings.[118]

In this view, death, as a social category, is always related to violence. Scholars have argued, in various contexts, that declaring certain individuals or population groups to be socially dead can serve as a justification for killing them. Patterson, Giorgio Agamben—whose category of "bare life" provides a legal formulation of social death—and René Girard have all proposed homicidal theories of social death.[119] But social death can also be related to suicidal violence. Howard I. Kushner has argued that suicide is a product of integration into "fatalistic" social structures that negate the individual's personhood.[120] Similarly, Chikako Ozawa-de Silva has argued that suicide must be understood as an individual response to a larger cultural loss of meaning.[121] Such

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[117] Orlando Patterson, *Slavery and Social Death: A Comparative Study*,)Cambridge, Mass.: Harvard University Press, 1982).

[118] João Guilherme Biehl, *Vita : Life in a Zone of Social Abandonment*, (Berkeley: University of California Press, 2005); Judith Butler, *Antigone's Claim : Kinship between Life & Death*, (New York: Columbia University Press, 2000); Lisa Marie Cacho,*Social Death: Racialized Rightlessness and the Criminalization of the Unprotected*, (New York: NYU Press, 2012).

[119] Agamen, *Homo Sacer*; René Girard,*Violence and the Sacred*, trans. Patrick Gregory, (Baltimore: Johns Hopkins University Press, 1977).

[120] Howard I. Kushner, *Self-Destruction in the Promised Land: A Psychocultural Biology of American Suicide* (New Brunswick [N.J.]: Rutgers University Press, 1989); Howard I. Kushner, "Suicide, Gender, and the Fear of Modernity in Nineteenth-Century Medical and Social Thought," *Journal of social History* 26, no. 3 (1993): 461-90; Harold Braswell and Howard I. Kushner, "Suicide, Social Integration, and Masculinity in the Us Military," *Social Science & Medicine* 74, no. 4 (2012): 530-36.

[121] Chikako Ozawa-de Silva, "Too Lonely to Die Alone: Internet Suicide Pacts and Existential Suffering in Japan," *Culture, Medicine, and Psychiatry* 32, no. 4 (2008): 516-51; Chikako Ozawa-De Silva, "Shared Death: Self, Sociality and Internet Group Suicide in Japan," *Transcultural psychiatry* 47, no. 3 (2010): 392-418.

analyses indicate that an individual's internalization of his or her status as socially dead can provide a pretext for suicidal violence. Both these homicidal and suicidal conceptions of social death resonate with disability studies critiques of voluntary euthanasia as a form of internalized violence carried out by incurably ill individuals who have accepted society's judgment of them as socially dead.[122]

Nevertheless, though socially dead individuals are stripped of their personhood, there are social practices that can make the recognition of personhood possible. Vincent Brown and Judith Butler have respectively identified practices of mourning as central to the identification of personhood. Individuals who are socially dead are not mourned; their deaths, as organisms, are not registered as the death of a person.[123] Nevertheless, through mourning, it is possible that these socially dead individuals might reclaim their status as persons within the community.[124] Thus, from the perspective of social death, death is not an endpoint but rather a transitional phase between the individual's corporeal demise and his or her reincorporation into the community through practices of mourning and memorialization. Such practices are essential not only for preserving the individual's personhood following his or her demise, but also in allowing the community to recover from its own experience of loss. Social death, in this sense, though beginning with the

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[122] See Braswell, "Can there."

[123] Vincent Brown, "Social Death and Political Life in the Study of Slavery," *The American Historical Review* 114, no. 5 (2009): 1231-49; Judith Butler, *Precarious Life: The Powers of Mourning and Violence*, (London ; New York: Verso, 2004).

[124] Brown, "Social Death."

loss of personhood, is ultimately oriented toward resurrection through communal practices of mourning.

The death of the person, then, is not a static event, but rather part of a dynamic social process. This process is both performative and participatory, constituted by the practices and speech-acts of members of a particular community. The state of being "dead," within this process, is not absolute, but rather relative, defined in relation to the value structure being enacted, and constantly refined, by the members of a particular group. This death can, in turn, be reversed by altering such social practices. I will now explain how this understanding of the death of the person relates to my earlier rethinking of the death of the organism.

Between the Two Deaths: Toward an Integrated Definition

In a recent article, D. Alan Shewmon argues that, though putatively opposed, bioethicists advocating personhood and organism-based understandings of death both grasp valuable aspects of death.[125] Personhood advocates understand that death is a unity of corporeal and mental functions, while organism-advocates grasp how an organism can continue to exist as a unified whole even in the absence of consciousness. Shewmon urges bioethicists to abandon "the assumption that death is a single concept" in favor of an understanding of death that incorporates both poles of the personhood/organism dichotomy.[126] I will now elaborate such an understanding by situating the death of the organism within my larger account of the death of the person.

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[125] Shewmon, "Constructing."

[126] Ibid., 258.

There remain valuable bioethical debates about whether whole brain death should constitute the death of the organism.[127] But such debates should not focus on the philosophical consistency of an organism standard; rather, they should focus on the clinical utility of this conception of death in addressing the problems of end-of-life care. Though the whole brain standard may continue, for the moment, to be the most clinically beneficial, this standard could be revised were a more compelling alternative to appear. Such an alternative would not be valid because of its putatively more biologically consistent account of the organism, but rather because its understanding of biology is more clinically responsive. In this sense, though the whole brain standard itself can be changed, the terrain on which the death of the organism should be discussed should remain that of clinical need.

Nevertheless, however death is defined at the level of the organism, this definition should not exhaust the definition of death in bioethics. Rather, the death of the organism must be considered an isolated moment in the larger process of the death of the person. Bioethicists should continue to deliberate on how to identify the moment of an organism's death, but such deliberation should not be the ultimate focus of bioethical reflection on death. The focus of bioethical reflection on death should be the person, as it is only through the existence of the person that the biological organism has meaning.

At present bioethicists have resisted such an orientation because they have considered the concept of personhood, in the words of Miller and Truog, to be "inherently vague and contested."[128] But this critique is, in reality, a compliment. The

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[127] See for example, Miller and Truog, "Death," and Shewmon, "Constructing."

[128] Miller and Truog, "Brain Death," 95.

death of a person is "contested" because, in fact, there *are* multiple competing conceptions of personhood. Such conceptions cannot be understood without an exploration of the immanent logic of the social situation in which personhood is defined. They are thus not "inherently" vague; rather, they are vague only because bioethicists have chosen not to explore them. This choice is itself an immense failure, as it has caused bioethicists—like Miller and Truog—to base their field on concepts, such as "autonomy" and "informed consent" that, in not exploring the social dynamics of both individual choice and medical knowledge, exploit the very vulnerable populations that they were supposed to protect.[129] This failure is a direct result of the field's orienting itself around conceptions of death that, as I have argued, exclude a consideration of society. In this sense, orienting bioethics around a conception of personhood will assist in rectifying what others have recognized as the longstanding problems of bioethics in recognizing the underlying social dynamics of the clinical dilemmas they purport to address. Thus, the "vagueness" of personhood is ultimately much more illuminating than the misleading clarity of the organism.

Nevertheless, though personhood, as I have defined it, is a social concept, it is no less "biological" than the bioethical understanding of the organism. But rather than being located in a particular area of the individual's brain, the neurology of personhood would examine the communal practices of recognition that constitute a person's identity. The death of the person can thus be described in biological terms, but the biology of death

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[129] For a few examples of such critiques see Braswell, "Can There;" Corrigan, "Empty Ethics; Farmer, "New Malaise;" Paul K. Longmore, "Policy, Prejudice, and Reality: Two Case Studies of Physician-Assisted Suicide." *Journal of Disability Policy Studies* 16, no. 1 (2005): 38-45.

would not be that of “higher brain” functioning; rather, the biology of death would be that of attachment, mourning, and loss.[130] Thus, contrary to theorists who contrast social and biological definitions of death, understanding death as social deepens our understanding of its biology. In the process, it strengthens both the practical and conceptual aspects of the bioethical understanding of death.

This rethinking of the biology of personhood challenges the dominant understanding, with bioethics, of the relationship between the person and the organism. As I have argued, bioethicists argue that the organism is biological, while the person is social. This argument is misleading in two respects: First, the bioethical conception of the organism includes social value judgments, even as bioethical understandings of the person exclude the socio-cultural differences that they claim to represent. At the same time, though bioethicists understand the “person” and the “organism” to be opposing concepts, in reality, there is no substantive distinction between them. Both the “person” and the “organism,” as these concepts have been understood within bioethics, are defined by their isolation from society. This shared exclusion of society renders these concepts practically indistinct.

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[130] The work of John Bowlby is an excellent starting point for understanding the neurobiology of attachment and loss. See in particular John Bowlby, *Attachment and Loss*, 3 vols. (New York,: Basic Books, 1969). On mourning see Robin L. Carhart-Harris, Helen S. Mayberg, Andrea L. Malizia, and David Nutt, “Mourning and Melancholia Revisited: Correspondences between Principles of Freudian Metapsychology and Empirical Findings in Neuropsychiatry,” *Annals of General Psychiatry* 7, no. 9 (2008): 1-23 and George A. Bonanno,, *The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life after Loss*, (New York: Basic Books, 2009).

Unlike the dominant understanding within bioethics, in my account, the death of the person and the death of the organism are not distinguished based on a dichotomy between biology and society. The organism must be understood in its social context, even as the person must also be understood in biological terms. Consequently, the organism is not any more "biological" than the person is "social." Rather, they are both simultaneously social and biological. Acknowledging the necessarily hybrid nature of persons and organisms does not erase the distinction between them; on the contrary, it makes it possible to develop a series of distinctions between these concepts that are both robust and definitive.

The death of the organism is a static event; the death of the person is a moment in a dynamic social process. The death of the organism is absolute, while the death of the person is relative. The death of the organism is individualistic, even as it is conditioned by a social calculus; the death of the person is communal, even as it is experienced by an individual. The death of the organism is universal; the death of the person is always particular. While all organisms are equal in death, the death of the person is ruthlessly inegalitarian, and is in fact a key site where social power relations are consolidated. The death of the organism is an endpoint from which it is impossible to return. The death of the person is neither permanent nor irreversible; rather, it is a starting point for a process in which the deceased individual and the surrounding community will be resurrected. Consequently, erasing the false dichotomy between the "biological" organism and the "social" person makes it possible to conceive of the person and the organism as radically opposed. Nevertheless, though the death of the person is opposed to that of the organism, these two forms of death are also inherently related.

This relationship between the death of the person and that of the organism is of significant clinical and social utility. For example, the social recognition of an organism's death might mark the beginning of the deceased person's resurrection as a social being within the community. At the same time, in cases when the organism is alive, social death can be valuable in drawing attention to underserved populations, establishing a bioethical imperative to devise policy and clinical solutions to facilitate the recognition of their personhood. Such recognition is not merely symbolic, but can also manifest in the imperative to provide them with needed material support. Thus, by orienting bioethics around the social conception of personhood, it becomes possible to recognize ethical problems of which the field, based on an organism-centered conception of death, may not be aware. Addressing these problems both contributes to and goes beyond an understanding of death on the level of the organism.

The solution to current bioethical difficulties regarding the definition of death does not lie in siding with either a person-centered, nor organism-centered conception of death. Rather, it entails redefining death to encompass both a conception of personal death and death as an organism. The bioethicist must occupy a space between these two conflicting notions of death: on the one hand, regulating the definition of death as an organism; on the other hand, working with dying individuals and their families to ensure that the individual does not experience prolonged personal death both before and after their death as a biological organism. In this sense, this new definition of death entails redefining the role of the bioethicist and, indeed, the field of bioethics itself.

Defining Death, Redefining Bioethics: A Neverending Project

How does this new definition of death change the field of bioethics? Rather than regulating a preexisting definition of death, bioethics must analyze how "death" is defined within particular medical situations. In this sense, the task of bioethics must be to define death, but this task must be understood as a neverending project. At the same time, the goal of this project is not simply to bring individuals to their organismic deaths, but rather to design interventions necessary to facilitate the processes of mourning necessary for resurrection. By orienting itself around this task of defining death, the field will address its critics and stake out a valuable place for itself within US medicine.

This new definition of death builds on the definitions of death already present within bioethics. Both brain death—as defined by the Harvard Committee—and cardiopulmonary death are clinically useful starting points for negotiating social death. But by considering them to be ends-in-themselves, bioethicists misunderstand the ethical and clinical dimensions of death. In this sense, my critique of bioethical approaches to "death" mirrors Beecher's critique of "informed consent": While "informed consent" is a useful starting point, it cannot guarantee an ethical medical practice; this must be based in the technical skill of the physician.[131] But the skills required by the bioethicist to negotiate the death of the person are different that are required of the physician to negotiate the death of the organism.

Bioethicists must be trained to understand and negotiate the immanent logic of clinical situations within a broad social context. Such training would, by necessity, be very different than that which is the norm in bioethics centers today. At present, bioethics

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[131] See Belkin, *Brain Death* 51-91 for a fuller treatment of Beecher's formulation of informed consent.

remains a field oriented around standardized protocols designed to determine the correct course of action. As such, it is primarily based in the field of philosophy and, more particularly, the school of "principlism," which claims that ethics can be negotiated through adherence to putatively universal principles such as "autonomy."[132] But in its focus on the "universal," principlism discourages the exploration of the immanent logic of clinical situations. While the bioethical school of "casuistry" is oriented toward exploring such situations, its adherents are generally philosophers with limited training in the social sciences and humanities.[133] As such, their analyses of clinical problems often fail to consider the underlying social, cultural, economic, and political factors conditioning the ethical dilemmas they are attempting to resolve.[134]

In contrast to such approaches, bioethics must be oriented around an explicitly interdisciplinary methodology, drawing on the humanities, social sciences, and biological sciences. Bioethicists must be trained to understand and mediate between these fields in order to understand the interaction of social, cultural, economic, political, and biological forces at work in particular clinical situations, as well as larger problems of health policy. At the same time, the goal of interdisciplinary exploration in bioethics should not be to uphold existing bioethical categories, such as "autonomy," "informed consent," or even "death." Rather, through their interdisciplinary explorations of particular problems,

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[132] On principlism in bioethics John H. Evans, "A Sociological Account of the Growth of Principlism," *Hastings Center Report* 30, no. 5 (2000): 31-39.

[133] For a concise statement of the virtues of casuistry see John D. Arras, "Getting Down to Cases: The Revival of Casuistry in Bioethics," *Journal of Medicine and Philosophy* 16, no. 1 (1991): 29-51.

[134] On the lack of a deep knowledge of social processes in bioethics see Harold Braswell, "In Search of a Wide-Angle Lens," *Hastings Center Report* 41, no. 3 (2011): 19-21.

bioethicists must reformulate these concepts in a manner that is most responsive to the calculi of particular clinical situations.

With regard to the bioethical category of "death," the bioethicist can take the existing organism-based definitions of death as a starting point, but the definition of death—understood as impacting the person—can only be worked out in the context of contingent clinical situations. The term "clinical" here must be understood in the broadest sense possible, to entail the intersection of biological functioning, cultural belonging, and social, political, and economic power. The task of bioethics thus remains that of defining death, but the field can only do so in the knowledge that this task can never be complete. Only by acknowledging this seeming limitation, will it be possible to engage the contingency of death. I will now show the clinical utility of this new formulation of bioethics through a reading of Christopher Crenner's case study "A Brief History of Timelessness in Medicine."[135]

Bioethics and the Contingency of Death: Reading Christopher Crenner's "A Brief History of Timelessness in Medicine"

In "A Brief History of Timelessness in Medicine," physician and historian Christopher Crenner presents the case of a Katherine Scott, a patient who, following an asthma attack, entered a persistent vegetative state (PVS). While the patient's eldest daughter, Patricia, wanted "everything" to be done for her mother, the hospital team wanted to disconnect Katherine from life support. This procedure was arguably supported by the patient's own wishes. Katherine's younger daughter reported that her mother had

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[135] Christopher Crenner,"A Brief History of Timelessness in Medicine," in *Clio in the Clinic: History in Medical Practice*, ed. Jacalyn Duffin,, (New York: Oxford University Press, 2005), 269-82.

said that she did not want to be dependent on machines. Without denying this, Patricia claimed that her mother's decision had changed: Though in a vegetative state, Katherine was communicating to Patricia that she wanted to continue living under her care.[136]

In approaching similar conflicts, bioethicists have focused on establishing standardized protocols to guide decision-making.[137] Thus, cases like Katherine Scott's might be cited as rationales for the creation of living wills. Had Scott had a living will, it might be argued, it would have nullified this conflict. Even without a living will, bioethicists have argued, in similar cases, that the existence of general agreement regarding her previous desires might establish a sufficient standard to warrant her removal from life support out of respect for her autonomy.[138] Though a living will would be a valuable document in this situation, Crenner—facing the lack of such a document—takes a different approach. Without accepting Patricia's story of Katherine's communication to her, he imagines how Katherine, were she conscious, might view her situation. Had she been able to see her daughter's dutiful care for her, he reasons, it might change her assessment of the removal of treatment.

This act of imagination creates a new context in which to understand the administration of medical technology. Contrary to the putatively neutral language of a

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[136] Ibid., 274.

[137] On the history of living will laws see Scott P. Hays, and Henry R Glick, "The Role of Agenda Setting in Policy Innovation an Event History Analysis of Living-Will Laws," *American Politics Research* 25, no. 4 (1997): 497-516; Thomas J. Prendergast, "Advance Care Planning: Pitfalls, Progress, Promise," *Critical Care Medicine* 29, no. 2 (2001): N34-N39.

[138] Stephen S. Hanson and David J. Doukas. "Advance Directives." In *The Penn Center Guide to Bioethics*, ed. Arthur L. Caplan, Autumn Fiester and Vardit Ravitsky (New York: Springer, 2009), 749-60.

living will, Katherine is not dependent on a machine. Rather than being sustained by a machine, she is, as Crenner notes, dependent on her daughter. The grounding of Katherine's life support in her relationship with her daughter changes her relationship to the medical technology in a way that Katherine could not have anticipated prior to her loss of higher brain functioning. Even *if* Katherine had a formal living will, such a will would not have accurately described the circumstances that arose under her daughter's care. Far from neutral, such a will would violate the contingency of the clinic.[139] Crenner's empathy thus allows him to gain a significantly deeper understanding of the situation than an adherence to protocol.

Such empathy cannot be exercised without an understanding of the power dynamics of the clinic. Trained as a historian, Crenner is attuned to the racial and social context of Patricia's decision and Katherine's death. He is aware that the medical team is made up of entirely white physicians, like himself, while Patricia and Katherine are African-American women. At the same time, knowing that she lives in an economically marginalized part of town, he wonders if her attack was exacerbated by the notoriously inefficient ambulance service to that area.[140] This provides him with a deeper understanding of how Katherine's distrust of the medical team might be impacted by larger racial and economic inequality. Crenner's historical training thus makes him aware

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[139] For similar arguments about living wills working against the interests of the incompetent see John A Robertson, "Second Thoughts on Living Wills." *Hastings Center Report* 21, no. 6 (1991): 6-9; Laraine Winter, Susan M. Parks, and James J. Diamond. "Ask a Different Question, Get a Different Answer: Why Living Wills Are Poor Guides to Care Preferences at the End of Life," *Journal of Palliative Medicine* 13, no. 5 (2010): 567-72.

[140] Crenner, "A Brief," 273.

of the significant differences between Katherine and Patricia's experiences and those of the medical team.

This sensitivity influences his decision, as head of the medical team, to call a hospital ethics consultation to develop a plan of action. By illustrating "even more sharply" the conflicts between participants, the consultation improved communication between the medical team and Patricia.[141] As a result of this improved communication, Patricia could continue and even improve her care of Katherine at home. Hospitalizations became less frequent.[142] Over time, Patricia requested less interventions, and became more invested in "personal attention" to her mother.[143] The ethics consultation had thus increased both the caretaker's and the medical team's attentiveness to the patient; in the process, her health improved. Consequently, the consultation was clinically beneficial for all parties involved. Though these benefits did not keep Katherine Scott from dying, they did make her have a better death than otherwise would have been possible.

One year after Katherine's hospitalization, Crenner visited Patricia and Katherine at home. There, he assists Patricia in changing Katherine's bed. This experience provides the essay's organizing concept and culminating moment:

> Each one of our small, careful acts took its own time, and seemed to contain within it all the intentions and memories of the many similar acts that had

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[141] Ibid., 276.

[142] Ibid.

[143] Ibid.

> preceded and would follow it, so that all the time that they took together was both endless and already passed.[144]

The result is what Crenner calls "a moment of timelessness."[145] Though seemingly ahistorical, this moment is grounded in and conducive to his engagement with the present. This engagement responds to the contingencies of the clinic, even as it redefines the essential categories that typically govern clinical medicine, including the very category of "time" itself. Through his care of a dying patient, Crenner does not simply regulate death, but rather reformulates the very meaning of death for his patient, her family, and himself as a professional. This reformulation, though occurring outside the bounds of the clinic ethics consultation, epitomizes the vision of bioethics that I have developed above.

Crenner notes that, as they labor, both he and Patricia "seemed to be mourning" Katherine's passing her.[146] This mourning synthesizes Katherine's withering organic life with her daughter's conception of her as a living person. By bringing her biological matter into harmony with her caretaker's conception of her, mourning *allows* Katherine, the person, to die with her body. This mourning is both a response to and a rejection of medical futility. Medicine cannot save Katherine's life as a biological organism, but, through mourning, it can make her death meaningful and salvage her existence as a person. Through its acknowledgement of futility, mourning becomes clinically effective, attuning Patricia and Crenner to Katherine's needs, while facilitating their own grieving

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[144] Ibid., 277.

[145] Ibid.

[146] Ibid., 278.

for her passing. Mourning unites patient, community, and provider in a shared labor of healing.

The hospital ethics committee both facilitates and impedes this healing. By resolving the conflict between Patricia and the medical team, the ethics committee improves Katherine's clinical care. And yet, while providing a buffer, the team does not provide Crenner with the tools necessary to attend to Katherine and Patricia. On the contrary, bioethical concepts of autonomy and informed consent, in their current form, would actively thwart the nuanced social understanding of medicine and intimate clinical care that Crenner displays with Katherine and Patricia. Moreover, as Belkin has argued, through its standardized ethical protocols, bioethics facilitates a standardization of medical practice that hinders the ability of clinicians to negotiate clinical spaces.[147] Crenner concludes his essay, in fact, by noting that changes in his hospital's billing practices have made the experience of "timelessness" impossible.[148] In this sense, bioethics in its current form is, at best, an incomplete solution, and, at worse, part of the problem itself.

Strengthening bioethics entails redefining the field's key terms. In Crenner's narrative, "autonomy" does not arise from protecting the patient's static choice; rather, it is a product of Crenner's assisting her and her family to negotiate a dynamically changing medical situation in a manner that facilitates her healthy and meaningful dying. "Informed consent" does not entail providing Katherine with neutral medical information; rather, it involves working through the meaning of this information to her in

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[147] Belkin, "Technocratic Wish."

[148] Crenner, "A Brief," 281.

the context of an evolving clinical relationship. These new conceptions of autonomy and informed consent are grounded in Crenner's openness to consider "death" as a dynamic social process that entails working through conflicting biological, social, and psychological vectors. His essay thus provides a grounding for a bioethics open to the contingency of death. I will now conclude by proposing a bioethical project that explores this contingency in the context of the primary form of end-of-life care in the US: hospice.

Conclusion: Death in US Hospice Care

Since the 1960s, sociologists and anthropologists have used "social death" to describe the status of the terminally ill in US medical institutions.[149] This social death manifests itself in the denial of care these populations care, as well as in attempts, by medical personnel, to actively kill them. It is thus both a *precursor* to and *cause* of their biological death. Though the field of bioethics ostensibly emerged to protect such populations, sociologist Stephan Timmermans has argued that its putatively universal regulatory framework hides the existing inequalities linking biological and social death.[150] Consequently, there is a need for an alternative bioethical exploration of social death in US end-of-life care.

In this dissertation, I will conduct such an investigation through an interdisciplinary study of how death is defined in US hospice care. Doing so will entail examining how existing bioethical definitions of death generate social death in US hospice care. Through such an investigation it will be possible to suggest changes to existing institutions in bioethics and end-of-life care.

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[149] Kaufman, "And a Time…"; Sudnow, "Passing On"; Timmermans, "Social Death."

[150] Timmermans, "Social Death."

Hospice is an ideal subject for such an investigation because it has itself been premised on a particularly strong critique of the biomedical model of death.[151] In fact, the modern hospice movement emerged in part in response to the very same issues regarding the definition of death as the field of bioethics; nevertheless, while bioethicists attempted to define death in terms at once conceptual and narrowly biological, hospice professionals considered death to be a social process. As clinical providers, they attempted to help patients and families move through this process so that death might lead to resurrection. Thus, an examination of death within hospice has the potential to reformulate the bioethics of death, even as it addresses pressing problems in the current distribution and practice of US end-of-life care.

But such an investigation runs into an initial problem: According to many commentators, the modern hospice movement has already outlasted its potential to significantly change modern medicine.[152] These commentators argue that hospice, in the 1970s, became "medicalized," adopting the same medical model of death that had been dominant in US medicine and bioethics. If this is the case, then hospice might not provide a useful site for the development of an alternative conception of death. It is thus

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[151] Cathy Siebold, *The Hospice Movement : Easing Death's Pains*, (Twayne Publishers: New York, 1992);; Margaret Manning, *The Hospice Alternative: Living with Dying*, (London: Souvenir Press, 1984).

[152] Emily K. Abel, "The Hospice Movement: Institutionalizing Innovation," *International Journal of Health Services* 16, no. 1 (1986): 71-85; Ann Bradshaw, "The Spiritual Dimension of Hospice: The Secularization of an Ideal," *Social Science & Medicine* 43, no. 3 (1996): 409-19; Michael Brown,. "Between Neoliberalism and Cultural Conservatism: Spatial Divisions and Multiplications of Hospice Labor in the United States." *Gender, Place & Culture* 11, no. 1 (2004): 67-82; James, N., and D. Field. "The Routinization of Hospice: Charisma and Bureaucratization." *Social Science & Medicine* 34, no. 12 (1992): 1363-75.

necessary to conduct a historical investigation to examine how the US hospice movement’s conception of death evolved throughout the 1970s. I will conduct such an investigation through a study of Hospice, Inc., the nation’s first “modern” hospice.

Chapter 2

A Faithful Betrayal: Technology, Humanism, and the Medicalization of Death in the Modern US Hospice Movement, 1970-80

Introduction

Since its emergence in the early 1970s, the modern US hospice movement sought to provide an alternative to the ineffective and often harmful use of medical technology in end-of-life care.[153] Rather than try to cure incurable diseases or keep the patient alive in a state of pain and anxiety, hospice would couple palliative medical interventions with spiritual and psycho-social care aimed at the individual's anxiety about dying. Though such care might incorporate medical technology, its ultimate goal was to free patients from a medical enterprise whose dominion over the deathbed had, hospice leaders argued, began to produce tragically diminishing returns. Over the 1970s, the movement expanded from a grassroots organization located in New Haven, Connecticut to a national network centralized in the National Hospice and Palliative Care Organization. Hospice care subsequently became integrated into the US Medicare system in 1983 and the number of hospice organizations has grown throughout the 1980s, 90s, and 2000s.[154] At present, approximately 1/3 of all deaths in the US occur in hospice care.[155] Considering

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[153] For general accounts that frame the US hospice movement's origin and development in these terms, see: Stoddard, *The Hospice Movement* and Siebold, *The Hospice Movement.*

[154] Thomas Hoyer, "A History of the Medicare Hospice Benefit." *Hospice Journal*, 13 (1998): 61-70.; Stephen R. Connor *Hospice and Palliative Care: The Essential Guide* (New York: Routledge, 2009), 125-146.

[155] Henry L. Davis, "Growth in Hospice Care Redefines Its Role in Medicine," *Buffalo News*, 28 February 2009, accessed March 21, 2009, http://www.buffalonews.com/home/story/592871.html.

that the hospice movement began with few precedents and limited resources, this growth would seem an unparalleled success.

Nevertheless, historians of death and dying have considered the seeming success of hospice to come as the result of a fundamental betrayal. Historians claim that both the international and the US hospice movement betrayed the hospice tradition by privileging the use of medical technology over non-medical spiritual and psycho-social interventions. This accusation has taken various forms, hospice organizations having been characterized as "secularized," "routinized," and even "McDonaldized."[156] But, though each of these accounts highlight different aspects of the evolution of hospice, they are united in linking these aspects to the US hospice movement's increasing "medicalization" of death; by becoming medicalized, these authors claim, hospice organizations have lost the religious, context-specific, anti-corporate conception of death that characterized the movement's origins. This narrative of self-betrayal through medicalization is the dominant lens through which hospice historians understand the hospice movement's development, as well as the current state of hospice care in the US and abroad.

In this chapter, I examine the validity of this narrative by reading the papers of Florence & Henry Wald, the founding figures of the modern US hospice movement.

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[156] Bradshaw, "The Spiritual Dimension"; Joy Buck. "'I Am Willing to Take the Risk': Politics, Policy and the Translation of the Hospice Ideal." *Journal of Clinical Nursing* 18, no. 19 (2009): 2700-09; James, 1992; Donalee Unal. "Hospice Care Today: Compassionate or Mcdonaldized?" *Theory in Action* 4, no. 3 (2011): 57-64; George Ritzer. "The Mcdonaldization Thesis: Is Expansion Inevitable?" *International Sociology* 11, no. 3 (1996): 291-308; Deena Weinstein and Michael A. Weinstein. "Mcdonaldization Enframed," in *Resisting Mcdonaldization*, edited by Barry Smart, (London: Sage, 1999), 66.

These papers, housed at Yale University's Sterling Memorial Library, contain the meeting minutes, position papers, public statements, and both internal and external correspondence of Hospice, Inc., the nation's first modern hospice organization. I will particularly focus on the period from 1970 to 1980, the first ten years of the organization's development. By examining this germinative period, it will be possible to track the Hospice Inc.'s attitude toward the relationship between medicine and death as the organization evolved from a grassroots, volunteer-based operation to a large national organization integrated into the US healthcare system.

Based on this research, I argue, contra existing historical literature, that a study of this period does not reveal a self-betrayal of the hospice movement's vision of end-of-life care. On the contrary, hospice leaders self-consciously maintained adherence to a larger hospice tradition oriented toward the spiritual, psychological, and social dilemmas of death. They did so by creating a separation between what I—paraphrasing hospice leaders—refer to as "technological" and "humanistic" care: While technological care was aimed at the body's biological functioning, humanistic care aimed to attend to individual's psychological, social, and spiritual needs. Hospice leaders associated technological care with medicine, while considering humanism to pertain to fields such as religion, psychology, architecture, and community organizing. Though hospice leaders recognized the place of medical technology, they considered it to be a means toward their ultimate goal of caring for these individual's non-medical needs. Hospice leaders contrasted their subordination of technology to humanism with what they perceived as the excessive technology use of hospital IPUs. It was through this humanistic conception of medicine that the hospice movement distinguished itself, while maintaining fidelity to its initial principles as well as the broader hospice tradition.

This fidelity was precisely the problem. By maintaining a distinction between humanistic and technological care, the hospice movement defined itself by virtue of its exclusion from existing medical practice. This attempt to separate hospice from medicine ultimately left the US hospice movement with limited social, political, and economic capital to protect and implement the humanistic treatment modalities they were trying to defend. In particular, the US hospice movement's humanistic conception of care led it to cede cultural, political, and medical authority to the then emergent field of bioethics. Like hospice, bioethics was a response to perceived abuses of medicine at the end-of-life. But while hospice responded to these abuses by adopting a humanistic perspective, bioethicists excised the humanistic elements from medicine in favor of putatively neutral medical knowledge. This excision was most forcefully represented in what I have, in Chapter 1, discussed as the bioethical "redefinition" of death; by arguing that death should be defined via reference to laboratory criteria, bioethicists, eliminated the subjective, and situationally contingent aspects of definition of death. Their adherence to this explicitly medicalized conception of death allowed bioethicists to directly influence US medicine; in the process, they marginalized the humanistic interventions that Hospice, Inc.'s leaders believed to be of crucial import.

I conclude by arguing that, although Hospice Inc. based itself on a distinction between technology and humanism, the organization's ideology contained elements that subverted this distinction as well. In particular, I read Hospice, Inc.'s "Statement on Euthanasia," finding it to contain an understanding of death in which humanism and technology are co-constitutive. I label this hybrid conception “humanistic technology.” Placing this conception in conversation with current work in disability studies, I propose that, rather than consider hospice to be anti-technological, we should think of it as a medical technology that is itself essential to the very category of “natural death.” This new conception of death, in turn, makes it possible to imagine how hospice advocates can link their concerns with those of the disability rights movement. By synthesizing hospice with disability rights, it will be possible to not reject, but rather to redefine the use of medicine at the end-of-life. The result is a new narrative for the history of the US hospice movement—one in which the “medicalization of death,” rather than leading to a betrayal of the hospice tradition, provides a vehicle through which hospice can draw on this tradition to transform contemporary bioethics and end-of-life care. This narrative, in turn, will provide an entry to the ethnographic study of hospice that comprises this dissertation’s final two chapters.

Born Bad: The US Hospice Movement as a Betrayal of the Hospice Tradition

Prior to examining the modern US hospice movement, it is necessary to understand how historians have understood its relationship to its ancestors in the hospice tradition: late 19th century European and American religious hospices and the modern British hospice movement that emerged in the mid-1960s. Within historical literature, the modern US hospice movement is represented simultaneously as an inheritor of and a traitor to this hospice tradition, because it is alleged to have adopted a significantly more medical approach to hospice care. Thus, the very emergence of the US hospice movement is considered to be a manifestation of the usurpation of hospice care by medical technology.

The term "hospice" has been in use since the 13th century.[157] Early hospices were religious institutions that provided lodging and care for those in need of hosting, including pilgrims and the sick.[158] Only in the 19th century did European hospices come to specialize in the care of the dying. In the late 19th century, Anglican hospice institutions emerged in Ireland (Our Lady's Hospice) and England (Hostel of Good, Saint Joseph's Hospice, and Saint Luke's House of the Dying Poor).[159] Similar hospices were constructed in the late 19th and early twentieth century United States by the Dominican Sisters of Hawthorne, led by Nathanial Hawthorne's daughter, Rose Hawthorne Lathrop.[160] These turn-of-the-century century hospices were Christian institutions featuring limited medical treatment and existing on the outskirts of their respective national medical systems.[161] While many of them are still in existence—indeed, in Chapter 4 of this dissertation, I will examine a contemporary Dominican Hospice—they are no largely longer associated with the institutional category "hospice," and historians consider them to have been both marginalized and superseded by the "modern hospice movement" of the mid-twentieth century.

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[157] Siebold, *The Hospice Movement*, 17.

[158] Bradshaw,"The Spiritual Dimension," 411.

[159] Siebold, *The Hospice Movement*, 20; Grace Goldin, "A Protohospice at the Turn of the Century: St. Luke's House, London, from 1893 to 1921." *Journal of the History of Medicine and Allied Sciences* 6 (1981): 383-415; Claire Humphreys, "Waiting for the Last Summons": The Establishment of the First Hospices in England 1878-1914," *Mortality*, 6 (2001):146-66.; Michelle Winslow and David Clark, "St Joseph's Hospice, Hackney: Documenting a Centenary History." *Progress in Palliative Care*, 14 (2006): 68-74.

[160] Siebold, *The Hospice Movement,* 23.

[161] Bradshaw, "The Spiritual Dimension," 144; Siebold, *The Hospice Movement*, 20.

Nevertheless, in spite of such distinctions between “religious” and “modern” hospices, these earlier religious hospices were of key inspiration to the foundress of the modern hospice movement, Dame Cicely Saunders.[162] Working as a doctor, nurse, and social worker in England in the 1940’s and 50’s, Saunders observed significant gaps in the British healthcare system’s treatment of dying patients. These patients were socially excluded, subject to curative interventions that were frequently undesired and even harmful, and denied treatment for both their existential anxiety and larger marginalization from British society. Having worked at two religious hospices—Saint Joseph’s and Saint Luke’s—Saunders sought to create a facility for the care of the terminally ill that, while modeled on these religious institutions, would make a more concentrated attempt to influence the care of the dying in the British medical system as a whole. With this in mind, she founded Saint Christopher’s Hospice in 1967.[163]

In contrast to 19th century hospice leaders, Saunders was a doctor and considered medicine fundamental to hospice care.[164] But she was also a nurse and a social worker, and this interdisciplinary training shaped her belief that dying patients suffered from “total pain” that included psychological and social suffering.[165] In addition, she was devoutly religious, and considered the Christian caretaking tradition to be the ultimate basis for hospice work. Medicine could be a *means* for the expression of Christian care,

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[162] For a more extensive biography of Saunders see Shirley Du Boulay, *Cicely Saunders, Founder of the Modern Hospice Movement* (London: Hodder and Stoughton, 1984).

[163] David Clark, “Originating a Movement: Cicely Saunders and the Development of St Christopher's Hospice, 1957-1967.” *Mortality* 3 (1998): 43-63.

[164] Siebold, *The Hospice Movement*, 27.

[165] David Clark, “Total Pain', Disciplinary Power and the Body in the Work of Cicely Saunders, 1958-1967.” *Social Science & Medicine*, 49 (1999): 727-36.

but the *end* was the enactment of Christian virtues.[166] These priorities were reflected in the British hospice movement's initial reluctance to integrate into the National Health Services (NHS).[167] The modern British hospice movement was thus united by a charismatic leader, a religious foundation, and an oppositional stance to mainstream medicine that crystalized in its holistic conception of end-of-life care.[168] For this reason, historians have generally looked at it as a continuance of the earlier non-medical tradition of hospice care.[169]

Nevertheless, while historians have praised Saunders' initial conception of Saint Christiopher's as a religious institution, they have been highly critical of the British hospice movement's subsequent evolution. Writing in 1991, Nick James and David Field argued that the decision of British Hospice leaders to integrate into the National Health Service had led to the "routinization" and "re-medicalization" of hospice as a specialized component of the British medical system.[170] Ann Bradshaw would expand on this analysis to argue that British hospice care had been "secularized."[171] This loss of the religious basis of hospice had led medicine to become an end-in-itself, thus representing a betrayal of Saunder's original vision. Consequently, historians have represented the history of the modern British hospice movement as a story of the self-betrayal of

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[166] Bradshaw, "The Spiritual Dimension of Hospice," 414.

[167] Siebold, *The Hospice Movement*, 70.

[168] James and Field, "The Routinization of Hospice: Charisma and Bureaucratization."

[169] Bradshaw, "The Spiritual Dimension of Hospice"; Siebold, *The Hospice Movement*, 70.

[170] Ibid.

[171] Bradshaw, "The Spiritual Dimension of Hospice."

hospice's psycho-social and religious foundations as a result of an excessive involvement with medicine.

This narrative of self-betrayal is recapitulated in the historiography of the modern US hospice movement, but with an important twist: US hospice leaders, while critical of many aspects of medicine, were themselves medical professionals who looked forward to integrating hospice care with acute care and the medical system as a whole.[172] In addition, the US public was considerably more comfortable with medical technology than its British counterpart and both the public and hospice leaders were more religiously pluralistic than their British counterparts.[173] As a result of these factors, the US hospice movement emerged as more secular and more amenable to medical technology than either its British counterpart or the late 19th century hospices. Thus, while historians charge that the British hospice movement betrayed the earlier hospice tradition over time, the US hospice movement might be described as "born bad," its very existence representing a betrayal of the non-medical basis of the hospice tradition.

The most robust articulation of this claim is Cathy Siebold's history of the US hospice movement, *The Hospice Movement: Easing Death's Pains*.[174] Siebold's work—the only book-length historical study of hospice to date—argues that the US hospice movement was, from its modern origin in the 1970s, beset by a "central conflict" between wanting to demedicalize end-of-life care in favor of a more humanistic understanding of dying and a medicalizing ideology that aimed to provide patients with better palliative

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[172] Siebold, *The Hospice Movement,* 76.

[173] Ibid. and Bradshaw, "The Spiritual Dimension of Hospice," 416.

[174] Siebold, *The Hospice Movement*.

care.[175] For Siebold, this ambivalence towards medical care resulted in a "value conflict" that stripped the US movement of a clearly defined ideology and resulted in the weakening of hospice both internally and externally.[176] This internal contradiction in the attitude of the hospice movement towards medicalization ensured that the movement would eventually be colonized by the very medical forces that it had, from the beginning, only lukewarmly opposed. In contrast to this internal tension, Siebold suggests that the hospice movement should have rejected the use of medicine.[177] By refusing to do so, the US hospice movement inadvertently deepened the medicalization of end-of-life care.

Israeli historian Shai Lavi has also argued that the hospice movement's relationship to medical technology betrayed its holistic ethos of care. For Lavi—who neglects to distinguish between the British and US hospice traditions—hospice is symbolized by the advent of a morphine drip, a machine that administers a preset quantity of morphine to patients at regular intervals.[178] While Lavi acknowledges that the morphine drip was initially used with the goal of providing better patient care, he claims that it erodes the bond between the patient and providers, as well as the patient's very experience of personhood: "The dying patient who is hooked up to the morphine drip is… freed… from any other human experience…. The relation between patient and physician, already reduced to a minimum, is replaced by a new relation between pain and

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[175] Ibid., 75.

[176] Ibid, 138.

[177] Ibid.

[178] Shai Lavi, *The Modern Art of Dying : A History of Euthanasia in the United States* (Princeton, N.J.: Princeton University Press, 2005), 138.

machine.[179] As a result, the hospice movement's use of medical technology destroyed its holistic conception of care, and reduced the dying patient to a mere machine.

In his early book *On Death without Dignity: The Human Impact of Technological Dying* sociologist of dying David Wendell Moller characterized the hospice movement as a "reaction to and against bureaucratic management of and excessive technological involvement in the dying process."[180] Nevertheless, even here, he remained skeptical of hospice's ability to do more than "coexist with, rather than replace, medicalized dying."[181] Nearly ten years later, he would argue that hospice was complicit in a compartmentalization of medical care that had led to the "remedicalization" of dying.[182] Once again, US hospice movement further cemented the very medical technology that its ancestors had sought to combat.

Together, these arguments, in spite of their differences, constitute a relatively unified portrait of the US hospice movement as having betrayed the hospice tradition's commitment to establishing a non-medical paradigm of end-of-life care; on the contrary, these authors argue that US hospice leaders, by incorporating medicine into their work, inadvertently contributed to extending the dominion of medicine over the deathbed. The story they tell is one of self-betrayal, in which hospice's encounters with medicine betrayed the movement's holistic conception of care.

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[179] Ibid., 138-140.

[180] David Wendell Moller, *On Death without Dignity: The Human Impact of Technological Dying* (Amityville, NY: Baywood Pub. Co., 1990), 39.

[181] Ibid., 44.

[182] David Wendell Moller, *Life's End: Technocratic Dying in an Age of Spiritual Yearning* (Amityville, NY: Baywood Pub Co, 2000), 173.

Examining the validity of this narrative is important for four related reasons: More recent literature has bemoaned the marginalization of holistic care in US hospices.[183] Such care has become underfunded and the non-medical components of hospice teams are frequently given significantly less authority than their medical counterparts. Examining how the US hospice movement's attitude toward medicine shaped its evolution is fundamental to understanding these current problems.

Second, in spite of the hospice movement's intention to radically transform national policy on end-of-life care, recent commentators have noted that hospice is largely absent from prominent national discussions about both the legalization of voluntary euthanasia and the reform of the national healthcare system.[184] Examining the hospice movement's attitude toward medicine in a historical perspective might help explain how it came to be marginalized from the very national discussions it had intended to resolve.

Third, recent continental surveys of hospice care in Africa have urged that an integration of existing hospice facilities into national medical systems is necessary to improve the quality end-of-life care for the continent's population.[185] If such encounters with medicine eliminated the holistic elements of hospice care in the US, then the US

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[183] Elijah G. Ward and Audrey K. Gordon, "Looming Threats to the Intimate Bond in Hospice Care? Economic and Organizational Pressures in the Case Study of a Hospice," *OMEGA--Journal of Death and Dying* 54 (2007): 1-18.

[184] Daniel Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (Washington, DC: Georgetown Univ Pr,1993), 38; Amitai Etzioni, "On Hospice Care," *Huffington Post*, January 15, 2010, accessed January 15, 2012, http://www.huffingtonpost.com/amitai-etzioni/on-hospice-care_b_424536.html.

[185] Michael Wright and David Clark, *Hospice and Palliative Care in Africa: A Review of Developments and Challenges* (Oxford: Oxford University Press, 2006).

experience can provide a cautionary tale of how not to integrate medicine into hospice. Examining the potential problems with the US hospice movement's relationship with medical technology may thus be helpful to implementing hospice care in international contexts.

Finally, this narrative of hospice history as an exercise in self-betrayal is based on a view of medical technology that medical sociologist Stefan Timmermans has called "technological determinism." In such a view, "[t]echnology becomes such an overwhelming interpretive force that it irrevocably alters the social fabric and renders it meaningless."[186] From such a perspective, medical technology is seen a uniform and wholly negative force that irrevocably changed the meaning and practice of hospice. One potential problem with such a view is that it places the site of meaningful political action in an imagined pre-technological past. Since this past has been lost as a result of the introduction of medical technology, all further attempts at innovation within the hospice tradition will be futile, as they will move hospice away from its origins. The result is a stultification that makes it impossible to conceive of productive changes within current hospice care. Implicit in this framing of hospice's relationship to medical technology is the conclusion that hospice should be abandoned—as opposed to reformed—as a modality of caring for the dying. It thus has major implications for current medical care and political action. In what follows, I will examine the validity of this framing of hospice's relationship to medical technology through an analysis of archival data from the first decade of US hospice care.

The Archive

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[186] Stefan Timmermans, "*Life's End: Technocratic Dying in an Age of Spiritual Yearning* by David Wendell Moller," 30 (2001): 301.

My source for this reconstruction is the papers of Florence Wald—generally regarded as the founder of the US hospice movement—and her husband and fellow hospice leader Henry Wald.[187] These papers contain the meeting minutes of Hospice, Inc. from 1970 to 1980, as well as a significant portion of the organization's internal and external correspondence, funding applications, marketing brochures, news clippings, financial records, and employee training manuals. Taken together, these materials provide a rich portrait of the general trajectory of Hospice, Inc. during the 1970s, as well as of the organization's attitude toward medical technology.

In addition to these papers, I also rely on two then contemporary studies of hospice written by individuals close to the movement: First, Yale undergraduate Lawrence Kerns' 1975 senior psychology thesis "A Study of the Creation of a Community Setting: Hospice"—found in the Wald archives—contains a detailed chronology of Hospice, Inc.'s development up to 1975, as well as in-depth interviews with hospice staff members during that period.[188] Second, *First American Hospice: Three Years of Home Care* written in 1978 by Hospice, Inc. staff members Sylvia A. Lack and Robert W. Buckingham III, contains a detailed institutional chronology of the organization up to 1978.[189] Together with the aforementioned internal documents, these sources provide a rich basis to reconstruct Hospice, Inc.'s history and conception of

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[187] Florence and Henry Wald Papers, Yale University, New Haven, Sterling Memorial Library.

[188] Lawrence Kerns, "A Study of the Creation of a Community Setting: Hospice," Box 5, Folder 80, Florence and Henry Wald Papers, Yale University, Sterling Memorial Library.

[189] Sylvia A. Lack and Robert W. Buckingham III, *First American Hospice: Three Years of Home Care*, (New Haven, CT: Hospice, Inc.,1978).

technology. I will begin doing so with a general overview of Hospice, Inc.'s trajectory from 1970 to 1980.

Hospice, Inc., 1970-1980

The generally accepted beginning of the modern US hospice movement was the visit of Dr. Cicely Saunders to Yale University in 1963.[190] On the visit, Saunders—who, four years later, would found St. Christopher's Hospice in London—met Florence Wald, Dean of the Yale Nursing School. The two became friends, and, under Saunders' influence, Wald and her husband, Henry, began to take interest in the care of the dying.[191] She received NIH funding to conduct an interdisciplinary study of the needs to dying patients. Over the course of this work, Wald met other Yale faculty members—including Edward Dobihal, a pastor who would become President of Hospice, Inc.—who were also interested in transplanting Saunders' model to the US. After a series of meetings in 1970 and 1971, Hospice, Inc. was founded in November, 1971 as a non-profit corporation located in New Haven, Connecticut.[192]

In the initial years after its founding, Hospice, Inc. had two related goals: to set up a home care program and to construct and inpatient unit. It had been decided as early as 1970 that the initial focus would be on setting up the home care program.[193] To do so,

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[190] Lack and Buckingham, *First American Hospice*, 9.

[191] Ibid., 10.

[192] Ibid., 10; Kerns, "A Study of the Creation of a Community Setting,"1; "Certificate of Incorporation: Hospice, Inc.," November 19, 1971, Box 1, Folder 9, Florence and Henry Wald Papers.

[193] "Interdisciplinary Committee on the Dying Patient," March, 4, 1971, Box 1, Folder 9, Florence and Henry Wald Papers.

hospice leaders needed to, first, hire certified medical professionals to supervise the program; they did so by hiring Dr. Sylvia Lack, who came to Hospice, Inc. from St. Christopher's hospice, and Sister Mary Kaye Dunn, an oncology nurse from the Mayo Clinic in Minnesota. But when Lack and Dunn arrived in New Haven in April, 1973, they encountered the initial difficulty that Hospice, Inc. was not, at the time, certified by the state to provide outpatient care.[194] Certifications were quickly procured, however, and the homecare program was set up in May, 1974.[195]

Setting up an inpatient center proved to be a much more difficult venture. Hospice, Inc.'s initial problem was obtaining licensure from the State of Connecticut to build a 44-bed "chronic disease hospital."[196] Their application was rejected twice throughout 1972-3. Due to this difficulty, the organization obtained the assistance of Dennis Rezendes, in December 1973.[197] Rezendes was a consultant whose knowledge of local politics would prove to be invaluable to hospice in obtaining certification, even as his business-minded managerial style is often cited as a departure from Wald's less hierarchical model of organization.[198] With Rezendes' help, the State of Connecticut approved Hospice, Inc.'s request for certification in May, 1974.[199]

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[194] Kerns, "A Study of the Creation of a Community Setting,"1; "Certificate of Incorporation: Hospice, Inc.," 26.

[195] Lack and Buckingham, *First American Hospice*, 17.

[196] "Letter from Franklin M. Foote to Reed Nelson," Sept. 13, 1973, Box 1, Folder 11, Florence and Henry Wald Papers.

[197] "Special Meeting of the Board of Directors," December 26, 1973, Box 1, Folder 11, Florence and Henry Wald Papers.

[198] Kerns, "A Study of the Creation of a Community Setting," 32.

[199] Lack and Buckingham, *First American Hospice*, 15.

Having obtained certification, Hospice, Inc.'s leaders were confronted with the difficulty of acquiring funding for the project. Hospice, Inc.'s architect had estimated expenses for the project to cost approximately three million dollars, a figure well in excess of Hospice, Inc.'s capital and, indeed, of what any one donor could provide the organization.[200] As a result, the organization spent the majority of the period from 1971 to 1980 in a massive, continuous fundraising effort. This effort began by seeking funds from the national Department of Health, Education, and Welfare and the National Cancer Institute, as well as a variety of non-profit corporations.[201] While the majority of these efforts were unsuccessful, through a combination of public and private donors, Hospice, Inc. obtained sufficient capital to buy a suitable piece of land in Branford, Connecticut and to begin construction on a facility in November 1977.[202] The facility finally opened its doors in June 1980.[203]

This is a broad outline of what happened in Hospice, Inc. from 1970 to 1980. It describes Hospice, Inc.'s development from a grassroots organization to one that had the sufficient social and economic capital to realize its goals; obtaining this capital meant forging alliances with both public and private actors, as well as integrating sufficiently into the medical system so as to gain the accreditation necessary to practice hospice care. In what follows, I describe how this trajectory was influenced by Hospice, Inc.'s attitude

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[200] Ibid., 13.

[201] Ibid.

[202] Ibid.

[203] "The Connecticut Hospice, Inc. Newsletter," June 1980, Box 1, Folder 21, Florence and Henry Wald Papers.

toward and use of medical technology. Far from changing during this process of organizational growth, this attitude remained remarkably consistent, and clearly grounded in an understanding of the organization's relationship to the broader hospice tradition, as well as its resistance to the hospital medicine of the time.

Everything in Moderation!: The Medical Humanism of Hospice, Inc.

In order to understand how Hospice, Inc. conceived of its relationship to medicine, it is necessary to examine the organization's critique of the hospital care of the dying. In a pamphlet entitled "To Honor All Life: The Case for Support of Hospice, Inc.", then president of Hospice, Inc., Edward Dobihal describes this care:

> In primitive and pre-industrial societies, death occurred most often in the home or other familiar surroundings…. With our advanced science and technology, we have made death a solitary, mechanized, inhuman, and often gruesome picture…. [The terminally ill are] rushed to an ambulance to be "plugged in" to the life support machinery of a hospital intensive care unit.[204]

Dobihal contrasts an idyllic pre-technological vision of society in which the dying are well integrated and cared for, with the hell of modern hospital care. The defining feature of this care is its excessive and, indeed, abusive reliance on medical technology. This use of medical technology strips patients of their very humanity, rendering them mere machines waiting to be "plugged in." It is this "inhuman" excess of medical technology that Hospice, Inc. chose to confront.

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[204] Edward F. Dobihal, "To Honor All Life: The Case for Support of Hospice Inc.," 1975, Box 3, Folder 23, Florence and Henry Wald Papers, 3.

The organization did so through what I will describe as a "moderate" conception of technology. In this "moderate" conception, medical technology was an essential starting point that cared for the body's biological functioning. But, while depending on technology for their work, hospice leaders would insist that their care be defined by what they conceived as non-technological measures, including relationships with family members, spiritual advisors, and psychological professionals. Borrowing a term from Hospice, Inc.'s leaders, I will argue that this emphasis on non-technological care marked a "humanistic" attitude toward medicine, which hospice leaders contrasted with a solely "technological" approach.

This split between technological and humanistic medicine can be found in Florence Wald's 1972 lecture "Hospice, Inc.: From Dream to Reality."[205] The lecture—which was given at the Foundation of Thanatology and Union Theological Seminary—discussed the early developments leading to the founding of Hospice, Inc. in the previous year. Describing the motivating factors leading to the formation of Hospice, Inc., Wald highlighted the limitations of a medical approach to dying:

> When the patient goes to a physician or a hospital, the difficulties he presents are analyzed by listening to an account of his physical symptoms, by examination of the body, by biochemical assay of fluids, and pathologic examination of tissues…. [But] the patient with a fatal illness isn't faced

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[205] Florence Wald, "Hospice, Inc.: From Dream to Reality," 1972 lecture given at the Foundation for Thanatology and Union Theological Seminary, Box 20, Folder 16, Florence and Henry Wald Papers.

> with only a disease, he is also faced with the task of separation from life on this earth.[206]

Wald distinguishes hospice from hospital care by marking a separation between the biomedical tests practiced in the hospital and the larger existential questions addressed, presumably, in hospice care. She emphasizes that a medical approach, by itself, would be insufficient to tend to the needs of dying patients. As a result, medicine had to be combined with a type of care specifically tailored to address the patient's existential anxiety.

Wald clarified this relationship between medical and non-medical care in a talk given later that year at the University of Rochester, "Hospice – A Way of Caring for the Terminally Ill."[207] Wald begins the lecture with a lengthy description of medieval hospices, focusing specifically on the then still-operating Hotel Dieu in Baune, France. Highlighting, the "sense of peace and quiet, beauty and charm, comfort and care, and the spirit of the community within a community" found in the courtyard of the Hotel Dieu, Wald then imagines that the listener is asking "'What has this to do with modern medical care, or care of the terminally ill in an age when x-ray therapy, organ transplants, chemotherapy, are commonplace procedure?'"[208]

Wald's response to this presumptive question is telling: "This question is exactly the point. Hospice care is an attempt to restore the concern for man's spiritual side as

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[206] Ibid., 2.

[207] Florence Wald, "Hospice – A Way of Caring for the Terminally Ill," 1972 lecture given at the University of Rochester, December 12, 1972, Box 20, Folder 17, Florence and Henry Wald Papers.

[208] Ibid., 2.

well as retaining modern medical expertise in the management of symptoms caused by illness."[209] Thus, the goal of service in hospice is to provide expert palliative care, but a second equally important goal is to fulfill the explicitly non-medical function of spiritual care. According to Wald, this commitment to non-medical care links the modern hospice movement with its medieval forbearers. While it depends on excellent symptom management, this non-medical care is what defines hospice, creating a unified hospice tradition that circumvents differences in time and place.

Wald stresses that this non-medical care would be tailored to the personality of the particular patient. The goal of hospice was to provide the patient with the resources so that he or she could express and maintain this personality as robustly as possible throughout the stress of dying. The organization did not espouse a normative model according to which the patient would negotiate this process. For some patients, it would entail "being with people—friends and family," while for others it could mean just "getting the house in order."[210] In either case, the care for medical symptoms in hospice was there as a means for the nourishing the individual's unique identity. In this sense, Hospice, Inc.'s leaders explicitly subordinated medical technology to humanistic care.

This project was not simply one of curtailing medical interventions; rather, it entailed creating new humanistic interventions to complement existing palliative treatments. In designing the organization's inpatient unit, Hospice, Inc. made particular effort to consider the role of the environment in patient care. In the same talk in which she emphasized the healing power of the Hotel Dieu's courtyard, Wald claimed that the

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[209] Ibid.

[210] Ibid., 3.

inpatient unit of Hospice, Inc. would have "a nursery school," so that dying patients would have the option of spending time with young children, as well as "a garden where everyone can share, including patients."[211]

This desire to create innovative humanistic interventions held consistently throughout the 1970s, even after Wald's departure from the organization. Thus, in a 1977 article about the then soon-to-be-constructed inpatient unit, Hospice, Inc. media liaison Frank T. Kryza mentioned that the organization intended the facility to have a "screaming room," where patients would be able to "let it all out," as well as special rooms designated for artistic and musical creation. He highlighted that, in these rooms, there would be "oxygen and suction machines," but no "respirators."[212] Thus, while medical technology still figured in the hospice vision, its use would be minimized and its role would be relegated to that of supporting humanistic care.

This split between a technocratic and a humanistic medicine was a feature of the internal documents of Hospice, Inc., as well. In the "Principles of Hospice Care," a training document that was regularly included in materials for new staff members throughout the 1970s, medical technology is designated an essential, but limited starting point for patient care.[213] The first "principle"—to maintain the patient as "symptom free as possible"—is justified by the stated goal: "The goal of skilled health care is optimum relief of noxious symptoms so that the patient/familys [sic] are alert, comfortable and

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[211] Ibid.

[212] Patricia McCormack. "Hospice Movement Helps Terminally Ill and Their Families," United Press International. March 10, 1977, Box 4, Folder 36, Florence and Henry Wald Papers.

[213] "Principles of Hospice Care," 1975, Wald Papers, Box 2, Folder 19.

themselves."[214] Here, medicine permits patients to be "themselves," but does not impact their personality in significant ways.

Nevertheless, in the "Principles," hospice leaders acknowledge the need for a separate form of caretaking for these non-technological aspects of the patient's identity. They note that "[l]oneliness and isolation is a significant source of anguish to patients who are dying" and, as a result, "[c]are givers must always be available where and when the patient needs them."[215] In addition to the necessity of personal relationships, an interdisciplinary team of hospice professionals would be necessary to address the "physiological, legal, social, spiritual, economic and interpersonal" issues facing the terminally ill.[216] Physiology—the domain of medical technology—was thus given equal weight to, but also differentiated from non-technological means of care.

Together, these non-technological means affected the patient on a level that, as described in the "Principles of Hospice," medical technology alone could not: the level of the "human being." Principle 10 states: "Caring for the patient/family as human beings affects the physiologic state."[217] Here, as throughout Hospice Inc.'s statements throughout the 1970s, there is a distinction between the patient as a medical entity and the patient as a "human" with psychological, social, and spiritual needs. Through humanistic interventions aimed at the human, Hospice, Inc. maintained fidelity to the hospice tradition. But this fidelity ironically marginalized the humanistic elements of hospice. To

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[214] Ibid.

[215] Ibid.

[216] Ibid.

[217] Ibid.

illustrate why this is the case, I will examine the relationship of the US hospice movement with the field of bioethics.

Bioethics and Hospice: Two Strategies, Two Results

The relationship between the US hospice movement and the rise of bioethics is grounded in a shared historical evolution. Bioethics arose, like hospice, in the late 1960s and early 1970s, in response to a similar set of problems: As I described in Chapter 1 of this dissertation, bioethicists argued that the development of new end-of-life technologies had led to a need to redefine death and, in the process, rethink the nature of end-of-life care. These technologies could maintain individuals alive in states that seemed, to those around them, to be either equivalent to death or qualitatively worse than it. Previously, bioethicists argued, these individuals would have died. But now they were being subjected to medical procedures that were often unwanted by the patient and family and of dubious clinical benefit. Consequently, it was necessary to provide an alternative means of caring for the dying that avoided the excessive medical treatments that had become commonplace at the end-of-life.

But while hospice tried to develop an alternative medical treatment that combined humanistic therapeutics with moderate technological care, bioethicists did not seek to devise an alternative to existing medical practices. Rather, they sought to regulate them. With regard to the end-of-life care, they did so via two complementary strategies. First, as I explained in Chapter 1, they sought to redefine death. Bioethicists argued that individuals who had lost whole brain functioning had effectively died. By characterizing such individuals as dead, bioethicists intended to spare them—and the US medical system—unnecessary medical treatments that would likely do more harm than good.

While this strategy was effective for those with whole brain death, it did not directly address the situations of individuals who might have lost only higher brain functioning. But such individuals could also be subjected to unwanted medical interventions. In order to address their situations, bioethicists did not succeed in classifying them as dead, but rather provided them with regulations that gave them the ability to reject unwanted medical care.[218]

The principle manner in which they did so was by orienting medicine around "patient autonomy," a concept that was at once an ethical principle, a model of decision making, a theory of patient subjectivity, and an interpretation of American law. According to "patient autonomy," the patient was defined as a self-governing individual, who ideally made medical decisions in isolation from relations with others, including doctors, family members, and, more broadly, the State.[219] Such relationships raised the possibility of "coercion," in which persons external to the patient might convince him or her to make a decision based on their own desires.[220] Patient autonomy relied on existing privacy law—established particularly in the New Jersey Supreme Court's decision in the 1976 case of Karen Quinlan—as well as a series of medical procedures, to ensure that the

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[218] Pernick, "Brain Death in a Cultural Context."

[219] Rothman, *Strangers at the Bedside*; O'Neill, *Autonomy and Trust in Bioethics*.

[220] On the relationship between autonomy and coercion, see the early bioethical article Gerald Dworkin, "Autonomy and Behavior Control," *Hastings Center Report* 6:1 (1976): 23-28. For more contemporary treatments of the autonomy/coercion dichotomy, see J.S. Taylor "Autonomy, Duress, and Coercion." *Social Philosophy and Policy*, 20 (2003): 127-55; and Willard Gaylin and Bruce Jennings, *The Perversion of Autonomy: Coercion and Constraints in a Liberal Society*, (Washington, DC: Georgetown Univ Press, 2003).

patient's decision was truly his or her own.[221] While such an individualistic conception of the patient has since been highly criticized, at the time it was viewed as a necessary protective to excesses of physician authority at the end-of-life.[222]

From its origin, patient autonomy was paired with the practice of "informed consent." "Informed consent," which emerged in the 1960s, mandated that doctors provide patients with the relevant medical information necessary to make a decision on their treatment.[223] The purveyance of such information was considered to be a neutral act that would not itself influence the patient, but rather provide him or her with the ability to exercise patient autonomy. Thus, patient autonomy putatively restrained medical providers from impacting the patient's decision, even as these providers provided him or her with the information that made this decision possible. This was only possible because the medical data included in informed consent was considered to be of a neutral character, in contrast to the psycho-social variables encompassed by patient autonomy. Patient autonomy was thus based on a positivistic conception of medical science, in which medicine was considered to be isolated from psychological and social factors.[224]

Though responding to a different set of circumstances than "brain death," the bioethical concepts of "patient autonomy" and "informed consent" adhered to the same

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[221] Rothman, *Strangers at the Bedside*.

[222] For some contemporary critiques of patient autonomy, see Gill, "The False Autonomy of Forced Choice"; Susan Dodds "Choice and Control in Feminist Bioethics," in *Relational Autonomy*, ed. Catriona Stoljar and Natalie Mackenzie, (Oxford: Oxford University Press, 2000), 213-35; and Alfred I. Tauber, *Patient Autonomy and the Ethics of Responsibility*, (Cambridge: The MIT Press, 2005).

[223] Rothman, *Strangers at the Bedside*, 85-100.

[224] A more extensive treatment of the positivistic basis of patient autonomy can be found in Tauber, *Patient Autonomy and the Ethics of Responsibility*, 27-56.

underlying logic. As Gary Belkin, whose work I examined in Chapter 1, has explained, the bioethical enterprise fueled the standardization of medical practice.[225] This standardization was explicit in both the rejection of clinical contingency underlying bioethical approaches to brain death, as well as in the standardized protocols of both autonomy and informed consent. At the same time, this standardized approach was, as Jeffrey P. Bishop has argued, predicated on the excision, from medicine, of a consideration of both social power dynamics and questions of metaphysical import.[226] This excision occurred not only through the consolidation of brain death, but also through patient autonomy and informed consent. Though patient autonomy, in theory, provided patients with authority over their decision making, it, in reality, bolstered medical authority by considering the medical data included in informed consent to be scientific fact that existed outside of psychological and social factors. Thus, the bioethical regulation of death and dying was predicated on an attempt to remove the patient-provider relationship from end-of-life care in favor of protective regulations and ostensibly asocial medical knowledge.

As Hilde Lindemann has indicated, bioethical approaches to death and dying would seem to be diametrically opposed to the key tenets of the hospice movement.[227] While hospice proposed a humanistic conception of medicine, oriented toward treating the patient as a whole person, bioethicists severed the patient from relationships with medical providers so as to protect him or her from coercion. Hospice considered medical

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[225] Belkin, "The Technocratic Wish."

[226] Bishop, *The Anticipatory Corpse*.

[227] Hilde Lindemann Nelson, "Pictures of Persons and the Good of Hospice Care," *The Hastings Center Report 33* (2003): S18-20.

science and technology to be the starting point of comprehensive care. According to bioethicists, medical science and technology were, in themselves, the fullest extent of patient care that could be provided without compromising the provider's neutrality and coercing the patient. Thus, the very medical humanism that defined hospice would have, it seems, been anathema to a bioethical enterprise that aimed to protect the person from medicine.

And yet, this is not entirely the case. As Bishop has argued, although seemingly opposed, the projects of bioethics and the medical humanities share a common defining feature: both bioethics and the medical humanities accept the putative autonomy of medical science.[228] Neither field attempts to redefine the body as constituted in medicine; instead, they seek to either add on to medical knowledge, in the case of the medical humanities, or, in the case of bioethics, to regulate it via legal means. Rather than reimagine medicine, they seek to quarantine it within seemingly manageable borders. For Bishop, such attempts at regulating medicine are self-defeating, inadvertently bolstering the very medical authority that they mean to oppose. Thus, in the very process of "humanizing" medicine, the medical humanities further entrench an anti-humanistic medical epistemology.

Although Bishop is writing about the contemporary field of the medical humanities, his observations hold for the US hospice movement's conception of medical humanism as well. Like the medical humanities, hospice did not seek to redefine medicine, so much as to add onto it. Through adding humanism to "technological" medicine, they maintained a rigid separation between medical technology and humanistic

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[228] Bishop, "Rejecting Medical Humanism" ; Bishop, *The Anticipatory Corpse*.

therapeutics in which the objects of each—the human being, the biomedical body—were understood to be of a different nature. In this separation, they were maintaining fidelity to the larger hospice tradition, which itself had rigorously separated medical and non-medical therapeutics.

As Bishop argues, the same is true about the relationship of bioethics to medicine—with bioethics enshrining medical positivism—but with an important twist: though bioethicists abstained from redefining medical science, the field was, from the beginning, defined by a political orientation that led it to rethink the underlying principles governing the exercise of medical practice. As a result of this political orientation, bioethicists had great success in instantiating themselves in universities and medical centers throughout the US, as well as in the federal government. They have also had great success in obtaining funding for its research projects and institutions. The politicization of bioethics has helped the field to gain a foothold in medical institutions.

The same cannot be said for the humanistic elements of hospice care. Although hospice and palliative care has been relatively widely accepted in the US healthcare system, this acceptance has come at the cost of the marginalization of the humanistic elements that were, throughout the 1970s, central to the modern US hospice movement. Medicare does not reimburse spiritual and psychosocial interventions, and scholars of hospice have noted a general denigration of chaplains and social workers by doctors and nurses operating on interdisciplinary hospice teams.[229] At the same time, though hospice was successful in integrating into Medicare in the 1980s, its current Medicare funding is in jeopardy and, as Amitai Etzioni has noted, hospice was almost completely absent from

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[229] Siebold, *The Hospice Movement*; Ward and Gordon, “Looming Threats.”

a 2008 national discussion of healthcare reform that centered, in large part, on end-of-life issues.[230] Such discussions have instead been dominated by a bioethical framing of end-of-life decision making based on living wills and the legitimacy of voluntary euthanasia.

The reason for this discrepancy is that, while bioethics sought to regulate medicine, hospice leaders wanted to separate from it. In a classic article on the US hospice movement, Emily K. Abel criticized the idea—prominent after the passage of the 1983 Medicare Hospice Benefit—that the hospice movement had originated with a commitment to a radical shift in US medicine, but then gradually abandoned its zeal over time.[231] Instead, she argued that hospice's strategy had never been to alter the prevailing medical order, but rather to produce an alternative vision of medicine separate from the existing healthcare system. Drawing on the work of Paul Starr, she claimed that organizations that adopt such a strategy of separation weaken their ability to combat the existing order and eventually become coopted by the very forces they oppose. Thus, rather than hospice betraying itself over time, the movement's very desire to abstain from involvement with medicine led to the marginalization of the vision of healthcare it wanted to protect.

This chapter expands on Abel's argument, claiming that the hospice movement's fidelity to a non-medical conception of humanistic care led it to cede the authority necessary to implement this conception to begin with. Nevertheless, in what follows, I argue that, although the hospice movement in general maintained a rigid separation between technology and humanism, it also contained contradictory elements that

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[230] Callahan, *The Troubled Dream of Life*; Etzioni "On Hospice Care."

[231] Abel, "The Hospice Movement."

proposed an alternate vision of their relationship. I will find such elements—and with them, a new narrative for the history of hospice care—in the hospice movement's writings on euthanasia.

Hospice, Bioethics, and the Question of Euthanasia

From its origins in England, throughout its development in the US, the modern hospice movement was opposed to euthanasia. This opposition was a motivating factor for the rise of hospice in the 1960s, and the leaders of Hospice Inc. maintained it consistently throughout the 1970s.[232] In internal documents, they bemoan reports of suicides by the terminally ill. In response to one such suicide, Dennis Rezendes wrote to the Board of Directors:

> I'm sharing this [account of suicide] with you first out of the sense of anger that these things happen in our country when it need not be so. Secondly because it points out why it is Hospice is needed here and elsewhere and that our mission is <u>not</u> to help people die but indeed it is to help people live out their lives more fully until they do die.[233]

Rezendes, like other members of the hospice board, viewed euthanasia as a form of violence against the terminally, as well as an indicator of the failure of end-of-life care in the United States. The persistence of this failure made the hospice movement necessary.

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[232] Siebold, *The Hospice Movement*; Stoddard*, The Hospice Movement*; James and Field, "The Routinization of Hospice"; Kathleen Foley and Herbert Hendin, *The Case against Assisted Suicide: For the Right to End-of-Life Care* (Baltimore: Johns Hopkins University Press, 2002).

[233] Dennis Rezendes, "Letter to Hospice Board of Directors and Greater New Haven Capital Fund Driven Committee re: D.L. Ansley Letter," March 3, 1976, Box 2, Folder 16, Florence and Henry Wald Papers. Emphasis in text.

This view of euthanasia entailed an implicit dissent from the bioethical discourse around the issue at the time. In general, bioethicists viewed the issue of euthanasia through the prism of the individual's right to privacy. In this conception, euthanasia was an individual's private decision to end her life in response to an intractable chronic or terminal medical condition. This framing of euthanasia colored arguments for active euthanasia—the direct administration of life-ending substances by the attending physician—as well as passive euthanasia, in which desiring individuals were disconnected from technologies on which they depended to live. Though courts rejected active euthanasia, the New Jersey Supreme Court's 1976 decision in the case of Karen Quinlan established a precedent from the legalization of passive euthanasia under the right to privacy.[234]

The legalization of passive euthanasia depended on a consistent understanding of the relationship between humanism and technology. In this understanding, technology was considered extraneous to the human being, something that *sustained* the individual's life, but did not *constitute* it. Thus, by removing such "life-sustaining" technology, medical personnel would not be harming the patient, but rather facilitating a "natural" death.[235] This division between the human being and technology underpinned the legal case for passive euthanasia. Hospice leaders shared this division themselves, and it

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[234] Ian R. Dowbiggin, *A Merciful End : The Euthanasia Movement in Modern America*, (Oxford, Oxford University Press, 2003); Ian R. Dowbiggin, *A Concise History of Euthanasia : Life, Death, God, and Medicine*, (Rowman & Littlefield, Lanham MD, 2005).

[235] Patrick D. Hopkins, "Why Does Removing Machines Count as 'Passive' Euthanasia?" *The Hastings Center Report* 27 (1997): 29-37.

influenced their own general agreement with conservative bioethicists like Edmund Pelligrino, whom hospice leaders consulted regarding euthanasia.[236]

Nevertheless, the hospice movement also contained within it an alternative view of euthanasia that would have radically challenged the framing of the issue in US bioethics. I find this alternative in Hospice, Inc.'s "Statement on Euthanasia," which was approved by the Board of Directors in 1976. The statement reads:

> Hospice opposes all attempts to legalize, promote, or condone euthanasia… which is to cause death by the intentional use of medical technology or by the withholding of ordinary, appropriate, reasonable and prudent medical care…. On the other hand, Hospice supports the true use of the term "death with dignity"… meaning to allow death to come naturally to the terminally ill, using appropriate treatment rather than heroic and extraordinary measures to prolong life.[237]

In this statement, hospice leaders condemn active euthanasia as an excessive use of medical technology, but, rather than adopt an attitude of technological determinism, they simultaneously criticize passive euthanasia as withholding necessary medical technology from the patient. Instead of these positions, they propose that the provision of "appropriate" medical care is necessary for "natural" death to occur. Rather than contrasting, nature and technology are here co-constitutive. By eliminating the boundary between nature and technology, hospice leaders implicitly reconfigured the boundary

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[236] "Note from Edmund Pellegrino to Henry J. Wald," 1976, Box 2, Folder 19, Florence and Henry Wald Papers.

[237] Hospice, Inc., "Statement on Euthanasia," 1975, Box 2, Folder16, Florence and Henry Wald Papers.

between humanistic and technological medicine that underpinned both sides on the euthanasia debate, as well as the movement's own dominant conception of medical care. The result is a novel conception of technology, in which technology precedes and is inseparable from the nature of the human.

It is also a novel conception of death. In the "Euthanasia Statement," Hospice, Inc.'s leaders argue that death, as a natural event, does not occur in isolation of the provision of medical care and the broader social reality. These social elements are integral to the nature of death itself and, without them, death would be considered an "unnatural" event. This hospice "redefinition" of death operated according to a diametrically opposed logic from the bioethical redefinition of death. While bioethicists defined death as a state defined by the removal of medical care, hospice leaders situated medicine at the heart of death. Thus, in the "Euthanasia Statement," the leaders of Hospice, Inc. did not respond to the medicalization of death via an attempt to excise death from medicine; rather, they advocated an *alternative* medicalization of death, one that provided a new framework for understanding and addressing the emerging dilemmas of end-of-life care.

Nevertheless, Hospice, Inc. never fully articulated this novel conception of death. Doing so would have entailed abandoning the split between humanistic and technological care that was the bedrock of the hospice tradition. This split cordoned off the patient from medical technology. In the process, it ceded cultural authority to medical science precisely via excluding medicine from this psycho-social realm. Through their fidelity to a humanistic understanding of technology, hospice leaders thus ceded authority to the very technocratic medicine they opposed. By *not* expanding into medicine—by keeping their moderate approach—hospice leaders left themselves with no option but to capitulate to a bioethical discourse that marginalized the very elements that were the foundation of the hospice tradition.

This exclusion from bioethics is tied to the struggles in obtaining funding that the hospice movement experienced throughout the 1970s. In their efforts to seek funding, hospice leaders consistently presented hospice as a low-cost, yet more effective, alternative to hospital end-of-life care.[238] Doing so entailed not only accentuating hospice's lack of reliance on technology, but also downplaying the social and economic value of the humanistic elements of hospice care. These elements were not considered worthy of remuneration to the same extent as hospice's more medical procedures. This division between humanistic and technological care thus contributed to what various authors have identified as current marginalization of psycho-social care within US hospices.[239]

As a result, the hospice movement's division between technological and humanistic care inhibited its ability to receive funding for its interventions and to intervene in pressing bioethical debates about end-of-life care. These two issues are related: As bioethical issues are understood to center on fundamental ethical values, they maintain an enormous ability to generate capital from both public and private sources.[240]

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[238] See, for example: "Meeting of the Board of Directors," January 30, 1974, Wald Papers, Box 2, 12; also, "Proposal: Development of a Core Staff for Patient Care, Home Care Program, Hospice Inc.", Jan. 1-Oct. 30, 1975, Box 5, Folder 59, Florence and Henry Wald Papers.

[239] Ward and Gordon, "Looming Threats."

[240] Leigh Turner, "Bioethic$, Inc." *Nature biotechnology* 22 (2004): 947-48. Alexander C. Tsai, "Who Is Buying Normative Bioethics Research?" *The American*

Consequently, tying hospice to bioethics could be an enormous boon for the diffusion and practice of effective end-of-life care. Doing so entails betraying the hospice movement's conception of the proper role of medical technology.

Fidelity through Betrayal: Hospice, Humanistic Technology, and Disability Rights

The seeds of such a betrayal are present in the "Statement on Euthanasia." By arguing that hospice is a technology essential to the human subject, this statement blurs the hospice movement's generally rigid barriers between technology and humanism. The result is an alternative conception of technology which I will term "humanistic technology." In this conception, technology is not antithetical to human subjectivity, but rather a constitutive component of it. At the same time, the relationships that formed the basis of Hospice Inc.'s medical humanism should, in this view, be considered as technologies in their own right. Thus, a humanistic conception of technology runs both ways: theorizing technology as a humanistic relationship and humanistic relationships as technologies.

This conception of humanistic technology draws on and deepens existing theorizations of technology within the field of disability studies. Disability studies scholars, such as Fiona Kumari Campbell, David Serlin, and Rosemarie Garland-Thomson have argued that medical technologies should be understood as fundamental aspects of human identity.[241] Such scholars build on the work of feminist science studies

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Journal of Bioethics 8 (2008): 62-63.

[241] Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009); Rosemarie Garland-Thomson, "Misfits: A Feminist Materialist Disability Concept." *Hypatia* 26, no. 3 (2011): 591-609; David Serlin, *Replaceable You: Engineering the Body in Postwar America*. (Chicago: University of Chicago Press, 2004).

scholar Donna Haraway and Karen Barad in advocating for an understanding of humans as "cyborgs," perpetually at the intersection of both nature and technology.[242] Nevertheless, while Haraway and Barad's focus is largely ontological, the emphasis of disability studies is on transforming medical practice. For such scholars, the relationship between the human subject and technology cannot be posited in the abstract, but rather must be negotiated in particular clinical contexts. While some technologies can bolster an individual's identity, others can negate it. Thus, rather than advocate a standardized approach to technology, disability studies scholars argue that, though technology and humanism are co-constitutive, the matter of their constitution is a clinical problem that must be explored.

Such exploration, though occurring within the clinic, also exceeds it. Though disability studies scholars situate technology at the center of human identity, they also highlight how the provision of technology and the designation of which technologies are appropriate are influenced by broader social forces, including the marketplace, legal regulations, and political power. Such forces have, in the United States, historically discriminated against persons with disabilities by denying them the resources necessary to participate as full members of society. The provision of such resources ties the disability studies project of rethinking the relationship of medical technology and human identity to the *political* project of the Disability Rights Movement. From the perspective of this movement, clinical discrimination against persons with disabilities cannot be

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[242] Karen Michelle Barad, *Meeting the Universe Halfway : Quantum Physics and the Entanglement of Matter and Meaning* (Durham: Duke University Press, 2007); Donna Haraway, "Simians, Cyborgs and Nature: The Reinvention of Nature," (New York: Routledge, 1991).

separated from the larger constitution of power in US society. At the same time, these power dynamics cannot be separated from the formulation of medicine in the clinic.

This understanding of the political nature of medical practice is incarnated in Disability Rights approaches to end-of-life decision making. Like the Hospice Movement and the Euthanasia Movement, the Disability Rights Movement responded, in the 1970s and later, to the conflicts brought about by the advent of new medical technology.[243] Nevertheless, while hospice and bioethics considered these conflicts to be problems of proper regulation or, alternatively, the provision of care, the Disability Rights Movement understood them as political problems, brought about by the pervasiveness social discrimination against persons with disabilities. Such discrimination, disability advocates argued, had produced a broad social consensus that life with an incurable disability was unworthy of living. Disability rights activists understood this consensus to be the dominating force behind the bioethical movement to legalize both passive and active euthanasia, as well as the broad social support for the euthanasia of machine-dependent individuals such as Karen Quinlan and, much later, Terri Schiavo. They argue that the bioethical principle of "patient autonomy," though putatively liberating in fact enshrines these dominant social forces; similarly, they criticize the idea that the medical information contained in "informed consent" is neutral, instead arguing that it obscures

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[243] James I. Charlton, *Nothing About Us without Us : Disability Oppression and Empowerment*, (Berkeley: University of California Press, 1998); Doris Zames Fleischer, and Frieda Zames, *The Disability Rights Movement : From Charity to Confrontation*. (Philadelphia, PA: Temple University Press, 2001); Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Rights Movement* (New York: Times Books, 1993).

the social dynamics underlying individual decision-making.[244] Thus, disability studies scholars have criticized the core tenets of bioethical thinking at the end-of-life.

The Disability Rights Movement, and disability studies scholarship, are ideal allies to the hospice movement. While disability studies scholars focus on chronic conditions and hospice professionals on terminal ones, they share an orientation with hospice providers toward the social aspects of medical care, as well as a similarly measured view of the uses and abuses of medical technology. Most importantly, they share a critique of bioethical formulation of end-of-life issues. While disability studies scholars have viewed bioethical accounts of end-of-life decision making as problems of discrimination, hospice professionals have considered them to be failures to guarantee the provision of adequate end-of-life care.[245] But these perspectives are not exclusive and, indeed, disability advocates and hospice professionals can collaborate to criticize bioethical thinking on end-of-life care.

Ultimately, such a collaboration must develop an integrated approach to the phenomenon of death. I began to develop such an approach in Chapter 1 of this dissertation; in this chapter, I have argued that the modern US hospice movement's "Statement on Euthanasia" provides an innovative approach to the definition of death, but that this approach was never fully developed because of its contradictions with the

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[244] For disability studies perspectives on the bioethics of end-of-life decision making see Ackerman, "Assisted Suicide"; Braswell, "Can there be"; and Gill, "The False Autonomy."

[245] Ira Byock, *The Best Care Possible: A Physician's Quest to Transform Care through the End of Life*. New York: Avery, 2012; Foley and Hendin, *The Case against Assisted Suicide.*

movement's underlying conception of the division between humanistic and technological medicine. The work of disability studies scholars provides an opportunity to think through this distinction, even as these scholars have yet to apply their insights to the phenomenon of death.

In this sense, synthesizing disability studies with hospice provides an ideal framework for thinking through not only the contradictions in hospice care, but also those present in the bioethical understanding of death. Such a framework would not de-medicalize hospice, but it would provide an opportunity to further the hospice movement's challenge to how medical practice is conceived, and to further integrate hospice into US medical practice, policy, education. At the same time, it opens up the possibility of developing an approach that unites a socially attuned bioethics with the clinical exigencies of end-of-life care. Thus, developing a unified conception of end-of-life care that combines the insights of disability studies and hospice can address the contemporary problems of both fields, while serving as a powerful challenge to bioethical thinking about end-of-life care.

In Chapter 1 of this dissertation, I argued that "death," as a category in bioethical discourse, had to be defined in a context-specific, historically contingent fashion. Here, I have shown, contrary to historiographical literature arguing that hospice ceded its dynamism via its incorporation into US medicine, that hospice remains an intriguing site to examine and develop a new conception of death around which to orient US bioethics. Such a conception cannot, however, be postulated in the abstract; rather, it entails examining the dynamic manner in which death is constituted in contemporary hospice organizations. I will now undertake such an examination through an ethnographic study of death in a contemporary hospice institution.

Chapter 3

A Gap in the System: Patients with Limited Kinship Support under the Medicare Hospice Benefit

Introduction

This chapter is an ethnographic study of an organization that I will refer to as "Amberview Hospice."[246] Amberview Hospice is a metro-Atlanta branch of a major national hospice organization of the same name. It is a for-profit organization that accepts payment from private payers, Medicaid, and—predominantly—Medicare. Though Amberview is, in many ways, a particular institution, it is also a representative one in that it adheres to the federal regulations governing the administration of hospice care in the United States. This chapter will examine the organizational constraints that these regulations place on Amberview's functioning, and how these constraints are negotiated by patients, families, and staff members involved in Amberview's care.

I focus particularly on the Medicare Hospice Benefit's requirement that hospice care be provided primarily on an outpatient basis. This requirement redefines death as a matter of private kinship; in the process, it presumes that patients will have, at home, a kinship network that possesses the suitable financial, physical, and emotional resources to provide them with long-term care. The goal of hospice is not to supplant this kinship network, but rather to support it via the provision of "interdisciplinary" (or "holistic") medical care, including pain control and both psycho-social and spiritual interventions. In

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[246] Both "Amberview Hospice" and "The Amberview Hospice Corporation" are pseudonyms. The use of such pseudonyms is pursuant to my agreement with the Amberview Hospice Corporation regarding the conduct of this research. All persons mentioned in this chapter have also been de-identified. Informed consent was obtained for all study participants. All research in this chapter and Chapter 4 was carried out under the supervision of Emory University's Institutional Review Board.

this sense, the Medicare Hospice Benefit is based on the underlying politico-economic philosophy that the provision of public services should be both contingent on and secondary to the work of individuals in the private sphere. I claim that this philosophy, rather than a betrayal of the "modern hospice movement," was an outgrowth of the very "humanistic" hospice philosophy that I analyzed in Chapter 2. Through a combination of ethnographic interviews and observation, I examine the impact of this philosophy on Amberview's patients, families, and staff.

Drawing on this fieldwork, I argue that the Medicare Hospice Benefit's structure leads to the creation of routine problems in the care of patients who lack sufficient kinship support. Such patients can be left isolated in home situations that can be neglectful. Rather than providing neutral sites for the provision of hospice care, these home environments actively subvert the delivery of care. I examine this subversion of hospice care through a case study of a patient whom I will refer to as "Steven." I analyze Steven's case through anthropologist Joao Biehl's account of the production of "zones of social abandonment" within neoliberal health policy.[247] While Biehl focuses on abandonment in institutional settings, I argue that, in US hospice care, abandonment is not centered in institutions, but rather diffused throughout private homes. This abandonment is, I claim, a direct result of the way that the Medicare Hospice Benefit understands death.

I then examine the institution within the US health care system that is charged with rectifying such abandonment: the nursing home. Hospice patients who lack sufficient kinship support are sent to nursing homes. These nursing homes provide them

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[247] Biehl, *Vita: Life in a Zone of Social Abandonment*.

with long-term care, including room, board, and assistance with activities of daily living. But, as nursing homes do not themselves provide end-of-life care, terminally ill patients in these settings receive outpatient hospice care. In this sense, the nursing home supplants the kinship network that, within the Medicare Hospice Benefit's structure, is necessary for the delivery of hospice care. I examine this putative union of hospice and nursing home care through interviews with Amberview's staff, and observation of both outpatient hospice team meetings and the provision of hospice care in the nursing home setting.

I argue that the coordination of hospice and nursing home care is fraught with problems. These problems are inherent in the coordination of two distinct caretaking modalities with conflicting economic incentives, professional skills, and organizational cultures. Such conflicts lead to routine service failures in the provision of hospice care in the nursing home setting, "fragmenting" patients between modalities of care that are structurally conflicting. Such fragmentation is a byproduct of economic incentives and distinct medical cultures embedded in the structure of the US health system.

If, throughout this chapter, I examine the medical impact of this economic organization, in my conclusion, I examine how the medical epistemology underlying US hospice care reinforces larger economic structures. I claim that the systemic gap that I describe in this chapter is a product of the manner in which the Medicare Hospice Benefit conceives of interdisciplinary medical care. By excluding long-term care from hospice, the Benefit subverts the delivery of interdisciplinary care to patients lacking kinship support. In order to gain a deeper understanding of this subversion, I will now turn to an examination of the major piece of legislation regulating US hospice care: the Medicare Hospice Benefit.

Family First: The Kinship Structure of the Medicare Hospice Benefit

The structure of US hospice care has been largely determined by the 1983 Medicare Hospice Benefit (MHB).[248] The Medicare Hospice Benefit marked the incorporation of hospice into the US Medicare system. This incorporation was due, in large part, to the work of the National Hospice and Palliative Care Organization (NHPCO). But it was also facilitated by the economic ideologies prevailing in US politics. The Benefit was passed under the Reagan administration, during a time when lawmakers in both chambers of Congress were concerned with what they deemed to be the excessive cost of end-of-life care in US hospitals. As such costs were largely borne by Medicare itself, decreasing them would also, presumably, decrease government spending. Thus, by incorporating hospice into Medicare, lawmakers were attempting to shrink the size of governmental spending on health care.

The central vehicle for such cost-savings was the redefinition of hospice as a primarily outpatient treatment modality. The Benefit mandates that of the care received by any particular patient, 80% has to be outpatient care, carried out at home, while only 20% can be inpatient care housed in a hospice institution.[249] This proportion has dramatically limited the extent of hospice inpatient services. As a result of the Benefit,

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[248] Herbert Lukashok, “Hospice Care under Medicare--an Early Look,” *Preventive Medicine*, 19, no. 6 (1990): 730-736; L.F. Paradis and S.B. Cummings, “The Evolution of Hospice in America Toward Organizational Homogeneity” *Journal of Health and Social Behavior*, 27, no. 4 (1986): 370-386; The Medicare Regulations for Hospice Care, Including the Conditions of Participation for Hospice Care 42 CFR418, Current as of November 2 2010; Siebold, *The Hospice Movement*.

[249] Lukashok, 732.

only 1 in 5 US hospices currently have inpatient facilities.[250] These inpatient facilities, in turn, only provide short-term care.[251] To certify patients to receive care in an inpatient facility, hospices must show that the patient is undergoing a medical problem that cannot be addressed in the home care setting. This care cannot last for longer than five days, at which point Medicare will no longer reimburse hospices the full rate of care; instead, they will reimburse hospice inpatient care at the significantly cheaper outpatient rate.[252] As a result, the Benefit strongly disincentivizes hospices from providing long-term inpatient care.

This privileging of outpatient care over inpatient care was a dramatic shift in the history of the modern hospice movement. Beginning with Saint Christopher's in London, the modern hospice movement had been a primarily inpatient treatment modality.[253] Inpatient care was similarly central in the modern US hospice movement. Though the US movement had begun with home care, this decision was based solely on the lack of available funds for an inpatient unit. In fact, as I explained in the second chapter, the struggle to raise funds for an inpatient unit had been central to Hospice Inc.'s activities in the 1970s. In neither Great Britain, nor the US was home care intended to *displace* in-

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[250] National Hospice and Palliative Care Organization, "NHPCO Facts and Figures: Hospice Care in America," (2012), http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

[251] Office of Inspector General, "Memorandum Report: Medicare Hospice : Use of General Inpatient Care," OEI-02-1 0-00490, (2013), http://oig.hhs.gov/oei/reports/oei-02-10-00490.pdf.

[252] Ibid.

[253] Siebold, 118.

patient care as the primary modality of care within hospice; the two were understood as complementary.[254] By changing hospice to a predominantly home-based service, the Medicare Hospice Benefit not only has not only transformed the hospice movement's perspective on the site of care, but also limited the choices that hospices can offer patients: Home care has become an almost mandatory aspect of hospice for patients, even if patients might prefer to receive inpatient care.[255]

Even as the MHB does not provide long-term inpatient care, it also does not provide long-term outpatient care. Rather, the patient's long-term care needs are to be presumably met by the patient's local kinship network. Such needs include assistance with basic activities of daily living (ADLs), such as bathing, clothing, feeding, and daily hygienic maintenance. More fundamentally, such assistance entails monitoring the patient daily and nightly to ensure that he or she is safe. The Benefit only allows for such twenty-four hour care in the case of an emergency; while it allows for home health aide services to assist patients with ADLs, it limits the extent of such services to a part time basis.[256] While the Benefit does require that hospice services provide volunteer laborers to address the additional companionship needs of patients, these volunteer laborer are restricted in the activities they can perform and the amount of time they can spend with patients.[257] In this sense, the Benefit's combined emergency care, CNA visits, and volunteer services do not amount to comprehensive long-term care; rather, they *support*

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[254] Ibid.

[255] Siebold, 142.

[256] Conditions of Participation for Hospice Care 42 CFR418.76.

[257] Ibid, § 418.78

the patient's kinship network, which presumably provides such care without reimbursement.

This reliance on unpaid familial labor in the private sphere is a direct result of the Medicare Hospice Benefit's focus on cost-efficiency. By placing the burden of long-term care on unpaid kinship networks, the Benefit, in theory, saves the government money. In this sense the Medicare Hospice Benefit epitomizes what geographer Michael Brown has identified as a "neoliberal" approach to health policy. According to Brown, such approaches attempt to cut health care costs by making public services contingent on the provision of unpaid labor in the private sphere.[258] Various commentators have argued that this neoliberal turn in the regulation of US hospice was a betrayal of the more welfarist tendencies of earlier leaders in the modern hospice movement.[259]

Nevertheless, though changing the hospice movement's conception of the site of care, the Medicare Hospice Benefit's approach to hospice was itself an outgrowth of this movement's own underlying philosophy. In Chapter 2 of this dissertation, I argued that the "modern US hospice movement" was characterized by its ambivalent approach to medicalization of death. Hospice advocates believed that medicine was central to end-of-life care, but sought to limit its power by making it secondary to explicitly non-medical "humanistic" interventions, such as psycho-social and spiritual care. Drawing on the work of Emily Abel, I argued that this approach to medicine was analogous to the

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[258] Brown, "Between Neoliberalism and Cultural Conservatism."

[259] Cynthia Adams, "Dying with Dignity in America: The Transformational Leadership of Florence Wald," *Journal of Professional Nursing* 26, no. 2 (2010): 125-32; Siebold, *The Hospice Movement*; C. Tehan, "Has Success Spoiled Hospice?" *Hastings Center Report* (1985): 10-13; Unal, "Hospice Care Today."

hospice movement's approach to politics: Though seeking a greater incorporation of hospice into political structures, the modern hospice movement limited its definition of care to the nostalgically non-politicized area of the "family."[260] The result was an ironic and ambivalent conception of the medicine and politics of death: the hospice movement was willing to medicalize and politicize death only to the extent that death could be preserved in the non-medical and non-political space of kinship.

This protected kinship network that would become the vehicle for the realization of the Medicare Hospice Benefit. The Benefit redefined death as a matter of private kinship. Kinship relations would become the sites of hospice care under the MHB, even as they were only included in the Benefit's structure in a manner that absolved the Medicare program of responsibility for maintaining them. The Medicare Hospice Benefit was thus an outgrown of the "humanistic" conception of death I outlined in this dissertation's second chapter; rather than "betraying" the modern hospice movement, the Benefit was the realization of the movement's conception of death. I will now examine how this conception of death as a matter of private kinship configured the organization of care in a facility that I will refer to as "Amberview Hospice."

Amberview Hospice: A Local Institution with a National Institutional Structure

Amberview Hospice is an Atlanta-area branch of the Amberview Hospice Corporation, a major provider of hospice services at the national level. The Amberview Hospice Corporation is a for-profit corporation, and this for-profit structure is consistent in the organization's branches throughout the United States. These branches vary greatly in size and patient populations. Nevertheless, in their organizational structure, they

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[260] Abel, "The Hospice Movement: Institutionalizing Innovation."

comply with Medicare regulations. Such compliance is necessary because Medicare pays for 84.1% of hospice services in the US.[261] As a result of this compliance, while Amberview has many characteristics that are particular to its metro-Atlanta area, it also mirrors the broader structure of both other branches of the Amberview Hospice Corporation, as well as Amberview's competitors throughout the United States. I will now describe this organizational structure as I observed it in my fieldwork, which lasted from May 2012 to November 2012.

As the MHB mandates that hospice be primarily an outpatient benefit, the vast majority of Amberview's clinical staff was oriented toward outpatient care. This outpatient staff was divided into two "teams": Team 1 and Team 2. As stipulated in the MHB, each team was "interdisciplinary;" the "interdisciplinary" structure of each team was a manifestation of the holistic orientation of hospice care, encompassing, in theory, the medical, psycho-social, and spiritual dimensions of care.[262] The team's members each represented one of these dimensions. Each team was led by a Medical Director, who was a trained physician, and a Patient-Care Manager (PCM), who was a registered nurse. The Medical Director prescribed medications, care plans, and ensured that each patient meet hospice eligibility requirements. The PCM managed the administration of medications through the case managers, who were also registered nurses. He or she was joined by the Assistant to the Patient Care Manager, who did paperwork to ensure that the hospice was appropriately reimbursed by its payers for each patient. Each outpatient team had two

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[261] National Hospice and Palliative Care Organization, *Facts and Figures: Hospice Care in America*, 10.

[262] Conditions of Participation for Hospice Care, 42 CFR418.56.

case managers, though that amount varies. Together, the Case Mangers, Medical Director, and PCMs made up each team's medical staff.

This medical staff was complemented by one chaplain, who oversaw "spiritual" care for patients, families, and, occasionally, hospice staff. "Psycho-social" care was carried out by a range of individuals: a social worker, who oversaw placement, discharge planning, and, occasionally, counseling; the volunteer coordinator; and the bereavement coordinator. In addition, both team meetings were attended by the hospice's Bereavement Coordinator and Volunteer Coordinator. Combining these interdisciplinary treatment modalities, the team contained nine total members: a medical director, a PCM, two case managers, a chaplain, a social worker, the Volunteer Coordinator, the Bereavement Coordinator, and the Assistant to the PCM.

In addition to this clinical team, Amberview also included several professionals who, though not attending team meetings, provided clinical care. In the nursing staff, such individuals include "critical care" nurses, who cared for patients who were "actively" dying—meaning they would die within twenty-four hours—as well as CNAs or HHAs who visits patients up to three times a week to provide assistance with activities of daily living. Finally, as stipulated in the MHB, the hospice included a staff of volunteers that was sufficient to account for 5% of the organization's total patient care hours.[263] Though volunteers did not generally attend team meetings, they were discussed at meetings as professionals who could be requested to serve patients who needed companionship.

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[263] Conditions of Participation for Hospice Care 42 CFR418. 78.

Amberview also featured a number of staff members concerned with non-clinical aspects of the organization's functioning. Such members included two admissions personnel, who recruited patients for admission to the hospice. It also included a financial manager, who oversaw the hospice's financial operations, a medical records coordinator, and an administrative assistant. Though not participating in clinical care directly, these staff frequently popped in on team meetings to update team members on a variety of issues, including new admissions, missing paperwork, and financial pressures. Together, these non-clinical and clinical members made up the totality of Amberview's outpatient staff.

This outpatient staff was complimented by Amberview's inpatient facility. That Amberview had such a facility made it a rarity among hospice providers in the United States, where—as I mentioned earlier—4 out of 5 hospices do not offer inpatient services.[264] This facility was equipped to handle twelve patients, though its census dropped to as low as four during the time that I was conducting research. As inpatient services comprised a significantly smaller portion of the hospice's care, the inpatient center featured only one clinical team. This team was, like the outpatient teams, interdisciplinary, comprised of a medical director, one or two registered nurses on duty, an office manager, a social worker, and a chaplain. In addition to these members who worked specifically and solely in the inpatient setting, inpatient meetings were also attended by the hospice's volunteer coordinator. Finally, team meetings were also supervised by the manager of the inpatient facility, who was a nurse, and played a function that was similar to that of the PCM in the outpatient setting.

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[264] National Hospice and Palliative Care Organization, *Facts and Figures: Hospice Care in America.*

The totality of the hospice's caretaking was overseen by the Executive Director (ED). The ED performed a variety of functions, including ensuring that the hospice was taking in a sufficient number of patients, monitoring and supporting the activities of team members, and helping to troubleshoot with difficult patients who required services that were outside of those normally provided by the hospice. Such patients could include those who required home care that would not be reimbursed by Medicare—including additional CNA visits—those patients and family members who might be considered dangerous, and non-funded patients whom the hospice may be continuing to treat. Ultimately, the ED was responsible for communication between the local branch and the national office. Such communication ensured that the hospice was meeting the national office's stipulations for patient care, profitability, and organizational efficiency.

This is the general outline of Amberview's organizational structure during the time of my fieldwork. This structure cohered with that of other hospices throughout the United States: It was primarily an outpatient facility that provided holistic, interdisciplinary care to terminally ill patients. This care was provided to patients throughout the metro-Atlanta area and, as Amberview's staff explained to me repeatedly, was meant to "support" not supplant the patient's primary caretakers. As a primarily outpatient facility coordinated toward the administration of supportive, interdisciplinary end-of-life care to terminally ill patients, Amberview was structurally identical to hospices throughout the United States.

To examine how Amberview's overarching structure configured its practice of hospice care I conducted extensive ethnographic fieldwork in the facility over a six month period from May 2012 through November 2012. This fieldwork consisted of thirty-one interviews with Amberview staff in both the inpatient and the outpatient facility, as well as the hospice's corporate office. In addition, it consisted of ethnographic observation of both inpatient and outpatient care and weekly attendance at the staff meetings of the inpatient team and the outpatient "Team 2." My focus in the fieldwork was the examination of how the Medicare Hospice Benefit's presumed supportive kinship network impacted Amberview's functioning as an organization, as well as its patient care. While the Benefit functions very well when sufficient kinship support is present, I will here argue that the absence of such kinship networks creates routine problems for patients, families, and hospice staff.

Home Alone: Kinship and the Subversion of Care under the Medicare Hospice Benefit

The modern US hospice movement emerged in response to what its members perceived as a significant—and, indeed, constitutive—gap in the US medical system. As this system was oriented around curative care, it was structurally designed to exclude patients with terminal illnesses. This desire to respond to the situations of the terminally ill was one of the foundations for the incorporation of hospice care into Medicare. Nevertheless, the provision of hospice care under the MHB was, as I have shown, based on an exchange with the individual's local kinship network: In exchange for hospice care, this local network would have to attend to the terminally ill patient's needs. In this section, I will argue that this precondition, though making it possible to extend hospice to terminally ill patients, creates its own "gap": terminally ill patients who lack kinship support. The Medicare Hospice Benefit impedes the ability of hospice organizations to care for such patients; such obstruction, though a product of the Benefit's foundation in cost-savings, ironically creates significant additional costs in both staff burnout and unnecessary care.

In order to explain why this is the case, it is necessary to examine the level of kinship care required to sustain a terminally ill patient until the time of his or her death. Such care will, by necessity, depend on the nature and severity of the terminally ill person's condition. For example, a person with Chronic Obstructive Pulmonary Disease (COPD) may have significant difficulties in transporting him or herself to the bathroom, while an individual with dementia may be able to move to the bathroom, but unable to recognize the need to perform routine activities of self-care. Due to the nature of hospice as a modality of end-of-life care, most hospice patients have extremely significant conditions that limit their ability to perform basic activities of daily living, as well as to maintain compliance with their medications.

Such difficulties are complicated by the presence of co-morbid conditions among terminally ill patients. These co-morbidities could be life-long conditions that, though not immediately related to a patient's terminal diagnosis, could significantly complicate it: For example, a patient with pancreatic cancer whose mobility is significantly reduced as a result of a lower extremity amputation dating to the Vietnam War. Such co-morbidities can also be related to mental health: The ability of an individual with Parkinson's disease to take his medications may be adversely impacted by the chronic depression that he has experienced on and off for the past ten years. The presence of such co-morbidities in hospice patients at Amberview provided the justification for a saying that was used by several different staff members over the course of team meetings: "The end-of-life does not begin at the end-of-life."

This adage applied not only to the presence of co-morbidities among patients, but also illnesses and disabilities in their familial caretakers. While Amberview staff did not treat such conditions themselves, they had a direct—and potentially devastating—impact on the provision of hospice care. For example, a woman was unable to provide her terminally ill husband with consistent care because she herself had breast cancer; as a result, she was absent from the home while receiving treatment and, even while at home, was often too tired to sufficiently carry out the physically grueling labor of caring for his needs. In another case, an elderly man with a heart condition and lower back problems could not perform the daily labor of assisting his wife into a wheelchair that was necessary for her to move. In this case, neither his wife's wheelchair use, nor the man's own coronary and lumbar problems would be classified as "terminal" conditions, but both colluded to impede the delivery of end-of-life care.

In addition to such diagnosed conditions, dysfunctional family dynamics also hindered the provision of Amberview's hospice care: In one team meeting, hospice staff discussed a patient whose wife was routinely forgetting to give him his pain medication. The PCM claimed that such "forgetting" was a manifestation of the aggression that the wife felt for her husband, whom the PCM characterized as "a guy who was probably very controlling, and dominating to [the wife] earlier in life." Whether it was conscious or unconscious, the wife's noncompliance was thus a form of "payback" for her husband's treatment of her. While I could not observe patient care in this case specifically, the PCM's scenario provides an example of how dysfunctional family dynamics subvert the provision of hospice care. In such cases, the hospice's interdisciplinary team must attempt to either address these noxious familial relations before they actively harm the patient, or have the patient removed from the home.

While many co-morbidities are unrelated to the end-of-life, terminal disease itself is a prolific generator of co-morbid conditions. At Amberview, nearly every patient had, in addition to the terminal diagnosis necessary to admit them, a series of comorbid conditions most likely related to this disease. One man, for example, had been admitted to hospice for "failure to thrive," but also had significant recent hearing loss; an eighty-seven year old woman with dementia had significant lower extremity bruising as a result of a fall that occurred in her own house. In addition to such disease-related accidents, terminal conditions like cancer, COPD, and dementia, though often localized in a particular region of the body, have effects that impinge on the body's ability to function as a whole. The disabling nature of such conditions makes it difficult for hospice patients to care for themselves, while also complicating their kinship network's capacity to attend to them.

Moreover, the rapidly escalating nature of such conditions may outpace the means or the ability of the terminally ill individual to make his or her house accessible. A person who becomes unable to walk over a matter of weeks may thus be trapped in a house filled with stairs. Compounding these problems with accessibility internal to an individual's own environment, are problems particular to the metro-Atlanta region itself. The City of Atlanta is geographically very spread out.[265] Its public transportation network, MARTA,

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[265] For more extensive studies of sprawl in Atlanta, see Robert Bullard, Glenn S. Johnson, and Angel O Torres, *Sprawl City: Race, Politics, and Planning in Atlanta*, (Washington DC: Island Press, 2000).

though itself relatively accessible to persons with disabilities, has limited coverage.[266] As a result of this lack of accessible transportation and diffuse arrangement of urban space, it was extremely difficult for Amberview's patients—who, in general, were too disabled to drive themselves—to leave their house to attain basic necessities.

As a result of their rapidly escalating terminal conditions, coupled with the lack of accessible housing and transportation, terminally ill patients at Amberview generally required intensive care. This care had an important medical dimension, in that these patients may require round-the-clock pain control, as well as treatment for neurological conditions like dementia, as well as psychological anxiety. But in order to be successful, this medical treatment had to occur in a context that was responsive to activities of daily living. While Amberview could provide assistance with such activities on a part-time basis, it was not reimbursed for daily assistance, nor for providing patients with a sitter. Without assistance from Medicare, the high cost of home health care designed to care for such activities—approximately $300 a day, according to an Amberview social worker—was prohibitive for most Amberview patients, who were generally individuals of middle or lower socio-economic status. As a result, most Amberview patients had to depend on their family members for full-time care that included companionship as well as assistance with activities of daily living.

In my fieldwork, I observed several obstacles to the provision of such kinship care. First, many patients lacked family members who lived in sufficient proximity to provide them with routine care. Second, even if such family members were present, the

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[266] For a more extensive treatment of the MARTA system, see Miriam Fiedler Konrad, *Transporting Atlanta: The Mode of Mobility under Construction*, (Albany: State University of New York Press, 2009).

emotional dynamics of familial relationships often impeded the provision of care. Caretakers who were—for either valid or invalid reasons—upset at their terminally ill relatives were reluctant to provide him or her with necessary care. Third, even if caretakers were committed to providing care, they might be economically unable to do so. If a caretaker needs to work a full-time job, for example, they may leave their terminally ill relative at home in a potentially precarious position. Finally, even if a person had sufficient economic resources so that they could provide care themselves—or even hire a full-time sitter—the progressive nature of terminal illness placed significant strains on the mental, emotional, and physical resources of even the most dedicated caretakers. As a result of this, the Medicare Hospice Benefit presumes—and implicitly requires—the presence of a kinship network that has sufficient physical, mental, and emotional abilities to provide care for a dying loved one; it also includes the financial resources necessary to either not have to work or to pay for a full-time caretaker out of pocket.

When such resources are present, the Benefit functions extremely well. Through interviews with hospice staff, as well as observation of both inpatient and outpatient care, I saw the extent to which the Benefit's interdisciplinary structure supports families so that they can care for their loved ones at home. Such support satisfies the preference of patients to die at home, as well as the desire of family members to care for their loved ones. It is also generative for hospice personnel, who generally chose the field over more lucrative options because of their commitment to holistic, patient-centered end-of-life care. Finally, it is cost-effective, in that it satisfies patient and familial preferences while minimizing corporate and governmental expense. Thus, when patients have a supportive kinship network, the Medicare Hospice Benefit is an extremely effective piece of legislation.

My concern here is those cases in which patients lack such a supportive kinship network. In these cases, I claim that the Medicare Hospice Benefit limits the ability of hospice professionals to care for patients. In the process, it can undermine the supportive holistic care that hospice already provides. The result does not serve these patients well, and leaves staff frustrated and burnt out. I will now the obstacles that the Medicare Hospice Benefit presents to patients without kinship support through a case study of a patient whom I will refer to as "Steven."[267]

Steven's Case

When I first walked into Steven's apartment, all I saw were paper plates and pills. Or, rather, paper plates *filled* with pills. They were colorful pills in diverse shapes: capsules, circles, even diamonds, in blue and green and red and yellow. Amidst such resplendent litter, there was also more quotidian trash: withered sweatshirts, microwavable ravioli tins—their insides long dried out—and tissues with dark stains of ominous origin. There was a twin "bed" rendered unusable and effective invisible by the clothing, books, pill bottles, and even paintings atop it, a sink stacked lumberingly with dirty dishes, and a small safe lying open on the back floor, its exposed insides consisting of a few dollars and more half-empty bottles of pills.

Steven had bipolar disorder. He was also fifty-four years old, white, male, and divorced, a former construction worker and former amphetamine addict. He lived in a

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[267] This case is based on an interview with "Steven." In the interest of preserving his anonymity, I have changed Steven's name, age, medical and vocational history, family dynamics, and possibly his gender. Informed consent was obtained for this interview.

facility run by a nationally recognized addiction recovery organization. This “facility” was, in reality, a long, two-story building filled with studio apartments whose size and level of maintenance mirrored that of a cheap motel. This complex was itself located in an area of the city that was not only unsafe, but extremely inaccessible: a residential neighborhood without sidewalks, where the closest supermarket was over a mile away. Steven had been mugged one day while walking back from that market. He had stopped going after that, but only partially because of the robbery: In reality, it had become too hard for him to make the trip.

Steven had cancer of the throat. He had this cancer for over two years and, in fact, had been on hospice service for it for a year-and-a half. The disease was terminal, but it was uncertain when exactly it would kill him. In the meantime, his main concern was not so much the cancer as it was his stomach. Steven had terrible ulcers. These ulcers were, he argued, due to his chronic back pain. Because of his work in construction, he had suffered routine back injuries since the 1980s. He had addressed these back injuries by taking pain medications. These pain medications had, in turn, eroded his stomach lining, giving him ulcers and acid reflux. His stomach condition caused him constant pain, and, coupled with his throat cancer, made it extremely difficult for him to ingest food. As a result, he ate only a limited range of microwavable foods—mainly beef ravioli and chicken pot pie. But even when he was able to obtain and prepare such foods, he could take down only a small amount—often leaving the pre-measured portions more than half uneaten.

Steven lived alone. He had divorced a long time ago and never remarried. He subsisted entirely on Social Security Disability. Though he was under sixty-five, he had been disabled for more than two years—thus making him eligible for Medicare, which paid for the hospice care that he had been receiving for the previous year-and-a-half. During his time as a hospice patient, Steven had developed close relationships with several Amberview staffers. "Have you met Steven yet?" one Amberview social worker had asked me in the middle of an interview. "I love Steven." She was not alone. Steven was well-loved by his attending social worker, chaplain, and nurse. And, indeed, he was easy to love: chatty, energetic, cheerily self-deprecating, genuine, and somewhat naïve. It was hard not to enjoy his company, hard not to want to help him out.

Steven needed help. Although Medicare covered his hospice care, he lacked a local caregiver. He had long been estranged from his wife. His two brothers lived on the other side of the country. His daughter lived in New York and had a young child at home. In part, Steven's lack of a kinship network may have been the result of his own actions. As he readily admitted, he was no saint, and a lifetime of addiction, mental illness, and psychological trauma led him to, if not completely burn, then at least deeply singe, many of his bridges. But, regardless of the cause, he was now alone in a small apartment, with neither access to an automobile, nor the physical capacity to drive one. He had access to all of the resources that Amberview Hospice could provide him with: high-level pain medications, as well as visits from nurses, chaplains, social workers, and volunteers. But though these visits were frequent, the total amount of time that Steven spent with hospice personnel was, at most, around fifteen hours a week. For the most part, he was alone.

Steven lived alone, and his situation in his residential facility for recovering addicts was highly problematic. The facility's other residents had, by his own account, stolen his drugs on two occasions. Such drugs included both the psychiatric medications for his bipolar disorder, as well as the high intensity pain medication given to him by hospice. At the same time, due to his psychiatric condition, he was, in general, incapable of adequately organizing and hiding his medications, and also unable to defend himself from robbery. Amberview Hospice attempted to help him with such theft by providing him with a locked pillbox, but he frequently forgot to use it. In the meantime, the outpatient psychiatric care he received from a local non-profit, while helpful, was having only a limited impact because it depended on his ability to comply with medication regimens. But, for Steven—bipolar, terminally ill, in constant pain and anxiety—such compliance proved impossible.

Steven's only reprieve from the pain, anxiety, and isolation he experienced at home were his trips to Amberview's inpatient unit. While Steven's condition was not significant enough to qualify him for general inpatient care, he was able to visit the inpatient facility for five days a month through the Medicare Hospice Benefit's allowance for "respite" care. At the inpatient facility, he received regular meals delivered to his room; having been a patient for a year-and-a-half, he knew the cook well, and she prepared special meals that he would be able to eat. He also knew, and was well-liked by, the inpatient facility's nurses, social worker, and chaplain. He socialized regularly with these staff, as well as volunteer visitors. In addition, the facility also had even, well-maintained floors, which, unlike those of his apartment, he could walk on freely, without tripping over a pile of junk. In this sense, Steven's respite visits to Amberview's inpatient unit provided him with the care that his home environment lacked. Nevertheless, each month, after five days of comfort and care, he would have to return to his pill-littered apartment.

Both the quirkiness of Steven's personality and the desperation of his situation manifested themselves in his dying wish: to donate his body to science. In what would be the final weeks of his life, Steven spoke enthusiastically to me about his desire to give his body to a local university. This desire was, in part, motivated by his own intellectual curiosity. But, beyond this, there was also a financial motivation: Steven did not have money to pay for his own burial. Body donation was an alternative to this unpaid burial: In exchange for receiving his body, the university would cremate him and send his ashes to his son. This cremation was welcomed by Steven—who was happy to save his son the cost of the funeral.

Though I was perturbed by the economic implications of Steven's desire, there was also something inspiring, almost heart-warming about it: Steven *really* wanted to donate his body to science. He showed me the pamphlet several times when I visited, excitedly explaining both the physical procedures to be performed on him, as well as the memorial rituals that would follow. The prospect of donating his body to science seemed to give him a sense of control over both himself and his environment that was lacking in every other aspect of his life.

One Sunday, Steven woke up with a searing pain in his gut. He called the Emergency Room in response to the pain, and was taken to the nearest hospital. There, the doctors discovered that his cancer had spread to his stomach. Over the course of the operation, he had begun to lose a large amount of blood. While he had signed a DNR order that would have prohibited life-saving procedures, the doctors asked him if he wanted to rescind it to receive a transfusion. Panicked, Steven rescinded his DNR. He received the transfusion, but died hours afterward regardless. As a result of this transfusion, he was no longer eligible to donate his body to science.

Scattered Crumbs: The Home as a Site of Neoliberal Abandonment

In *Vita: Life in a Zone of Social Abandonment*, anthropologist João Biehl examines the aftermath of the Brazilian government's decision to desinstitutionalize care for the mentally ill.[268] This deinstitutionalization was accompanied by two related factors: first, drastic cuts to the social services needed to support the mentally ill in local communities; second, a dramatic increase in the use of pharmaceuticals in Brazilian public health approaches to psychiatry. As a result of these factors, mentally ill individuals were entrusted to the care of family members who had neither the economic resources nor professional skill to care for them. These family members responded to this situation by drugging their relatives to sedation, then leaving them, at first, in the home—and then, eventually, in ramshackle, informal facilities that were equally deficient.

Biehl develops the term "zone of social abandonment" to refer to such facilities.[269] But his study highlights that, in a neoliberal economic context, abandonment is not confined to such institutions: It can also exist in the home. Indeed, as neoliberal styles of governance dismantle large public institutions, the home is arguably a more emblematic site for such abandonment than the institution. As such, abandonment in the neoliberal context is dramatically different than that of the "total institutions" that Erving Goffman chronicled in his studies of asylums and penitentiaries.[270] Though such

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[268] Biehl, *Vita,* 130-7.

[269] Ibid., 2.

[270] Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and*

institutions persist, abandonment, in the neoliberal context, lacks their centralized structure and clear visibility. This abandonment is scattered throughout individual homes that, from the outside, may look quite innocuous. In this sense, neoliberal abandonment has dramatically different spatial, political, and visible characteristics than the “liberal” abandonment of Goffman’s institutions: Scattered throughout private homes, neoliberal abandonment is at once diffuse and invisible.

Steven’s case highlights the presence of such abandonment within the US hospice system. This abandonment was not the result of negligence on the part of Amberview hospice. On the contrary, he was receiving hospice care from highly trained professionals who, because of their long-term relationship with him, cared for him deeply and knew him well. And yet, because the provision of this care depended on the presence of unpaid kinship labor in the private sphere, Steven was abandoned. He did not have a kinship network to support him, and the hospice organization’s potential to provide such a network was limited by the very same regulations that permitted it to provide Steven interdisciplinary end-of-life care.

Without such a network, Steven did not receive his medical care: His drugs were either stolen, lost, or forgotten without regular frequency. In addition, he lacked assistance with basic activities of hygiene and cleanliness. While he could prepare his own food, when his stockpile of frozen meals began to dwindle, he had to live with uncertainty about when someone could pick him up another batch from the store. When he did die, it was not at the home, but in an emergency room, bleeding out among

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Other Inmates, (Chicago: Aldine Transaction, 1961).

strangers, most likely without even knowing that he was losing the one wish he had held onto in the preceding weeks. It was not a good death. But it was also not a fluke.

Steven died because of the structural design of the Medicare Hospice Benefit. Because the Benefit does not provide long-term care to patients receiving hospice, it thrusts the burden of care onto these patients themselves and their unpaid kinship networks. When patients like Steven lack such networks, they are left abandoned in their own homes. There is no sturdy place for these patients within the US hospice system. Nevertheless, that does not mean that they lack all options within the US health system as a whole. Exploring such options entails leaving the terrain of the private home and entering an institution that, though resembling the one Biehl depicts in *Vita*, also differs from it in important ways: the nursing home.

Plugging Gaps, Creating Holes: Hospice Care in the Nursing Home Setting

Nursing homes are long-term inpatient facilities for the chronically disabled.[271] They are designed to provide room, board, and assistance with activities of daily living (ADLs) to chronically disabled patients who are no longer able to live at home. Such activities of daily living include feeding, bathing, clothing, and daily hygienic maintenance. Skilled Nursing Facilities (SNFs) are nursing homes that, in addition to caring for activities of daily living, are also capacitated to provide skilled nursing care. Within the US healthcare system, such care includes the provision of antibiotics, IV fluid, and feeding tubes, as well as rehabilitative services designed to help individuals regain

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[271] For an extensive and accessible guide to the regulation of US nursing homes, see James E. Allen, “Nursing Home Federal Requirements Guidelines to Surveyors and Survey Protocols, 2006 : A User-Friendly Rendering of the Centers for Medicare and Medicaid's (Cms) Nursing Home Inspection and Requirement Forms,” (New York: Springer Pub. Co., 2007).

lost functionality and, ideally, return to life in their own homes, if possible as paid laborers.[272] Thus, while regular nursing home services are for assistance with ADLs for the chronically disabled, skilled services are specifically *medical* treatments for individuals with chronic disabilities.

Skilled and non-skilled nursing home services have different payment structures within the US health system. Skilled nursing services can be reimbursed via either Medicare Part A, Medicaid, private insurance (either long-term or employment-based), or out-of book. Non-skilled nursing home services can only be reimbursed through Medicaid or private payer; Medicare does not contain a long-term care benefit that will pay for them. Overall, both skilled nursing services and regular nursing home services are extremely expensive: In 2012, a semi-private room in a nursing home cost, on average, more than $81,000/year.[273] Due to the extremely high costs of nursing home care, approximately two-thirds of nursing home patients pay for their care through Medicaid.[274]

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[272] "Nursing Home Federal Requirements Guidelines to Surveyors and Survey Protocols, 2006 : A User-Friendly Rendering of the Centers for Medicare and Medicaid's (Cms) Nursing Home Inspection and Requirement Forms," (New York: Springer Pub. Co., 2007), § 483.5.

[273] Emily Mullin, **"**How to Pay For Nursing Home Costs, US News and World Report," February 26, 2013, http://health.usnews.com/health-news/best-nursing-homes/articles/2013/02/26/how-to-pay-for-nursing-home-costs

[274] AARP, "Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2001 Through 2007. Across the States: Profiles of Long-Term Care and Independent Living," (Washington, DC: AARP Public Policy Institute, 2009).

In theory, terminally ill patients who lack sufficient kinship networks are placed in nursing homes. There, they receive assistance with activities of daily living. Nevertheless, as nursing homes specialize in care for the chronically disabled, they are not equipped to provide end-of-life care. This deficiency is remedied, in the US health system, by pairing inpatient nursing home care for activities of daily living with the provision of outpatient hospice care. This care focuses on pain management, though psycho-social and spiritual care is also included both for the terminally ill individual and their family. Thus, the nursing home serves the same function as the kinship network that the terminally ill patients under their care are lacking. This environment ostensibly facilitates the provision of hospice's medical, spiritual, and psychosocial care. Thus, by coordinating hospice and nursing home care, the US health care system theoretically plugs the "gap" created by the needs of terminally ill patients without sufficient kinship networks.

In the following section, I will consider the success of this solution through an analysis of my ethnographic fieldwork at Amberview Hospice. I will draw on my observation of several outpatient team meetings, in which staff discussed the provision of hospice care to nursing home patients. In addition, I will draw on interviews with 31 Amberview staff members about their experiences coordinating hospice and nursing home care. Based on this combination of interviews and observation, I will argue that, rather than plugging the gap between long-term and end-of-life care, the provision of hospice care to nursing home patients creates an entirely different hole.

"Like a Hamster in a Wheel": On Negotiating Two Conflicting Modalities of Care

Interviews with Amberview staff members at various levels—including case managers, medical team directors, PCMs, and senior members of the national corporate office—revealed the provision of hospice care in nursing home settings to be one of the organization's central problems. Though, in what follows, I will describe the problems that arise in the nursing home setting in some detail, I will argue that these seemingly isolated problems are rooted in a basic organizational incompatibility between hospices and nursing homes.

This incompatibility is based in each treatment modality's orientation toward death: While hospice care is organized to bring patients to a comfortable death, nursing home care is organized to prevent death at practically all cost. This distinction is rooted in the diagnostic categories in which each institution specializes: nursing homes care for chronically disabled individuals—maintaining them alive with a disability, possibly rehabilitating them—while hospices are designed for terminally ill patients for whom death is, theoretically, both imminent and inevitable. Consequently, hospice and nursing homes are facilities designed to treat conditions that are not simply distinct, but—according to the logic of the US health care system—opposing. This opposition manifests itself in each institution's internal culture, professional training, and economic incentive structure.

The opposition between hospice and nursing home care is best illustrated by the reimbursement structure of Medicare Part A: Medicare Part A is available to pay for *either* hospice care *or* skilled nursing care. Nevertheless, Medicare will not pay for both hospice and skilled nursing care. As a result, hospice and skilled nursing providers are in direct competition for the same pool of money. Other authors have noted that this direct economic conflict significantly impedes patient care: For example, a team of investigators at the University of California, San Francisco argued that the conflict over Medicare funding between hospice and nursing providers leads to nursing home patients not receiving sufficient palliative care[275]. Nursing home providers are not only untrained to provide such care, but also disincentivized from doing so, as it would involve their compromising their institution's Medicare reimbursement. At the same time, patients may be reluctant to abandon skilled nursing interventions that they believe could improve their quality of life as well as lengthen their lifespan. The result is that chronically disabled patients are systematically denied—or incentivized to themselves deny—palliative interventions that might otherwise significantly benefit them.

This economic and medical conflict produces a larger cultural conflict between nursing home and hospice providers. In various interviews and observations of outpatient team meetings, I heard hospice providers complain that their palliative interventions were regarded with suspicion by nursing home staff. Such staff considered hospice to be "giving up" on patients who might be eligible for rehabilitation or, at the very least, able to live for long periods of time with mechanical assistance. Hospice staff, in turn, suspected that nursing home providers maintained patients alive through "artificial" means like feeding tubes and ventilation largely in order to extract more money from them. Consequently, their organization around distinct diagnostic categories—"terminal illness" and "chronic disability"—produces a conflict between hospice and nursing homes that is at once medical, economic, and cultural.

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[275] K. Aragon, K. Covinsky, Y. Miao, W. Boscardin, L. Flint, and A. K. Smith, "Use of the Medicare Posthospitalization Skilled Nursing Benefit in the Last 6 Months of Life," *Archives of internal medicine* 172, no. 20 (2012): 1573-79.

This conflict subverts the delivery of hospice care in the nursing home setting. Though nursing home providers cannot prescribe palliative medicine, they can administer such medications to patients if they are regularly required. But, because they lack training and, at times, a belief in the validity of such interventions, nursing home providers often administer them irregularly. At outpatient team staff meetings, hospice team members repeatedly emphasized the need to "educate" nursing home personnel on various aspects of patient care, including the administration of Roxanol and other pain medications, fall protection, turning bedbound patients, and, more generally, getting "comfortable with death." Through such educational interventions, hospice staff tried to minimize the negative impact of the nursing home's conflicting organizational culture.

Such "educational" interventions were complicated by the high staff turnover rate at area nursing homes where I conducted fieldwork. Nursing home employees are relatively poorly paid, while negotiating high caseloads under stressful circumstances. This combination has been found to lead to high turnover rates among nursing home staff.[276] For Amberview's staff, this high turnover transformed "education" from an occasional practice to a full-time aspect of providing hospice care in the nursing home setting. The constant need for such pedagogical interventions was considered by team members to be a necessary, but inefficient use of time, as they only marginally helped to

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[276] On staff turnover in nursing homes see Jane Banaszak-Holl and Marilyn A. Hines, "Factors Associated with Nursing Home Staff Turnover," *The Gerontologist* 36, no. 4 (1996): 512-17; Nicholas G. Castle, John Engberg, and Aiju Men, "Nursing Home Staff Turnover: Impact on Nursing Home Compare Quality Measures," *The Gerontologist* 47, no. 5 (2007): 650-61; Nicholas G. Castle and John Engberg, "Organizational Characteristics Associated with Staff Turnover in Nursing Homes," *The Gerontologist* 46, no. 1 (2006): 62-73.

stem the tide of service failures. The result was that hospice staff members were left feeling, in the words of Dr. Sewell, an Amberview medical director, "like a hamster in a wheel."

Resistance to the provision of hospice medication in the nursing home setting is more than a matter of education. It is a direct result of the regulations governing medical treatment in the nursing home. As Dr. Sewell explained:

> [T]hey have so many different regulations about what they can do with their medications. Some of them have a pharmacy they can access twenty-four hours. Some of them don't. So if they need pain medication or some other symptom medication in the middle of the night, you may be out of luck. Sometimes they'll allow you to have what we call a "comfort kit" in the...nursing home…. But then it has to be assigned to that one patient. So that you now have a comfort kit that may have the morphine, or Ativan, or Haldol that they may need, but suppose it happens to another patient, unexpectedly... that other patient has to wait.

Dr. Sewell highlights how the inability of nursing homes to prescribe high intensity pain medication leads to routine problems in the delivery of hospice care. These problems stem from the structural difficulty of addressing unexpected complications at the end-of-life in medical institutions that are not themselves designed to provide end-of-life care.

Even nursing home regulations designed to help chronically disabled patients can, in the context of end-of-life care, have dramatically different results. For example, nursing home staff must document that they are feeding patients; regulations mandating such feeding emerged as necessary responses to the neglect of chronically disabled patients in the nursing home setting.[277] But in the hospice context, such mandatory feedings can be disastrous, leading nursing home staff to provide feeding tubes to patients in whom cessation of appetite is, in Dr. Sewell's words, "a natural part of the disease progress." The result can be harmful, lead to patient aspiration, and unnecessarily prolong the dying process among patients whose bodies cannot process the nourishment they receive. Although there are regulations through which such mandatory feeding can be discontinued, Dr. Sewell emphasized that the high caseloads of nursing home staff regularly preclude such regulations from being followed. Consequently, regulatory solutions to the coordination of hospice and nursing home care only superficially mitigate the more fundamental conflict between these two treatment modalities.

To account for these structural difficulties in coordinating hospice and nursing home care, hospice professionals adopt standardized routines. Dr. Sewell explained the rationale and method of such standardization:

> [W]hat we do [in hospice] is often is to use medications PRN—"as needed"—[and], well, you can't do that in a nursing home. Because one nurse on one shift may think that pain looks like one thing. And one nurse on another shift may think that pain looks like one thing. And they may not medicate the patient. So sometimes we sit down and we go "Ok, well let's make a happy medium, let's give it to them just twice a day so that we know they get some medication in them." You know, that's not the way

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[277] John F. Schnelle, Barbara M. Bates-Jensen, Lily Chu, and Sandra F. Simmons, "Accuracy of Nursing Home Medical Record Information About Care-Process Delivery: Implications for Staff Management and Improvement," *Journal of the American Geriatrics Society* 52, no. 8 (2004): 1378-83.

> to practice good medicine and good care for the patient. But it's almost like we've accepted that as being the way to do it, because of the fact that there really is no other easy way to get around the system.

The standardization of pain medication described by Dr. Sewell is a response, not to the patient's pain, but to a nursing home context which makes "good" medical care impossible. The result is the potential overtreatment of patient pain, as well as the waste of expensive medications. But such risks are necessary, in Dr. Sewell's view, to avoid the greater danger of allowing terminally ill patients to stay in a nursing facility with limited resources to palliate them.

This divided economic structure of Medicare Part A not only impedes the delivery of hospice, but also leads patients to leave hospice in order to receive skilled nursing care. Mr. Riglin, a Patient Care Manager at Amberview, claimed that such structural departures were his "biggest problem" with the Medicare Hospice Benefit. He explained:

> You can be [in a nursing home] on hospice. You can be dying. And nursing homes will call the family [who will say] "Oh, send them to the hospital." So now they're a hospice patient, they're DNR, but now they're at the hospital. But now they'll say "well, while he's here, we'll let him be treated." And I say to them "Well you have two choices. You can either have him come off hospice, and Medicare will cover the hospital bill. Or you can have him stay on hospice, and you'll be responsible for the hospital bill." So you can imagine what most people decide to do. So when they leave the hospital and they go back to the nursing home, even if they have a hospice order, the nursing home will say, "you need to IV

> antibiotics, we’re going to skill him.” I can’t admit a patient who’s being skilled, even though they're dying.

Mr. Riglin lays out what, by his account, is a routine pathway by which terminally ill nursing home patients are transferred from hospice to skilled nursing care. When patients begin to actively die, the nursing home contacts the family, who—believing that they are saving their family member’s life—override their DNR, sending them to the hospital, and revoking hospice so that Medicare covers the hospital bill. When their family member returns to the nursing home, they are “skilled.” As “skilled” patients, they cannot, according to Medicare guidelines, be enrolled in hospice care. Consequently, although they are terminally ill and hospice eligible, they must forsake hospice. As a result of this, terminally ill patients may experience untreated pain at the end-of-life.

Such untreated pain in the nursing home setting is not a matter of happenstance. It is a byproduct of the competing incentive structures of hospice and nursing providers. Such competing incentive structures, as Mr. Riglin recounted, can themselves be fatal:

> Literally, they can skill you to death. I had a patient who was actively dying, and they were sent to the hospital—nursing home should have called hospice, but didn’t. “My bad” [the nursing home staff said]. Hospital gives them a round of antibiotics. Discharges them back to the nursing home with 10 days of IV antibiotics…. This happens a lot. You get a doctor in a nursing home who will write an order for hospice. And yet still they will skill them. “Oh, well, you can admit them after the 100 days [of reimbursable skilled care] are passed, if he hasn't expired.” And a lot of times they will die while they are being skilled.

By the expression “skilled to death,” Mr. Riglin means that patients will “die while they are being skilled.” And yet, it is possible to understand being “skilled to death” in another sense as well. In this sense, it would mean that the patient was not only skilled until the moment in which they died, but that their death was itself *caused* by skilled nursing care. Studies have shown that the administration of palliative care can lengthen a patient’s lifespan by between one and three months.[278] By denying patients palliative care, the provision of skilled nursing home care can itself shorten their lives. Such shortening is not inherent to skilled nursing care itself, but rather the conflict between hospice and skilled nursing care within Medicare Part A.

The Fragmentation of the Patient

This conflict produces what Dr. Oberlin, one of the Amberview Hospice’s corporate board members, referred to as “the fragmentation of the patient.” Dr. Oberlin was commenting on how hospice patients in nursing homes are pulled in two different directions by their long-term and end-of-life providers. This fragmentation was embodied in the service failures and inefficiencies that Amberview staff experienced in their dealings with various local area nursing homes: The conflicting incentive structures of hospice and nursing home providers made it difficult for providers to collaborate with nursing home providers, and frequently placed these two forms of medical care at odds.

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[278] Stephen R. Connor, Bruce Pyenson, Kathryn Fitch, Carol Spence, and Kosuke Iwasaki, “Comparing Hospice and Nonhospice Patient Survival among Patients Who Die within a Three-Year Window,” *Journal of pain and symptom management* 33, no. 3 (2007): 238-46; Jennifer S. Temel, Joseph A. Greer, Alona Muzikansky, Emily R. Gallagher, Sonal Admane, Vicki A. Jackson, Constance M. Dahlin, Craig D. Blinderman, Juliet Jacobsen, William F. Pirl, J. Andrew Billings, and Thomas J. Lynch, “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *New England Journal of Medicine* 363, no. 8 (2010): 733-42.

This fragmentation is not only figurative. Both in discussion with Amberview team members, as well as in my own observation of patient care in the nursing home setting, I witnessed various accounts of nursing home patients whose bodies were bruised from repeated falls, who suffered from untreated pain, and who endured bedsores due to a lack of proper turning on the part of the nursing staff. In one such patient, an Amberview staff member commented, that her "arms are tearing from where [the nursing home nurses] pull her." This patient indicates that the "fragmentation" of nursing home patients is more than a metaphor. Her torn body was a literal manifestation of the conflict between hospice and nursing providers. It was not a result of a biological process, nor an isolated service failure; it was a product of the underlying structure of the US health care system.

This fragmentation is different from the abandonment that, I argued, was characteristic of the provision of hospice to patients without kinship support in the home care setting. The logic of abandonment was a product of the ways in which the lack of long-term care in the US hospice system subverted the provision of end-of-life. The logic of fragmentation, in contrast, is a result of the simultaneous provision of both these caretaking modalities. Fragmented patients receive hospice and nursing home care. And yet, because these forms of care are, in the US health care system, structurally opposed, their provision can pull the patient apart.

Such fragmentation is ironic since, as I described earlier, hospice care is characterized through its interdisciplinary approach to the person. But, in patients without sufficient kinship networks, this impact of this interdisciplinary care is limited. I will conclude this chapter by examining how the structure of the Medicare Hospice Benefit allows patient fragmentation to persist among interdisciplinary care.

Conclusion: Interdisciplinarity and the Fragmentation of the Patient

There have been several critiques of the provision of interdisciplinary services within US hospice care. As various commentators have noted, the Medicare Hospice Benefit itself adopts a two-tiered payment structure for such services, reimbursing only the specifically medical aspects of patient care, while merely requiring the provision psycho-social, spiritual, and bereavement care.[279] This two-tiered payment structure denigrates the very caretaking modalities that are oriented toward an understanding of the "whole" person. This denigration within the benefit's structure has, commenters have argued, produced a marginalization of both spiritual and psycho-social interventions in practice.[280]

But this critique of the marginalization of psycho-social and spiritual services misses the deeper problem with the Medicare Hospice Benefit's definition of interdisciplinary care. Such interdisciplinary care omits long-term care. By omitting long-term care, the Benefit omits the very context necessary for the delivery of its interdisciplinary end-of-life therapeutics. By excluding this context from their provision of care, the MHB inadvertently subverts the delivery of care in both insufficient home environments and long-term care settings whose organizational structure conflicts with the priorities of end-of-life care.

Though such interdisciplinarity is buoyed by the neoliberal philosophy, its internal contradictions result in a subversion of the purported goal of neoliberal economic policy:

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[279] Siebold, *The Hospice Movement*, 135.

[280] D. Reese and M. Sontag, "Successful Interprofessional Collaboration on the Hospice Team," *Health and Social Work* 26, no. 3: 165-179; Ward and Gordon, "Looming Threats to the Intimate Bond in Hospice Care?"

to save the government money. I have described here how patients without kinship networks can find relative refuge within the health care system through the coordination of hospice and nursing home services. Such coordination is extremely cost-ineffective, adding costs in time spent in bureaucracy, both over- and undertreatment, and unnecessary emergency room visits. In this sense, organizing two conflicting caretaking modalities is inherently less efficient than supplying one unified form of long-term inpatient end-of-life care.

The cost of this inefficiency is largely borne by the government. Over two-thirds of nursing home patients receive Medicaid, while over 84% of hospice patients have their care paid for by Medicare.[281] As a result, both federal and state governments are responsible for paying for the majority of the long-term inpatient end-of-life care. By attempting to pass the cost of this care onto unpaid kinship networks, the Benefit ironically results in it boomeranging back to the government in a form that is inherently inefficient in both medical and economic terms.

This shortcoming of neoliberal health policy and interdisciplinary care raises the question of through what other medical and economic structures it might be able to organize the provision of end-of-life care to patients lacking kinship support. In the following chapter, I will examine such an alternative organization through a case study of a unique institution within the US health care system: Atlanta's Our Lady of Perpetual Help Home.

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[281] AARP, "Nursing Facilities"; National Hospice and Palliative Care Organization, *Facts and Figures: Hospice Care in America*, 10.

Chapter 4

Death and Resurrection in Our Lady of Perpetual Help Home: The Dying God, The Eucharistic Enactment, and the Totality of Catholic End-of-Life Care

Introduction

This chapter is an ethnographic study of a facility named Our Lady of Perpetual Help Home.[282] Located in Atlanta, Georgia, "Our Lady" —as it is know to locals— combines services that, within the US health care system, generally pertain to two distinct medical institutions: the hospice and the nursing home. Like a hospice, the home offers holistic end-of-life care to patients with terminal illnesses. It unites this end-of-life care with long-term inpatient care that is typically found only in nursing homes. This synthesis of two distinct caretaking modalities makes Our Lady a unique institution in US health care: a long-term inpatient facility designed for the terminally ill. In this chapter, I will examine the conditions that make Our Lady's unique form of care possible, and the impact of its services on patients and providers throughout the Atlanta area.

I argue that Our Lady's treatment modality is made possible by the home's financial structure. The facility operates only on donations. As a result, it is not dependent on Medicare or Medicaid regulations that would prohibit it from combining long-term and end-of-life care. At the same time, the home's independence from patient reimbursement enables it to care for patients who would otherwise be unable to pay. In this sense, Our Lady's exclusion from the normal payment structures governing US

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[282] I refer to "Our Lady of Perpetual Help Home" by its actual name as per my agreement with the home's management. All other medical institutions mentioned in this chapter are identified by pseudonyms.

health care enables it to both create a new kind of end-of-life care and to provide this care to a patient population that lacks access to end-of-life care elsewhere in the system.

I examine the functioning and impact of this care on the home's patient population. Drawing on ethnographic interviews and observation. I argue that Our Lady's payment structure and treatment modality lead to the formation of close relationships amongst patients and between patients and staff. The result is the creation of a dynamic communal context that undercuts distinctions between patient and provider, as well as between patients of diverse racial, socioeconomic, and religious backgrounds. This communal context facilitates the delivery of medical care, while obviating both the isolation and the fragmentation characteristic of the hospice or nursing home setting.

Our Lady's exclusion from normal payment structures must, I claim, be understood in the context of the home's particularly Catholic conception of end-of-life care. Through interviews with members of the religious sisterhood that operates the home, as well as observation of patient care and daily mass, I argue that Our Lady's sisters base their care on the narrative of the death and resurrection of Jesus Christ. Because of Christ's death, the home's sisters are able to expedite their entry to Heaven through the act of caring for the dying poor. This incentive structure not only provides a basis for Our Lady's charity, but also transforms the home's conception of medical epistemology, patient-provider relations, and the substance of end-of-life care. Through this examination, I will show that Our Lady is not primarily a medical institution. It is a religious institution oriented toward the diffusion of the resurrected body of Christ. The vehicle for this diffusion, however, is the home's high quality long-term end-of-life care.

Our Lady's Catholic worldview might seem to limit its ability to reach a diverse patient population. Nevertheless, I claim that Our Lady's Catholicism enables the home to provide members of diverse religious faiths not only with excellent medical care, but also with the experience of Christ's resurrection. To make this claim, I will perform a structural analysis of one of the home's weekly leisure activities: Bingo. I will claim that the bingo game provides a vehicle for Christ's body precisely because of its lack of overt theological content. This lack of theological content makes the Resurrection digestible to a pluralistic population, who experience it not as a religious ceremony, but rather as a communal experience of joy. In this sense, the game not only conveys the content of the Eucharist, but also functions according to the Eucharistic mechanism of transubstantiation. This mechanism suffuses the totality of Our Lady's end-of-life care, giving the home a dramatically different character than other medical institutions.

I conclude arguing that Our Lady's Catholic practice of end-of-life care provides a starting point to address the problems in US hospice care that were discussed earlier in this dissertation. I begin by examining the facility's place in the US hospice system.

The Place of Our Lady of Perpetual Help in the Structure of US Hospice Care

As I discussed in Chapter 3 of this dissertation, within the US health care system, hospice care is defined as an outpatient benefit, delivered almost entirely to patients at home. This outpatient delivery structure presumes that the patient's long-term care needs will be addressed by their local kinship network. Such needs include, primarily, assistance with activities of daily living (ADLs), including eating, bathing, dressing, grooming, and basic hygienic maintenance. When patients lack sufficient kinship support to meet these needs, they are sent to nursing homes. Nevertheless, nursing homes, though meeting the patient's long-term care needs, cannot provide end-of-life care. Terminally ill patients in the nursing home setting must continue to receive hospice care on an outpatient basis. Consequently, the US health care system addresses the needs of terminally ill patients without sufficient kinship support by coordinating the services of two distinct medical institutions: hospices and nursing homes.

In Chapter 3, I examined such attempts at coordination through an ethnographic study of the relationship between Amberview Hospice and various Atlanta-area nursing homes. I argued that hospices and nursing homes are structured to have opposing attitudes toward death: While nursing home staff are professionally trained to perform every possible intervention to maintain patients alive, hospice staff are trained to remove interventions that delay or complicate their passing. These disparate training regimens are grounded in conflicting economic incentive structures, in that nursing homes and hospice compete with each other for the same pool of Medicare funding. The result is the creation of conflicting organizational cultures. Attempts to coordinate such conflicting treatment modalities are inherently problematic, resulting in routine services failures in patient care; these service failures, in turn, lead to staff burnout, unnecessary emergency room visits for patients, and complicated grieving processes for their loved ones and families.

Atlanta's Our Lady of Perpetual Help Home provides a radically different way of organizing end-of-life care. The home merges the qualities of a nursing home with those of a hospice. Like a nursing home, it provides long-term care with a focus on activities of daily living. And, like a hospice, it provides a range of holistic end-of-life treatments, including medical, spiritual, and psycho-social interventions. And yet, rather than understand these disparate treatment modalities to be conflicting, Our Lady's staff considers them to be complementary: Long-term care facilitates the delivery of end-of-life care, while successful end-of-life care can significantly increase the duration of the patient's "final days." By synthesizing these disparate treatment modalities, Our Lady represents an anomaly—and, to an extent, an impossibility—within the US health care system: a long-term, inpatient facility design for patients at the end-of-life.

The facility is operated by nuns. There are approximately twelve nuns in the home at a given time. These sisters are all nurses, both LPNs and RNs. They range from 40 to 90 years of age, but with most sisters in their 50s and 60s. The nuns preside over a health care facility that features one doctor and one social worker—both of whom work part-time—as well as approximately ten male nurses. Both the facility's architecture and its division of labor are gender segregated. On the first floor, male nurses care for male patients. The second floor features female patients who are cared for directly by the sisters. Nevertheless, the nuns themselves regularly visit with the male patients as well, and the sister serving as Nursing Coordinator oversees care on both floors. In addition, there is a receptionist, a social worker, janitors, groundskeepers, and an events coordinator, who schedules daily activities in the home. These 40 odd staff are responsible for the care of the home's approximately 20-25 patients.

To be admitted to Our Lady, these patients must meet three criteria. First, they must have a diagnosis of terminal cancer. Second, they must have foresworn all life-saving medical interventions such as chemotherapy. Third, all of the home's patients must show proof that they are unable to pay for their care or find immediate placement in another end-of-life facility. Such proof is generally provided not by the patients themselves, but rather by the social worker at the institution that refers them to Our Lady.

It can include financial statements as well as general explanations of why Our Lady's services are needed. Once admitted, these patients who were previously not able to find care in any facility are, ironically, able receive end-of-life care that would otherwise be virtually unavailable to even the most resource-rich patients in the health care system.

Our Lady can provide such anomalous care because of its unique financial structure. The home is a charitable institution. It operates entirely on donations, and refuses to accept any remuneration from patients or their families, including payments from Medicare or Medicaid. Because of its charitable status, Our Lady does not have to follow Medicare and Medicaid regulations that disincentivize the provision of long-term inpatient end-of-life care. Though its reliance on charity places limitations on Our Lady's funding structure, it also makes it possible for the home to combine treatment modalities that, within the US health care system, are considered to be incompatible. In this sense, though Our Lady's refusal of conventional forms of funding can be financially limiting, it is also generative in that it makes the home a site for a form of end-of-life care that is unique within the Atlanta region and the US health care system as a whole.

Our Lady's exclusion from the payment structures governing US health care makes the home extremely valuable to area end-of-life providers. Local hospices and hospitals rely on the home to care for patients whom they cannot easily accommodate in their own institutions. Such difficulties in accommodation may stem from a variety of factors, including a patient's lacking Medicaid or independent means to pay for nursing home care, a lack of available beds at area nursing facilities, or a patient's unwillingness to enter a nursing home. In such situations, hospice social workers may have to leave patients in home environments that are neglectful. In theory, these patients may be cared for at a hospice’s own inpatient facility. But the provision of such care is difficult: The vast majority of hospices do not have inpatient facilities; even if they do, they will not receive full Medicare reimbursement for providing patients with long-term inpatient care. Consequently, Medicaid and Medicare regulations strongly disincentivize hospices from accommodating patients without sufficient economic resources and kinship support. Area social workers refer such patients to Our Lady both as a means to care for these patients, as well as to spare their own institutions the cost of unreimbursed care.

And yet, Our Lady’s charitable payment structure is not the only reason why it remains a preferred discharge site for unwanted patients. Area social workers refer patients to the home because they believe that, Our Lady, patients will receive care that is significantly superior to that which they would otherwise receive at a nursing home. One social worker noted that, for cancerous patients without kinship support, her “first choice” was to place them at Our Lady. She clarified her opinion in the following terms:

> These nursing homes, some are less desirable. Have you been in them? [They’re] disgusting…. [Our Lady’s patients] get great care, and they’re a hospice. They provide all the pain and symptom control a patient needs.

This quotation reveals that Our Lady provides form of long-term end-of-life care that area providers consider to be significantly *better* than the provision of hospice care in the nursing home setting. This care is superior than the coordination of hospice and nursing homes because it is offered in an institution that seamlessly combines these two treatment modalities. The significance of Our Lady’s charitable structure is not solely that it allows the home to care for otherwise unwanted patients, but also that this structure makes it possible for the home to provide extremely high quality inpatient end-of-life care. I will now examine both the functioning of this care and its impact on Our Lady's patients.

"More Freedom": Medicine and Community in Our Lady of Perpetual Help Home

To gain a better understanding of Our Lady's care, I spent fifteen months conducting ethnographic research in the home. During this time, I visited the facility weekly, spending between six and eight hours per visit. At each visit, I talked with patients and staff, participated in leisure activities, and observed patient care in over forty patients. In addition to interviews with the home's staff—which I will discuss later—I interviewed eight terminally ill patients about the circumstances through which they came to the home, as well as the care they received. This combination of interviews and observation forms the basis of this analysis of Our Lady's practice of end-of-life care.

All of patients with whom I spoke at Our Lady had extremely positive assessments of the home. Many credited it with saving their lives. This plaudit may seem ironic, as Our Lady marked the end of their "life-saving" interventions; nevertheless, it was accurate in that their arrival at the home produced an immediate improvement in their condition. This improvement was due partly to the high quality of Our Lady's care and partly to the low quality of care they had received previously. Six of these patients had been home alone or with caretakers who were unable to meet their needs. The other two patients had come from inpatient hospices, where they had been expected to live only a few days. After surviving this prognosis they were discharged to Our Lady, generally with the expectation that they would die within a number of weeks. But, at the home, they stabilized and continued to live for months or—in two cases I observed—years.

Many of Our Lady's patients do not outlive their prognoses. But these patients enjoy a benefit that they might be stripped of were they in the regular US hospice system: They know where they are going to die. While, in theory, hospice patients know that they will die at home, such security eludes those patients who do not have sufficient kinship support. These patients are constantly at the risk of being moved—from home to the inpatient facility or the hospital, back to their home, or perhaps to a nursing home. Such shifts create anxiety in patients regarding both where they are going and who will be paying the bill. At Our Lady, terminally ill patients without means can spend their final days, weeks, and months of life without such concerns. As a result, they are able to focus on making their remaining time—however little—as meaningful as possible.

In addition to this security, Our Lady features various opportunities for socialization. Every day, the facility's event coordinator has arranged an event. Such events vary, including movies, Bible study, barbeques, Nintendo Wii, and—as I will discuss later—Bingo. Though attending the events is not required, the activities director strongly recommends them to patients, visiting patients daily to invite them to come. Should patients not choose to attend these events, they are free to spend time in the lounge, walking or wheeling along the home's garden paths, or just sitting at a bench or a shrine. Regardless of how much or little socialization the home's patients desire, socialization is an inextricable part of life at Our Lady. This socialization is a key reason why many of the home's patients enjoy the facility, as it presents a stark contrast to their situations as terminally ill individuals isolated at home or in nursing homes.

While such opportunities for socialization might be present in a conventional nursing home, what distinguishes Our Lady from such facilities is its scale. On each gender-segregated floor, there are generally between 15 and 20 patients. These patients are cared for by between 8 or 10 nurses in shifts of four. Nurses are encouraged to participate in home activities with patients. Through such familiarity, these activities facilitate the development of relationships among patients, as well as between patients and staff. Indeed, the high staff-patient ratio makes it possible for staff to have downtime, during which they congregate with patients. For example, it is not difficult, on a given weekday afternoon, to find two of the home's nurses watching *Walker, Texas Ranger* or *Family Feud* with a diverse group of patients in varying proximity to death.

From a conventional economics perspective, such "downtime" might be considered a waste of labor. Nevertheless, this perspective ignores the work that such moments of shared leisure perform in the context of Our Lady's end-of-life care. Such moments provide opportunities for staff members to relate with patients in a capacity *other than* as medical professionals. Through such non-medical practices of conviviality, patients come to see staff not as adversarial or superior figures, but rather as confidantes, fellow travelers, and even friends. In the process, they come to see themselves as more than patients with terminal cancer. They are able to reintegrate themselves into the sense of who they were prior to being stricken with terminal disease. This renewed sense of self encourages patients to socialize with Our Lady's other patients, thus creating a convivial environment that, though supported by patient-staff relations, is relatively self-sustaining.

In the context of such conviviality, medical care is not an intrusion, but rather an essential part of the relationship that develops between patient and staff. Each patient is assigned to one regular nurse, who attends to his or her daily needs regarding feeding, bathing, and hygiene. Every patient I spoke with highlighted that these extended relationships with their caretakers were a significant benefit of Our Lady's approach. Embodied caretaking practices such as cleaning, feeding, and bathing foster intimacy between patients and staff that complements the non-medical relationships they formed during leisure. For example, a nurse changing a patient's dressings may talk with him about non-medical subjects such as football, politics, or family life. Such non-medical conversations make medical care more palatable, even as the intimacy of corporeal labor fosters attachment between patient and provider alike. Our Lady's care thus epitomizes both the relational aspects of medicine, as well as the medical benefits of relationships.

This medical care is improved by the ability of Our Lady's staff to prescribe high intensity pain medications typically associated with hospice. Such medications are prescribed regularly to patients, but they are also available on an as-needed basis. The availability of such medications is a huge advantage over the delivery of high intensity pain medications in the nursing home setting. As I noted in Chapter 4, in such facilities, pain medications are assigned in standardized dosages because hospice personnel have no guarantee that a qualified nurse will be available to administer them. In contrast to this standardized approach, Our Lady offers pain medication that responds directly to patient need. The result is both more economically efficient and more medically effective.

Our Lady's unique structure also allows for the creation of new spaces of conviviality between patients. One such space is the smoking lounge. The home features one designated "smoking lounge" on each floor. These smoking lounges are necessary because, though many of Our Lady's patients continue to smoke, they are not allowed to do so in their rooms. Each smoking lounge is adjacent to the floor's regular lounge, separated from it by a glass window and door. Such smoking lounges force patients to congregate in a communal space. In this process, they foster relationships between patients who, outside of Our Lady, would likely never have interacted at all.

I observed one such relationship in a group of patients whom the home's staff affectionately referred to as the "Three Musketeers." The Three Musketeers were three women, all in their 60s, who were dying of cancer. One woman was a white drug addict who had recently watched her own daughter die in hospice. Another was a white divorcee who had previously worked as schoolteacher. The last was a recently widowed African-American woman whose son worked for the CIA. These women came from radically different racial, class, and professional backgrounds. And yet, they congregated every afternoon for several hours to smoke cigarettes and gossip about the day's events, their own respective familial problems, their issues that they were having within Our Lady, and, occasionally, their thoughts and feelings about dying. Though such a smoking lounge might not seem to be a health-promoting space from a traditional public health perspective, in the context of end-of-life care, it provided a venue for the formation of nourishing personal relationships that would have otherwise been difficult to cultivate.

Within liberal political theory, the creation of such communal spaces is typically seen in opposition to the promotion of individual liberty in the private sphere.[283] And yet, it is precisely through its dynamic communal environment that Our Lady provides its patients with a sense of freedom that is lacking in traditional medical institutions. The benefits of such freedom was highlighted to me by a patient whom I will refer to as Bill:

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[283] For an excellent survey on the relationship between individual liberty and communal belonging in liberal political theory, see Hans Theodorus Blokland, *Freedom and Culture in Western Society* (London: Routledge, 1997).

> [At Our Lady] they don't do what many places do—that is to say, they order you about. And this place doesn't. And to that extent you have more freedom and feel freer… [T]he feeling of freedom this place engenders is better than the places I've been to before--the hospital and the rehabilitation place for the muscular drills…. The hospital used one of my arms for a needle trial of some new nurses... And that was not fun…. The hospital did that, not the rehabilitation people, who… let me go my own way with a wheelchair, which I enjoyed. So it was somewhat freer, but you always had the feeling that you could be told what to do, and the feeling that this place engenders is so much freer by not giving you that feeling, that I enjoy being here considerably more than being at the other places.

Here, Bill contrasts Our Lady with the hospitals and rehabilitation centers where he previously received treatment. While those others sites inhibited his freedom through their rigid schedules, Our Lady gave him "more freedom" simply by allowing him to live as he sees fit. And yet, this freedom is based in the home's high quality provision of end-of-life care. In this sense, Bill's experience undercuts the dichotomy between individual liberty and communal belonging structuring much liberal political thought. He was able to exercise his freedom as an isolated individual precisely because Our Lady provided him with a sustaining communal environment. I will now emphasize the profound impact that the home's care can have on patients—as well as the means through which patients arrive there—through a case study of a patient whom I will refer to as Simon.

Simon's Case

When I met Simon, he was 48 years old. Prior to arriving at Our Lady, he had worked in the hospitality industry in Florida. When the financial crisis hit in 2008, he was laid off from this job of over ten years. He lived alone at the time, but decided to move to Missouri to be near his son, as well as his first wife, with whom he was still close. There, he found work at a supermarket, but began feeling a pain in his left arm. After a severe episode, he went to the emergency room, where he was found to have tumor in his lung so large that it was breaking his ribs.

Simon paid for his chemotherapy and radiation through a combination of Medicaid and charitable donations. But after there was no remission, his doctor recommended hospice. At some point, his hospital social worker recommended that Simon obtain Social Security Disability Insurance (SSD). SSD gave him an income, but this income was too high for him to qualify for Medicaid and too low for him to pay for a nursing home. But, while eliminating his Medicaid, Simon's SSD was not sufficient for him to live alone. He thus moved to his brother's house in Atlanta.

At his brother's, Simon began home hospice care. As he was under 65, he did not yet have Medicare, and he would need to receive SSD for two years to qualify for it—an infinity of time, given his prognosis of a few months. Simon did not pay for his own hospice care. Though the identity and means through which he paid was unclear to him—he emphasized that his hospice social worker had arranged it—it is likely that the hospice organization provided him with charitable care at home. This care was sufficient until his brother found work as a trucker, a job that required that he spend long stretches of time away from home. Simon's niece cared for him in his brother's absence, but then, in the fall of 2011, she left for college. As a result, Simon was left alone in the house.

Simon deteriorated after his brother and niece’s departure. His brother’s house was filled with stairs, and he fell several times. At the same time, the suburban Atlanta neighborhood isolated him. He went weeks with little more than sporadic face-to-face interactions with his hospice caretakers, whose work largely consisted of providing him with pain medication, which he would later administer himself. Due to these factors, Simon became depressed. He slept as much as fourteen hours a day, and largely stopped eating. He experienced significant cognitive impairments for the first time, including a general lack of awareness and short-term memory loss.

Simon and his brother decided that he needed to be transferred to an inpatient facility. But while his Social Security Disability disqualified him from Medicaid, it was insufficient by itself to pay for a nursing home stay. Though he may have been able to give up his SSD to go back on Medicaid, he was reluctant to resign his only source of income; in addition, neither he nor his social worker looked forward to the prospect of his living in a nursing home. Furthermore, transferring him to Medicaid and then placing him in a nursing home could have taken weeks, and his hospice lacked an inpatient facility in which to house him in the meantime. There was thus no easy way in which Simon would be given adequate hospice care in the immediate future. He could continue home care, but such care was decreasing his quality of life and likely hastening his death.

Following his hospice social worker’s advice, Simon applied for and received admission to Our Lady. After entering, his quality of life and condition significantly improved. He resumed sleeping eight hours a night and eating regularly. He had daily opportunities for socialization with the home’s patients, nuns, and nurses, and was able move freely in the institution, which is completely accessible. He had regular visits from family and friends, as well as volunteers. He stayed there for nine months—having outlasted his initial prognosis by almost a year—and, though the home did not cure him of cancer or prevent his death, it gave him the opportunity to live out the final months of his life in relative calm, with high level medical care, a stable environment, and regular socialization. He was one of the patients I spoke to who claimed that Our Lady had, indeed, "saved" his life.

Simon's case illustrates both how patients arrive at Our Lady, as well as the profound impact the home's care has on them. This impact is made possible by Our Lady's charitable structure, which allows the home to provide its unique blend of long-term and end-of-life. Nevertheless, Our Lady's generative exclusion from normal payment structures raises a fundamental question: *Why* does Our Lady function according to a financial incentive structure that differs radically from other medical institutions in the US health care system? Understanding this incentive structure entails studying the order of nuns that operates Our Lady: the Hawthorne Dominicans.

Rose Hawthorne Lathrop and the Hawthorne Dominicans

Our Lady of Perpetual Help Home is run by the Dominican Sisters of Hawthorne (also known as the "Hawthorne Dominicans"), a group of Dominican nuns who were founded in 1900 by Rose Hawthorne Lathrop, the youngest daughter of American novelist Nathaniel Hawthorne. Raised a Unitarian, Lathrop converted to Catholicism at the age of 40, in 1891.[284] This conversion was a formative moment in Lathrop's life, and

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[284] Patricia D. Valenti, *To Myself a Stranger: A Biography of Rose Hawthorne Lathrop*, (Baton Rouge: LSU Press, 1991), 100.

it eventually led her, in 1896, to leave her husband, become a nun, and consecrate her life to the charitable labor of caring for the cancerous poor.[285]

Taking out a small apartment in Manhattan's Lower East Side, Lathrop placed an advertisement in the *New York Times*, in which she invited all cancerous patients in need of treatment to come to her for free care.[286] Such patients were particularly in need of care since, at the time—shortly after the discovery of germ theory—cancer patients were shunned by physicians as being both incurable and contagious.[287] Nevertheless, Lathrop cared for them, at first by herself, then later with the aid of a group of females followers. In 1906, these women eventually succeeded in gaining official recognition from the Catholic Church, and joining the Dominican Order.[288]

With the help of many donors, the Hawthorne Dominicans have undergone a remarkable expansion. Over the 20th century, they opened up as many as seven nursing homes in the US and one in Kenya. Nevertheless, in recent years, the sisters have scaled back their activities, closing their Kenyan location as well as four of the US homes. As members of the order have explained to me, this downsizing has not occurred due to a lack of financial resources, but rather because of decreased recruitment and older members passing away.

At present, there are three active Hawthorne Dominican facilities: Rosary Hill Home, located just outside of Manhattan, in Hawthorne; Sacred Heart Home, in

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[285] Ibid., 129.

[286] Ibid.,137.

[287] Ibid.,144.

[288] Ibid.,152.

Philadelphia; and Atlanta's Our Lady of Perpetual Help Home. Though these homes differ in size, they all have a similar structure: They provide long-term, charitable end-of-life care to patients who have no other feasible options for end-of-life care. This institutional identity gives them a unique place in the US health care system. Nevertheless, this identity cannot be disentangled from their uniquely Catholic framework through which they both understand and practice their work.

In what follows, I will draw on conversations with four members of the Hawthorne Dominicans—all of whom work or have worked at Our Lady—and one of the order's priests in order to reconstruct the worldview that informs and enables the Hawthorne Dominicans' practice of end-of-life care. Though my knowledge of this worldview is mainly drawn from these conversations, I will, when possible, provide citation to relevant passages from the *Cathecism of the Catholic Church*. Together, these interviews and textual sources provide a rich picture of a practice of end-of-life care that is grounded in an idiosyncratic and powerful understanding of death.

Death, Works, Resurrection: A Catholic Framework for End-of-Life Care

As Catholics, the sisters of Our Lady of Perpetual Help Home believe that the universe was created by a being they call "God." God's chief characteristic is having created something from nothing. He is simultaneously invisible, yet present in all that exists. As the creator, God created humans in his own image and gave them free will. Adam and Eve, the first humans, used this free will to betray God. As a result of this Original Sin, they condemned all of humankind to a condition of sinfulness.[289]

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[289] United States Conference of Catholic Bishops, *United States Catholic Catechism for Adults*, (Washington, DC: USCCB Communications, 2006), 67-77.

Nevertheless, though angry at humanity, God also loved them. Because of this love, he sent them his son, Jesus Christ. Christ, in the Catholic understanding solidified after the first Council of Nicaea, is equally God and human.[290] As a human, Christ was capable of free will, and also capable of death. To atone for humanity's Original Sin, he gave himself up to die on the cross. And yet, three days after his death, Christ was resurrected from the dead. If his death proved his humanity, then his resurrection from death asserted his divinity. By having faith in Christ, humans can share in this Resurrection and overcome, at least partially, their own sinful nature. As a result, they can live on spiritually, after their physical deaths, with God and his son.[291]

This belief in Christ's death and resurrection is, in large part, common to all Christian denominations.[292] What makes Catholicism unique is its belief that Christ's will is embodied in an Earthly institutional structure, the Catholic Church, whose chief representative is the Pope. The Church is in place to interpret the will of God in the context of a shifting social reality.[293] Though, during my research—which occurred under the papacy of Pope Benedict XVI—some US nuns questioned the Papacy's teaching on social issues such as abortion and gay marriage, the sisters of Our Lady were extremely

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[290] Diarmaid MacCulloch, *Christianity: The First Three Thousand Years*, (New York. Viking, 2009),146-7.

[291] United States Conference of Catholic Bishops. *United States Catholic Catechism for Adults*, 77-88.

[292] MacCulloch, *Christianity: The First Three Thousand Years*.

[293] United States Conference of Catholic Bishops. *United States Catholic Catechism for Adults*, 32.

conservative in their adherence to the Magisterium.[294] As one sister put it: “The Holy Father represents Jesus Christ. If we can't be faithful to Jesus' representative… then why are we doing what we are doing?”

Adherence to the Papacy is reinforced by the sisters’ views on faith and works. As Father Brewer—the priest I interviewed—put it: “In the Catholic interpretation of salvation… humans are saved by grace through faith, but we are called to cooperate with that grace… by doing good works.” Thus, in Catholicism, though faith is a precondition of salvation, works are valuable means of demonstrating one’s commitment to Christ and ensuring one’s place in Heaven. This relationship between faith and works is another distinction between Catholicism and Protestant strands of Christianity. This distinction can only be understood in the context of the Catholic conception of the afterlife.

Within Catholicism, the afterlife is divided into three realms: Heaven, Hell, and Purgatory. Heaven is where the Holy Trinity, the Virgin Mary, and the angels and saints reside; as a result of Christ’s death and resurrection, it is open for all those who love God.[295] Purgatory is the realm for Catholics who need their love of God purified prior to gaining access to Heaven.[296] Hell is the region for individuals who have willfully forsaken God.[297] It is considered to be “eternal death.”[298] In other words, because of the

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[294] Stephanie Simon, “Vatican Crackdown on U.S. Nuns a Long Time Brewing,” *Reuters*, April 20, 2012, http://www.reuters.com/article/2012/04/20/us-usa-vatican-nuns-idUSBRE83J1B720120420.

[295] United States Conference of Catholic Bishops. *United States Catholic Catechism for Adults*, 153.

[296] Ibid., 154.

[297] Ibid., 155.

doctrine of resurrection, Earthly death is transient, with the deceased transitioning to a different form of life with God. “Eternal death” is the *abandonment* of the individual by God. In this sense, both death and life and in the Catholic tradition are fundamentally intersubjective: They are particular forms of a relationship between the individual and God.

The spiritual transitioning of individuals from life on Earth to life in Heaven, Hell, or Purgatory is a preface to their eventual material resurrection at the Last Judgment. Within the Catholic tradition, at the Last Judgment, Christ will return to Earth and cast judgment on the resurrected dead.[299] Those who have loved God will be allowed to live in body with him in the Kingdom of God. Those who have not been good Catholics, however, will be banned from the Kingdom and sent to the “eternal fire” with the devil.[300] In this sense, though death does precede resurrection in the Catholic tradition, resurrection itself does not guarantee escape from eternal death. Escape from such death is an *act*, a consequence of both Christ’s judgment, as well the individual’s own performance of good works in life. In this sense, through the performance of good works, one facilitates one’s own resurrection to the Kingdom of God.

This enactment of resurrection through good works is the primary justification that the sisters I interviewed gave for the enormous sacrifices they make by entering religious life. As a sister I whom I will call “Matilda” explained:

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[298] Ibid., 161.

[299] Ibid., 157.

[300] Ibid.

> I've given my whole life because I believe this. I believe in the Resurrection. I believe that one day our body and our souls will be reunited with the lord and we will go to heaven and be with the Heavenly Father, the Trinity, all the saints, our relatives, our family members that have gone before us…. And I hope and pray that [Jesus] will say to me "Well done, my good and faithful servant." Because that's what I long to hear, those words "Well done, you have served me well. Come share my father's joy."

Sister Matilda reaffirms her belief that her works will give her a place in Heaven. In this sense, she emphasized that she was not doing this work as an act of charity offered without hope of recompense; on the contrary, she worked for the recompense of resurrection, one that can only be understood within the terms of Catholic religious belief. This compensation is what justifies what, in a sense, is the sister's sacrifice of her Earthly life by entering the order; indeed, though Sister Matilda expressed her extreme joy at being a nun, she also emphasized that it had been a difficult decision for her, because she had wanted to have a family. Such sacrifices were, in the sisters I interviewed, only comprehensible in the light of the Resurrection. And it is by virtue of their understanding of compensation through resurrection that the sisters formulate a unique perspective on exactly *who* the actors are involved in end-of-life care.

Through Sister Matilda's description of herself as *giving her own life*, she draws an implicit parallel between her situation and that of Jesus, as well as God. As she noted to me later in our conversation, both God and Jesus had to make enormous sacrifices—that of Jesus's very life—to save humanity. Through her own sacrifice of the life she could have enjoyed, Sister Matilda is at once inspired by and representative of Jesus's sacrifice. In fact, Sister Matilda referred to herself in the conversation as "on the cross" with Jesus. This identification with Jesus might seem narcissistic, but it is the very point that enables the sisters of Our Lady to empathize with their patients—patients whom, to them, represent the suffering Jesus just as much as they do themselves.

"Seeing Jesus:" The Human God, the Wounded Healer, and the Community of the Dying

All of the sisters I spoke with were emphatic about their attempts to "see Jesus" in the patients under their care. By "seeing Jesus," the sisters treat each patient as if he or she were Jesus Christ. This goal of seeing Christ in each patient is enforced in the training that the sisters receive as they enter the order. Prior to being officially placed, sisters undergo training at the "Mother House," Rosary Hill Home in Hawthorne, New York. This training begins with an education in religious empathy, in which sisters are taught to see Jesus in the world, and, particularly, in the patients under their care. This religious education precedes any formal medical training the sisters receive, and all subsequent medical education is congruent with and based upon this initial injunction to see Jesus. The practice of "seeing Jesus," then, defines care at Our Lady.

In the context of end-of-life care, Christianity is perhaps uniquely qualified to foster such identification because it is a religion centered around a dying man and his grieving family. As such, the nuns identify Christ with terminally ill patients, while understanding these patients' families through other key biblical figures, such as the Virgin Mary, Mary Magdalene, and Saint Joseph. At times, this identification can be extremely literal, and facilitated by the iconographic representations of the crucifixion that are present in each one of the home's rooms. One sister remarked to me that as dying cancer patients become increasingly thin, "their cheeks hollow out and they look just like Jesus on the cross." But such a literal interpretation of "seeing Jesus" was rare among the sisters I spoke with; instead, Christ's iconographic body opened a gateway toward a world of shared resemblances that undercut physical appearance.

As Father Brewer describes, the identification between Jesus and dying patients would not, in a "mature" formulation, be based on physical resemblance, but rather on a shared suffering that underlies surface appearances and contemporary medical categories. Describing the relationship of his practice of seeing Jesus in patients to his looking at the cross, he explained: "When I look at the cross of Christ I think of [the patients] going through their cross. Or me going through my cross." Here, the physical suffering of Jesus on the cross is shown to have a broader meaning than its literal resemblance to the suffering of dying patients. It signifies Father Brewer's own suffering, suffering that is a universal aspect of the human condition, even as it is grounded in his own particular life experience. Thus, the dying Jesus is present not only in the literal bodies of dying patients, but also in *all* bodies, including those of Our Lady's religious staff.

The universality of Jesus' suffering—its presence in our very embodiment—radically reconfigures the relationship between patient and provider at Our Lady. Rather than a binary opposition between the healthy and the sick, patient and provider are themselves both sick and, in a sense, dying. As one sister commented: "So we see Christ in the patients and their families and we hope they see Christ in us. And so it's just like a continuous thing of going from Christ to Christ to Christ." As the sister explains, at Our Lady, there is no outside of Christ: The practice of seeing Jesus breaks down the typical barriers structuring the delivery of medical care, revealing a common substance underlying both patient and provider. This substance is nothing less than death itself. The sisters carry the dying Christ within their very bodies, bodies which, in their own mortality, are, like Christ, bound for death.

In this sense, the sisters of Our Lady epitomize Henry Nouwen's ideal of the "wounded healer," a medico-religious provider whose own sense of suffering is the very tool through which patient care is enacted.[301] In the process, they will into being Nancy Eiesland's conception of an all-inclusive community based on the presence of Christ's body in the world.[302] But while Eieseland's conception of Christ is based on disability, the sisters of Our Lady believe in the *dying God*. At Our Lady, it is through the dying Christ that all humans are united in a shared orientation toward death.

Thus, though the sisters only accept patients who adhere to the medical category of "terminal illness," their own religious understanding of end-of-life care is a powerful rejection of this category. For the sisters of Our Lady, to be "terminally ill" is not a state confined to those with a prognosis of six months or less to live. It is a constitutive feature of human embodiment in the wake of Christ's self-sacrifice. The home's sisters are, in this sense, every bit as "terminal" as the human-God they worship and the patients they treat. And yet, though the sisters believe that all humans are, like Christ, bound toward death, the Christ narrative also assures them that death is not the endpoint of life.

The Resurrected Body: Morning Mass and the Eucharistic Enactment

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[301] Henri J. M. Nouwen, *The Wounded Healer: Ministry in Contemporary Society*, (New York: An Image Book Doubleday, 1979).

[302] Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability*, (Nashville: Abingdon Press, 1994).

If Christianity is oriented around a dying man, it is also oriented around the resurrected Son of God. And just as the sisters use Christ's death to identify with their own suffering as well as that of their patients, Christ's resurrection from the dead serves as an example that even the most heinous suffering can be relieved. The result is not only a new conception of patient-provider relations, but also a transformation of the very *substance* of medical care. Understanding this transformation entails studying the Catholic conception of the Eucharist, and the role that the mass plays in the sisters' life.

The sisters I spoke with highlighted the importance of mass in their daily activities. The sisters attend mass every morning at 6:30AM and every afternoon at 4:00PM. In mass they relive the story of the death and resurrection of Jesus Christ. The service concludes with their receiving the communion wine and wafer. They then follow the priest out to the rooms of the patients. There, the priest gives communion to all the Catholic patients, and says a prayer over the patients who are not of the Catholic faith. The sisters I interviewed all agreed that receiving communion was the singular most important activity in giving them the strength to carry out the grueling work of caring for the dying. It is also the defining act that differentiated them from secular medical professionals. As Sister Matilda explained: "The mass is our food, our nourishment for the soul. Without that, I could go anywhere and be a nurse, do oncology work, do hospice." The mass, then—and specifically the Eucharist—gives care at Our Lady both its underlying meaning and motivational force.

The seemingly mystical power of the communion wine and wafer is grounded in a Catholic understanding of the Eucharist. As Father Brewer explained:

> [T]he resurrected Christ truly becomes present and alive to us... in the

> Eucharist … [W]e claim even though the elements appear still to be bread and wine that it actually is Christ there. So when we receive it, Christ comes into our hearts and as such his power dwells in our hearts. To inspire us and to strengthen us to go out and to live the Catholic faith. To do the Christian work.

As Father Brewer explains, the Eucharist is, for the sisters, the literal resurrected body of Christ. Taking communion every morning, then, not only affirms their faith in Christ's resurrection, but also allows them to take part in it. Thus, though they suffer as Christ, they are also saved through him as well.

But to be saved through Christ is not itself enough. Such salvation contains within it the desire to spread it to others. But unlike missionary Christian denominations, Our Lady's sisters do not spread salvation through the Holy Word. Rather, they spread salvation it through the holy body. But the vehicle of this resurrected body is not the literal Eucharist. It is the very medical care that they provide to dying patients and their families. Sister Matilda explains:

> [W]e receive [Christ] into our soul through communion. And it's that that gives us strength, knowing that the lord died on that cross… [W]e take in that divinity of Christ within us, and we have to be Christ bearers…. What would we do if we received him and did not take him to others? That's not what he wants us to do. What we do is, we take him out to the patients, the families, to visitors. In other words, that love of Christ has to dwell within us. It has to be something that nourishes us so that we can also nourish others, nourish them through the love of Christ.

Sister Matilda explains that through communion the sisters become the bearers of the resurrected body of Christ. This resurrected body is the substance of the medical care they provide. Thus, Our Lady is not, in a strict sense, a medical institution. It is a religious institution oriented toward spreading Christ's resurrection. And yet, it spreads this resurrection not by proselytization, but rather through its high level of medical care.

This emphasis on Christ's resurrected body might seem to impede the ability to Our Lady's sisters to care for a religiously diverse population. But precisely the opposite is the case. Our Lady is a medical institution that precisely *because* of its strong Catholic faith, provides an exemplar of religious pluralism. The home shows that religious belief can be used to create an environment in which people of diverse backgrounds can experience a particular tradition's vision of the divine. I will illustrate this claim through an example that is fitting in part because it seems neither seems neither religious nor medical: Bingo.

Bingo and the Sacred: Christ's Body, Pluralism, and the Totality of Care

Leisure activities are a huge part of life at Our Lady. The home's event coordinator schedules such activities every day. They range from games of poker and Nintendo Wii bowling to excursions to watch the Braves play at Turner Field, which is located next door to the home. While these leisure activities seem innocuous, I will here argue that they serve functions that are both medical and religious. They are vehicles for Christ's resurrected body; as such, they reconfigure communal relations in a manner that nullifies existing dichotomies between the dying and their caretakers. They do so, however, without any explicit medical and religious content. In order to understand how this is possible, I will conduct an analysis of a Bingo game at the home.

The Bingo game began at 3:00PM on a Monday in November. Attending the game were five patients. All of them had late-stage terminal cancer. There were two women and three men. Two of the patients (one woman and one man) were Caucasian, while the other three (two men and one woman) were African-American. They were all from extremely different backgrounds. And yet, in spite of their differences, the patients had an easy rapport with one another that had come from their having spent several weeks—and in some cases months—at Our Lady, in an environment that, because of its small size, high level of care, and regular activities, encouraged such easy relationships.

These five patients were accompanied by four staff members: the event coordinator, a male nurse, and two female janitors; in addition to these staff, I also assisted in the game in my capacity as an ethnographer. The event coordinator rolled the balls in the Bingo cage and then called them out. The two janitorial staff members—both female—and I helped patients with placing their chips on the correct numbers, and cheered them on throughout the game. The male nurse took a seat at the table and spent the entire game joking with the patients—teasing them about splitting their winnings with him, and also mock scheming to get his hands on the prizes. In another context, such jesting might seem inappropriate, but it came as a result of the rapport that had developed between this nurse and both patients and staff after many months working together. Everyone there knew everyone else. As a result, the staff members did not seem as if they were tending to patients; they seemed as if they were spending time with friends.

The friendly rapport among patients and between patients and staff was aided by the prizes available for the game. Winners would be able to choose between lottery tickets, large gift baskets, or various food items. There were over fifteen rewards available for the five patients playing. As a result, every participant won at least one reward, and some as many as three. But, because each person ended up a winner, the game was devoid of acrimony among the participants. On the contrary, the players actively rooted for each other, with the winners cheering on those who had yet to score a winning ticket and everyone cheering when someone won.

As a result of these factors—the close relationships among patients and between patients and staff, the non-competitive reward system—something happened that was, for me, rather unexpected: The Bingo game was a lot of fun. In fact, going into the game, I was accompanied by a sense of dread that had been reinforced by previous Bingo (and gaming) experiences at other facilities for the elderly and terminally and chronically ill—static environments with patients in varying states of consciousness fighting with each other to win a Twix bar. But at Our Lady, the predominant sense of the Bingo game was one of joy, the predominant moment of expression was not speech so much as laughter. Patients and staff alike spent the game in one rollicking festival of laughter, teasing each other as they worked their way through the prizes. The result was not only a burst of enthusiasm from all of the participants, but also a memory that everyone who had played would use to relate to each other for weeks to come, and would be placed in conversation with the myriad of other social opportunities available to the home's patients.

The bingo game illustrates Our Lady's conception of death and resurrection. It embodies a conception of dying as a universal state of being that cuts across the secular distinction between patient and provider, allowing both to participate in the game as equals. This egalitarian framework is embodied in the non-competitive nature of the game, in which the prizes, like the Resurrection, are available to everyone who plays.

Thus, just as both the patients and provider playing the game were, within Our Lady's framework, terminally ill, so to the game itself can be seen as a vehicle of Christ's resurrected body. In this sense, the game is not different from the home's "medical" care and, indeed, the home's Catholic framework cuts across the distinctions between medical, psycho-social, and home health care that structure secular end-of-life institutions. Our Lady's end-of-life care is unified in its transmission of Christ's resurrected body.

This raises a question: How can a Bingo game provide a group of non-Catholics with the experience of Christ's resurrection? There are three major obstacles to such a diffusion of the Eucharistic body. The first comes from the Church itself, which prohibits the administration of the Eucharist to non-Catholics. The second comes from non-Catholic patients themselves who, presumably, would be reticent to ingest the resurrected body of a man in whose divinity they may not believe. The third comes from Our Lady's sisters themselves, who, though welcoming converts, do not proselytize and fastidiously respect the religious preferences (or lack thereof) of their patients. Consequently, Catholic doctrine, non-Catholic queasiness, and the principle of religious tolerance would all seem to obstruct the provision of Christ's body to Our Lady's patients.

These obstacles are circumvented through a mechanism than can be understood in innately Catholic terms: The Bingo game operates like the Eucharist. The Eucharist is, for Catholics, the literal body of Christ. And yet, it cannot appear as such. If it did, Catholic congregations would be averse to ingesting it. It is because of this aversion that Christ's body appears not in its literal form, but rather in the Communion wafer. Catholic congregations have no such aversion to the consumption of wafers. Though, by doing so, they are technically consuming Christ's body, their consumption of this body depends on its appearance as an innocuous food product (United States Conference 2006, 213-232). Consequently, the communion wafer enacts a superficial separation between its manifest form (a wafer) and its latent content (Christ's body). This superficial is necessary so that Christ's body may be consumed.

At Our Lady, end-of-life care functions in a manner that is structurally identical to the communion wafer. The home's care is, like the wafer, an embodiment of Christ's resurrected body. Nevertheless, while the wafer does so in a way that is digestible to Catholics in particular, the home's end-of-life care conveys its theological content in a way that it can be digested by non-Catholics. Consequently, if Christ's resurrected body is the substance of Our Lady's end-of-life care, then the Eucharist provides a model for the mechanism by which this body is converted into end-of-life care that can be received by a pluralistic patient population. The transmission of this body is not limited to any particular aspect of Our Lady's care. Much like Our Lady's caretaking environment blurs the lines between medical and non-medical forms of care, so too the transmission of this body permeates the institution as a totality.

Because of the totalizing nature of its care, it might seem that Our Lady is a "total institution," in the model of Erving Goffman.[303] Goffman argued that such "total institutions," such as the asylum, the hospital, or the prison, segregate a certain population group and rigorously control every aspect of their lives. Such total institutions define patients solely in terms of their stigmatized identities. In the process, they submit patients to a rigidly controlled environment that seeks to eliminate all freedom; in such

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[303] Goffman, *Asylums*.

cases, freedom is only possible through the subversion of institutional norms. Anthropologists and sociologists have produced admirable catalogs of such institutions.[304] In Chapters 3 this dissertation, I identified similar features in hospice and nursing home care.

And yet, though Our Lady's care is totalizing, the home is a different kind of total institution. Though the home cares for every aspect of the patient's life, this care is oriented toward *de-stigmitizing* the patient, toward separating the patient from his or her identity as an isolated terminally ill individual, and integrating him or her into the community of the dying. Such integration does not nullify patient subjectivity, but rather provides a novel vehicle for its expression—helping patients to reinhabit the body that was, initially, ruptured by the onset of terminal disease. In this sense, the basis of Our Lady's totality in Christ's resurrected body makes the home into an unusual total institution: a total institution that promotes freedom among its inhabitants.

Conclusion: Resurrecting the Socially Dead

In Chapter 1 of this dissertation, I argued that the field of bioethics should be oriented around a concept of "social death." This concept is a counterpoint to the dominant conception of death in bioethics, which understands death to be an isolated biological event impacting either the "person" or the "organism." "Social death," in contrast, understands death to be a social process that is relatively autonomous of the

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[304] Howard S. Becker, "The Politics of Presentation: Goffman and Total Institutions," *Symbolic Interaction* 26, no. 4 (2003): 659-69; Debora A. Paterniti, "The Micropolitics of Identity in Adverse Circumstance: A Study of Identity Making in a Total Institution," *Journal of Contemporary Ethnography* 29, no. 1 (2000): 93-119; Susie Scott, "Revisiting the Total Institution: Performative Regulation in the Reinventive Institution," *Sociology* 44, no. 2 (2010): 213-31.

individual's biological matter. Thus, it is possible for biologically deceased individuals to maintain social life through practices of memorialization, just as biologically living individuals can be socially dead through their processes of social neglect. Such neglect is holistic, involving cultural, social, economic, legal, and biomedical dimensions. By examining the production of social death, bioethicists can significantly improve the field's ability to negotiate both cultural differences and power dynamics in clinical settings and health policy. At the same time, "social death" provides a normative orientation for bioethics, as a field oriented to the resurrection of the socially dead. In this sense, "social death" refigures the epistemology, methodology, and goals of bioethics as a field.

This concept of social death provides a valuable rubric to understand this dissertation's larger argument about US hospice care. By defining death as a matter of private kinship, the US hospice system excludes those patients who lack kinship support. As a result of their inability to cohere with the normative understanding of death in hospice, such patients are condemned to "social death;" such social death is manifest in either the abandonment of the private home or the fragmentation of the nursing home. The production of such social death is inherent to the normal functioning of the hospice system, as it is conceptualized in the economic incentive structure and medical epistemology of the Medicare Hospice Benefit. Responding to this social death entails developing a new model of medicine and economics and, ultimately, a different understanding of death itself.

Our Lady of Perpetual Help Home provides a starting point for such a model. The home takes patients who were abandoned within the US health care system and integrates them into a dynamic community in which they are considered equal members. In the process, it provides these patients with holistic care that allows them to reclaim their sense of identity and experience a form of joy would otherwise elude them within ambit of US end-of-life care. In this sense, Our Lady provides an example of an "exceptional" institution within the US health care system: an institution that is oriented toward the resurrection of the socially dead. This orientation, however, is only made possible because of the home's foundation as a theological institution based in the diffusion of Christ's resurrected body.

But, while Our Lady's Catholic worldview makes possible its exceptional form of care, it also limits the home's ability to serve as a model for the reorganization of US hospice care. Our Lady's charitable payment structure restricts the number and kind of patients the home can accept, as well as the form of care that it can offer. Though the institution subverts the normal logic of the US hospice system, it also depends on this system to provide outpatient care to patients at home and to care for patients whose diagnosis or personal situation would disqualify them from admission to Our Lady. More fundamentally, while Our Lady's care is—as I have shown—highly effective within a pluralistic patient population, it is limited in its ability to serve as a model for the secular medical and political institutions governing the administration of US end-of-life care.

In this sense, if Our Lady is to provide a way forward, it will first be necessary to translate the home's theological foundation into the secular lexicon of US medical and political institutions. In the conclusion of this dissertation, I will draw on this research to enact such a work of translation and, in the process, to present a new model for the organization and functioning of US hospice care. To do so, I must return to the defining methodological project of this dissertation: the development of a disability studies approach to the bioethics of death.

Conclusion

The Reform of US Hospice Care as a Bioethical Project

This dissertation has been an attempt to develop a disability studies approach to the bioethics of death. I began by examining how the definition of death within bioethics served as a barrier to a consideration of the socio-historical context in which death occurred. Such a context was not, I claimed, "contextual," but rather constitutive of death itself. Through such an understanding, I was able to argue that an inquiry into the practice of US hospice care could simultaneously be a bioethical exploration of the definition of death. Then, I undertook this exploration through a historical and ethnographic analysis of US hospice care. In this analysis, I argued that, by defining death as a matter of private kinship, the underlying medical epistemology of US hospice care leads to either the abandonment or the fragmentation of patients without kinship support. Through a study of Atlanta's Our Lady of Perpetual Help Home, I explored an alternative manner of organizing the epistemology, institutional structure, and treatment modality of this care.

In this "Conclusion," I will link my bioethical reflections on the definition of death with my historical and ethnographic research on hospice. I will begin by rethinking the category of "natural death" in US bioethics. Through this rethinking, I claim that the provision of appropriate end-of-life care is the precondition of a "natural death." But this raises the question: What is "appropriate" end-of-life care? Drawing on my fieldwork, I argue that the current definition of end-of-life care within the US hospice system is, in fact, highly "inappropriate" for patients who lack sufficient kinship support. I then advocate for a number of reforms in US hospice care that will better address the needs of these patients. By linking such reform projects to the very nature of death, I propose a new model for both the bioethical regulation of end-of-life care and the medical and economic structure of end-of-life care in the US health system. Tying these two projects together epitomizes a disability studies approach to bioethics at the end-of-life.

Redefining a "Natural Death": Toward a Bioethics that takes End-of-Life Care Seriously

Since the inception of bioethics, the field's practitioners have debated the regulation of end-of-life care. This debate has been manifested in three procedural categories: voluntary active euthanasia (VAE), physician-assisted suicide (PAS), and voluntary passive euthanasia (VPE).[305] In voluntary *active* euthanasia, the medical provider directly administers a life-ending substance. In physician-assisted suicide, the provider prescribes the fatal substance, which the patient then takes on his or her own. Voluntary *passive* euthanasia does not involve the prescription or administration of any deadly substance; rather, it entails removing medical technology that had been sustaining a patient's life. Bioethical debates about end-of-life decision making have examined which of these procedures to support and why to support it. Though bioethicists have produced thousands of pages of scholarship in defense of each of these positions, both the rationale for these underlying defenses and the overall organization of these debates have remained largely static for over forty years.

These debates about the regulation of end-of-life care are structured by each side's position on the "nature" of death. For conservative bioethicists, like Leon Kass, Daniel Callahan, and Wesley J. Smith, death is only "natural" when it results from a

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[305] For a good breakdown of these categories, from opposing ideological perspectives, see Rachels, *The End of Life* and Kass *Life, Liberty, and the Defense of Dignity*.

disease process.[306] Death that is caused by medical treatment—whether voluntary or involuntary—is "unnatural." Both VAE and PAS are, from this perspective "unnatural;" because of their status as such, these bioethicists argue that these procedures should be prohibited. Nevertheless, passive euthanasia, from this perspective, could still be considered a "natural" death because death is the result not of medical care, but rather of the *removal* of treatment. Death, in this last case, is considered to be caused by the individual's terminal disease.

Advocates for physician-assisted suicide and voluntary active euthanasia have argued that this distinction between "natural" and "unnatural" death is hypocritical. Such advocates—including Peter Singer, Ronald Dworkin, James Rachels, and Franklin Miller and Robert Truog—argue that putatively "unnatural" deaths are just as much the result of medical care as "natural" ones.[307] By removing an individual from life-sustaining treatment, these authors argue, medical professionals are causing their death in a way that is not qualitatively different from injecting them with fatal chemicals. Consequently, there is no valid analytical difference between a "natural" and "unnatural" death; both are the result of medical care. These authors use this lack of a distinction to argue for the legalization of physician-assisted suicide and even voluntary active euthanasia. They claim that such legalization is merely an extension of the logic that already protects the removal of life-sustaining treatment.

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[306] Callahan, *The Troubled Dream of Life*; Kass, *Life, Liberty, and the Defense of Dignity*; Wesley J. Smith, *Forced Exit: The Slippery Slope from Assisted Suicide to Legalized Murder*, (New York, NY: Times Books, 1997).

[307] Dworkin, *Life's Dominion*; Miller and Truog, *Death, Dying, and Organ Transplantation*; Rachels, *The End of Life*; Singer, *Rethinking Life and Death*.

A counterpoint to this argument is made by scholars in disability studies. Disability studies scholars have agreed with these euthanasia advocates that the distinction between voluntary active euthanasia and the removal of treatment at the end-of-life is specious. But, rather than argue for the legalization of active euthanasia, they claim that this lack of a distinction calls into question the legal and moral status of the removal of life-sustaining treatment.[308] The removal of such treatment, they argue, is a form of discrimination against individuals who are dependent on feeding tubes, ventilators, and other forms of mechanical assistance in order to life. Such assistance, they claim, is neither "artificial," nor even "life sustaining." It is "natural" and might even be described as "life constituting." This point is strengthened by reference to cases in which disabled individuals who lacked terminal illnesses were legally allowed to end their lives via the removal of treatment. For disability studies scholars, such cases are not examples of "natural" deaths, but of deaths that are every bit as violently "unnatural" as voluntary active euthanasia.

In this sense, both euthanasia advocates and disability studies scholars marginalize—and arguably even eliminate—the very category of "natural death." For these thinkers, the advances in medical technology in the 1960s permanently placed death within the realm of medicine. As a result, death will be inherently "unnatural." The question is under what conditions it might be possible to conceive of a death that, while "unnaturally" due to medical practice, remains ethically appropriate. For euthanasia advocates, such conditions are supplied by the presence of a "significant" incurable medical condition, as well as suicidal ideation on the part of the chronically ill patient.

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[308] Ackerman, "Assisted Suicide"; Braswell, "Can there be"; Gill, "The False Autonomy;" Longmore, "Policy, Prejudice, and Reality."

Disability studies advocates generally avoid this question—focusing instead on how the lack of appropriate conditions in the present renders such deliberations specious and even implicitly violent. Though these two positions are opposing, they are united in a shared rejection of the claim that, in the contemporary context, death has a "nature" of its own.

An exception to this approach can be found in Alicia Ouellette's book *Bioethics and Disability*.[309] As I mentioned in the "Introduction" to this dissertation. Ouellette examines the cases of individuals whose bodies are actively harmed by life-sustaining medication. For Ouellette, removing life-sustaining treatment from such patients is *not* tantamount to the removal of medical care. Rather, it is *providing* them with care that is, in Ouellette's words, "medically appropriate." She argues that disability studies scholars should support such care, as the real ableist violence lay in continuing to provide terminally ill patients with care that, because it was medically inappropriate, is just as harmful as the premature removal of life sustaining treatment.

Ouellette's analysis challenges dominant bioethical understandings of the removal of life-sustaining treatment. She justifies this removal because, in the case of certain terminally ill patients, the act of removing life-sustaining treatment is itself an appropriate practice of medical care. In this sense, the removal of life-sustaining treatment should not be confused with the removal of end-of-life care. By removing treatment, doctors paradoxically *provide* their patients with appropriate end-of-life care. This understanding of treatment removal challenges that of both advocates and opponents of euthanasia: Rather than understand treatment removal to be categorically opposed to PAS and VAE, all three procedures would be different manners of providing end-of-life

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[309] Ouellette, *Bioethics and Disability*, 312.

care. There is thus, contrary to the dominant framing of bioethical debates, no coherent position on the regulation of end-of-life decision making that occurs outside the context of the provision of end-of-life care.

This reconceptualization challenges the dominant bioethical understanding of a "natural death." In this dominant understanding, a natural death occurs in the absence of end-of-life care, while an unnatural death is caused by end-of-life care. But Ouellette's approach provides the foundation for a more complex model of causation for a "natural death." In this model, the fundamental question is not whether or not a death occurs in the context of end-of-life care. Both natural and unnatural deaths can occur in this context. Rather, the key question in determining whether a death was "natural" is discerning whether the end-of-life care provided was "appropriate."

But what is "appropriate" end-of-life care? At the end-of-life, death is inevitable. Nevertheless, even though death is inevitable for terminally ill patients, these patients can still suffer violent discrimination that would end their lives prematurely. In this sense, the purpose of "appropriate" end-of-life care is to obstruct such discrimination. Such obstruction does not prevent the terminally patient from dying; rather, it allows him or her to die a "natural" death. Thus, "appropriate" end-of-life care functions by eliminating all fatal factors not specifically originating in the patient's terminal disease.

This rethinking of "appropriate" end-of-life care both builds on and redefines the "social model of disability." At the end-of-life, there are various social factors that can cause a terminally ill individual's death. Such factors can easily be theorized through the social model of disability, as they establish a link between disability to death that is definitively *not natural*. At the same time, eliminating these factors will not sever the relationship between disability and death altogether. Rather, it will allow for the establishment of a *natural* relationship between disability, an underlying terminal illness, and an eventual death. Unlike in cases of chronic disability, the goal of a disability studies approach to such states is not to sever such a link. Rather, it is to *nurture* this link by using "appropriate" end-of-life care to obstruct those social factors that might prevent a patient from dying from his or her disease.

The result is what I would call the "social model of terminal illness." This model accepts some form of death as natural in terminally ill patients, even as it rejects other forms of death as manifestations of social discrimination. Its goal is to protect patients from violence, while providing them with end-of-life care that is "appropriate" so that patients are able to die naturally of their disease. To illustrate this approach—and how it differs to from dominant bioethical conceptions of a "natural" death—I will return to the case of Simon, the patient at Our Lady whom I discussed in Chapter 4.

In that discussion, I considered Simon's state in two radically different contexts of end-of-life care: his brother's home and Our Lady of Perpetual Help Home. At his brother's house, Simon was receiving home hospice care in accordance with the guidelines of the Medicare Hospice Benefit. But, under his care, his condition swiftly deteriorated, leaving him depressed, malnourished, and bruised from repeated falls. At Our Lady, his depression vanished, he gained weight, and he was able to move about the facility freely, interacting with patients and staff. The contrast between these two forms of end-of-life care was almost absolute: While home care failed to meet his basic needs, Our Lady's care supplied him with the necessary medical, psycho-social, and spiritual interventions for him to live his life until the end.

And yet, within the dominant typology of Western bioethics, this radical discrepancy between Simon's two forms of end-of-life care has no bearing on the "nature" of his death. Had Simon died in his house while suffering from depression and malnutrition, his death would, from this perspective, be registered as "natural" because it was not directly caused by the provision of life-ending medication. The same justification would be used to classify Simon's death at Our Lady as "natural" as well. There would be no difference between these two deaths. The only substantive question, from this "bioethical" perspective, is whether his hospice team injected him with a fatal substance. The quality or quantity of the *non-fatal* care that they provided him with would be irrelevant.

I would interpret Simon's story through a different understanding of the "nature" of death. In this understanding, the provision of end-of-life care is appropriate precisely because it allows an individual to die from his or her disease. But when such care is *not* provided, the death is not the result of disease, but rather of a failure of care. Thus, had Simon died in his home, he would not have died a natural death because his death would have occurred as a result of medical care that was both worsening his quality of life and hastening his demise. At Our Lady, in contrast, he received care that alleviated many of the conditions not specifically related to the terminal nature of his disease. Although the home did not "cure" him of cancer, by eliminating those aspects of cancer that were non-fatal, it allowed him to die of his disease. Thus, this new definition of "natural death" makes it possible to both consider end-of-life care essential to the nature of death, and to qualitatively distinguish between appropriate and inappropriate forms of end-of-life care.

With this new definition comes a new orientation for the bioethical regulation of end-of-life care. The field of bioethics should be oriented toward providing individuals with natural deaths. But this orientation consists of far more than simply making it possible for individuals to remove life-sustaining treatment. Rather, it includes providing end-of-life care that manages, in a matter as effective as possible, all aspects of an individual's terminal illness *except* for the one aspect beyond its grasp: death. Though bioethics cannot, in the end, prevent terminally ill patients from dying, it can ensure, through the provision of end-of-life care, that, when they do die, it is from their disease.

This more expansive understanding of a "natural" death makes it essential for bioethicists to actively engage end-of-life providers. Nevertheless, it also raises a question: If the bioethical regulation of end-of-life care should be oriented toward providing patients with appropriate treatment, does this regulation require the presence of bioethicists at all? It would seem that such a conception of end-of-life care would lead to the very professional identity of the bioethicist to become irrelevant. The role of the bioethicist would be taken over by those most skilled at providing such care: end-of-life providers themselves. Nevertheless, my research highlights that, though bioethicists may need to change their professional identity, the field can still play a crucial role in the regulation of US end-of-life care. Understanding this role entails revisiting Simon's case one last time.

I have argued that, at home, Simon was receiving inadequate end-of-life care. And yet, he was, at the time, receiving what, according to the classificatory categories of the US health system, was the definition of end-of-life care itself. Consequently, Simon's case highlights how dominant definitions of "end-of-life care," though claiming to be sufficient, can themselves be inadequate and even neglectful to those terminally ill patients that they are supposed to serve. This gap between the definition of "adequate" end-of-life care within the US health system and the lived reality of terminally ill patients receiving this care provides an opening for a new understanding of the bioethical regulation of end-of-life care.

In this understanding, the role of the bioethicist is not to regulate a preexisting conception of end-of-life care. Rather, it is to actively explore how end-of-life care functions and, based on such exploration, to promote reforms that make this care more responsive to patient need. The bioethical "regulation" of end-of-life care must thus be an ongoing project of *redefining* end-of-life care. Through such redefinitions, the ability of the US end-of-life care system to promote "natural" deaths will be incrementally, but substantively improved. Having drawn on my research to redefine the role of the bioethicist at the end-of-life, I will now carry out this role by postulating a number of suggestions for the reform of hospice care in the United States.

Reforming Hospice

In this dissertation, I have examined how the implicit kinship structure underlying US hospice care hinders the delivery of hospice services. This kinship structure is based on the assumption that terminally ill individuals will have sufficient kinship support to take care of their long-term needs. Hospice care is intended to "support" this kinship network, but not to displace it. This assumed kinship network is the product of both neoliberal economic philosophy as well as the "interdisciplinary" medical philosophy underlying the modern US hospice movement, in which the space of the family was understood to be outside of medical care and political action. And yet, this exclusion of the family from the hospice system leads terminally ill patients without kinship support to be caught in a grueling oscillation between the abandonment of the home and the fragmentation of the nursing home. Addressing this problem does not necessarily entail redesigning the entire hospice system—which functions reasonably well for patients who have strong kinship networks—but rather attending to the needs of this particular patient population. Such needs can be addressed through a number of practical measures.

First, it is necessary to include, within Medicare, a long-term care benefit that can be synthesized with hospice. Such a benefit can assist patients who lack kinship support, and can give further assistance to caregivers who, while perhaps able to care for their relatives much of the time, also can benefit from more frequent assistance. The lack of such a benefit does not necessarily cut costs. Terminally ill patients without kinship support are sent to nursing homes. As most of these nursing homes are funded by Medicaid, they still cost the government an enormous amount of money. At the same time, as they are not designed to provide end-of-life care, they routinely fail patients and subvert the functioning of hospice organizations. By integrating long-term care into Medicare, it would be possible for patients who need long-term care to receive it. The result will save hospices and nursing homes wasted time and expense and, in the process, save the government money as well.

But the attempt to integrate two opposing modalities of care will, regardless of its funding structure, be problematic. As a result, it is necessary to reconceptualize the relationship between long-term care and end-of-life care in the US medical system. These two modalities of care are distinguished by their putatively opposing orientations toward death: Long-term care is designed for patients who, though chronically disabled, lack diseases that will cause their death, while end-of-life care is for patients who will die imminently. Nevertheless, though there are significant differences between long-term care and end-of-life care, it is better to understand them not as a continuum—in which chronic disability leads to terminal illness—but rather as a constellation of techniques and practices that can be useful in both modalities. Thus, the palliative care characteristic of end-of-life care should be integrated into long-term care facilities and home health care, while the assistance with activities of daily living—characteristic of long-term care—should also become a more fully integrated component of hospice organizations. By understanding these two modes of treatment as potentially complementary, it will be possible to offer patients treatments that are, for now, unfortunately separated by the organizational structure of the US health care system. This integrated approach will simultaneously make long-term and hospice providers more comfortable with each other's approach.

More valuable than even this integrated approach to the coordination of nursing home and hospice care would be to integrate long-term care into the existing hospice system. This integration should occur in both inpatient and outpatient settings. Hospice should include a more substantive home health component. This component will allows patients to stay at home longer, thus defraying the potential cost of inpatient treatment. But, when inpatient treatment is available, it should be available on a long or at least medium-term basis. The current short-term nature of this inpatient care highly limits its utility to most patients. Though it lessens the expense of hospice care, as many patients who require long-term care are subsequently sent to nursing homes, the cost of their care will still most likely end up being paid by the government, albeit in a highly inefficient forms. Creating inpatient and outpatient care that, like Our Lady's, blends long-term and end-of-life care into one unified treatment modality will mark the most significant improvement in both the cost efficiency and medical functioning of hospice in the US.

Given the current institutional pressure within US politics to downsize government spending, it may seem like an inopportune time to advocate for the creation of such new medical institutions. But, as I have argued, health economics needs to be complemented by a historical and ethnographic approach that is capable of examining how seemingly cost-effective economic reforms can significantly complicate the delivery of care. Before a comprehensive economic analysis can be made, there needs to be a preliminary examination of the particular incentive structures of patients, families, and the diverse groups of medical providers taking part in the coordination of care. In this dissertation, I have performed such a preliminary analysis. Drawing on this analysis to develop a new model for conceptualizing the economics of end-of-life care is one potentially fruitful area in which this current project might be expanded into a book.

The goal of this dissertation is more modest. It is to argue that, such a model, were it to be developed, would be a *bioethical* project. Within the current epistemological and methodological frameworks dominant in bioethics, it would not be recognized as such. Nevertheless, as I hope to have shown, even with matters as seemingly self-evident as death itself, bioethicists must take the social, cultural, economic, political, and medical context seriously—and not only as a "context," but also as the very intrinsic matter of the objects whose ethics they purport to assess. Doing so does entail abandoning a conception of bioethics as a field dedicated to the enforcement of putatively universal principles. But, in the process, it provides a new direction for bioethics as an interdisciplinary field capable of mediating between the clinic, the research university, and the realm of public policy. I hope to have shown that the result will be of significant benefit not only to bioethicists, but also to disability studies scholars, as well as a variety of actors involved in the distribution and practice of medical care in the United States.

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