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# Doctors, Death, and Denial: The Origins of Hospice Care in 20th Century America

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Sarah E. Pajka

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Doctors, Death, and Denial: The Origins of Hospice Care in 20<sup>th</sup> Century America

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History of Science, Medicine, and Public Health

April 3, 2017

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## Introduction

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

-Cicely Saunders, founder of the modern hospice movement, 1959<sup>1</sup>

Today, when most people hear the word “hospice,” nothing like Saunders’ quote comes to mind. To most, hospice is thought to be the antithesis of life, an option used only in the last days or weeks of a person’s life. To Saunders and the leaders of the hospice movement, however, at its original founding, hospice stood for human dignity and support. The story of hospice is about the triumph over long-standing tradition, and the reintroduction of compassionate care for the dying by a small group of medical professionals, who advocated for a group that did not have the resources to call for these changes themselves.

In order to demonstrate why hospice was such a feat, this essay will begin by exploring the emergence of a need for hospice care in the United States, which originated before the start of the twentieth century. It will first examine the history of hospital practices in relation to the dying patient, including the competitive nature of mortality rates and the enforcement of “incurable policies.” Next, it will discuss the rise of institutionalized medicine and delve into the organization of medical professionals into a cohesive and influential assembly. With the progression of medical science and a focus on curative medicine, the status of physicians as a body of expert healers left no place for the patient who could not be healed. Death was a

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<sup>1</sup> Cicely Saunders, “The Problem of Euthanasia (Care of the Dying-1),” first published in *Nursing Times* 72, no. 26 (1976): 1005, published to Oxford Scholarship Online (2011). doi: 10.1093/acprof:oso/9780198570530.001.0001

representation of what medicine could not master, and as the medical profession became more prestigious, its refusal to accept death became prominent.

Highlighting key figures in this movement, this essay will follow the efforts of the medical practitioners that strayed from tradition in order to demonstrate, and later address, the problem of the denial of death in American society. While psychologists and psychiatrists were largely responsible for bringing the issue to the forefront of public attention, it was the determination of two nurses that identified and implemented hospice as a solution, first in London with St. Christopher's Hospice, followed by Connecticut Hospice in the United States.

This paper will conclude with the opening of Connecticut Hospice, the first modern hospice center in the United States, and the way in which its creation was a direct response to the tradition of denying death in twentieth century American medicine. Although hospice facilities still exist today, many are unable to provide the type of care its founders envisioned, largely as a result of the current U.S. healthcare system and the prohibitive costs of long-term care. The hospice movement was crucial to reshaping medical perceptions about the end of life, reminding society that the dying patient was still, first and foremost, a person.

### **The “Incurable” Problem**

The end of the nineteenth century marked a changing scene for patients with terminal illness in America. Before the establishment of new institutions like tuberculosis sanatoriums and cancer centers, patients who could afford it received in-home care, and were visited by individual physicians for all types of illness.<sup>2</sup> Patients who required medical care at an institution

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<sup>2</sup> Thomas M. Daniel, “The History of Tuberculosis,” *Respiratory Medicine* 100, no. 11 (2006): 1862-1870.

reluctantly went to hospitals, where they were treated until they recovered, or until they proved incapable of doing so. If a patient was deemed “incurable” at any point during the treatment process, he or she could be immediately discharged.<sup>3</sup> In fact, patients that fell under this classification were often refused admission to the hospital entirely, before receiving any type of treatment.

Our current code of medical ethics may seem above the systems of the past, but in actuality, the two may not be so different. Take, for example, the modern practice of triage. During disasters or large-scale emergencies, responders designate “color tags” for patients based on the priority of their immediate care and transport. Patients who are expected to die are given black tags, matching those of patients who have already passed away, and are only treated and transported after all other patients have received care, including those with non-life-threatening conditions.<sup>4</sup> The mantra behind this system is provision of the “greatest good for the greatest number of people,” which often entails giving priority to some patients while others are neglected.<sup>5</sup> Although the definition of “incurable” has evolved alongside medicine, the system itself has only undergone minor updates. To the doctors of the past, late-stage tuberculosis was every bit as hopeless as the conditions facing a black-tag disaster patient today, despite the wide discrepancy between the time from diagnosis to death in each case.

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<sup>3</sup> Emily K. Abel, *The Inevitable Hour: A History of Caring for Dying Patients* (Baltimore: Johns Hopkins University Press, 2013), 31.

<sup>4</sup> Andrew N. Pollak, et al., *Emergency Care and Transportation of the Sick and Injured*, 10th ed. (Burlington: Jones & Bartlett Learning, 2011), 1396.

<sup>5</sup> *Ibid.*



While time is typically the limiting factor for current patients in need of emergency medical care, in the nineteenth century, patient admission to the hospital was principally governed by the availability of space and resources. Up until a push for the construction of hospitals the mid-twentieth century, the number of sick patients in America grossly outnumbered the hospital beds available for them.<sup>6</sup> With the organization of hospitals into separate voluntary and private institutions, the fates of those who could not pay for their care were left to administrative boards or charity organizations. Hospitals at this time were not entirely trusted or respected, and patients did not visit them if they could avoid it. While private hospitals were viewed as underutilized, exclusive, profit machines, voluntary hospitals were considered little more than public charities.<sup>7</sup> Neither type of facility was particularly flattering to the reputation of medicine, but given that three out of every four sick patients exclusively received care in the home until the 1920s, the majority of physicians were more concerned with their individual professional status. Unfortunately, this indifference often resulted in poorly funded institutions with low standards of care.<sup>8</sup>

If a dying person had a family with the ability to care for them, there was rarely a question of hospital death. Preferable to the rejection and isolation offered by hospitals, home-based care allowed patients to receive care from a visiting physician while maintaining autonomy and some connection to the living.<sup>9</sup> As they lived out their last days, the chronic and

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<sup>6</sup> Lawrence J. Clark et. al, "The Impact of Hill-Burton: An Analysis of Hospital Bed and Physician Distribution in the United States, 1950-1970. *Medical Care* 18, no. 5 (1980): 532-550.

<sup>7</sup> "The Hospital Question," *JAMA* 38, no. 12 (1902): 770.

<sup>8</sup> W.H Smith, "Adequate Medical Service for a Community: Some Factors of Importance," *JAMA* 76, No. 16 (1921): 1058.

<sup>9</sup> Abigail McCarthy, "Hers," *The New York Times* (New York, NY), Nov. 23, 1972.

terminally ill often resided in main-floor bedrooms, and when they were unable to get out of bed, the door would be left ajar to keep the sick person included in household affairs.<sup>10</sup> When the time came, the family signaled the death to the neighborhood and tended to the funeral arrangements, which usually also took place in the home. As a result, death was a familiar experience for the majority of the public, no more distant than the next room over.

In hospitals, infectious diseases flourished, patients were often neglected, and many treatments were known to be unpleasant.<sup>11</sup> Needless to say, most individuals were in no rush to visit. Yet, for those with nowhere else to turn, hospital care was in relatively high demand. For decades, the lack of hospital space allowed hospital boards to defer or deny admission to their facilities based on characteristics they deemed disagreeable, such as race, social status, or health condition. This screening process was especially pertinent to private hospitals, whose admission decisions were typically made by Boards of Trustees. In many cases, boards like these decided that the admission of known terminally ill patients was more than undesirable, it was forbidden. Some hospitals even had clauses defined within their handbooks which explicitly prohibited the admission of all patients who were thought to be “incurable.”<sup>12</sup> One annual report from Boston City Hospital in 1891 claimed that funds for hospital treatment of terminally ill patients were better utilized when reserved for the costly care that was required of patients with acute illness or severe injury. According to the Board of Trustees, the responsibility of the incurable and

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<sup>10</sup> McCarthy, “Hers,” 1972.

<sup>11</sup> “The Hospital Question.” *JAMA* 38, no. 12 (1902): 770.

<sup>12</sup> Boston City Hospital, *Twenty-Seventh Report of the Trustees of the City Hospital*, (Boston, Rockwell and Churchill City Printers, 1891): 146.

chronically ill patients was better left to almshouses, where care was simple and inexpensive.<sup>13</sup> In spite of claims like this, historians have long suspected alternative, self-serving motives. Most commonly, it has been postulated that “incurable” policies existed as an assurance of low mortality rates, during a time when hospitals had reputations to shape.<sup>14</sup> If hospitals avoided admission of those patients expected to die, they could boast of higher cure rates than their competitors, and patients who could afford to pay would be more likely to choose their center for care. More paying patients, of course, meant better business for the hospital, and more importantly, it meant distinction from charity hospitals and almshouses.

For patients without money or family, the almshouse was a last resort. Often falsely classified as the precursor to the modern hospice, almshouses were public charity centers created to house the chronically ill.<sup>15</sup> While almshouses were intended as refuges for those close to death, they were typically primitive, unpleasant, and were unable to provide real treatment or pain relief.<sup>16</sup> Dependence on almshouses was intended more to keep the dying off of the streets than to help them obtain a comfortable death, and was reserved for patients who were very poor, homeless, or without family to care for them.

### **The Assembly of the Medical Profession**

The mission to improve the status of hospitals was not limited to the physical buildings, but also extended to the men who staffed them. As more of the population became concerned

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<sup>13</sup> Ibid., 13.

<sup>14</sup> Abel, *The Inevitable Hour*, 31.

<sup>15</sup> Siebold, *The Hospice Movement*, 19.

<sup>16</sup> Ibid.

with the organization of hospitals, many physicians found themselves in a new place of authority. For physicians of the past, medicine had primarily been a solitary profession. Doctors tended to their patients in their own homes, and rarely consulted others in their field.<sup>17</sup> Hospitals – although still unpopular – gave physicians a place to work together, and provided a new setting for medical coordination and discourse.

In 1913, the formation of the American College of Surgeons created a new body to regulate medicine, and to a larger extent, to regulate hospital care.<sup>18</sup> Although the American Medical Association had been around for more than half a century prior to the ACS, they had not yet taken ownership of institutionalized medicine, and instead focused more on individual practices. Organizations like the American Hospital Association and the Council of Medical Education and Hospitals had also been around since 1898 and 1905, respectively, but efforts at reform from these parties had been meager at best.<sup>19</sup> The American College of Surgeons, however, took on the role with vigor, projecting recommended standards for hospitals almost immediately after its inception.<sup>20</sup> These guidelines were generally accepted, and became policy

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<sup>17</sup> Abraham Flexner, Medical Education in the United States and Canada: A Report to The Carnegie Foundation for the Advancement of Teaching, (Carnegie Foundation Bulletin 4, New York, 1910): 26.

<sup>18</sup> Gabriel, John. “The Hospital and the Changing Social Order.” *Journal of the American Hospital Association*, January ed. (1936):17

<sup>19</sup> Ibid.

<sup>20</sup> Ibid.

at the American Conference on Hospital Service in 1921 with the promise that the ACS could take control of the standardization process if it did not satisfy their expectations.<sup>21</sup>

Gradually, medical professionals – especially those working in hospitals – transitioned from individual practice into careers as part of the larger body of the medical profession. Despite efforts to create a cohesive authority that could be entrusted with the health of the general population, the extreme heterogeneity of the medical training process prevented any such organization.<sup>22</sup> In the sense that a team is only as strong as its weakest player, the medical profession as a whole could only be as reputable as its least trustworthy physician. According to the president of the Carnegie Foundation, Henry Pritchett, an investigation was necessary to afford well-trained physicians and their educators the significant respect they deserved, as they had “taken upon their shoulders the burden of medical education.”<sup>23</sup>

When the Foundation’s report was published in 1910 by Abraham Flexner, it provided quantitative proof of the variance between medical universities across the US and Canada and specifically criticized inadequate curricula at a number of schools.<sup>24</sup> Reflective of the rise of laboratory science at the time, the report promoted the superiority of scientific medicine, using

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<sup>21</sup> “Conference on Hospital Service: Policy of the American Conference on Hospital Service.” *JAMA* 76, No. 14 (1921): 939.

<sup>22</sup> Andrew H. Beck, “The Flexner Report and the Standardization of American Medical education,” *JAMA* 291, no. 17 (2004): 2139-2140.  
doi:10.1001/JAMA.291.17.2139

<sup>23</sup> Pritchett, Henry S. *Introduction to “Medical Education in the United States and Canada: A Report to The Carnegie Foundation for the Advancement of Teaching” by Abraham Flexner.* Carnegie Foundation Bulletin 4, New York, 1910: xiv.

<sup>24</sup> Flexner, Medical Education, 21-24.

experimental reasoning to support its claims.<sup>25</sup> In addition, the report highlighted the necessity of regulation of medical schools by respectable medical leaders. Flexner's use of scientific argument convincingly incorporated his definition of "well-trained" physicians into the increasingly elite scientific community, placing their "professional" education well above that of "college" and technical school graduates. Based on his analysis, other forms of education were "less difficult, less trying, less responsible" than a medical education.<sup>26</sup> In addition, he formally introduced the idea that physicians had responsibilities that extended past human life. According to Flexner, the ethical duty of the physician included the whole of society, which relied on physicians "to ascertain, and through measures essentially educational to enforce, the conditions that prevent disease and make positively for physical and moral well-being."<sup>27</sup> Although he had no medical background himself, Flexner believed that it was up to those at the forefront of the medical profession to serve all of society by educating the public and reforming the medical education system to produce a cadre of well-trained doctors.<sup>28</sup>

### **For the Glory of the Profession**

As early as 1895, medicine and its practitioners had come to be assigned a status that was almost holy. In one extreme example, in a speech supposedly about "Tuberculosis and Its Prevention" at the 46<sup>th</sup> Annual Meeting of the American Medical Association, physician and

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<sup>25</sup> Molly Cooke et al., "American Medical Education 100 Years After the Flexner Report," *New England Journal of Medicine* 355, no. 13 (2006): 1339-1344, doi: 10.1056/NEJMra055445

<sup>26</sup> Flexner, Medical Education, 23

<sup>27</sup> *Ibid.*, 26.

<sup>28</sup> Cooke et al., "American Medical Education 100 Years After."

public health reformer Charles A.E. Winslow used his time to praise advances in medicine and the brave men who had achieved them, stating:

For thousands of years, it may be from the time Adam and Eve bade adieu to fair Eden, to battle with sorrow and death, consumption has been the great enemy of mankind. Men of thought and action have for the sake of their fellow men, stood up and fought, with the best weapons at their command, and failed to conquer this great destroyer. Here and there down the ages have been seen the beacon fires of progress, until in 1882, Koch kindled a blaze that illuminated the whole world.... An earnest seeker of dauntless courage may achieve brilliant results in this line of work that will add new luster to our glory as physicians, and longer life to humanity. To-day, men are beginning to judge a physician's success by his ability to prevent as well as to cure disease. The field is broadening. As we gain knowledge we increase in strength.....<sup>29</sup>

In his speech, Winslow painted a biblical saga of the fight against tuberculosis, which he seemed to believe was nearing its end. In mentioning "men of thought and action" he alluded to past practitioners who, despite their valiant efforts, could not triumph, not due to their own faults, but as a result of the insufficient weaponry available to them. Just before the start of the century, Robert Koch had announced his identification of the tubercle bacillus, definitively proving that the disease could be passed from person to

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<sup>29</sup> Charles A.E. Winslow, "Tuberculosis and Its Prevention," *JAMA* 25, no. 10 (1895):

person.<sup>30</sup> Casting Koch as a Christ-like figure for this discovery, Winslow transformed “modern” medicine into religion and physicians into saviors.

While the knowledge that tuberculosis was caused by a germ, rather than “bad air,” was certainly a step in the right direction, in truth, in the ten years since Koch’s discovery, little progress had been made in treatment of the disease, aside from isolation practices.<sup>31</sup> Still, Winslow attributed success to the medical profession, and poetically encouraged a new class of heroes to pursue preventative medicine. Although clearly intended to inspire medical progress, his call to action did not seem motivated by improvement of individual or public health. Prioritizing “brilliant results” that would “add new luster to [their] glory as physicians,” Winslow only stated the provision of “longer life to humanity” as an afterthought.<sup>32</sup> In his reference to glory, he not only illustrated its pursuit, but also its preexistence, which had served to elevate medical professionals to a level of prestige above that of the general public.

As the twentieth century progressed and medical education improved, the responsibility of medical professionals only grew. Due to the attributions of individuals like Flexner, in addition to being revered, physicians came to hold a public presence as a class of educated, influential health heroes. As a result of Flexner’s report and its subsequent revitalization of the American medical education system, a greater number of physicians received their primary training within hospital walls and by the twenties, much of American medical care had begun to

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<sup>30</sup> “There is Hope for Consumptives,” *Los Angeles Times* (Los Angeles, CA), Apr. 6, 1902.

<sup>31</sup> “There is Hope for Consumptives.”

<sup>32</sup> Winslow, “Tuberculosis and Its Prevention.”



relocate to hospitals.<sup>33</sup> Still, most large hospitals were under the direction of nonmedical trustees until the thirties, and due to economic pressures, were forced to run as businesses, complete with publicity departments.<sup>34</sup> Charged with the task of attracting middle-class patrons, those in charge of advertising denied the existence of death in each of their facilities, employing tactics such as the careful selection of patient populations, emphasis on innovative cures and successes, and concealment of death when it occurred.<sup>35</sup> Under the guise of efficiency, hospitals could turn the sickest away while maintaining their status as healing facilities.<sup>36</sup> Strategies like these minimized the presence of death in hospitals, which strengthened the public's faith in medical care and provided physicians with a viable excuse to avoid the subject of death. When the death of a patient in the hospital could not be deflected, medical professionals were encouraged to distance themselves in order to avoid forming attachments that might prohibit them from tending to other patients who might actually benefit from their care.<sup>37</sup> Unfortunately, this meant that the majority of destitute, terminally ill patients were either cast aside or made to suffer in isolation.

### **The Disappearance of Death**

Regardless of where the death occurred, in the first half of the 20<sup>th</sup> century, the dying process was not considered a part of medicine. Despite the vast number of medical journals discussing tuberculosis and other fatal chronic diseases of the time, for several decades after the

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<sup>33</sup> Cathy Siebold, *The Hospice Movement: Easing Death's Pains*, (New York: Twayne Publishers, 1992): 22.

<sup>34</sup> Abel, *The Inevitable Hour*, 46.

<sup>35</sup> *Ibid.*, 41.

<sup>36</sup> *Ibid.*, 46.

<sup>37</sup> Siebold, *The Hospice Movement*, 33.

dawn of the century, death was seldom mentioned. With a focus on laboratory research and innovative treatments, the trend of medical science during this time has come to be known by some historians as “biological reductionism,” in which patients came to be defined almost entirely by their symptoms and bacteriology.<sup>38</sup>

In the years prior to the 1890s, publications in *JAMA* had openly discussed the prognosis of incurable diseases, even when the most likely outcome was fatal termination.<sup>39</sup> However, as medicine progressed, death came to be discussed only in terms of its avoidance, and any other conversation on the topic, at least from the AMA, was practically nonexistent. Instead, articles regarding terminal diseases focused on symptoms and new treatment options rather than outcomes or mortality rates. Despite acknowledgment by at least some specialties in the medical profession that death was a part of patient care, the AMA was not willing to make this concession of inadequacy.<sup>40</sup> As a powerful coalition representing the entirety of the white medical profession, the AMA was the medical authority of the time, and their refusal to acknowledge dying patients greatly influenced society’s perception of terminal care.<sup>41</sup> In the

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<sup>38</sup> Abel, *The Inevitable Hour*, 37.

<sup>39</sup> To define “fatal termination”, I referenced a piece by Reverend Doctor Solis Cohen published in *JAMA* in 1883 about the prognosis of tuberculosis of the larynx in which he stated, “Acute tuberculosis of the larynx is almost certain to terminate fatally at a period varying from six weeks to six months.”

J. Solis Cohen, “On the Elements of Prognosis and of Therapeusis in Tuberculosis of the Larynx,” *JAMA* 1, no. 9 (1883): 261-263.

<sup>40</sup> “Cancer: A practical quarterly journal devoted to the best interests of cancer.” *Cancer* 1, no. 1 (1923): 5.

<sup>41</sup> In 2014, the AMA admitted and apologized for a long, sordid history of exclusionary practices against African American doctors which spanned over a period from 1870 through the 1960s. Due to these racist and discriminatory practices, the voices of African American and non-white

eyes of the medical profession, however, if it could not be visibly cured, it was not a medical concern, and discussion of such conditions was seen as counterproductive to medical efforts. To acknowledge dying was to admit that medicine had failed, and that the authority which the public had assigned to the medical profession was not deserved.

For those with tuberculosis, until the discovery of streptomycin and subsequent cure of the disease in America in 1937, exclusionary practices only worsened with the medical address of the disease.<sup>42</sup> Until the incidence of the disease began to decline in the late twenties, late-stage patients were more than “incurable,” they were infectious, and thus, dangerous. Due to a limited knowledge of its transmission, Koch’s discovery elicited fear rather than improved understanding of the disease, and lead to the exclusion of tuberculosis patients from hospitals.<sup>43</sup> In the words of Henry Chadwick, the State Commissioner of Public Health in Massachusetts, although it took fifty years for physicians to accept Koch’s discovery, they eventually, “very reluctantly acknowledged the communicability of the disease” and used their authority to recommend prohibition of tuberculosis patients in hospitals.<sup>44</sup>

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physicians were not considered equal to those of white physicians, and were not included in the *Journal of the American Medical Association* until much later.

Robert B. Baker, “The American Medical Association and Race,” *AMA Journal of Ethics* 16, no. 6 (2014): 479-488,  
<http://journalofethics.ama-assn.org/2014/06/mhst1-1406.html>

<sup>42</sup> John Frith, “History of Tuberculosis. Part 2 – the Sanatoria and the Discoveries of the Tubercle Bacillus,” *Journal of Military and Veterans’ Health* 22, no. 2 (2014): 36-40.

<sup>43</sup> Henry D. Chadwick, “Tuberculosis as it Affects the General Hospital,” *Bulletin of the American Hospital Association* 8, no. 4 (1934): 36.

<sup>44</sup> Ibid.

In place of hospital care, sanatoriums were advertised as specialized, revolutionary alternatives. Based on scientist Edward Trudeau's research with TB-infected rabbits in the 1870s, sanatorium treatment included cold, mountain air, outdoor life, proper nutrition and rest for the sick patient.<sup>45</sup> Due to the initial report of falsely high recovery rates in these facilities, sanatoriums quickly came to be considered essential for tuberculosis control.<sup>46</sup> Although in the next decade, the rise of bacteriology and Koch's discovery cast a shadow of doubt on the validity of the open-air treatment, due to a lack of better treatment options, the demand for sanatorium care remained high.<sup>47</sup> As an answer to this demand, within the first three decades of the 20<sup>th</sup> century, over 500 sanatoriums were constructed, and accommodations for tuberculosis patients increased almost eight-fold.<sup>48</sup> Given the new availability of beds in specialized treatment facilities, the admission of "incurable" tuberculosis patients gradually became common practice near the end of the twenties. However, fatality rates had not changed much over the past several decades, and many of the patients who were admitted never recovered.<sup>49</sup> Provided the nature of sanatorium care, these facilities were often located far away from municipal centers, in remote mountain areas. As a result, rather than improved care, most tuberculosis patients that were sent to sanatoriums experienced intense isolation. Instead of dying at home, surrounded by loved

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<sup>45</sup> Chadwick, "Tuberculosis as it Affects the General Hospital."

<sup>46</sup> Abel, *The Inevitable Hour*, 64.

<sup>47</sup> Frith, "History of Tuberculosis. Part 2, 38.

<sup>48</sup> Benjamin Goldberg, "The General Hospital in the Care of the Tuberculosis," *Bulletin of the American Hospital Association*, 5, no. 10 (1931): 78-79.

<sup>49</sup> Here, the use of "fatality rates" refers to the ratio of those killed by the disease to those infected.

ones, patients in sanatoriums often died alone.<sup>50</sup> While this type of death was obviously damaging to the patient, it also played a key role in shift of death away from the public eye.

The avoidance of patients with cancer, the other prominent “incurable” diagnosis at the time, paralleled that of tuberculosis. Unlike tuberculosis, cancer was not fended off and it was rarely beaten. Survivors were usually those who had undergone extensive surgery and even then, the disease could return.<sup>51</sup> Due to its high fatality rates and the lack of promise in its treatments, medical authorities like the AMA were reluctant to address the disease, and for the most part, its address was seen as a waste of medical time. The majority of care was left to religious associations, and took place in almshouses or centers resembling hospitals.<sup>52</sup> A few large centers like Calvary Hospital in New York City existed to provide charity comfort care for cancer patients, and were staffed by nuns rather than physicians.<sup>53</sup>

In the fall of 1923, a new, specialized journal set out to provide physicians with the best methods of handling cancer, and in doing so, unabashedly called attention to the terminal nature of the disease.<sup>54</sup> In contrast to the American Medical Association, *Cancer* was more than willing to discuss the mortality rates associated with the disease, assigning cancer responsibility for at least 80,000 deaths in the United States each year.<sup>55</sup> In its very first edition, *Cancer* went so far

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<sup>50</sup> Chadwick, “Tuberculosis as it Affects the General Hospital.”

<sup>51</sup> Carl Voegtlin, “Approaches to Cancer Research,” *National Cancer Institute Journal* 1 (1940): 15.

<sup>52</sup> Siebold, *The Hospice Movement*, 23.

<sup>53</sup> *Ibid*, 25.

<sup>54</sup> “Cancer: A practical quarterly journal.”

<sup>55</sup> *Ibid*.

as to publish an article entitled, “The Prognosis of Cancer” which stated outright that despite great efforts, the recorded mortality of all those affected by cancer was around ninety percent. According to the author, this rate was “plain enough evidence that the profession in general [had] not arrived at the proper solution of the cancer problem.”<sup>56</sup> This openness represented a faction of medicine that was willing to admit its faults for the sake of the patient, and was in stark contrast to the attitude purported by the AMA. As an example, 2 years prior to the launch of *Cancer*, the AMA published an article in its journal on the topic of rectal cancer which attempted to provide what seemed to be a full discussion of the disease, complete with methods of discovery and diagnosis, as well as patient experience, symptoms and treatment.<sup>57</sup> Not once, however, did the article mention the high fatality rates among cancer patients, or the fact that most treatments were ineffective at achieving long-term recovery.<sup>58</sup> Cancer surpassed tuberculosis as the leading fatal illness in America in 1925, but even that was not enough to encourage discourse on the terminal nature of the disease.<sup>59</sup> In fact, it was not until more than a decade later, with the creation of the National Cancer Institute (NCI), that it received appropriate attention.<sup>60</sup>

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<sup>56</sup> A. Hirst Appel et al., “The Prognosis of Cancer,” *Cancer* 1, no. 1 (1923): 57.

<sup>57</sup> Jerome M. Lynch, “Cancer of the Rectum,” *JAMA* 77, no. 13 (1921).

<sup>58</sup> Appel et al., “The Prognosis of Cancer.”

<sup>59</sup> Grove and Hetzel, “Vital Statistics.” 571-573.

<sup>60</sup> American Society of Clinical Oncology, “Major Milestones Against Cancer,” *CancerProgress.net*, accessed February 3, 2017, <http://www.cancerprogress.net/timeline/major-milestones-against-cancer>.

## Medicine and the Mid-Twentieth Century

In 1929, the onset of the Great Depression served to demonstrate the problems harbored within the American healthcare system. When patients and philanthropic organizations could no longer afford to make donations, voluntary hospitals struggled to stay afloat. Approximately 20,000 beds and 418 hospitals were withdrawn from use during this time, and private institutions were forced to take on some of the burden of sicker patients.<sup>61</sup> In addition, a sense of social consciousness and state responsibility was forming with regard to chronic and terminally ill patients, resulting in a call to action for the improvement of care for tuberculosis, cancer, and other terminal diseases.<sup>62</sup> In one article from 1936 in *Hospitals: A Magazine for the Hospitals of the United States and Canada*, the system for care of the chronic sick was still described as being in the “almshouse stage,” and was categorized by inadequate or nonexistent care.<sup>63</sup>

Acknowledging the existence of homes for the aged, homes for the incurable, general and special hospitals, and convalescent homes, the author stated that none truly met the needs of those with chronic illness. Very little progress was made for this population until after the Depression ended in 1942, with the exception of the U.S. government’s 1937 creation of the National Cancer Institute.<sup>64</sup> The foundation of a national institution for this disease brought attention to an issue

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<sup>61</sup> John Gabriel. “The Hospital and the Changing Social Order,” 17.

<sup>62</sup> Michael C. Kearl, *Endings: A Sociology of Death and Dying*. Oxford University Press (1989): 144.

<sup>63</sup> Ernst P. Boas, “A Community Program for the Care of the Chronic Sick,” *Hospitals: A Magazine for the Hospitals of the United States and Canada* February (1936): 18-19.

<sup>64</sup> American Society of Clinical Oncology, “Major Milestones Against Cancer,” *CancerProgress.net*, accessed February 3, 2017,

<http://www.cancerprogress.net/timeline/major-milestones-against-cancer>.

that had long been avoided by much the American medical world and with funding specifically set aside for cancer research, the disease could no longer be ignored by medical authorities.

The 1940s marked a time of scientific and medical discovery, and with it, an increasing faith in medical authority. The development of injectable penicillin in 1941 and streptomycin in 1945 demonstrated an immense amount of promise in medical progress and the treatment of infectious disease.<sup>65</sup> The advancement of these drugs excited the public and upheld the authority of medical science, which was able to boast of rapidly diminishing rates of infectious and parasitic diseases, with 1950 death rates from these conditions falling to 1/3 of what they had been a decade earlier.<sup>66</sup> With the development of more anti-tuberculosis therapies in the 1950s, soon the disease was under control and, without sufficient patient populations, sanatoriums were no longer necessary. Around the same time, medical authorities motivated by the NCI finally had reason to give cancer the attention it deserved, despite continued misgivings. In the first volume of the *National Cancer Institute Journal* in 1940, one article did well to encapsulate the medical profession's own doubt of their competence in dealing with cancer when it stated, "It is unlikely that a curative chemical agent for all forms of cancer will ever be found."<sup>67</sup> Although the author did not believe the medical profession would ever be able to find a cure for all forms of cancer, still, not one of the articles in the entirety of the issue covered management of a patient that could not be cured. Twenty years after the specialists at *Cancer* had attempted to shed light on

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<sup>65</sup> Frith, "History of Tuberculosis. Part 2, 38.

<sup>66</sup> Robert D. Grove and Alice M. Hetzel, "Vital Statistics Rates in the United States: 1940-1960." *U.S. Department of Health, Education, and Welfare*, (Public Health Service Publication No. 1677, Washington D.C., 1968): 580-590.

<sup>67</sup> Voegtlin, "Approaches to Cancer Research," 15.



the situation, the mainstream medical professionals at *NCIJ* had fallen right back into the same trap.

With the passage of the Hill-Burton Act in 1946, a five-year plan allotted \$3,000,000 for state conducted surveys of need, with an annual appropriation of \$75,000,000 specifically for the construction of hospitals and related facilities.<sup>68</sup> Despite segregationist policies in the initial draft of the bill, which specified the creation of separate but equal” facilities, Hill-Burton went on to finance nearly one-third of all hospitals in the United States by 1975.<sup>69</sup> In an attempt to associate itself with this monumental legislation, the AMA took to its journal, and designated the medical profession as the rightful counsel for such important work, stating that physicians had a “responsibility to make certain that its development and administration proceeded along rational lines.”<sup>70</sup> Unfortunately, this responsibility did not carry over to the treatment of the dying.

After the implementation of this act, hospital care for the sick became the norm, and in a new turn of events, the dying were included. However, the provision of space in the hospital did not necessarily demand the delivery of adequate care. The attitude that death was a failure of the medical profession lingered on, and terminally ill patients were still largely ignored by medical

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<sup>68</sup> “The Hospital Survey and Construction Act.” *JAMA* 132, no. 3 (1946): 148-149.

<sup>69</sup> The segregationist section of the law was not overturned until 1963, when it was challenged and overturned in federal court. Afterward, Hill-Burton served as a major force for hospital desegregation, as funds from the act were only appropriated to hospitals who complied with the integration standards.

John Henning Schumann, “A Bygone Era: When Bipartisanship Led to Health Care Transformation,” *National Public Radio*, Oct. 2, 2016, accessed February 4, 2017, <http://www.npr.org/sections/health-shots/2016/10/02/495775518/a-bygone-era-when-bipartisanship-led-to-health-care-transformation>

<sup>70</sup> “The Hospital Survey and Construction Act.” 149.

authorities.<sup>71</sup> The establishment of this large number of hospitals was certainly a feat for the majority of the United States population, but for the dying, it mostly resulted in a new, though similar, place to end the journey.

### **Psychiatry, Psychology and The Meaning of Death**

After World War II, with the undeniable loss of over 50,000,000 people, death took on a new relevance to society. Although most medical authorities were not yet willing to discuss the issue, a small, specialized group of healthcare providers refused to shy away. Most prominent among these professionals were psychiatrists and psychologists, who had only recently come to be seen as a true part of the medical profession.<sup>72</sup> Representative of a less traditional, seemingly less scientific side of medicine, psychiatrists and psychologists did not hold the same clout as mainstream medical professionals.<sup>73</sup> With a focus on “sound knowledge of a man’s body as well as his mind,” as defined by renowned psychiatrist, Dr. Charles Burlingame, it was exactly psychiatry’s divergence from tradition that made it so valuable to the origins of the hospice movement.<sup>74</sup> In this sense, practitioners of psychiatry were better at sensing patient needs which extended beyond the physical than were traditional physicians.

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<sup>71</sup> Tracey H. McCarley, “Psychological Aspects of Pain in Patients with Terminal Cancer,” *California Medicine* 99, no. 1 (1963): 16.

<sup>72</sup> Harriet Jean Anderson, “Psychiatry Seen Misunderstood by the Public,” *New York Herald Tribune* (New York, NY), Dec. 29, 1950.

<sup>73</sup> “Mainstream medical professionals” is used here to refer to traditionally trained medical doctors who were often represented by larger bodies like the AMA and the ACS.

<sup>74</sup> Anderson, “Psychiatry Seen Misunderstood.”

In 1956, psychologist Herman Feifel organized a symposium at the annual conference of the American Psychological Association to address “The Concept of Death and Relation to Behavior.”<sup>75</sup> Despite the remarkable collaboration of individuals from diverse professional backgrounds, the APA refused to review the proceedings at first, stating that they didn’t deal with “these things,” in reference to death and dying.<sup>76</sup> Feifel attempted to publish the conference papers several times before they were finally accepted, albeit with a few misgivings and added chapters. In 1959, McGraw-Hill released the book, The Meaning of Death, which later went on to receive international acclaim and has more recently been cited as a noteworthy inspiration for the modern hospice movement.<sup>77</sup>

The Meaning of Death finally called attention to the problem that had plagued the medical profession for over half a century, and demonstrated that, by the second half of the twentieth century, at least some medical professionals had come to acknowledge the denial of death as a detriment to quality care. Psychiatrists and psychologists were typically the most receptive to Feifel’s work and many agreed that U.S. physicians rarely devoted full attention to care of the terminally ill.<sup>78</sup> In the words of Dr. Tracy McCarley, a psychologist who studied the psychology of pain in terminal cancer patients, among other reasons, mainstream physicians avoided death based on “the attitude that ‘curing’ [was] the only worthwhile activity of a doctor

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<sup>75</sup> William M. Lamers Jr., “Classics Revisited: Herman Feifel, The Meaning of Death,” *Mortality* 17, no. 1 (2012): 64.

<sup>76</sup> *Ibid.*

<sup>77</sup> Siebold, *The Hospice Movement*, 57.

<sup>78</sup> McCarley, “Psychological Aspects of Pain in Patients with Terminal Cancer,” 16.

of medicine.”<sup>79</sup> Although The Meaning of Death effectively demonstrated the existence of a large void in medical care, its range was limited, and did more to inspire further work in psychology and psychiatry than it did to inspire mainstream physicians.<sup>80</sup>

### **A Formal Study of the Dying**

In the fall of 1965, a small group of students from the Chicago Theology Seminary approached Dr. Elisabeth Kübler-Ross for help with a research project. The group had been assigned to cover “crisis in human life,” and they were convinced that the biggest crisis a person could face was death.<sup>81</sup> Given her previous history and her past research on the subject, they hoped that Kübler-Ross could advise them in their pursuit to understand an incredibly taboo topic.

Moving from Zurich, Switzerland, in 1958, Kübler-Ross first came to live in the United States in New York, where she specialized in psychiatry. She then moved to the University of Colorado to begin work as a professor, and it was here that she began to devote much of her attention to the subject of death.<sup>82</sup> Much of her curiosity and frustration stemmed from the stark contrast between the care of the dying in her home country of Switzerland and that of the United States. In Switzerland, dying was treated as another part of the life cycle; people died

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<sup>79</sup> Ibid.

<sup>80</sup> Lamers Jr., “Classics Revisited: Herman Feifel,” 64.

<sup>81</sup> Elisabeth Kübler-Ross, *On Death & Dying: What the Dying Have to Teach Doctors, Nurses, Clergy & Their Own Families* (New York: Scribner, 1969): 21.

<sup>82</sup> Holcomb B. Noble, “Elisabeth Kübler-Ross, 78, Dies; Psychiatrist Revolutionized Care of the Terminally Ill.” *New York Times*, Aug. 26, 2004.

comfortably, surrounded by family and friends, with a focus on the individual person.<sup>83</sup> This type of death was similar to that which had been the norm years before in the United States, declining with the rise of sanatoriums and hospitals.<sup>84</sup> Kübler-Ross was troubled by the state of the medical field in the United States, which she said seemed to take an “increasingly mechanical, depersonalized approach” to health care. Rather than holistic care, the U.S. medical professionals seemed to depend on physiological markers, new technology, and the prolongation of life at all costs, with almost no consideration for those whose primary needs were social or emotional.<sup>85</sup>

After another move in 1965, Kübler-Ross became an assistant professor at the University of Chicago, where she began work at Billings Hospital, and was soon approached for the project. She and the group of students decided on an interview-based seminar, during which they would invite terminally ill patients to speak about their thoughts and experiences. As the group attempted to gather participants, it quickly became evident that health care professionals were not only uncomfortable with the idea of their patients taking part, many were downright resistant.<sup>86</sup> According to Kübler-Ross, “approximately nine out of ten physicians reacted with discomfort, annoyance, or overt or covert hostility when approached for their permission to talk to one of their patients.”<sup>87</sup> Physicians cited the poor physical and emotional health of their patients, or denied having any terminally ill to begin with. Many became angry or defensive, and

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<sup>83</sup> Laura Newman, "Elisabeth Kübler-Ross," *BMJ: British Medical Journal* 329, no. 7466 (2004): 627.

<sup>84</sup> Richard Kalish, "The Changing Face of Death," *The North American Review* 249, no. 4 (1964): 77.

<sup>85</sup> Kübler-Ross, *On Death & Dying*, 21.

<sup>86</sup> *Ibid.*, 22.

<sup>87</sup> *Ibid.*, 235.

some nurses went so far as to call the team “vultures.”<sup>88</sup> Complicit with the attitudes previously described, dying patients made their caretakers uncomfortable, and when Kübler-Ross attempted to address this, it was likely seen as an attack on their professional abilities.<sup>89</sup>

Of the nurses who were willing to work with Kübler-Ross’s team, many voiced anger and frustration for their patients and their patients’ families, and resented their own lack of training in matters of death.<sup>90</sup> Practices had largely evolved from the time when nursing care for the dying was seen as a waste, and instead, nurses were encouraged to study psychiatry and assist with comfort care.<sup>91</sup> Yet, a large number of nurses in Kübler-Ross’s hospital admitted to avoiding dying patients out of fear that they would die on their watch, and blamed the doctors for their inability to convey the seriousness of their illness to their terminal patients.<sup>92</sup> Apparent in these statements was an immense fear of incompetence in dealing with death, which only some of the nurses and almost none of the doctors were willing to admit.

Given these attitudes, the pushback toward the study was not surprising. Many physicians were likely reluctant to concede that their past treatment of patient illness could have been better and were afraid to hear the opinions of the patients they had neglected. Admitting their ineptitude with regards to death meant surrendering some of the authority which their profession had conferred upon them. Kübler-Ross herself, as a new member of the faculty who was strangely

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<sup>88</sup> Ibid., 238.

<sup>89</sup> Kalish, “The Changing Face,” 79.

<sup>90</sup> Kübler-Ross, *On Death and Dying*, 239.

<sup>91</sup> “Care of the Dying,” Nursing Times Reprint, ca. 1960-1970, Box 17, Folder 93, Florence and Henry Wald Papers (MS 1659), Manuscripts and Archives, Yale University Library.

<sup>92</sup> Ibid., 238.

comfortable with death, may have actually contributed toward their apprehension. On top of her fascination with an incredibly taboo topic, she had what would have been perceived as an odd accent, and was known to be both difficult to relate to and single-minded. Not to mention, she was a female and a psychiatrist, both of which contributed to her status as an outsider.<sup>93</sup> Yet, for some reason that other physicians at the time could not understand, Kübler-Ross could relate to their patients in a way that many of them could not.<sup>94</sup>

When the team was finally given a chance to interview patients, the response was overwhelmingly positive. With over two hundred patients visited, less than 2 percent refused to take part in the seminar, and only one patient completely avoided talking about the seriousness of her illness.<sup>95</sup> Patients, in contrast to the staff, were often excited to work with the group. Most were greatly relieved when given a chance to speak openly about their illness, and many benefitted from freely speaking about death.<sup>96</sup>

Elisabeth Kübler-Ross and her team had set out to understand the discrepancies between the needs and treatment of the terminally ill, in order to work toward a better system of helping patients and the rest of society cope with death. By opening up a concrete, straightforward dialogue with dying patients, Kübler-Ross and her team were able to simultaneously help those individuals manage their deaths and help the medical profession study their experiences and

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<sup>93</sup> Newman, “Elisabeth Kübler-Ross,” 627.

<sup>94</sup> Ibid.

<sup>95</sup> Kübler-Ross, *On Death and Dying*, 245.

<sup>96</sup> Loudon Wainwright, “A Profound Lesson for the Living,” *Life* 67, no. 21 (1969): 36-43.

emotions as they were described.<sup>97</sup> Simply by listening without judgement, Kübler-Ross was able to understand and provide a new perspective on death and dying, which she published in her 1969 book, *On Death and Dying: What the Dying Have to Teach Doctors, Nurses, Clergy and Their Own Families*. Written for physicians, nurses, social workers, as well as laypeople, the book revolutionized the way people thought about death, and is often credited with sparking the public push for more humane treatment of the dying.<sup>98</sup> Leaders in the field of terminal care, such as Cicely Saunders in England and Florence Wald in Connecticut, had sought to draw attention to the field years before, as early as the 1950s, but it was not until the release of *On Death and Dying* that the issue gained sway with the general public.<sup>99</sup>

After more than two and half years' experience with terminally ill patients during her study, Kübler-Ross was able to outline trends in the way that people faced death. In her book, she described a progression of coping mechanisms which she called the "Five Stages of Death," which consisted of denial, anger, bargaining, depression, and acceptance.<sup>100</sup> Although now the subject of controversy, this model held that most dying patients would progress through the phases in sequence, and in order to provide the best care for them, it was important for healthcare providers and family members to recognize which stage a patient might be experiencing.<sup>101</sup> Kübler-Ross's model made the dying seem more approachable, and made death seem like a process that could be understood, with a little effort. Her use of a relatable psychological theory

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<sup>97</sup> Kübler-Ross, *On Death and Dying*, 246.

<sup>98</sup> Newman, "Elisabeth Kübler-Ross," 627.

<sup>99</sup> Kübler-Ross, *On Death and Dying*, Introduction.

<sup>100</sup> Kübler-Ross, *On Death and Dying*. Preface.

<sup>101</sup> *Ibid.*



grabbed the public’s attention and made it easier for people to appreciate the desire for dying patients to continue to live full lives until their deaths.<sup>102</sup>

The influences of important themes in the book, especially Kübler-Ross’s “Stages” and her emphasis on the maintenance of hope, greatly influenced the final plan for the program and building structure of the first American hospice Center, Connecticut Hospice.<sup>103</sup> Kübler-Ross was a strong supporter of the center, forming a friendship with its founder, Florence Wald, which lasted until the end of her life.<sup>104</sup> Kübler-Ross served as the Chairwoman of the National Advisory Council for Hospice, and after a series of speech tours, received worldwide acclaim for her work.<sup>105</sup> Perhaps most importantly, Kübler-Ross provided a window through which members of the American public could see the immense need for better care of the dying. As a result, she helped to shift attitudes away from the denial of the death, and paved the way for the hospice movement.<sup>106</sup>

### **A Modern Hospice Concept**

If Elisabeth Kübler-Ross is credited with calling the public’s attention to the “dying problem,” a separate award must be given to Dame Cicely Saunders, as the founder of the

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<sup>102</sup> Dennis Klass, “Elisabeth Kübler-Ross: Facing Death,” *The Gerontologist* 45, no. 3 (2005): 426-428, doi.org/10.1093/geront/45.3.426-a

<sup>103</sup> “To Honor All of Life: The Case For Support of Hospice, Inc.,” ca. 1960-1970, Box 3, Folder 23. Florence and Henry Wald Papers (MS 1659), Manuscripts and Archives, Yale University Library.

<sup>104</sup> Elisabeth Kübler-Ross, *selected letters*, 1976-1996, Box 5, Folder 6, Florence and Henry Wald Papers (MS 1659).

<sup>105</sup> Elisabeth Kübler-Ross, “Hospice is Approved!” *Hospice Newsletter*, June, 1974, Box 7, Folder 86, Florence and Henry Wald Papers (MS 1659),

<sup>106</sup> Kübler-Ross, *On Death and Dying*, Introduction.

movement that identified a solution. Serving as a nurse between 1940 and 1944, and a social worker from 1947 to 1951, Saunders entered into medical study with a perspective which was quite distinct from that of most physicians.<sup>107</sup> In her years prior to becoming a doctor, she had met and cared for many dying patients, and was well aware of the problems they faced. It was actually her conversations with one patient in particular, David Tasma, which moved her to dream about the creation a home for the dying.<sup>108</sup> Upon the advent of his death, Tasma left Saunders £500, saying, “I’ll be a window in your home.”<sup>109</sup> After graduating from medical school, Saunders immediately began to pursue her dream, beginning with the study of pain management research at St. Joseph’s and St. Luke’s Hospices, which she continued for seven years.<sup>110</sup> Although both institutions were traditionally non-medical, staffed by nuns, and largely considered old-fashioned, their emphasis on comfort and quality of life heavily influenced Saunders’ vision for her own, modern hospice.<sup>111</sup>

In England, Saunders’ experiences in palliative care introduced her to a medical hesitance toward death which mirrored that of the United States. During an interview in 1974, Saunders stated that treatment of the dying was limited by “the fact that the modern hospital has become

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<sup>107</sup> “Lifeline: Cicely Saunders,” *The Lancet* 349, no. 9068 (1997): 1850, [http://dx.doi.org/10.1016/S0140-6736\(05\)61742-4](http://dx.doi.org/10.1016/S0140-6736(05)61742-4)

<sup>108</sup> David Clark, *Cicely Saunders: Founder of the Hospice Movement: Selected Letters 1959-1999*, (Oxford, Clarendon Press, 2002): 7.

<sup>109</sup> “Lifeline: Cicely Saunders,” *The Lancet*;

<sup>110</sup> David Clark. *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century* (Oxford, Oxford University Press, 2016): 88.

<sup>111</sup> *Ibid.*, 10

an institution where the patient is processed efficiently from dying to death.”<sup>112</sup> Likely influenced by Kübler-Ross herself, Saunders identified the problems associated with the mechanization of medicine. However, perhaps as a result of her own medical training, Saunders was more forgiving of the medical profession than Kübler-Ross, stating, “it is not that the physician or the hospital authorities are indifferent or callous. In some profound way, however, the physician sees his work as ended when there is no longer any hope of defeating the patient’s disease.”<sup>113</sup> Saunders did not claim to understand the popularity of this belief, but seemed to attribute it more to standards set by society than by individual practitioners. With the development of her hospice concept, she hoped to change these standards, as they neglected to elicit care for the person inside the patient.<sup>114</sup>

In 1963, Saunders began a speaking tour throughout the United States, during which she intended to introduce her concept to Americans. As expected, Saunders’ subject matter mostly drew audiences of ministers, nurses, social workers, and other support staff, but this did not hinder her influence. At one stop on her tour, Saunders spoke at the Yale School of Medicine and perhaps, exactly as she hoped, inspired a revolution in American care for the terminally ill. According to several in attendance at the lecture, Saunders was a commanding speaker, with a presence and a passion for her topic that was nothing short of inspirational. Photographer and hospital historian Grace Goldin, after attending Cicely Saunders’ first lecture at Yale in 1963, wrote a powerful account to a friend in which she divulged that the talk was “the first time [she]

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<sup>112</sup> “London Hospital Eases Plight of the Dying,” *Hospital Tribune*, Feb. 11, 1974, Box 17, Folder 91, Florence and Henry Wald Papers (MS 1659).

<sup>113</sup> *Ibid.*

<sup>114</sup> *Ibid.*

heard anybody in the medical field describe what pain contributes to human life (both to the afflicted and to those who serve them, and simultaneously of death as the dignified culmination of mortality). When the lights were dimmed for Cicely to show and comment on the slides, at least in my row there were several faces with tears. Cicely's matter-of-fact tone of voice gave her message an eloquence no public relations rhetoric could equal."<sup>115</sup> Continuing, Goldin excitedly mentioned that she was surprised to see a number of doctors who were not only present, but who seemed to be emotionally affected by the presentation.<sup>116</sup>

Among those deeply affected by Saunders' presentation was Florence Wald, then Dean of the Yale School of Nursing. Wald had previously been known for creating her Nursing Study at Yale in 1960, which emphasized the changing role of the nurse, and regarded nursing as a skilled professional practice.<sup>117</sup> In this study, Wald had noted that a nurse must be conversant in all disciplines related to patient care, including epidemiology, sociology, anthropology, and medicine, and included psychiatry as part of that definition. She believed that the best nursing practices were those that addressed the patient rather than the disease, stating that "the essential part of the nurse's role is to make it possible for the patient to express himself clearly and correctly."<sup>118</sup> Given these sentiments, it was not surprising that Wald received Saunders' ideas positively. What was surprising, however, was the enormous inspiration she drew from the modern hospice concept, which later resulted in her credit as the founder of the American

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<sup>115</sup> Grace Goldin, *Letter to unknown recipient*, ca. 1963. Grace Goldin Collection, Box 4, Cushing/Whitney Medical Library, Yale University.

<sup>116</sup> *Ibid.*

<sup>117</sup> Florence Wald, "Nursing Study at Yale," Box 19, Folder 21, Florence and Henry Wald Papers (MS 1659).

<sup>118</sup> *Ibid.*

hospice movement.<sup>119</sup> By the time Saunders' facility, St. Christopher's Hospice, finally opened its doors in London in 1967, Florence Wald and Cicely Saunders had already formed a fast friendship. After her first visit to New Haven, Wald had invited Saunders to meet with students and faculty at the Yale School of Nursing, as well as with the nurses of Yale-New Haven Hospital to share her ideas.<sup>120</sup> From that point on, the two were in frequent correspondence, writing numerous personal letters to one another, and including notes in the margins of their respective newsletters to maintain a dialogue for their parallel facilities.<sup>121</sup>

In spite of their reforms in the field of traditional medicine, it was the women's embrace of alternative training that led to their initial struggles and eventual successes. While both women helped achieve great strides in the field of nursing early on, neither initially received the respect they deserved from physicians. Although this was somewhat expected for Wald, who had been trained solely as a nurse, for Saunders, as a licensed medical doctor, it was quite odd. Although Saunders lectured several different times at the Yale School of Medicine and even stayed for a spring as a visiting professor at the Yale School of Nursing, she was not asked to join the staff at the medical school.<sup>122</sup> Her work, straying far from the tenets of technical, scientific medicine, was likely considered beneath the caliber of the rigorous medical curriculum. Her behavior, also, plainly separated her from mainstream medical professionals, as she was

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<sup>119</sup> Dennis Hevesi, "Florence S. Wald, American Pioneer in End-of-Life Care, Is Dead at 91," *New York Times*, Nov. 14, 2008.

<sup>120</sup> "Hospice Groundbreaking Makes History," *Hospice Newsletter* 5, no. 1 (1978) Box 3, Folder 30, Florence and Henry Wald Papers (MS 1659).

<sup>121</sup> Florence Wald and Cicely Saunders, *assorted letters* (ca. 1974-1979), Folder 90-93, Box 14, Florence and Henry Wald Papers (MS 1659).

<sup>122</sup> "Hospice Groundbreaking Makes History," Florence and Henry Wald Papers (MS 1659).

known for her casual presence at St. Christopher's, where she fostered personal relationships with her terminally ill patients.<sup>123</sup> Rather than accepting the traditional idea of cure as success and death as failure, Saunders took pride in the holistic care of the individual, which in her mind ended in a painless, good death.<sup>124</sup>

In order to obtain this type of death, treatments at St. Christopher's were palliative rather than curative, and were based on those which Saunders had witnessed at St. Joseph's and St. Luke's. Specialized drug therapies were designed to allow patients to live in the absence of pain, and with enough mental clarity to maintain meaningful relationships.<sup>125</sup> With this goal in mind, one of the main tenets of Saunders' treatment plan was the rejection of the hospital tradition of PRN administration of medication. From the Latin "pro re nata," PRN meant that medication was administered as needed, or in other words, after the onset of pain. In the words of Saunders, "The letters PRN [were] probably most responsible for the all too frequent suffering of patients with cancer," and served as prime example of treatment of symptoms rather than treatment of the person.<sup>126</sup> To adequately control pain, Saunders prescribed a rigid medication schedule of powerful drugs, many of which are now considered illicit in the United States, including diamorphine (heroin) and cocaine.

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<sup>123</sup> "London Hospital Eases Plight of the Dying," Florence and Henry Wald Papers (MS 1659).

<sup>124</sup> *St. Christopher's Hospice Newsletter* 26, (1973), Florence and Henry Wald Papers (MS 1659).

<sup>125</sup> Edward Dobiha, "First Observations and Impressions of St. Christopher's Hospice," Sept. 15, 1970, Box 17, Folder 89, Florence and Henry Wald Papers (MS 1659), 13.

<sup>126</sup> Joan Craven and Florence Wald, "Hospice Care for Dying Patients," Box 20, Folder 20, Florence and Henry Wald Papers (MS 1659).

Once St. Christopher's was fully operational, in the summer of 1968, Wald spent a month in London visiting and working at the center. Upon her return, she faltered on how exactly she was to proceed. In a speech which she gave to the Foundation of Thanatology in 1972, Wald describes the moment when she "stood at the crossing of the main arteries of the Yale-New Haven Medical Center – York and Cedar Streets, and felt overshadowed by the sea of buildings; asked myself 'Can it happen here?' By 'it,' I meant having a setting where people can die with dignity."<sup>127</sup> Suddenly, three men – two physicians and one reverend – arrived at the corner, and the four decided to discuss the question over lunch. After that lunch, Wald was inspired to apply for a research grant from the United States Public Health Service for a project which she called, "A Nurse's Study of the Dying Patient," which sought to investigate the care experiences of 26 terminally ill patients.<sup>128</sup> Wald was awarded the grant, and within the next year, Reverend Edward Dobihal, one of the original four from the street, followed Wald's example, traveling to St. Christopher's to work, and more importantly, to learn.<sup>129</sup> Based on both of the individuals' experiences in London and the results of Wald's study, in the fall of 1970, the two decided that the United States was ready for a similar endeavor.

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<sup>127</sup> Florence Wald, "Hospice, Inc.: From Dream to Reality." *Speech to The Foundation of Thanatology and Union Theological Seminary*, Nov. 4, 1972, Box 20, Folder 16, Florence and Henry Wald Papers (MS 1659).

<sup>128</sup> Lawrence L. Kerns, "A Study of the Creation of a Community Setting: Hospice," (baccalaureate thesis, Yale College, 1975): 11, Box 5, Folder 80, Florence and Henry Wald Papers (MS 1659).

<sup>129</sup> Dobihal, "First Observations," Florence and Henry Wald Papers (MS 1659), 16.

## A Final Resting Place in America

On October 29, 1970, seven years after Wald and Saunders were introduced, the two lead a meeting which Wald later described as the moment at which Hospice, Inc. began. Although the first modern American hospice center, would not open doors until 10 years later, in 1974, Hospice, Inc. began providing in-home care services.<sup>130</sup> Heavily influenced by St. Christopher's ideals and Wald's nursing expertise, the goal of hospice was "to provide expert medical management of symptoms, and comfort always," with an emphasis on patient and family care.<sup>131</sup> With this mindset, advancement of the care of the dying in America was finally in the works.

Two years after Wald and her group had announced their plans for Hospice, Inc., a three-day congressional hearing was held on the topic of "Death with Dignity."<sup>132</sup> As the U.S. government's Special Committee on Aging discussed the problem of dying in America, hospice care was welcomed as a cost-effective, dignified answer. Kübler-Ross herself initially disagreed, testifying that although St. Christopher's Hospice in England was "a beautiful place to be" with an atmosphere of "love, care, and acceptance," this system could never work in the United

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<sup>130</sup> Julie Miller, "The View From: Branford; A Caring Hospice for Those Living Out Their Last Days," *New York Times*, June 26, 1994.

<sup>131</sup> Florence Wald, "Hospice – A Way For Caring of the Terminally Ill," (unpublished manuscript, University of Rochester, 1972): 4, Box 5, Folder 80, Florence and Henry Wald Papers (MS 1659).

<sup>132</sup> U.S. Congress, Senate, Special Committee on Aging, *Death With Dignity, An Inquiry Into Related Public Issues: Hearings before the Committee Special Committee on Aging*, 92<sup>nd</sup> Cong, 2<sup>nd</sup> sess., August 7-9, 1972: 3.



States.<sup>133</sup> Although she eventually had a change of heart and even went on to assist Wald after Hospice, Inc.'s inception, in this moment, she made a strong case. While the British health system allowed for the administration of drugs like diamorphine at no cost to the patient, the U.S. system would not permit the use of illicit drugs as medication, nor would it pay for them. Kübler-Ross thought we would do better to train nurses, physicians, and social workers to provide higher quality care to the dying patient population.<sup>134</sup> Although this was not exactly promising for Hospice, Inc. as an institution, it was promising with regard to changing the conversation about death. By suggesting further training of medical professionals at a federal hearing, Kübler-Ross publicly recommended that death be included as part of the healthcare curriculum, and as a popular medical figure, her suggestions were likely to be received. While the hearing did not actually finalize any decisions on hospice, it did begin a discourse about a population that had long been neglected, and demonstrated that there was more the U.S. healthcare system could do to care for its people.

Even with an accepting population, the construction of Connecticut Hospice (CT Hospice), as it came to be named, was no easy task. In addition to the issues discussed at the congressional hearing, the fact that CT Hospice was based on a British facility lent itself to several unforeseen obstacles. Without a healthcare system like that of England, long-term care facilities in the U.S., much like today, were forced to run as businesses. While St. Christopher's was registered as a nursing home, Hospice, Inc. had difficulty obtaining licensure as such, due to fear from the Nursing Home Association that CT Hospice would create competition for patients

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<sup>133</sup> Testimony of Elisabeth Kübler-Ross, U.S. Congress, Senate, Special Committee on Aging, *Death With Dignity, An Inquiry*, 17.

<sup>134</sup> Testimony of Elisabeth Kubler Ross, U.S. Congress.

among long-term care facilities.<sup>135</sup> Although Wald and her Hospice, Inc. group advertised that CT Hospice would provide a unique, humanitarian function for the terminally ill which would not compete with other long term care options, it cost Hospice staff almost a year and over \$48,000 in staff salaries and legal fees to “convince” the NHA that it was not a threat.<sup>136</sup> Once construction finally began, the state building commission did not know how to categorize the facility and placed constraints on the site that were intended for hospitals, which greatly slowed the construction process. In addition, the reimbursement for care that covered a large portion of St. Christopher’s fees was not available in the United States, and Hospice, Inc. was forced to rely on funding from the National Cancer Institute, donations, and rarely, private insurance.<sup>137</sup> As a result, at CT Hospice. the challenge of keeping patients awake, pain free, and comfortable enough to interact with family was what Wald referred to as a “delicate titration,” and required expertise.<sup>138</sup>

At the root of many of these problems was the fact that Hospice was an entirely new service. It was not a hospital, but it was not entirely non-medical. It provided more care than a patient’s home, but was still intended to be cozy. While on one hand hospice stood for all of the inadequacies that medical authorities had denied, on the other, it depended on physicians and nurses to provide an appropriate standard of care for its patients. Despite these difficulties, Wald

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<sup>135</sup> Henry Wald, *Corrections to “A Study of the Creation of a Community Setting: Hospice”* by Lawrence L. Kerns, (baccalaureate thesis, Yale College, 1975):5. Florence and Henry Wald Papers (1659). Box 5, Folder 80. Manuscripts and Archives, Yale University Library.

<sup>136</sup> Kerns, “A Study of the Creation of a Community Setting: Hospice,” 56.

<sup>137</sup> National Association of Social Workers, Inc, “The Hospice: Changing Society’s Approach to Death,” *NASW News* 23, no. 10 (1978):5, Box 16, Folder 77, Florence and Henry Wald Papers (MS 1659).

<sup>138</sup> *Ibid.*

and her followers did not lose heart. Through each bump, the group learned something new and continued to move forward, fueled by their strong desire to see this dream materialize, and after 1976, by the support from families of Hospice, Inc.'s past patients.<sup>139</sup>

Finally, in 1980, after 6 years of providing in-home hospice service, the in-patient Connecticut Hospice facility in Branford opened its doors to the dying. According the chief architect, Lo-Yi Chan:

Support, in the broadest sense of the word, [was] the basic idea for the design of the Hospice building. For patients, support means allaying the fear of isolation and abandonment, a feeling of being driven apart from the rest of the world...Even those with little mobility can share with others, and from this sharing will come a sense of self that is so critical in this stage of life...For patients, family, volunteers and staff, the building says, 'you are not alone.'<sup>140</sup>

In this sense, CT Hospice served as much more than a care facility. The Hospice was a tangible representation of the fact that dying patients were no longer to be ignored, and that physicians had a responsibility to them.<sup>141</sup> Wald's hospice, like Saunders', also served as an educational facility, which welcomed visiting physicians and laypeople.<sup>142</sup> For those who sought

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<sup>139</sup> Various Newsletters from *Hospice, Inc.*, (ca. 1973-1978), Florence and Henry Wald Papers (MS 1659).

<sup>140</sup> Lo-Yi Chan *quoted by Lawrence Kerns in* "A Study of the Creation of a Community Setting: Hospice," 62. Box, 5, Folder 80, Florence and Henry Wald Papers (MS 1659).

<sup>141</sup> National Association of Social Workers, Inc, "The Hospice: Changing Society's Approach to Death," *NASW News* 23, no. 10 (1978):5, Box 16, Folder 77, Florence and Henry Wald Papers (MS 1659).

<sup>142</sup> Associated Press, "Hospice Marks Decade with Award to Friend," *The Hartford Courant*, June 12, 1984.

more formal training, Connecticut Hospice offered seminars and medical fellowships to teach healthcare professionals and family members hospice care concepts.

CT Hospice existed as the antithesis to the type of medical care that had prevailed for so long, and provided a place where support was personal and patient centric. Perhaps even more impressive, CT Hospice and those who founded it defied medical authority of the time, openly admonishing their past denial of death and subsequent low care quality for this specific set of patients. Working tirelessly on behalf of those who had been cast aside by this system, the founders of CT Hospice refused to let go of the dream of death with dignity and in the end, they were tremendously successful. More than 200 hospice programs had sprung up around the country by 1978, with plans for more permanent facilities in works.<sup>143</sup> By 1994, Hospice, Inc. had expanded from an 89-patient home-care program to a 44-bed, state-of-the-art facility and an annual home-care service population of around 2,000 patients and families in the state of Connecticut.

## **Conclusion**

The achievements of the modern hospice movement can perhaps best be described by the striking account published in *JAMA*, which was republished by the National Hospice Organization in its pamphlet, “Hospice in America,” in the late seventies. In this article, a physician who had visited a modern hospice stated, “Although I arrived with an initial resistance continual contact with the dying patient, the actual experience was quite different from what I had expected. Instead of terminal care of ‘death house’ environment with cachectic, narcotized,

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<sup>143</sup> National Association of Social Workers, Inc, “The Hospice: Changing Society’s Approach to Death.”

bedridden, depressed patients, I found an active community of patients, staff, families and children of staff and patients.”<sup>144</sup> The author’s candid comparison of his expectations and the reality he experienced in dealing with the dying, combined with the article’s publication by *JAMA*, represented the long overdue acknowledgement of the subject which had long given medical authorities discomfort.

The modern hospice movement originated as a direct response to the medical profession’s historical rejection of death in the twentieth century. With the rise of hospitals, tuberculosis sanatoriums, and cancer centers, patients who could not afford the luxury of an in-home physician began to seek care in specialized medical facilities. Due to limited space in these facilities, efficient practice was considered to be the admission of patients who would improve, rather than “incurables” who might simply take up bed space. The increasing popularity of scientific medicine and the call for improved medical education standards by Flexner in 1910, began to elevate physicians to an elite status. Furthermore, the rise of hospitals gave physicians a place where they could coordinate care and serve as the cohesive body of a single, medical profession. This body established itself as a fine-tuned class of superiorly educated professionals, and the majority of the public relied on its authority for all types of medical care, excepting death. When a patient failed to improve, the doctor’s job was considered finished, and any further intervention was seen as a waste of time. If a physician acknowledged death, he or she admitted to a deficiency in knowledge, and so outright medical avoidance of terminal patients was common. In terms of specific illnesses such as tuberculosis and cancer, this avoidance manifested itself as an outright denial of death in an attempt to hide what doctors feared patients

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<sup>144</sup> National Hospice Organization, “Hospice in America,” ca. 1977-1978. Box 16, Folder 77, Florence and Henry Wald Papers (MS 1659).

would perceive to be failures in medicine. With the increase in tuberculosis sanatoriums and the lack of improved treatment through the thirties, a greater number of patients experienced death alone, away from their families. When government legislation in 1946 provided funds for mass hospital construction, the hospital became a common place to die, and death was removed from the public's view almost entirely.

The importance of “alternative” medical specializations in the origins of hospice cannot be overemphasized. Through the work of psychiatrists and psychologists like Herman Feifel and Elisabeth Kübler-Ross, the investigation of death became a popular field of study. Perhaps more importantly, these individuals painted death as a trendy topic of conversation, paving the way for public concern. Still, it was nursing that played the most instrumental role in the establishment of hospice. Without the impassioned efforts of former nurse, Cicely Saunders, and former dean of the Yale School of Nursing, Florence Wald, modern hospice may never have come into existence. Due to Wald's license as a nurse and Saunders' initial training as a nurse and social worker, the two were able to see dying patients as people, and recognized that their needs went far beyond those for which the medical profession had taken responsibility. Although the authority of the American medical profession was strong, the vision that these two women had for the improvement of care for the dying was much stronger. Through their work, they illustrated that proper patient care is holistic, and extends much further than a cure, especially when cure is not an option.

During its founding years, hospice care in the United States resulted in better outcomes than its founders ever could have imagined. More than the proper provision of care for the terminally ill, CT Hospice taught an entirely new attitude towards death and dying, and guided patients and families who used the service to a more peaceful acceptance of death. In addition, it

demonstrated that a physician's work did not have to end when treatment did. With the creation of lasting infrastructure like the National Hospice Organization in 1977, leaders in the movement attempted to ensure that the ideas behind the hospice movement were never lost.

In recent years, however, the hospice movement has begun to decline. With an ever-increasing emphasis on science in medicine as a result of exciting technological breakthroughs, protection of the person is often considered second to protection of life. Although hospice care is still in high demand in the United States, with around 90 million adults reported to have life-threatening illnesses, physical and financial resources to support this burgeoning population are insufficient.<sup>145</sup> As a result, patients relying on Medicaid or private insurance companies often cannot afford to utilize hospice services until the last week of their lives, undermining the key tenets of hospice and a good, peaceful dying process. By revisiting the origins of the movement, it is possible to remind medical authorities as well as the public that the ideals that served to drive the movement were, and still are, incredibly important and should not be overlooked today. The goal of medicine should not only be the cure of the patient, but also the comfort of the person, to help each individual live until they die.

FINAL WORD COUNT: 12,112

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<sup>145</sup> Rita Rubin, "Senate Committee Holds Hearing on Palliative and Hospice Care," *JAMA* 316, no. 6 (2016):575.

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### **Bibliographic Essay**

At the beginning of this project, I would never have guessed that it would focus so much on death. I began my work with the study of care of the aging individual. Older adults have always had a special place in my heart, perhaps due to my familiarity with the older adult patient base of my father's ophthalmology practice. Still, it was not until my grandmother was sent to live in a nursing home back in the mid-2000s that I became interested in older adult care, and more specifically, long-term care facilities. A few years later, I held a resident aide position at a facility in my hometown, and it was there that I came face to face with the many needs that these facilities fail to serve. Last year, I read Atul Gawande's best-selling work, Being Mortal, which discusses the current structures of older adult health care and shines light on the battle over defining the purpose of the medical profession. As Gawande makes clear, physicians, rather than patients, control the unique middle-ground between protection of an individual's life and his well-being, and it was this nexus that I hoped to investigate.

Initially, my goal was to study the foundation of the modern nursing home in relation to the medical profession, in order to better understand to the current problems that plague our long-term healthcare systems. However, with guidance from my advisor, I soon found that another untold story lies within hospice care in the United States. After a bit of digging, it was hospice that held my attention. While nursing homes seemed to evolve as yet another solution to the institutional problem of crowded hospitals, hospice seemed more human. The hospice fight was waged by a small group of passionate medical professionals for their patients and families, and that was what drew me to it.

The project was decided for me after my second visit to Yale Library's Manuscripts and Archives. Scouring through the papers of Henry and Florence Wald, I felt personally connected

to the founding members of the movement. As I struggled to decipher the handwriting of the friendly correspondences between Cicely Saunders and Florence Wald, the excitement with which both women discussed each of their progress was virtually palpable. Furthermore, the dedication and persistence of the founding board of Hospice, Inc. was overwhelming, despite numerous setbacks and a general lack of support from medical authorities.

As a clearer picture of Hospice, Inc. began to form, so too did questions about why it was necessary, and more importantly, why it had been such a difficult vision to realize. After noting her frequent appearance in the Florence and Henry Wald Papers, as well as in various secondary sources, I sought out information on Elisabeth Kübler-Ross. While reading her renowned work On Death and Dying and its sequel, Questions and Answers on Death and Dying, her importance became glaringly apparent to me. In Kubler's Ross's assertion that doctors had a tendency to neglect dying patients, she defined a significant fault in the treatment provided by medical professionals. In this sense, the Hospice Movement was much more than a necessary expansion of healthcare. Instead, it was a deliberate repudiation against the medical attitudes about death that had existed for over half a century. Although Kübler-Ross acknowledged these attitudes, I was unable to find any historical justification for them in her work.

At this point, I realized that I needed to look a bit further back in time. Several secondary sources were instrumental in guiding me toward the themes discussed in my project. Emily K. Abel's "The Inevitable Hour: A History of Caring for Dying Patients in America" was especially important in my decision to begin the discussion at the start of the 20<sup>th</sup> century, rather than near the middle. The congruency between her work and that of Cathy Siebold on institutional medicine convinced me that the story began much earlier than I had previously thought, drawing me back toward the rise of tuberculosis sanatoriums. Although I found Siebold's "The Hospice

Movement: Easing Death's Pains" particularly harsh toward physicians, it did challenge me to question the motivations of the medical profession. Siebold's negative interpretation of medical motives seemed based in modern conceptions of the role of a physician, which lead me to seek primary source evidence. As a result, I looked through many volumes of the *Journal of the American Medical Association* as well as various other medical journals from the past 100 years, which were available in the Yale Historical Medical Library in print.

As the medical profession gained authority, the Journal of the American Medical Association became the main medical voice of the profession, and it still serves as such today. Although the National Medical Association also existed and published its own journal during this time, I did not include its work in my discussion due to the large amount of racism and discrimination against African American doctors which lasted late into the 20<sup>th</sup> century and largely prevented this group from having equal authority to that of the AMA. Due to the redundancy in the attitudes reflected in a large number of JAMA volumes, I was able to include a small selection of articles rather than an extensive collection. My inclusion of other medical journals was motivated by my desire to showcase the voices of physicians from specialties that may have otherwise been silenced by the AMA. The two reports included in the project, that of Abraham Flexner in 1910 and the "Death with Dignity" congressional hearing of 1972, served to demonstrate examples of important medical discourse surrounding the movement within two very different historical contexts.

Given more time with this material and the resources available to me, I would have enjoyed the further study of Hospice, Inc. in Branford, Connecticut, after it opened its doors. Although this project ends with the foundation of this first American hospice center, I would have liked to look at the evolution of American hospice in later years, and in subsequent

locations across the U.S. Provided knowledge of the historical fight for the rights of the terminally ill, I believe further study of hospice could highlight parallels to the problems that still exist in our long-term care systems, and perhaps, revive the idea of the “good death” of which Saunders and Wald envisioned.