How We Die: AIDS and Aging in a Biomedicalized Society

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“The purpose of the art of medicine is not primarily to cure disease or fight back death but to relieve human suffering.” – Sherwin B. Nuland

Introduction

On February 21st, 2014, an 83 year-old man lay in private room of a large urban hospital. He had been admitted because a T-4 spine fracture had caused severe bleeding. That was only the most recent in a long string of ailments. The patient had metastatic prostate cancer. He was weak and severely immune-compromised. He was terminal. A well-meaning pulmonologist was getting ready to enter the room when the man's wife stopped the doctor and asked what he thought he was doing. The pulmonologist explained that the patient's chest x-ray revealed fluid in his lungs, so the doctor was coming to drain the fluid. The patient's wife told the pulmonologist to remove his gown and go to his next patient. Her husband was dying. She knew it. He knew it. No treatment for fluid buildup was going to stop death from coming. They were going home so that her husband could live out his final days as he wished: without suffering and with his family.

Many people do not know when they are dying. They do not know what dying looks like or what to expect as the body deteriorates. As a result, they do not know when to stop medical tests and treatments. But that was not the case for the 83 year-old man in our story. He was a doctor. He knew what was happening to his body and this knowledge empowered him, through the proxy of his wife, to stop medicine from its relentless fight against death. His name was Sherwin B. Nuland. Among the many legacies he left, one of his most important was sharing with the world *How We Die.*

Published in 1994, *How We Die* provides a biological account of six common ways that Americans die. Although the initial idea for the book was not his own, everything else about *How We Die*, from the writing style to the conclusions it reaches, reflects who Sherwin Nuland was as a thinker, physician, and human being. A historian of medicine and general surgeon at Yale School of Medicine, Nuland grew up surrounded by death. At the age of 11, he lost his mother to colon cancer. As a young adult, he watched his grandmother wither away from the infirmities of old age. As a middle-aged man, he watched his brother suffer and succumb to colon cancer. The familiarity of death, along with a deep fascination for the human being and his skill as a writer, made Nuland the ideal author for *How We Die.*

In his 1992 proposal to Knopf publishing, Nuland expressed that his goal in the book was to "demythologize death."

> Readers want to know, need to know, what it is like to die, and this book will tell them in a way that is accurate and interesting. It is by a frank discussion of the very details of dying that we can best deal with its most feared depredations, far more effectively than we have ever been able to by constructing a set of fables and myths which, in the end, must certainly be exposed for the false promise they hold. By knowing the truth and being prepared for it, we can free ourselves of that fear of the terra incognita of death that leads us to lies and disillusions.[1]

Human beings are simultaneously fascinated by and terrified of death. This fear, coupled with a lack of knowledge about what it is like to die, has resulted in what Nuland saw as the fabrication of a mythology of death, a mythology that claims there is dignity in death. Nuland wanted to show that in modern America there is no such thing as a dignified death. While this objective sounds cynical, Nuland's point is realistic: guided by the mythology of death, people are not prepared for the true experience of death. Their lack of preparation will inevitably lead to disillusionment when death approaches. A good death instead comes from a good life. Understanding *How We Die* is, for Nuland, a way for people to begin to live a good life, unburdened by the fear and myths of death.

Despite the bitter realism of Nuland's message, *How We Die* met with enormous success. In 1994, it won the National Book Award, selling over half a million copies

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[1] First Draft of Proposal, 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

worldwide.[2] Recent books like Atul Gawande's *Being Mortal* have reignited national conversations about death and dying, conversations first sparked by Nuland's book. Thus, understanding the contemporary discourse on death and dying benefits from examination of past discourse, much of which was fueled by *How We Die.*

In this essay, I explore the ways in which *How We Die* is a reflection of and a response to its historical context, specifically a context dominated by increasing biomedicalization that was redefining meanings of "natural" and "normal." Conceptions of "natural" are culturally constructed, a reality made clear when routine medical practice and technology converge to transform our understanding of what is natural.[3] Thomas Laqueur, in his review of *How We Die,* argues that none of the deaths described by Nuland constitute natural history, but rather, are "deeply intertwined in Western, technological, and materialist medical culture."[4] I agree with Laqueur, that the deaths Nuland describes are deeply intertwined with sociotechnological aspects of medical culture. However, this does not have to mean that the deaths described by Nuland are not natural. Instead, we must understand "natural" as a product of the sociocultural and medical context in which it is conceived.

Thus, I ask: using *How We Die*, can we tease out the influences of biomedicalization to uncover what physiological processes of death should be considered "natural?" Conversely, how can we use conceptions of "natural" to guide our expectations about medicalization and biomedicalization? In this discussion, I do not assume that what is

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[2] James Baron. "Study of Death Wins a National Book Award." *New York Times,* November 17, 1994.

[3] Sharon Kaufman. *And a Time to Die: How American Hospitals Shape the End of Life*. (New York: Simon and Schuster, 2005), 324.

[4] Thomas Laqueur. "Review of the Book *How We Die* by Sherwin Nuland." *London Review of Books* 16, no. 6 (1994): 7-8.

"natural" is necessarily "good." I do not seek to elucidate a fixed definition of "natural," for such a definition does not exist. Rather, I seek to demonstrate that there are shifting conceptions of "natural," and these shifting conceptions provide new ideas of what is "normal." This essay focuses on conceptions of "natural" specific to the historical moment of *How We Die* and shows how Nuland's book provides an idea of "normal" kinds of death for a biomedicalized age.

In Section 1, "Biomedicalization of Death," I define biomedicalization and describe its impact on conceptions and approaches to death, an impact reflected in the way that Nuland presents death in *How We Die.* Biomedicalization, a term coined by Adele Clarke and colleagues in 2003, describes a sociomedical phenomenon that evolved from medicalization.[5] Medicalization is defined as the process by which conditions previously outside the realm of medicine come to be designated as medical problems deserving medical treatment. With increasing technoscientific innovation and changes in the distribution and consumption of medical knowledge, medicalization became biomedicalization.[6] Death was one such condition that was transformed by the forces of medicalization and then biomedicalization. To appropriately present the process of death in late 20th century America requires recognition of the ways in which death had become biomedicalized. By addressing the biomedicalization of death, Nuland is able to provide depictions of how we die appropriate to the time and place in which he was writing. As a result, Nuland empowers individuals functioning within a biomedical system with the knowledge to approach decisions regarding their death and the deaths of their loved ones.

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[5] Clarke *et al*. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." *American Sociological Review* 68, no. 2 (2003): 164-165.

[6] Clarke *et al*., "Biomedicalization: Technoscientific Transformations," 166.

It is important to clarify that biomedicalization is not Nuland's term, but rather, is a term scholars have developed to make sense of the kinds of changes Nuland responds to in his book. Therefore, in proposing that *How We Die* responds to biomedicalization, I am proposing that Nuland's book responds to a collection of changes in the medical profession and in society at large that together comprise a phenomenon termed biomedicalization.

In Sections 2 and 3, I examine Nuland's response to the biomedicalization of death from two different processes: AIDS and old age. Examining AIDS and aging side by side reveals the influence of pathogenicity and normalcy in Nuland's views about when and how medicine should be used to avoid death; in discussing what Nuland understands as natural versus unnatural, I refer both to the degree to which the process is considered pathological and the degree to which it deviates from normal expectations about the life cycle. Importantly, expectations about what is normal are historically situated, and thus, conceptions of natural also must be understood within their historical context.

In Section 2, "AIDS: How the Young Die," I argue that disease and death from HIV/AIDS was historically, scientifically, and socially unprecedented, due in part to the ways that HIV/AIDS challenged the existing medical establishment. Nuland's response to the uniqueness of HIV/AIDS is itself a comment on biomedicalization. With regard to HIV/AIDS, Nuland supports what might be understood as a tempered or soft version of biomedicalization, one that recognizes the limits of science and medicine, but also continues to try to find ways to increase survival and decrease the suffering of those with the disease. Support for a tempered biomedicalization can be attributed to the understanding that death from AIDS is unnatural as it represents a pathogenic process and an abnormal inversion of the life cycle, and therefore, it can be argued that medicine is justified, to a degree, to intervene to extend life.

But is aging natural? In the case of the elderly, what is non-pathogenic versus pathogenic is blurred because it is difficult to tease apart illness from normal physical decline, and though it is generally considered normal for old people to die, there is no concrete definition of the normal age to die.[7] Yet, as becomes clear in Section 3, "Aging: How the Old Die," Nuland firmly believed that aging and death from old age are natural processes, and therefore, he opposed the biomedicalization of aging. Section 3 describes how medicalization turning aging into a disease subject to medical intervention and how biomedicalization created a technological imperative to intervene in conditions of old age, thereby exacerbating the knowledge gap between patients, their families, and the medical profession. Ultimately, I argue that Nuland bridges this knowledge gap by resisting the biomedicalization of aging and emphasizing that aging is not pathogenic and death from old age is a normal, necessary part of the expected life cycle.

In this essay I seek to push back against a surface level reading of *How We Die.* I argue that *How We Die* functions as more than a biological account of six processes of death; it functions as a critique of forms of biomedicalization that deny death as a natural process. I analyze *How We Die* as a kind of primary source that tells us how Nuland wanted people to understand what it means to die given the social and medical circumstances of the time. In this way, *How We Die* becomes a historical snapshot that participates in a larger discussion describing how "normal" ways of death are historically situated, dependent on shifting cultural definitions of "natural."

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[7] Kaufman, *And a Time to Die,* 78-81.

Biomedicalization of Death

In order to understand the significance of *How We Die* we need to understand transformations in medicine that were happening around the time it was written. These transformations have been discussed in terms of medicalization and biomedicalization.

Historians have long observed changes in the medical profession motivated by shifting social, cultural, political, and economic realties of American society. In *The Social Transformation of American Medicine*, historian Paul Starr describes the period from 1890-1980*,* dividing the transformation into two distinct stages: the first stage, from 1980-1945, focused on the professionalization of medicine, while the second stage, beginning after the Second World War, focused on the corporatization of medicine.[8] A mention of Starr's arguments sets the stage for understanding the historical phenomena that form the basis of this essay.[9] Specifically, professionalization and corporatization of American medicine produced a medical profession with an unprecedented level of cultural authority and expertise, contributing to the medicalization of American society.

Medicalization theory can be understood as the sum of two interrelated processes. The first is what Peter Conrad has called the "negotiated quality of disease." According to Conrad, "new disease designations are not solely the product of medical discovery or knowledge, but often…emerge from a complex interaction with sufferers and interested publics."[10] Disease is *both* a social and biomedical phenomenon as disease designations are

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[8] Paul Starr. *The Social Transformation of American Medicine*. (New York: Basic Books, 1982), 27-28.

[9] Discussion of the specific processes and consequences of professionalization and corporatization of the American medical profession is beyond the scope of the present essay. For more on this topic, see Starr, Paul *The Social Transformation of American Medicine.* (New York: Basic Books, 1982).

[10] Peter Conrad. "Medicalizations." Review of Framing Disease. Studies in Cultural History, Charles E. Rosenberg, Janet Golden. *Science* 258, no. 5080 (1992): 334-35.

constructed through human actions and interactions.[11] The second part of medicalization theory is the expansion of medical jurisdiction, which has the effect of expanding what is perceived as a medical problem warranting medical treatment. Thus, not only are disease designations products of social construction, but so too are appropriate treatments. Importantly, these disease designations and treatments are no less "real" although social forces have imbued them with particular meaning. Instead, we must understand disease designations and treatments in a medicalized society as products of both scientific and social realities. Synthesizing these two aspects, we can understand medicalization as the processes by which conditions previously outside the realm of medicine come to be designated as medical problems deserving medical treatment.[12]

Medicalization continued to grow in scope and influence throughout the second half of the 20th century. However, as Clarke et al. argue in their important essay "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine," the nature of medicalization began to shift in 1985.[13] It was not that medicalization transformed into a new phenomenon. Rather, the cumulative effects of technoscientific innovations associated with new social forms shifted the focus of medicalization such that it evolved into biomedicalization.[14] The *bio* term is used by Clarke and colleagues to signal the role of biotechnology in the intensification of medicalization processes.[15] Taking this one step further, we can understand the addition of the *bio* term as a signal of the addition of "life itself" into the realm of medical jurisdiction; medicine and its

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[11] Clarke *et al.*, "Biomedicalization: Technoscientific Transformations," 164.
[12] Clarke *et al.*, "Biomedicalization: Technoscientific Transformations," 164.
[13] Ibid.
[14] Ibid.
[15] Ibid., 162.

biotechnologies were no longer limited to processes of disease, but now, through biomedicalization, came to influence processes of life, and transitively, processes of death. This aligns with Clarke and colleagues' description of the shift in focus in moving from medicalization to biomedicalization as a shift from increased *control* over biomedical phenomena to *transformation* of biomedical phenomena.[16] Control over biomedical phenomena alludes to the ways in which the medical profession came to define and treat disease processes, while transformation of biomedical phenomena refers to the ways in which medicine and its technologies came to transform life (and death) itself.

Clarke and colleagues describe five processes, which account for the co-production of technoscience and new social forms while simultaneously defining and generating biomedicalization.[17] Of these five processes, two prove especially important for the present discussion: increasing technoscientific intervention and transformations in the distribution and consumption of biomedical information.

Coupled with increased medical control over life and death processes, these two processes of biomedicalization frame conceptions of death in late-20th century America. Technoscientific intervention has enabled medicine to increase control over life and death. The examples of this relationship are numerous: from the mechanical ventilator and feeding tube, to targeted cancer drugs and cholesterol lowering statin medications, innovations in science and technology have provided medicine with the tools to improve, sustain, and extend life, and thus, alter experiences of death. Changes in the way that biomedical information is distributed and consumed refer specifically to increased

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[16] Ibid., 164-165.

[17] For a more detailed discussion of these five processes of biomedicalization see Clarke *et al*. "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. 164-165. Biomedicine." *American Sociological Review* 68, no. 2 (2003)

availability and expectations of availability of biomedical information.[18] Expansion of medicine into American society is thus promoted and reinforced by the ways that biomedical information has become "popularized" and incorporated into mainstream discourse. Although this transformation in biomedical information has not necessarily increased medical control, it has furthered medical influence in society and altered the physician-patient dynamic, and thus complements the process of medicalization.

Social, cultural, and technological changes in the mid to late 1900s helped transform the dissemination of scientific and medical information, a transformation accompanied by a shift from paternalistic to patient-centered medical care. The late 1960s and 1970s saw the emergence of a new social reality: medical information could no longer be walled off from the public.[19] Undoubtedly, larger historical developments, such as the Vietnam War, Counter Culture, and Second Wave Feminism (especially the women's health movement), contributed to the shifting expectation about the transparency of information.[20] These shifts in expectation about what types of information constituencies should have access to, paired with technological innovations that made it easier to widely disseminate information, paved the way for the women's health and consumer health movements to acquire and distribute scientific information.[21] The women's and consumer health movements challenged the medical profession's monopoly over medical knowledge and promoted a historic transformation in the dynamic between doctor and patient;

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[18] Clarke *et al.*, "Biomedicalization: Technoscientific Transformations," 177-178.

[19] Jerome Groopman (physician and friend of Sherwin Nuland) in discussion with the author, October 2016.

[20] Ibid.

[21] There were undoubtedly more factors influencing the shift from paternalistic to patient-centered medical care. The women's health and consumer health movements are mentioned as emblematic examples of movements that propelled the shift in doctor-patient relations in the mid-late 20th century.

paternalism became partnership, and the emphasis on informed, autonomous, patient-centered care emerged.[22]

Such emphasis on informed, autonomous, patient-centered care was institutionalized by the Patient Self-Determination Act, which became federal law in 1990.[23] The act required hospitals to uphold the right of all patients to be informed about and determine their own medical treatments, which included refusal of treatment.[24] Though the Self-Determination Act promotes patient autonomy, it contains a crucial flaw: the act assumes that providing patients with information is sufficient to make informed decisions. Although access to information promotes autonomy, information is not the same as knowledge, and ultimately, knowledge is required to make informed, autonomous medical decisions.[25]

Distinguishing between knowledge and information is important for understanding how both biomedicalization impacts the doctor-patient relationship and *How We Die* responds to this impact. Because Clarke and colleagues do not emphasize the influence of biomedicalization on the doctor-patient relationship, they avoid the task of differentiating between knowledge and information. However, the influence of biomedicalization on the doctor-patient relationship is brought into stark relief in an examination of processes of death; therefore, for this essay, discussion of biomedicalization must explicitly refer to transformations in distributions of medical information. Unlike biomedicalization, which increased access to medical information, *How We Die* increased access to knowledge;

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[22] Kaufman, *And a Time to Die,* 67-68.
[23] Ibid., 73-74.
[24] Ibid.
[25] Sarah Nuland (wife of Sherwin Nuland) in discussion with author, January 2017.

providing medical information in context, Nuland hoped to impart applicable medical knowledge about death to the layperson.[26]

Providing the public with medical knowledge about death and dying, *How We Die* counterbalanced expanding medical control over death, which occurred as death moved into and became determined by the hospital and "doctors gained a monopoly over witnessing death and the drugs that may hasten it."[27] Prior to the 20th century, death largely occurred in the home, without the intervention of medical technology.[28] Movement of death from the home to the hospital relates to the fact that after the Second World War medicine became a "worthy opponent" of death, such that going to the hospital did not mean automatic death.[29] Death was no longer an inevitable outcome of hospital admission because the hospital and medicine were able to intervene in the dying process.

Death became determined by the hospital in the sense that the hospital as an institution intervenes in death in tangible and intangible ways; to die in the hospital is not a passive process. Rather, as described by anthropologist Sharon Kaufman in *And a Time to Die*, dying in the hospital is a process mediated by the tools, rules and relations within the hospital setting.[30] Tools, including medical technology and algorithms that determine treatment plans, have a clear influence on the path patients take as they approach their final days.[31] According to Kaufman, what is less visible, but no less important, are the "hospital procedures and bureaucratic mandates of health care systems that produce the

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[26] Sarah Nuland (wife of Sherwin Nuland) in discussion with author, January 2017.

[27] Thomas Laqueur. ""Dying Well" and the Doctors." In *Medical Challenges for the New Millennium*, Springer (2001), 24; Kaufman, *And a Time to Die*, 25.

[28] Ibid.

[29] Laqueur, ""Dying Well," 24.

[30] Kaufman, *And a Time to Die*, 95-97.

[31] Ibid.

conditions for death."[32] These procedures and mandates, often developed by outside, non-medical personnel, have the cumulative effect of moving the patient along routinized tracks of care that, in the case of terminal patients, dictate the dying process. [33]

More than pushing patients along standardized pathways toward death, the hospital functions to redefine life and death. Medicine can keep a patient's body alive, but does that constitute life? If the patient is breathing, but has no brain function, is that death? As the boundary between life and death increasingly blurs, the hospital creates the gray zone - "'it is a gray zone between health, awareness, function, and viable *life* on the one hand, and "no longer a person," "death in life," or *death* on the other hand.'"[34] It is the hospital's role in creating and maintaining the "gray zone" that, according to Kaufman, most dramatically manifests the "problem of death" in America.[35]

The "problem of death," as described by Kaufman, has its origin in the conflict between death and the technological imperative of medicine. At the heart of modern medicine is ambivalence about its role in death. On the one hand is the technological imperative of medicine: to use all available technology to prolong life.[36] On the other hand is the clinical imperative of medicine: to relieve suffering to make dying as tolerable as possible.[37] Max Weber articulates this conflict in his 1919 essay "Science as Vocation."

> The general 'presupposition' of the medical enterprise is stated trivially in the assertion that medical science has the task of maintaining life as such and diminishing suffering as such to the greatest degree possible… Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside, or assumes for its purposes, whether we should

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[32] Kaufman, *And a Time to Die*, 95.
[33] Ibid., 96.
[34] Ibid., 62.
[35] Ibid., 1-2.
[36] Daniel Callahan. "Death and the Research Imperative." *N Engl J Med* 342, no. 9 (2000): 654-6.
[37] Ibid.

> and do wish to master life technically and whether it ultimately makes sense to do so.[38]

Weber noted a tension – between the technological imperative, of "maintaining life as such" and the clinical imperative "to diminish suffering as such to greatest degree possible"— in 1919, decades before the introduction of blockbuster pharmaceuticals, intensive care units, and cardiopulmonary resuscitation. Whatever questions about "mastering life technically" that science and medicine grappled with at the start of the 20th century had grown more exaggerated and pressing by the end of the 20th century. This exaggeration arises not only because medical knowledge and technologies have made it increasingly possible to "master life technically." It also arises because biomedicalization has magnified the cultural and medical expectation that technoscience and biomedicine intervene in the dying process.

Thus far, discussion of the ways in which biomedicalization has shaped expectations of medicine's role in death, has been abstract. To help clarify this point, it is useful to examine the example of cancer, which illustrates how biomedicalization exacerbates the fundamental tension between the technological and clinical imperatives and how this then impacts the way we approach death from cancer. In the 1950s, cancer treatments had advanced at about the same pace as the rest of medicine – there was little medicine could do for people with aggressive cancer.[39] However the emergence of antibiotics, the polio vaccine, better treatments for heart attacks and heart disease, and "other seeming miracles transformed doctors, in the eyes of the public, into technological wizards who could conquer any malady."[40]

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[38] Max Weber. "Science as a Vocation." In *Science and the Quest for Reality*, Springer (1946), 387-388.
[39] Robert Bazell. "Growth Industry." *The New Republic*, March 15, 1993, 13.
[40] Ibid.

The “war on cancer,” declared by President Nixon in 1971, was a war that Americans believed the medical profession should fight and could win. Belief that medicine “should fight” and “could win” the “war on cancer” reflects biomedicalization. Patients’ (and physicians’) support of the “war on cancer” and expectations that medicine learn how to control cancer and cancer-caused deaths embody the medicalization process of expanded medical jurisdiction. Furthermore, the belief that medicine “could win” the war on cancer, specifically through increased funding for scientific research and drug discovery, typifies the biomedicalization process of increasing technoscientific intervention.

Yet, in the decades since Nixon declared the “war on cancer,” medicine has not come to a much better place when it comes to “controlling” cancer.[41] Expanding medical authority through medicalization has contributed to expectations that medicine be able to use its knowledge and tools to control cancer. Increasing technoscientific innovation has reinforced this expectation as improved technology suggests that medicine is in an even better position to fight cancer successfully. Belief in medicine’s ability and responsibility to control cancer is compounded by widely available medical information that may misrepresent medicine as omnipotent in the face of modern disease. Together, these processes of medicalization and biomedicalization have strengthened the technological imperative. And yet, with cancer, the technological imperative has proved less successful than the clinical imperative. Medicine has, with the emergence of hospice and palliative care, improved its ability to relieve end of life suffering caused by cancer, though has made minimal gains in the fight to control and cure cancer.[42]

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[41] Bazell, “Growth Industry,” 13.

[42] Callahan, "Death and the Research Imperative," 654-6.

Although more successful than the technological imperative, the clinical imperative has been slowed by constant resistance. Specifically, resistance to hospice and palliative care, especially with cancer patients, stems from deeper ambiguities about medicine's role in death (i.e. responsibility to preserve life versus promote a peaceful death) coupled with the current emphasis placed on curative and technological intervention.[43,44] If medicine were not seen as able to or responsible for preserving life – expectations developed in large part due to biomedicalization – then the medical profession would be less troubled by the conflicting clinical and technolgoical imperatives.

You may wonder how cancer fits into an essay discussing HIV/AIDS and aging? Cancer, both in its biology, epidemiology, and relationship to medicine and society, shares features of HIV/AIDS and aging. Cancer is pathogenic, but may also be a result of years of non-pathogenic accumulation of mutations. While medical technologies may be able to prolong life, they can rarely cure cancer entirely and ultimately death will occur. Cancer affects the young and the old alike, so at times it can be seen as an inversion of the normal lifecycle and at other times it can be seen as a part of the normal life cycle. Perceptions of cancer as a natural disease process and a normal cause of death are culturally and historically determined. Therefore, the argument and analyses presented in the following sections of this essay, though applied to *How We Die's* response to the biomedicalization of HIV/AIDS and aging, can also be harnessed to grapple with medicine's role in cancer and death.

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[43] Callahan, "Death and the Research Imperative," 654-6.

[44] W. Bulkin and H. Lukashok. "Rx for Dying: The Case for Hospice." *N Engl J Med* 318, no. 6 (1988): 376-8.

AIDS: How the Young Die

How We Die's section on HIV/AIDS concludes with a reflection on the way that HIV/AIDS represents an "inversion of the expected life cycle," an idea that opens a discussion on the implications of death from AIDS on medicine's relationship with nature.[45] Nuland writes: "An aberration has recently recurred from earlier centuries, just when we had complacently concluded that our science had conquered it. Not only the virus is turned back to front but so is the pattern of natural logic by which the young should bury the old."[46] Everything about HIV/AIDS, from its social effects to its biology, seemed unnatural given the historical context in which it emerged. This unnaturalness interacted with the unprecedented historical, social, and scientific aspects of the disease and the death it caused.

When discussing the uniqueness of HIV/AIDS, Nuland acknowledges the influence of biomedicalization, although he remains conservative in the amount of power attributed to biomedicine. In this section, I describe Nuland's perception of biomedicalization as contributing to progress in the understanding of HIV/AIDS and prolonging symptom-free periods, yet failing to stop death from AIDS.[47] To allow for more realistic expectations about death from AIDS, Nuland believed that society needed to keep biomedicalization in check, so as to be able to recognize the limits of science and medicine and acknowledge the social features of the disease and death it caused. Ultimately, I claim that in spite of its

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[45] Sherwin B. Nuland. *How We Die: Reflections on Life's Final Chapter*. (New York: Vintage, 1994), 200.

[46] Ibid.

[47] For the ease of understanding, I use the phrasing death from AIDS, recognizing that this may represent a simplification of the clinical cause of death in these patients. To refer to the disease, I use the term HIV/AIDS, because some patients were infected only with HIV while others had HIV that progressed to AIDS.

limitations, Nuland supported biomedicalization of HIV/AIDS, albeit in a tempered form that would fight against the socially and biologically unnatural form of disease and death.

Steven Epstein, in his book *Impure Science: AIDS, Activism, and the Politics of Knowledge*, describes how the AIDS movement was a movement of "expertification," where participants in the movement developed a knowledge base about HIV/AIDS to become a sort of expert that rivaled the scientific expertise of researchers and physicians.[48] Because HIV/AIDS disproportionately affected specific subcultures and communities that had already been stigmatized for other reasons, the disease was a particularly well-suited candidate for a new social movement.[49] Infectious diseases throughout history, especially those transmitted sexually, have been associated with stigma. HIV/AIDS is not just a sexually transmitted disease: it is a sexually transmitted disease associated with homosexuality. In fact, AIDS was initially called GRID, or gay-related immunodeficiency because at the beginning of the epidemic, clinical presentation of the disease was restricted to the gay population.[50] More than just affecting the already stigmatized homosexual population, HIV/AIDS also affected young people who were not willing to succumb passively to death, and were instead inspired to fight for rights and treatment during the pre-clinical (before symptoms appear) period of their disease.[51] What emerged during the AIDS movement was a band of lay activists that had as much if not more knowledge about the disease course of HIV/AIDS than medical professionals.[52]

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[48] Steven Epstein. *Impure Science: Aids, Activism, and the Politics of Knowledge*. (Vol. 7: Univ of California Press, 1996), 13-17.

[49] Ibid., 20.

[50] Randy Shilts. *And the Band Played On: Politics, People, and the Aids Epidemic*. (New York: Macmillan, 1987), 121.

[51] Epstein, *Impure Science*, 10-11.

[52] Ibid., 17.

When activists who were also patients became experts, it necessarily altered the dynamic of the doctor-patient relationship, challenging medicalization. With a more cooperative model of doctor-patient relationship, does the doctor lose his authority? To the extent that the doctor's authority comes from having a monopoly on medical knowledge, the cooperative doctor-patient relationship in HIV/AIDS cases represented a loss of medical authority. However, since the doctor still had the monopoly over treatment, the cooperative doctor-patient relationship in HIV/AIDS cases did not eliminate medical authority. Medicalization of HIV/AIDS therefore prevailed, though less unquestionably, when the patient became more an expert on his disease.

Importantly, the very fact that patients and activists were able to become experts reflects biomedicalization of society; the transformation of distribution and consumption of biomedical knowledge, a key process of biomedicalization, was embodied and exploited by the AIDS movement. Expertification required that the public have access to biomedical information, access that was possible through processes of biomedicalization. Thus, we can understand the expertification of the AIDS activists as a process that depended on processes of biomedicalization and reinforced medicalization, though in a more confined capacity.

Not everyone afflicted by HIV/AIDS was an activist and not everyone affected by the disease became an expert. However, we can view Nuland's section on HIV/AIDS in *How We Die* as a vehicle for helping the lay public become experts. Nuland does not link expertification to associations between HIV/AIDS, homosexuality and other social factors. At first, Nuland does not even explicitly mention the influence of homosexuality in HIV/AIDS.

> There is a good deal more to AIDS than its bare clinical facts disclose. Although such a statement may be made about any disease, how much more so it may be said of this specific plague. But no matter the cultural and societal implications of AIDS, certain of its clinical and scientific manifestations must be understood before the full tragedy unfolds of how it kills its victims.[53]

Although he acknowledges that HIV/AIDS is especially influenced by social factors, Nuland deliberately chooses to focus on the biology of the disease. In a way, this decision is typical of biomedicalization, which tries to ignore social factors of disease and focus instead on the technological and scientific aspects of illness. However, HIV/AIDS forced biomedicalized society to acknowledge social factors of disease in the same way that later on in the HIV/AIDS section, Nuland also acknowledges the social aspects of disease and death from HIV and AIDS.

At the end of the HIV/AIDS section, Nuland describes a discussion he had with a close friend of his – John Seidman, a gay actor who lost many friends to AIDS – that provides Nuland with an opportunity to reflect on the uniqueness of death from HIV/AIDS from a social perspective. What Nuland chooses to include in *How We Die* from his discussion with Seidman reveals what Nuland believes is important for the public's understanding of the social aspects of death from HIV/AIDS. One point that becomes evident from Nuland and Seidman's discussion is that, at the end of the day, it is not only medical intervention, but also social support, that is important for those dying of AIDS. Seidman describes how many people viewed gay men as deserving of death from AIDS due to their sinful sexual habits.[54] It became crucial for gay men to support one another, for "to neglect our friends who have to deal with the disease themselves is somehow to abandon

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[53] Nuland, *How We Die,* 168.

[54] Ibid., 196.

them to the judgment of the straight world."[55] According to Nuland, the worst way to die is alone.[56] For gay men dying from AIDS, to die alone was made much worse by the stigma, judgment, and accusations from American society. In sharing Seidman's story, Nuland sends a message about understanding death in a biomedicalized society: we cannot focus just on the science, but must also acknowledge the role of social factors in perceptions and experiences of death, especially death from a disease as socially unique as HIV/AIDS.

Though more subtle, the language Nuland uses in *How We Die* also reveals the social implications of HIV/AIDS, while also providing insight into Nuland's opinion of the biomedicalization of HIV/AIDS. In finalizing the HIV/AIDS section, Nuland relied most on his colleagues who were medical practitioners actively involved in the care of patients with HIV/AIDS. One important colleague was Dr. Gerald Friedland, the head of the AIDS care unit at Yale-New Haven Hospital when Nuland was writing *How We Die*.[57] Friedland's edits fall into two general classes: making HIV/AIDS sound less "evil" to paint a more realistic picture of the disease without reinforcing stigma, and updating Nuland's facts because the HIV/AIDS field was changing rapidly.[58] Painting a more realistic, less evil and stigmatizing picture of HIV/AIDS involved changes in terminology. For example, instead of the term "AIDS victim," which is stigmatizing, Friedland suggested the more neutral terms "person with HIV" or "patient with AIDS."[59]

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[55] Nuland, *How We Die,* 196.

[56] Sarah Nuland (wife of Sherwin Nuland) in discussion with author, January 2017.

[57] Sherwin Nuland, Letter to Gerald H. Friedland, 18 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[58] Gerlad H. Friedland, Letter to Sherwin Nuland, 29 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[59] Gerald H. Friedland, How We Die Correct Typescript, 29 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

Looking deeper into this change in terminology, we see that the term "victim" also connotes a sense of the powerlessness of medicine to save those suffering from HIV/AIDS. If medicine were to be portrayed as helpless in the face of HIV/AIDS, it may raise questions about the authority of medicine more generally, and thereby destabilize the biomedicalization of American society. Ultimately, Nuland uses the terminology "AIDS victim" in *How We Die*, a decision that can be understood as a manifestation of his tempered view of biomedicalization. Although he doesn't think that medicine is powerless to help those with HIV/AIDS, Nuland does believe that medicine's power is limited. The word "victim" for Nuland therefore functions to emphasize the horrific nature of HIV/AIDS as well as the limits of medicine in treating those afflicted by the disease.

Although Nuland does not change "AIDS victim" terminology, he does incorporate Friedland's edits emphasizing that HIV/AIDS is not contagious through everyday means of contact (e.g. shaking hands, using same facilities, etc.), which contributes to the de-stigmatization of the disease. Nuland initially used the language "creepy crawling things," "noxious discharges," and "draining sores" to describe opportunistic infections that characterize AIDS.[60] Friedland, concerned that this language suggests airborne and/or casual contact communicability of infection to the layperson, advised Nuland to rephrase.[61] In addition, Friedland suggested that Nuland stress that one cannot get HIV from one of the "four bug-bearers…eating utensils, insects, toilet seats, and kissing."[62] Fear of contracting HIV due to a lack of knowledge about the transmission of the virus contributed to the

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[60] Gerald H. Friedland, How We Die Correct Typescript, 29 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[61] Gerlad H. Friedland, Letter to Sherwin Nuland, 29 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[62] Gerald H. Friedland, How We Die Correct Typescript, 29 November 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

stigmatization and social isolation of HIV-infected individuals. Because Nuland's book was going to help readers better understand HIV/AIDS, it was critical that it adequately address fears of contagion.

Fears of HIV/AIDS stemmed beyond contagion; AIDS was killing in mass, targeting young men and leaving a large, visible gap in urban populations. Reports about HIV/AIDS in the early 1990s show that the burden of mortality from AIDS was highest in the young adult population.[63] In the late 1900s, prior to the AIDS epidemic, youth death had become anomalous, due in large part to the reality that infectious disease as a cause of death had become rare.[64] At the end of the 20th century, death from chronic disease was expected, which meant that people were expected to die at older ages. A CDC report from 1990-1991 stated that the death rates from most other leading (non-AIDS related) causes of death, the majority of which were non-infectious, declined or remained stable for men and women in 25-44 age group, while death rates from AIDS steadily increased.[65] In fact, by 1991, AIDS was the third leading cause of death among 25-44 year olds.[66] Although the 25-44 year old age group constituted only 7% of the population in 1991, the high death rate from AIDS in this group had a disproportionately large impact on society because it resulted in the loss of productive years of life as well as the loss of parents of young children.

In describing the historical shock of HIV/AIDS, Nuland emphasizes the incompatibility between expectations of science, medicine, disease and death from HIV/AIDS.

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[63] "Centers for Disease Control. "Update: Mortality Attributable to Hiv Infection/Aids among Persons Aged 25-44 Years -- United States, 1990 and 1991." *JAMA* 270, no. 3 (1993): 305-06.

[64] G.L. Armstrong, L. A. Conn, and R. W. Pinner. "Trends in Infectious Disease Mortality in the United States During the 20th Century." *JAMA* 281, no. 1 (1999): 62-64.

[65] CDC. "Update: Mortality Attributable to HIV infection/AIDS," 305-06.

[66] Ibid.

> In the calculus of death, no one before 1981 could have factored in HIV, the human immunodeficiency virus. The first hints of its gathering fury struck just at the instant when biomedical science was beginning to offer cautious congratulations to itself on having achieved a state of advancement where the final conquest of infectious disease seemed at least within sight. AIDS not only confounded the microbe hunters; it shook the confidence held by all of us that technology and science can keep humanity safe from the whims of nature. In a very few explosive years, virtually every young doctor in training was treating his or her share of those dying who were meant to live. [67]

HIV/AIDS appeared just as medicalization was intensifying to the point of becoming biomedicalization. As Nuland explains, both professionals and the public believed that technoscience was capable of and responsible for controlling infectious disease, protecting “humanity from the whims of nature.” Death from HIV/AIDS not only challenged such beliefs about the potential of technoscience, but also introduced the unsettling reality of doctors not being able to save young patients who were, in the age of biomedicine, expected to live many more productive years of life.

Although death from AIDS challenged beliefs about the potential of technoscience, faith in biomedicalization was so powerful that the medical profession and public still viewed science as the answer to solving the mystery of HIV/AIDS and developing a cure to thwart death. From its outbreak in 1981, an unprecedented explosion of knowledge and literature about HIV/AIDS appeared.[68] Although the rate of scientific progress in identifying and understanding HIV was unparalleled, science had not reached the stage of developing an optimal protocol for treatment or prevention.[69] Science journalists reported, “the more we learn, the less certain we are.”[70]

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[67] Nuland, *How We Die,* 164

[68] Steven E. Weinberger. "Recent Advances in Pulmonary Medicine." *New England Journal of Medicine* 328, no. 20 (1993): 1462.

[69] Barbara R Jasny. "Aids 1993: Unanswered Questions." *Science* 260, no. 5112 (1993): 1219.

[70] Jon Cohen. "Aids Research: The Mood Is Uncertain." *Science* 260, no. 5112 (1993): 1254.

In his description of the pathophysiology of HIV/AIDS Nuland enlists military rhetoric that enables him to simultaneously recognize the mystery of the disease and articulate the commitment of science and medicine to fight against HIV/AIDS. According to Nuland, HIV/AIDS lends itself particularly well to military descriptive comparisons because he saw HIV/AIDS as a uniquely violent and destructive disease that pit forces of nature against forces of medicine. [71] To this extent, military rhetoric reflects Nuland's response to the scientific uniqueness and devastation of HIV/AIDS. A revealing instance of this appears in the middle of *How We Die*'s HIV/AIDS section, when Nuland writes:

> Though pestilential offensives may be slowed or halted for a while by one or another of the newer pharmaceutical agents, they will always in time resume, if not in one form, then in another. A skirmish may be won here and there, or a battle prevented by a timely use of prophylactic drugs, and some months of stability thereby achieved—but the eventual outcome of the struggle is preordained. The determined microbial aggressors will accept nothing less than the unconditional surrender that comes only with the death of their involuntary host. [72]

Unlike pneumonia, syphilis, and countless other infectious diseases, HIV/AIDS was immune to the existing technologies of biomedicine: death from AIDS occurred in spite of medicine's persistent attempts to intervene. Although today many people live full lives with HIV, when Nuland wrote *How We Die,* HIV/AIDS was seen as scientifically unwinnable war.[73] Yet, Nuland did not seem to suggest that it is a war that shouldn't be fought by science and medicine. Rather, Nuland supported tempered biomedicalization: he believed that there is some benefit of technoscientific innovation in prolonging symptom-free periods, but he did not believe that technoscientific innovation alone would successfully thwart death from AIDS.

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[71] Nuland, *How We Die,* 185

[72] Ibid.

[73] Though today many people live long lives with HIV, at the time when *How We Die* was written, the science was too immature for HIV/AIDS to be seen as a manageable condition. Further discussion of the HIV/AIDS in America today appears in the epilogue.

Many in the scientific community disagreed with Nuland's position and instead maintained the belief that technoscience would find a way to halt death from AIDS. To a degree, this faith in biomedicalization was justified. For example, pneumocystis pneumonia (PCP), a secondary infection associated with immune-compromised HIV/AIDS patients, received a lot of attention from the medical profession, motivating efforts to improve knowledge about prevention and therapy.[74] Subsequent gains in knowledge came from scientific research and drug development, processes characteristic of biomedicalization. Because drug development in general was an expanding arm of technoscientific medicine, it was expected, and was the case, that in the 1990s there would be an increase in the number of drugs available to treat PCP.[75]

Treatment for HIV/AIDS itself was also expected to come from scientific research and innovation, and, at the beginning of the epidemic, science seemed to be meeting expectations. In the first decade of the HIV/AIDS epidemic, science appeared to provide the knowledge and tools that would ultimately lead to a treatment and cure for HIV/AIDS. On the diagnostic end, scientists discovered that HIV was the virus that caused the disease AIDS and developed a blood test to detect HIV.[76] On the treatment end, researchers discovered azidothymidine (AZT), a nucleoside reverse transcriptase inhibitor that was thought to delay the progression of HIV infection to clinical AIDS.[77] However, AZT was limited in its effectiveness because in the early 1990s no clear guidelines on when and how

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[74] Henry Masur. "Prevention and Treatment of Pneumocystis Pneumonia." *New England Journal of Medicine* 327, no. 26 (1992): 1853-60.

[75] Ibid.

[76] Lawrence K Altman. "Government Panel on Hiv Finds the Prospect for Treatment Bleak." *New York Times*, June 29, 1993, C3.

[77] Ibid.

to use the drug existed.[78] Moreover, clinical trial evidence showed that the drug's benefits were time-limited, with progressive disease and death occurring in virtually all patients.[79] Still, researchers boasted about learning more about HIV/AIDS faster than any other disease, and this implied that an effective treatment, cure, or even vaccine was in the pipeline.[80] Such promises contributed to growing expectations of scientific progress. However, just a few years into the last decade of the 20th century, it was becoming increasingly clear that science could not deliver on its promises.

In reporting on the findings of a government panel on HIV, *New York Times* writer Lawrence Altman called the panel "one of the bleakest moments in the fight against the disease since AIDS was recognized as a new disease in 1981."[81] The reason for Altman's characterization of this moment as "bleak" is twofold. For one, this bleakness stems from the recognition that neither effective drugs nor a HIV vaccine would be developed in the near future.[82] Secondly, at this moment that scientists were beginning to recognize that their overconfidence in being able to find a cure for HIV contributed to the public letdown about the promise of effective HIV therapy.[83] This however, was not all scientists' responsibility – popular media also played a part. For instance, just months before the aforementioned government panel, *Time* magazine published an article about some people being immune to AIDS, stating, "scientists may not discover a cure, but if they learn how to control an HIV infection the way diabetes can be managed with insulin, they will have

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[78] John G. Bartlett. "Zidovudine Now or Later?". *New England Journal of Medicine* 329, no. 5 (1993): 351-52.

[79] Ibid.; M.F. Goldsmith. "Hiv/Aids Early Treatment Controversy Cues New Advice but Questions Remain." *JAMA* 270, no. 3 (1993): 295-96.

[80] Lawrence K. Altman. "Conference Ends with Little Hope for Aids Cure: The Doctor's World Dim Hope Seen for an Aids Cure." *New York Times*, June 15, 1993.

[81] Altman, "Government Panel on Hiv," C3.

[82] Ibid.

[83] Ibid.

tamed one of the most feared killers of the 20th century."[84] While acknowledging that science may not be able to find a cure, the *Time* statement reflects popular optimism that science holds the answer to controlling HIV so as to prevent death from AIDS. This control was expected to come from a technoscientific innovation, in the same way that insulin had been developed as a pharmaceutical mechanism to control diabetes. The suggestion that it is the domain of technoscience to control HIV through discovery and innovation reflects and reaffirms biomedicalization.

I have based my discussion of HIV/AIDS on the popular and scientific media from newspaper and journal articles collected by Nuland while he was writing *How We Die*.[85] In doing so, I am able to frame Nuland's presentation of HIV/AIDS as a response to the optimistic portrayal of biomedical power in the face of HIV/AIDS. What becomes evident is that Nuland uses *How We Die* to push back against the media's unwavering support of biomedicalization of HIV/AIDS, and instead promote a moderated biomedicalization. Nuland's tempered biomedicalization accepts the limits of science and medicine, but within these limits, maintains the authority of medicine to fight against unnatural processes of death. Although HIV is a naturally occurring virus, its appearance in young Americans at the end of the 20th century was causing a form of death perceived as unnatural, both in its pathological clinical manifestation and in its inversion of normal, expected lifecycles. In the case of HIV/AIDS, biomedicalization contributed to the epidemiologic shift that made death from infectious disease (i.e. AIDS) abnormal. Yet, at the same time, biomedicalization was championed as the solution to stopping this unnatural process of death. What then does

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[84] Christine Gorman. "Are Some People Immune to Aids?". *Time* 141, no. 12 (1993): 49.

[85] Clippings, How We Die Box A, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

Nuland think about biomedicalization when it attempts to turn what is perceived as a natural process of disease and death into an unnatural process so as to justify medical intervention?

Aging: How the Old Die

Medical advancement in the 20th century brought about an epidemiological transition in the United States, where mortality from infectious disease (excluding AIDS) declined and chronic disease became more prevalent.[86]Moreover, improved medical technologies contributed to people living longer.[87]Though people died at older ages, many still died from old age; medicine was unsuccessful in decreasing the number of deaths from old age. That is not to say medicine didn't try. Processes of medicalization and biomedicalization functioned to transform aging into a pathological, unnatural process. Moreover, the same medicalization and biomedicalization processes that turned old age into a disease also changed the way that medicine cared for elderly patients and the way that medicine perceived death from old age. What resulted was an attempt to freeze the natural life cycle, such that to die from old age was no longer seen as normal, but rather as a failure of biomedicine.

Changing conceptions of old age and death from old age were important given the shifting age demographic in America. While the HIV/AIDS epidemic shrank the young adult population, the elderly population in America continued to grow. From 1900 to 1990, the American elderly population grew faster than the total population in each decade, so the

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[86] Armstrong, Conn, and Pinner. "Trends in Infectious Disease Mortality," 61.

[87] Frank Hobbs and Nicole Stoops. *Demographic Trends in the 20th Century*. Vol. 4: US Census Bureau, 2002, 11.

elderly came to comprise an increasing proportion of American society.[88] Furthermore, the elderly population itself was also getting older. In 1990, 4% of the elderly population was aged 85 and older.[89] By 2000, this proportion had tripled.[90] Not only were the number of elderly and average age of the elderly increasing, but perceptions of old age were also changing. Nuland, recognizing the transformations in the way that aging and death from old age were perceived and treated in society, responds to the biomedicalization of aging and death from old age in *How We Die*. In this section, I analyze how Nuland's response to theories of aging and death from old age in the late 20th century America reflect his criticism of the way in which biomedicalized society has transformed a natural, developmental process into a pathological condition causing an abnormal form of death.

Medicalization processes construct old age as a medical problem and therefore death from old age becomes neither inevitable nor natural.[91] By dissociating aging from nature and giving it a disease classification, medicalization opens the door for medicine to intervene; when a biological process is no longer viewed as an unavoidable product of the natural order, it becomes susceptible to human (medical) intervention. Consequently, when it comes to aging, medicalization begets medicalization: processes of medicalization define old age as an illness, which makes it subject to medical treatment, thereby expanding medicine's jurisdiction over old age, which reinforces medicalization.[92]

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[88] Hobbs and Stoops, *Demographic Trends in the 20th Century,* 58.

[89] Ibid.

[90] Ibid.

[91] Kaufman, *And a Time to Die,* 81-82; Sharon Kaufman, J. K. Shim, and A. J. Russ. "Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges." *Gerontologist* 44, no. 6 (Dec 2004): 735; C. L. Estes and E. A. Binney. "The Biomedicalization of Aging: Dangers and Dilemmas." *Gerontologist* 29, no. 5 (Oct 1989): 588.

[92] Estes and Binney, "The Biomedicalization of Aging," 589; Kaufman, Shim, and Russ, "Revisiting the Biomedicalization of Aging," 735.

Identifying the origin of this medicalization cycle requires answering the question: how did old age come to be equated with illness? According to Sharon Kaufman, this happened partly because of the language of medicine; medical language describes discrete diseases, and thus, any condition can be defined only in terms of specific illnesses.[93] In the case of old age, the biological realities of having lived for a long time come to be articulated as illness, and aging comes to be viewed the cause of these illnesses.

Further contributing to the conception of old age as disease is the way that the modern medical model emphasizes diagnosis, pursuit of underlying mechanisms, and therapeutic intervention, thereby encouraging medical professionals to view conditions of life in terms of discrete, diagnosable, and treatable entities. With medicalization, the medical model becomes increasingly dominant, thus strengthening the imperative to treat aging as a pathological process. This results in a perception of death from old age as representing a failure of medicine to effectively diagnose, intervene, and treat a specific disease.

In *How We Die,* Nuland argues that scientific medicine resists old age as a cause of death, an argument that implies his belief that medicalization, inappropriately, has turned death from old age into death from disease. One of the first statements Nuland makes in his chapter on aging is that it is "illegal to die of old age."[94] Though he does not mean this literally, Nuland makes the point that the American medical establishment deems it invalid to list "old age" as the cause of death on a death certificate. However, it is often old age that is the actual cause of death. Nuland explains, "Though their doctors dutifully record such distinct entities as stroke, or cardiac failure, or pneumonia, these aged old have in fact died

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[93] Kaufman, *And a Time to Die,* 82-83.
[94] Nuland, *How We Die,* 43.

because something in them has worn out. Long before the days of scientific medicine, everyone understood this."[95] The "scientific medicine" Nuland refers to is a practice based on a model emphasizing distinct diseases that have medical treatments, a model that came to dominate American society through processes of medicalization.

Having a specific disease written on the death certificate is not what Nuland takes issue with; rather, he objects to the insistence that "assigning a name to a natural biological state means *a priori* that it is a disease."[96] Put differently, Nuland takes issue with viewing natural biological processes of aging as evidence of disease, because for him, this reverses the causality: disease doesn't cause old age, but old age can cause disease. To elaborate on this point and provide a more personal example, Nuland tells the story of his grandmother, who died of old age but whose death certificate said that she died of a cerebral vascular accident (CVA), or stroke.

> This is not simply a problem of semantics. The difference between CVA as a terminal event and CVA as the cause of death is the difference between a worldview that recognizes the tide of natural history and a worldview that believes it is within the province of science to wrestle against those forces that stabilize our environment and our very civilization.[97]

CVA as a terminal event leaves room for aging as a natural process; although a CVA may have been the final nail in the coffin, it came after years of the body gradually deteriorating. CVA as the cause of death implies that the death was abnormal; it was not a result of a natural developmental process, but was the result of an unnatural specific medical event that could have been prevented with appropriate medical treatment. Believing aging is natural, Nuland emphasizes that the existence of humankind is a matter of balance, where death of the old must occur to make room for the birth of the young, thereby renewing the

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[95] Nuland, *How We Die*, 44.
[96] Ibid., 52.
[97] Ibid., 43.

population.[98] This balance is threatened when death from old age is seen as unnatural and therefore subject to intervention by science and medicine.

The authority of medicine to intervene in the conditions of old age is legitimized by its technological ability to prolong life.[99] The expansion of technoscientific innovation in medical practice has contributed to the development and widespread utilization of medical tools that sustain life. For instance, the mechanical ventilator can prolong the life of an elderly patient suffering from pneumonia. This pneumonia may be just the latest clinical manifestation of the deteriorating body of the elderly patient. However, by diagnosing pneumonia, medicine identifies a condition to treat. Furthermore, because of biomedicalization, medicine can, is expected to, and will treat the pneumonia with targeted antibiotics and mechanical ventilation. Still, the underlying reason (old age) for the pneumonia persists and will continue to drive the patient closer toward death, despite medicine's technological tools and imperative to continue to apply those tools to thwart death.

Medicalization and biomedicalization have generated a reality in which "even in late life, death has come to be considered an option to practitioners and consumers of health care," but this "option" is understood differently by doctors, patients, and their families due to differing levels of biomedical knowledge.[100] Patients and their families often have little knowledge of human physiology, disease processes, or what medical treatment entails.[101] Moreover, they are not often privy to the institutional and bureaucratic obligations faced

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[98] Nuland, *How We Die,* 43.
[99] Ibid.
[100] Kaufman, *And a Time to Die,* 81.
[101] Ibid., 53.

by medical providers (i.e. to keep patients moving through the healthcare system).[102] Yet, with biomedicalization, patients and their families have gained access to medical information describing high-tech, potentially lifesaving clinical care, accessible information that is itself a product of biomedicalization. Because the elderly patient has been diagnosed with a specific disease, it may seem to the patient and/or her family that with aggressive, high-tech medical intervention, the patient will recover completely. The technological imperative of families becomes a moral imperative in the sense that the "right" thing to is continue aggressive medical treatment.[103] While doctors are also guided by the technological imperative, they have an advantage over patients and their families: doctors understand human physiology and therefore will often know when death is imminent despite technological intervention.

Differing levels of medical knowledge of patients, their families and doctors hinder communication, which in turn, preserves and intensifies the knowledge gap. More specifically, the language of biology, disease, and the body is often lost on family members who do not have the medical knowledge to understand what the doctor's technical language means for the sick patient.[104] Because family members lack this medical knowledge, they may be unable to see the true meaning behind the doctor's use of the words "unlikely to recover" or even "never recover," instead interpreting the doctor's words to mean, "maybe recover."[105] The family may then maintain that there is hope of recovery, even when the doctor knows that no such recovery is possible, thus sustaining a knowledge gap between the doctor and the patient and her family.

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[102] Kaufman, *And a Time to Die*, 59-60.
[103] Kaufman, Shim, and Russ, "Revisiting the Biomedicalization of Aging," 736-737.
[104] Kaufman, *And a Time to Die*, 175.
[105] Ibid.

In the case of the elderly patient, the knowledge gap is even more pronounced because the illness that is the subject of discussion is not the whole medical picture, a point that can be best understood by returning to the example of pneumonia in the elderly patient. When the doctor says that the elderly patient has septicemia (blood infection) from the pneumonia and is "unlikely" to recover, the patient and her family may interpret the doctor's statement as the patient will "maybe" recover from the pneumonia, unaware of the medical implications of sepsis. What is more, the pneumonia and sepsis are just the most recent manifestations of physical decoration – the family, unlike the physician, is unaware that the underlying cause of their mother's condition is her old age. Instead, medicalization has labeled her condition as pneumonia, and brought the old woman to the hospital for treatment. Biomedicalization has fostered the family's intense faith that high-tech medicine will cure the problems of their aged mother.[106] As a result, the family and doctor walk away from the same conversation with different conclusions: the family thinks that treating the pneumonia will return their loved one to health, but the doctor knows that the patient's death is only a matter of time.

Nuland attempts to bridge this knowledge gap between patients, their families and physicians by describing the *natural* biological processes of aging, thereby reframing death from old age as a biological inevitability. In doing so, he also implicitly comments on what it means to age and die of old age in a biomedicalized society. Nuland goes into great detail describing the theories of why we age and how the cells, tissues, and organs of the body deteriorate with age.[107] Throughout his discussion of the biology of aging, Nuland underscores that aging is natural and ultimately death from old age is normal, and

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[106] Estes and Binney, "The Biomedicalization of Aging," 594.
[107] Nuland, *How We Die*, 44-87.

"whether its overt physical manifestation appears in the cerebrum or the sluggishness of a senile immune system, the thing that peters out is nothing other than the life force."[108] The "life force" gives out because it has to for the renewal of the human population. And yet, modern medicine doesn't want to recognize this. By calling aging pathological, medicine takes the "first step in the attempt to cure it [aging] and thereby thwart it [aging and death]."[109] To "cure" aging represents medicine's attempt to transform what it means to age – it is an attempt to biomedicalize aging, to stave off deterioration and death. According to bioethicist Daniel Callahan, this results in both society and the medical profession losing a sense of the natural lifespan, which entails a loss in belief in inevitable deterioration and death.[110]

Along with obscuring the natural lifespan, biomedicalization exaggerates the tension between the technological and clinical imperatives of medicine, the consequences of which we can observe by examining perceptions of geriatrics. Geriatrics, the medical specialty devoted to caring for the elderly, is motivated almost exclusively by the clinical imperative. A lot of the geriatrician's job is to help the patient and family understand what to expect as the patient continues to age and then discuss with the patient what his desires are regarding how he wants to live his life.[111] Within medicine, geriatrics is often perceived as an inferior specialty because it resists the hyper-specialization and technological imperative characteristic of most modern medical fields.[112] In fact, geriatrics was denied legitimation by most medical schools in the United States until aging was redefined as a

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[108] Nuland, *How We Die*, 44.
[109] Ibid., 58.
[110] Callahan, "Death and the Research Imperative," 654-656.
[111] Leo Cooney (physician) in discussion with the author, February 2017.
[112] Estes and Binney, "The Biomedicalization of Aging," 590.

biomedical puzzle that could support scientific research careers.[113] Geriatrics had to be biomedicalized in order to gain recognition as a modern medical specialty.

While the biomedicalization of geriatrics legitimized the specialty, it also created an identity crisis. Forced to demonstrate its technological imperative to gain entrance to the world of biomedicine, geriatrics became less certain of its stand on the relationship between aging and disease and how geriatricians should care for the elderly. Nuland, unknowingly, demonstrated the extent of this ambiguity in his discussion of geriatrics in *How We Die.* Nuland sent an initial typescript of his aging chapter to Dr. Leo Cooney, a geriatrician at Yale New-Haven Hospital.[114] Cooney took issue with the way that Nuland had presented geriatrics, specifically, Nuland's statement that the geriatrician's worldview "argues for vigorous intervention to treat the named pathologies with the aim of prolonging life."[115] Nuland thought that geriatrics was motivated by the same technological imperative as much of the rest of institutional medicine. Instead, Cooney explained, "most geriatricians are at the forefront of those who believe in withholding vigorous interventions designed simply to prolong life…We wish to improve the quality of life for older individuals, not to prolong its duration."[116] In other words, despite its outward appearances, geriatrics prioritizes the clinical imperative. The fact that geriatrics needed to have a particular, technologically oriented outward appearance for the rest of medicine is a testament to the extent of biomedicalization. Moreover, biomedicalization was so pervasive that Nuland initially assumed that, like the rest of doctors, geriatricians transformed

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[113] Estes and Binney, "The Biomedicalization of Aging," 590.

[114] Sherwin Nuland, Letter to Leo Cooney, 29 July 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[115] Leo Cooney, Letter to Sherwin Nuland, 11 August 1992, How We Die Papers Box B, Yale Collection of American Literature, Beinecke Rare Book and Manuscript Library.

[116] Ibid.

diseases of old age into targets of technoscientific intervention to prolong life and prevent what should be a normal form of death. Upon learning that his assumption was false, Nuland was ready to harness geriatrics as evidence of the possibility of medical care that can relieve suffering while also recognizing that aging and death from old age are parts of the natural order.

Nuland's championing of geriatrics occurred over twenty years ago. Has geriatrics been able to continue to resist biomedicalization both within its field and through the influence it exerts over medical care of the aging at large? In a recent interview Dr. Leo Cooney expressed the belief that yes, geriatrics had continued to resist biomedicalization in the sense that as a specialty, it has maintained a commitment to relieving suffering, not prolonging life indefinitely through technology. Recently, geriatricians, with the help of other healthcare professionals, have led efforts to increase the use of advanced directives.[117] According to Cooney, their goal is to get people to start having advanced care discussions starting around age 50. The key is to *start* these discussions early. Treatment preferences change with increasing age and the emergence of new illnesses.[118] However, with more frequent discussions, there is more information in the patient's record about his treatment preferences. Accordingly, when the elderly patient shows up in the Intensive Care Unit, the attending physician and patient's family will have an idea of the patient's preferences regarding levels of medical intervention. Importantly, the doctor is not a passive participant in these discussions. Cooney explained that it is the role of the doctor,

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[117] Leo Cooney (physician) in discussion with the author, February 2017.
[118] Ibid.

usually the primary care physician, to provide patients with the knowledge they require to make decisions about their treatment preferences.[119]

In *How We Die,* Nuland functions as a sort of primary care physician to his readers, providing the public with descriptions of what happens to the body as it ages. Like advanced care discussions today, Nuland's book informs patients to become their own protection against the tendencies of modern medicine to biomedicalize aging and death from old age. Also like advanced care directives, Nuland's *How We Die* is only the start of a longer discourse about how to understand and approach dying in a biomedicalized society.

Epilogue: *How We Die* Today

Margaret Lock, in *Remaking Life and Death: Toward an Anthropological Approach to the Biosciences,* writes that "death was social in pre-modern times, biological in modern, and once again social in the present."[120] The social nature of death is evidenced by the ways in which biomedicalization has transformed experiences and expectations about death. Biomedicalization, though a tool of science and medicine, is a product of social and cultural interactions. Paradoxically, biomedicalization contributes to the transformation of death into a social phenomenon, but then argues for the treatment of death as a biological phenomenon. Internalizing biomedicalization, science and medical professionals have redefined death as a biological cascade of a "series of preventable diseases."[121]

In *How We Die,* Nuland describes and subsequently opposes the biomedicalization of aging that turned death from old age into a "series of preventable diseases." The same

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[119] Leo Cooney (physician) in discussion with the author, February 2017.

[120] Cecilia McCallum. "Remaking Life and Death: Towards an Anthropology of the Biosciences (review)." *Anthropological Quarterly* 77, no. 1 (2004): 200.

[121] Callahan, "Death and the Research Imperative," 654.

could not be said of HIV/AIDS. In 1994, death from AIDS was seen as death from an incurable disease. Today, though still incurable, AIDS is not a death sentence. Much of this is due to advancements in antiretroviral therapy (ART) that have greatly diminished the rates of progression from HIV infection to AIDS.[122] The medical establishment is now faced with a new challenge: an aging population living with HIV.[123]

Not only are people living with HIV getting older, but HIV itself is associated with what is popularly known as "premature" or "accelerated aging."[124] Older patients with HIV may present with non-AIDS morbidities that are commonly associated with aging in the general population. These morbidities include: heart, kidney, and liver diseases, hypertension, cancer, and frailty.[125] The fact that these non-AIDS morbidities in older HIV patients have been described as "premature aging" reflects the new way that HIV/AIDS is medicalized; no longer viewed as a single, unique disease, HIV/AIDS is associated with common chronic morbidities. And, not just any morbidities, but morbidities associated with aging. Thus, like death from old age, death from HIV/AIDS has been transformed into death from a "series of preventable diseases."

If one who dies of old age is considered to have died "naturally," does it follow that an HIV-infected individual who dies of "premature aging" also died "naturally"? The adjective "premature" implies a degree of abnormality in this form of aging, and abnormality suggests unnaturalness. At the same time, who is to say that this form of aging is "premature" and therefore abnormal? Aging and HIV/AIDS are merging to create new

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[122] Jason B. Kirk and Matthew Bidwell Goetz. "Human Immunodeficiency Virus in an Aging Population, a Complication of Success." *Journal of the American Geriatrics Society* 57, no. 11 (2009): 2129.

[123] Ibid.; Steven G. Deeks, Sharon R. Lewin, and Diane V. Havlir. "The End of Aids: Hiv Infection as a Chronic Disease." *Lancet* 382, no. 9903 (10/23 2013): 1529.

[124] Deeks, Lewin, and Havlir, "The End of Aids," 1529.

[125] Kirk and Goetz. "HIV in an Aging Population," 2129.

challenges for the medical profession, raising important questions about changing conceptions of natural and normal. These questions are part of a complex discussion of the ways that science, technology, and culture interact to reconstruct notions of normal and abnormal, natural and unnatural, life and death.[126]

How We Die fits into this discussion, offering a response to these questions reflective of Nuland's historical moment, a moment when biomedicalization functioned to transform ways of dying. In 2010, a new version of *How We Die* was published, and with it, Nuland's perspective on the ways medicine, technology, and death have changed in the twenty years since he wrote *How We Die.* Through the 2010 Coda, *How We Die* enters the 21st century, revealing the ways that biomedicalization has intensified. In the Coda, Nuland describes how data and technology drive current medical practice; how the provider has replaced the physician, and the humanism and compassion of young doctors is bridled by the institutional demands of modern medical practice; how medical care has become formulaic and distanced.[127]

At the same time movements such as advanced directives, hospice, and physician-assisted suicide, have gained force. Each of these movements represents an attempt to promote a good death, often by restoring dignity to death. The modern day reader of *How We Die*, accustomed to ideals of "death with dignity" – ideals popularized in large part by the physician-assisted suicide movement – may be troubled by Nuland's conclusion that

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[126] For further discussion of this topic, see Lock, Margaret M, and Sarah Franklin (eds.). *Remaking Life & Death: Toward an Anthropology of the Biosciences*. (Oxford: School of American Research Press, 2003).

[127] Nuland, *How We Die,* Coda 2010.

there can be no dignity in death.[128] For, in the 21st century, a dignified death is synonymous with a good death. This association, between a dignified death and a good death, is a product of the cultural ideals of our society. Uncomfortable with ideas that challenge accepted cultural expectations about death, the reader may try to dismiss Nuland's perspective as too cynical. However, I believe that Nuland's message can be understood not as cynical, but as realistic, and in this realism, empowering for both for the patient and the doctor.

According to Nuland, it is in the patient's control to have a good death. One way the patient can have a good death is to live a good life. Nuland argues that *ars moriendi* is *ars viviendi:* the art of death is the art of life. [129] By living a full life, one is able to approach death with a feeling of fulfillment and surrounded by loved ones, which together promote a good death. The other way a patient can promote a good death is by making his death his own. Applying this to his own life, Nuland writes:

> I will not allow a specialist to decide when to let go. I will choose my own way, or at least make the elements of my own way so clear that the choice, should I be unable, can be made by those who know me best. The conditions of my illness may not permit me to "die well" or with any of the dignity we so optimistically seek, but within the limits of my ability to control, I will not die later that I should simply for the senseless reason that a highly skilled technological physician does not understand who I am. [130]

This was how Nuland died. He died a death not determined by the imperatives of biomedicalization, but by his imperatives of a meaningful life. A good death is possible

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[128] *How We Die* was published at the height of the debates about physician-assisted suicide, yet Nuland only mentions it briefly. Nevertheless, it was an important topic in Nuland's historical moment that participated in the construction of expectations about death. For more on physician-assisted suicide and its relationship with conceptions of death, see Nicholas A Christakis, "Managing Death: The Growing Acceptance of Euthanasia in Contemporary American Society," *Must we suffer our way to death* (1996).

[129] Nuland, *How We Die,* 268.

[130] Nuland, *How We Die,* 266.

when a patient is able to decide on limits of medical intervention so that he can, for as long as possible, live a good life.

If a good death is in the patient's control, then what is the role of the doctor? The role of the doctor comes from an understanding of the role of medicine. More precisely, Nuland believed that ultimately, medicine is an art informed by science.[131] However, with biomedicalization, the science comes to inform the art. How then can modern institutional demands for data-driven, algorithmic medical care be reconciled with the unstandardized, unquantifiable tradition of the art of medicine? Are algorithms, machines, and protocols, products of biomedicalization that drive the science of medicine, mutually exclusive with the art of medicine? I do not believe so. We do not have to look far to see how biomedicalization, through certain advances in technoscience (e.g. ART), has positively impacted medicine. A conflict between biomedicalization and the tradition of medicine emerges only when biomedicalization comes to *define* the practice of medicine, such that doctors begin to see themselves as capable of controlling and overpowering nature. Especially in death, the role of the doctor is not to be a master of *nature* but a master of *nurture.*

It is in his role as nurturer that the doctor embodies the art of medicine. Nurturing may involve giving the patient the knowledge he needs to make decisions about his medical care. It may involve giving the patient the technoscientific treatments that will help him recover. It may involve sitting at a patient's bedside listening to their experience with illness. Regardless of the form it takes, the practice of nurturing should be guided by a commitment to relieving patient suffering, not overcoming forces of nature.

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[131] Sarah Nuland (wife of Sherwin Nuland) in discussion with author, January 2017.

I am not a doctor. I do not know what it feels like to practice medicine. I do not know what it feels like to be responsible for life and death decisions. I have not experienced the ever-magnifying forces of biomedicalization that dominate medical practice and influence physician thinking and behavior. I hope to one day experience these feelings, to know what it means to carry the letters M.D. at the end of my name. As I approach that day, I will safeguard the same lessons that I hope you, as the reader, take from this essay: appreciation for the work of Sherwin Nuland; an appreciation for the intricate, constantly changing relationships between nature, medicine, technology, and society; and perhaps most importantly, an appreciation for the way in which historical analysis can be harnessed to transform the way that we, as patients, as doctors, and as human beings, understand and approach death.

Word Count: 11,714

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Bibliographic Essay

This essay originated from an interest in the transformation of experiences of death in modern America, an interest sparked by Atul Gawande's *Being Mortal.* Sharing this interest with my advisor, she suggested I read Sherwin Nuland's *How We Die*, as it was one of the first books written on the topic of modern death. Nuland's book would come to serve as the central primary source for my essay, with all subsequent analysis of primary and secondary sources working to help me make sense of the significance of *How We Die.*

During my meeting with Melissa Grafe, I learned that Sherwin Nuland's wife had recently donated all of the notes Nuland collected while writing *How We Die.* With the help of Melissa Barton and the Beinecke Rare Books and Manuscript library, I was able to obtain access to the How We Die papers, which provided the remaining primary sources for my essay.

Before examining the How We Die papers, I had the opportunity to meet with Dr. Jerome Groopman, a physician-researcher-writer at Harvard Medical School. Dr. Groopman, a colleague and friend of Nuland's, provided me with a valuable perspective on the social, medical and personal factors influencing Nuland's writing of *How We Die.*

With Dr. Groopman's advice in mind, I first examined the How We Die papers to get a sense of what went into Nuland's process of writing and what context-specific social and medical forces influenced his project. The papers included several types of primary sources: Nuland's book proposal; typescripts of *How We Die* edited by different physicians; clippings from newspapers, magazines, and scientific journals; and correspondences with Nuland's with those involved in the editing of *How We Die*. The book proposal supplemented the prologue of *How We Die,* shedding light on Nuland's goals in writing the book, which was important for my understanding of what he looked to respond to with his text.

When I first examined the contents of the How We Die papers, I expected that the clippings would be the most valuable primary sources because they provided direct evidence of the relevant historical discourse that was taking place when Nuland was writing. Most of the clippings discussed one of three topics: HIV/AIDS, aging, or physician-assisted suicide. Because I assumed that the clippings would be my main primary sources, I thought I would focus my essay on HIV/AIDS, aging, and physician-assisted suicide. However, because Nuland only briefly mentions physician-assisted suicide in *How We Die,* I decided not to focus on that topic, restricting my essay to HIV/AIDS and aging. While I made this decision initially because of the large amount of primary source material on HIV/AIDS and aging, by the end of my research it was clear that HIV/AIDS and aging were important case studies because they brought to light different, key aspects of biomedicalization, while also providing an opportunity to examine the relationship between natural, normal, and processes of death.

Having narrowed the scope of my research to HIV/AIDS and aging, I looked at the correspondences and corrected typescripts related to these two topics. Ultimately, the correspondences and corrected typescripts Dr. Gerald Friedland, an HIV/AIDS specialist, and Dr. Leo Cooney, a geriatrician, proved most useful. The edits of Dr. Friedland and Dr. Cooney functioned as evidence of what the medical profession was thinking about HIV/AIDS and aging (respectively) at the time Nuland was writing. Therefore, I used these primary sources to support my discussion of the medical profession's perspective on aging and HIV/AIDS and how Nuland responded to this perspective. In analyzing Nuland's response to these edits, using both the correspondences and the final text of *How We Die,* I was able to place Nuland in the larger medical conversations about HIV/AIDS and aging happening at the historical moment of his work.

To further help place *How We Die* into larger historical conversations about death, I turned to reviews of the book. Because I treat *How We Die* as a primary source, reviews of the book served as useful secondary sources. One review in particular, written by historian Thomas Laqueur, was especially valuable because it was the first source I examined to raise the question of what constitutes a "natural" death. Furthermore, Laqueur presents the deaths described in *How We Die* as intertwined with Western, technological, medical culture. To make sense of what Laqueur meant by this, I turned to Adele Clarke and colleagues essay, "Biomedicalization: Technoscientific Transformations of Health, Illness, and U.S. Biomedicine." This article was a central secondary source in my essay, allowing me to develop biomedicalization as a framework for understanding the greater social, scientific, and medical changes that described *How We Die*'s historical context. To supplement this work I used bioethicist Daniel Callahan's article "Death and the Research Imperative," which commented on modern medicine's relationship with death. Callahan's article highlighted the tension between the technological and clinical imperatives, a tension introduced and exaggerated by biomedicalization.

It was not until I read Sharon Kaufman's *And a Time to Die: How American Hospitals Shape the End of Life* that my thesis in its present form began to take shape. Kaufman's book, another of my major secondary sources, provided a comprehensive perspective on the ways death is understood and experienced by practitioners and consumers of modern medicine. Her book not only bridged the gap between the theory of biomedicalization and its manifestations in experiences of death, but also provided the foundation for my thesis. Specifically, I used Kaufman's book to guide my examination of *How We Die* as a narrative reconstructing conceptions of what is natural and normal. Moreover, *And a Time to Die* was especially useful for my discussion of death from old age. Two additional secondary sources important for my section on death from old age were "The Biomedicalization of Aging: Dangers and Dilemmas"(published before *How We Die)* and "Revisiting the Biomedicalization of Aging: Clinical Trends and Ethical Challenges" (published after *How We Die*). These articles described the biomedicalization of aging and helped me frame and situate Nuland's discussion of aging in a larger discourse about biomedicalization. Furthermore, these secondary sources helped me make sense of the primary source documents on the topic of aging (archival collection and the text of *How We Die*).

On the topic of HIV/AIDS, I looked for secondary sources to provide context for the relationship between science, medicine, and society in the midst of the AIDS epidemic. I found this in Steven Epstein's *Impure Science: AIDS, Activism, and the Politics of Knowledge.* I used Epstein's book to interpret the significance of Nuland's presentation of HIV/AIDS given its historical context at the height of the AIDS epidemic and activist movement. In addition, Randy Shilts' *And the Band Played On: Politics, People, and the AIDS Epidemic* gave useful background information on the social history of HIV/AIDS. I used Epstein and Shilts' books to identify and analyze the social aspects of death from HIV/AIDS embedded in the text of *How We Die.* In addition, these secondary sources helped me make sense of the importance of the primary source documents from Dr. Friedland included the How We Die papers.

To supplement the archival documents, I hoped to meet with some of the physicians who were involved in the editing of *How We Die*. Of all the physicians I contacted, Dr. Leo Cooney was the only to respond. My interview with Dr. Cooney provided more insight into Nuland's perception of geriatrics and Cooney's edits for Nuland's chapter on aging. More broadly, I was able to use my interview with Cooney to learn about the history of medicine's treatment of the elderly and relationship with their deaths, as well as the present day imperatives and initiatives of geriatrics.

I was fortunate to have the opportunity to interview Sarah Nuland in the house that she and Sherwin Nuland shared. Having the opportunity to see Sherwin Nuland's office, read his handwritten notes, and hear his thoughts expressed through the medium of his wife, gave this project a deeper level of personal meaning. Moreover, an intimate perspective of who Sherwin Nuland was and how he thought about medicine, life and death help me better interpret the text of *How We Die* and make sense of the way Nuland would have responded to information and ideas presented in my other sources. Along with my interview with Sarah Nuland, the 2010 edition of *How We Die,* which included a Coda from Nuland, served as a primary source that I used to bring *How We Die* into the 21st century, offering lessons for our present day.

Seeing as my interviews with Dr. Cooney and Sarah Nuland were so valuable, my research may have also benefitted from an opportunity to interview Dr. Gerald Friedland. Especially because a large part of my discussion of HIV/AIDS is based in an analysis of Dr. Friedland's edits of *How We Die,* I would have appreciated the perspective and insight he would have been able to provide in an interview.

With more time, I would have more critically examined Margaret Lock and Sarah Franklin's *Remaking Life and Death: Towards an Anthropological Approach to the Biosciences.* While I was not able to read the book in full (it was unavailable from the library and online), I used Cecilia McCollum's review of the work as a tool to frame the discussion of the historically dependence of conceptions of natural and normal in the realms of life, death, and the biosciences. A more complete analysis of *Remaking Life and Death* may have benefitted my argument about the role of *How We Die* in reconstructing conceptions of natural and normal and their relationship to understandings of life and death.

My essay only discusses two of the six processes of death described in *How We Die.* Though HIV/AIDS and aging were productive examples for my thesis, with more time and pages I would have hoped to include a discussion of the other processes of death described in *How We Die.* Perhaps an interesting continuation of this paper would examine how each of the different processes of death described in *How We Die* interact with biomedicalization and function to alter conceptions of natural, thereby redefining what constitutes a normal process of death in modern America.