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# Features And Flaws Of A Fair Hospital Policy For Allocating Expensive Charity Care To Noncitizen Patients

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FEATURES AND FLAWS OF A FAIR HOSPITAL POLICY FOR  
ALLOCATING EXPENSIVE CHARITY CARE TO NONCITIZEN PATIENTS

A Thesis Submitted to the  
Yale University School of Medicine  
in Partial Fulfillment of the Requirements for  
the Degree of Doctor of Medicine

BY

RYAN WILLIAM BLUM

2012

## ABSTRACT

### Title

A Fair Hospital Policy for Allocating Expensive Charity Care to Noncitizen Patients

### Authors

Ryan William Blum (Sponsored by Mark R. Mercurio, Program in Biomedical Ethics and Department of Pediatrics, Yale University School of Medicine, New Haven, CT and Robert A. Burt, Yale Law School, New Haven, CT)

### Summary

Commentators have asserted that “the existence of a genuine medical need constitutes a moral claim on those equipped to help.” However, this professional duty is sharply limited by the fact that resources are not available to help all the world’s patients with each of their problems. At some point, boundaries are drawn implicitly and by force; these boundaries can exacerbate inequalities and injustices, or they can contribute to making the medical system more fair for everyone it serves. To achieve a more just result, distributive justice must be employed, but any systematic way of allocating resources depends on being able to define who belongs to a public and thus deserves treatment, as well as what any minimum basic right to treatment should entail. By examining closely a case of an adolescent undocumented immigrant who traveled from her home country explicitly for treatment of a fast-growing tumor, we will explore a variety of ethical concerns related to this dilemma in its historical and political context. Finally, a pragmatic hospital-based policy to guide microallocation of expensive charity care will be proposed in hopes of seeking a reasonably fair process to adjudicate this increasingly common dilemma of politics, economics, and professional ethics.

TO MY PARENTS,

Two humble, brilliant public servants.

## ACKNOWLEDGEMENTS

Dr. Mark Mercurio provided me with at least ten times' my fair share of strong, thoughtful mentorship in this project, as he has done throughout the last five years of medical school. He exemplified what it means to be an advocate for patients and for medicine at large. Professor Robert Burt was instrumental formulating and refining this work and he patiently allowed it to change into something very different over time. His law school class taught me the inherent value of asking difficult questions instead of creating answers, a spirit which I hope I have carried through this work, even while attempting to formulate a pragmatic approach to a real problem which demands attention.

Considerable thanks to Dr. Andres Martin and Dr. Jim Leckman for conjuring up an ideal research year at the Yale Child Study Center (2010-11), and for personal mentorship and support. Thanks to members and families of the pediatric oncology service, who were so generous to me as a student during my six months on their service. Thanks to the wonderful members of the Office of Student Research for administering my research year award and to Dr. John Forrest, Dean Nancy Angoff, and others in our school for supporting medical research in the social sciences and the humanities.

I owe many members of Yale's two ethics committees gratitude for mentoring me in clinical ethics and for extensive conversation about this specific issue. This applies especially to Dr. Mark Siegel, chair of the adult committee. Dr. Thomas Duffy and other members of the committee debated and drafted an "extraordinary treatment" policy a few years back, which informed my own investigation into what would be a fair process. Helpful suggestions about the issue were provided by Dr. M. Gerard Fromm at Austen-Riggs Center; by various attendees at the Pediatric Bioethics conference in Seattle in July 2011, at which I was generously hosted by Dr. Douglas Diekema and Dr. Benjamin Wilfond; and by the presenters and attendees at the symposium "Access to Hospital Care for Foreign Patients in the U.S" held by Yale's Program for Biomedical Ethics in September 2011.

Most importantly, to my family for their love, support, and patience.

Features and Flaws of a Fair Hospital Policy for  
Allocating Expensive Charity Care to Noncitizen Patients

TABLE OF CONTENTS

	I. <u>INTRODUCITON</u>
pg. 1	1. Medicine, Migration, and Moral Communities
3	2. Case History
8	3. The Power of Language and Frame
12	4. Central Questions and Methods
	II. <u>HISTORY</u>
16	1. Charity and Noncitizenship in Professional Ethics
20	2. Hospital Charity in American Medical History
25	3. American Healthcare Policy on Charity and Noncitizen Healthcare
	III. <u>ETHICS</u>
33	1. Medical Care is Not an Unlimited Resource
37	2. A Policy is Required to Make Allocation Reasonably fair
37	3. Care Should Not be Withheld Based Solely on Immigration Status
31	4. Alternatives to Citizenship: Contribution, Attachments, Age, and Vulnerability
45	5. Preference Should be Given to Geographical and Temporal Proximity Physicians Should Participate in the Process, but
48	6. Patients' Own Physicians Should Have a Limited Role
52	IV. <u>A POLICY FOR THE ALLOCATION OF EXPENSIVE CHARITY CARE</u>
	V. <u>CONCLUSION</u>
61	1. An Imperfect but Necessary Solution
65	2. Who Should Pay?
69	<u>APPENDIX 2</u> : Charity Expenditures at Yale-New Haven, 2001-2010
70	<u>REFERENCES</u>

## I. INTRODUCTION

### 1. MEDICINE, MIGRATION, AND MORAL COMMUNITIES

The subject of this thesis—whether and how to provide medical treatment for non-citizen patients who require expensive hospital care but who lack funds and insurance to cover these services—is a dilemma of global proportions. The number of persons implicated in this problem is huge: of the 304 million people surveyed in the 2010 U.S. Census, about 7.1% of the population, or 21.6 million people, reported themselves to be noncitizens—or, in the language of American federal law, “aliens.”<sup>1</sup> This figure includes each of the 11.2 million undocumented immigrants estimated to be living in the U.S in 2010.<sup>2</sup> Furthermore, human migration is a phenomenon as old as society itself. In the United States alone, it is a core feature of our collective history and ethos, and immigrant communities remain a major influence on American social, cultural, and economic realities today, despite the hostility often on display in our national conversations about immigration.<sup>3</sup>

Most noncitizens lack eligibility for public health insurance based on criteria set forth in federal healthcare policy, leading to inequities of healthcare access that are unexplained by any factor.<sup>4</sup> This norm has left states, localities, hospitals, and providers themselves to render responsibility for these persons’ care, deciding in non-emergent cases whether or not to provide expensive, potentially life-saving treatment at their discretion, with a lack of professional guidelines about how to make these monumental judgments.<sup>5</sup>

Instead of consensus, there exists deeply-felt sentiment on both sides of this issue. Despite numerous studies documenting how illegal immigrants underuse health services compared with socio-economically alike legal residents or citizens,<sup>6</sup> these individuals have become, or are thought to be, significant economic burdens to the localities where they live and/or seek care.<sup>7</sup> For those politically opposed to immigration or morally opposed to awarding public services to noncitizens, it is clear that any expenditure would be too much. On the other hand, proponents of immigrant rights advocate compassion for these politically disenfranchised, medically vulnerable persons living amongst us.<sup>8</sup>

The stark disagreement about these individuals' moral status in society has resulted in their being almost entirely excluded from healthcare policy. Hospitals, therefore, are left with the problem of deciding whether or not to provide free (unreimbursed) or charitable (funded by private charitable contributions) care to these patients. This pressure can exacerbate inequities and therefore be unjust if not designed with a reasonable set of principles and processes in mind. Therefore, hospitals face what I believe is a moral duty to create a reasonably fair process for allocating the limited funds it has to help those without access to funds or insurance, and to maximize the ability of a community to care for those in its midst.

The problem resonates deeply with medical profession's moral duty to care for those in need, whatever their race, country of origin, ability to pay, or legal status. It is a duty shared by many members of society: "so show your love for the alien, for you were aliens in the land of Egypt."<sup>9</sup> But hospitals, healthcare systems, and society at large can



not provide all services for everyone in need without encountering financing ruin. How exactly to allocate these resources invokes the notion of justice as fairness.<sup>10</sup>

But how should a society adjudicate this dilemma? Should we decide based on their employment history, their duration of stay in the hospital's jurisdiction, their potential to contribute, or how many children they have? How do we define who belongs to a community or a public which which shares some mutual responsibility for its members' wellbeing? The problem hinges on the insufficiencies of American health policy's ability to grapple with some realities in the world at large, even if they make for unpopular politics, but this national and international problem has strong consequences on a local level. Hospitals are increasingly being forced to make these microallocation decisions in real time, without the luxury of waiting expectantly for a political solution to the deeply divisive issues of immigration and healthcare financing.

## 2. CASE HISTORY

Despite the global proportions of this problem, for me it will forever have the concrete form of a single Thursday morning at Yale-New Haven Hospital, when I was a student member of a child psychiatry consultation team working in pediatric oncology. When I walked out of the elevator onto the familiar seventh floor that morning, I knew something interesting was brewing. Before my attending and I could put down our coats, we were approached by two senior members of the unit's staff. They were clearly distressed. "Have you heard," they asked, "about A.?"<sup>11</sup> A., we were told, was 16 years old, and suffering from cancer. She was also described to us as an "illegal immigrant"

who might not receive treatment. The family might need our psychosocial services, we were told, because they were “under unbelievable stress.” Her story unfolded piecemeal.

A. first presented to the emergency room of a regional hospital which is affiliated with Yale. There she appeared lethargic, and she exhibited abnormalities in her cranial nerve exam indicating a pathological process affecting her brain. Doctors learned that she had been diagnosed with a “blood cancer” and had begun treatment at home in Guatemala, but had stopped after two courses of chemotherapy because, according to her parents, they could not afford to pay for treatment. They traveled to the United States on what they described as a “work visa” which they had applied for and received some years earlier. In Connecticut, A. spent one night at her maternal aunt’s home and was subsequently taken to the emergency department of the Yale-affiliated hospital the next day.

In the E.R., doctors noted her concerning mental status and learned about her oncological history. They ordered a computerized tomography scan of her head as well as as basic laboratory tests. These tests revealed blood counts consistent with a hematological malignancy, and the scan indicated that it had probably invaded her central nervous system. She was transferred to Yale-New Haven Hospital, where she underwent more specific testing including flow cytometry to establish a specific diagnosis so that she could begin treatment on a protocol. In the mean time, she received stabilizing treatment including steroids and a dose of chemotherapy, delivered intrathecally, aimed to prevent further neurological deterioration. The intracranial lesions were documented on an MRI of her brain. She was admitted to the pediatric oncology service and diagnosed

with Burkitt's lymphoma—a tumor which is one of the fastest to grow and, potentially, fastest to shrink. Her disease was assessed to be Stage IV because it involved her central nervous system, and although this stage of disease is associated with a significantly lower survival rate, her chance of survival was estimated as “at least 50%.”<sup>12</sup>

At some point after her admission, her hospital course began to veer off of what would be expected for any 16-year-old being treated for a malignancy. Between her admission and when she finally began protocol-driven treatment, she and her family spent a few terrifying days waiting while the “hospital” decided whether this patient would get the expensive treatment that could potentially save her life.<sup>13</sup> In the mean time, she also underwent surgical placement of a chemotherapy port, despite disagreements between hospital administrators and her physicians about whether to do this before her long-term plans were in place.

It was in this state of waiting that we found A., lying in bed, appearing deeply asleep, with her mother and father at her side. As a group, we filed into the small room where all the lights were off, and one by one introduced ourselves to A.'s mother and father, using a mix of English and Spanish. They were huddled in the corner of the room on the sofa, fit as close as possible to one another and to their daughter, looking sad and frightened. We all stood and spoke in soft tones, reflecting their mood. A few new details were acquired: A. seemed to be doing worse every day; the family was sleeping at the hospital but had family in a nearby town; A.'s health had been fine until about four months before, when she was seen for a recurrent sinus infection which turned out to be this cancer; they had possessed their visa for “years” but traveled to the U.S. only days

before; and the visa was sponsored by a relative in Arizona. Most of all, they had no money but were willing to do anything and sign anything that might assure their child of being treated. Outside the room, staff members were furious and exasperated, but also spoke softly, as if discussing a secret. They must have felt powerless to help this young person who was supposed to be under their direct care whilst a fast-growing tumor spread in her body and in her head.<sup>14</sup> A care coordinator informed us that she was not eligible for any public insurance because of her immigration status, and that she was unable to send a referral to a research site such as the National Institutes of Health or St. Jude's Hospital because she had already begun chemotherapy at home, and was therefore an unacceptable research subject. Besides, she was neurologically deteriorating and needed treatment immediately.

One team member reported that A.'s aunt, a former hospital nurse, had been present during the week and that she was interested in doing anything that help her niece, including having an ethics consultation. (It is unclear whether she proposed this or whether she agreed to it when it was mentioned by a physician, nurse, or another person.) I found her phone number in the chart and called her directly. She told me that she was upset because she thought her cousin should be treated. She confirmed the visa story and said they were living with her mother, and that their only other American relative is the uncle in Arizona who had sponsored the visa. She was interested in meeting with the ethics committee but said that she would be working long shifts for the next three days.

Our next call was to the chair of the pediatric ethics committee. He had already heard some details of the case, but was unaware of the entire story. He was on the floor

within a short time, and we all met with the family to gather more history. During this encounter, I remember being distracted by how still the patient looked. She was not moving in her sleep, not even blinking. I looked hard to see the covers rise and fall with her breath. An email went out to members of the ethics committee, and a meeting of a consultation team was scheduled for that evening, with a full committee meeting for the following day. At the same time, senior hospital leaders met with the girl's oncologist to discuss the case. I asked whether I could attempt to secure legal representation for the patient through the university law school's immigration clinic, but was told to wait.<sup>15</sup>

Later in the evening, the ethics team delivered its recommendation to the hospital administrators, which included a) instituting treatment on this patient without further delay, and 2) devising a clear mechanism to guide these decisions in the future. (Cases involving undocumented and uninsured persons were not uncommon to the committee; a few years before, the adult ethics committee had considered writing a policy for cases like this, which was drafted as an "Policy for Extraordinary Treatment," but it had not been developed nor approved.)

A. began receiving chemotherapy early the next day. The final word was said to come from the hospital's top physician, after receiving input from the committee. Nevertheless, the ethics committee met in a full session that day to discuss the situation. I joined as a member of the clinical team, which also included oncologists and department administrators, as well as members of social work, child life, and child psychiatry. Three of us were also on the ethics committee, balancing dual roles (but officially in the

capacity of clinical team members). The patient and family was not present, by committee choice.

The clinical history was presented by the patient's oncologist. At a certain point in his story, it seemed that he didn't know what to say. I wanted to treat her, he implied, *but I didn't have the power to do so*. A senior physician reacted strongly to this sentiment, and directed his anger at the lone administrator in the room, a former nurse who spends long days (so I know from two separate experiences on the unit) securing benefits and tricky placements for patients who might otherwise fall through the cracks. She, too, had her hands tied by a senior administrator who was not present at the meeting. The case also provoked a lengthy discussion on the adult ethics committee's email list, which spilled into an entire session of that group devoted to the subject.

### 3. THE POWER OF LANGUAGE AND FRAME

The problem of whether and how to treat noncitizens who require expensive care is a direct result of connections and boundaries in the real world: the busy routes of migration, travel, and trade which characterize the world today, and the legal boundaries which define a nation and its citizenry. But just as these real boundaries define the root of the problem, much of how the dilemma is understood and acted upon depends on the language and frame used in the story itself. In other words, the way this problem is conceived—as a problem of law, economics, or ethics—depends largely on the words chosen in the narrative itself.<sup>16</sup>

The first conversation in which this patient was described to me was exemplified this point. “A teenage girl was just admitted. She came from Guatemala, and was ‘probably illegal.’” Immediately, her marked vulnerability and, at the same time, her otherness were battling for moral status in the very same utterance. Her identity was split incommensurably between these two roles: a deserving cancer patient, and a freeloading medical traveler.

A recent front-page *New York Times* article, “Illegal Immigrant’s Transplant, Cheaper Over Life, Isn’t Covered,” performs the same narrative split:

Without treatment to replace his failing kidneys, doctors knew, the man in Bellevue hospital would die. He was a waiter in his early 30s, a husband and father of two, so well liked at the Manhattan restaurant where he had worked for a decade that everyone from the customers to the dishwasher was donating money to help his family.

He was also an illegal immigrant.<sup>17</sup>

This fragment of the story begins with a clear appeal to the patient’s vulnerability: without the transplant he would die. This sentiment deepens as the man’s social ties are described, and we are led, by the end of the lead paragraph, to feel how he became so beloved while working his laborious job that people who should be mere strangers to him were eager to help him and his family.

Narrative analysis of the news reports of the case of Jessica Santillian, the 17-year-old Mexican immigrant who received two heart and lung transplants at Duke in February 2003, thereby causing a public controversy about citizenship, charity, and the goals of medicine. The news depicted Jessica in similar polarities: either as “America’s angel” or a “thieving devil.”<sup>18</sup> Something befell the waiter from the *Times* story and to A. as well.

Commentators on this phenomenon have called our attitude towards these individuals one of ambivalence and irresolvable conflict between “sympathy and exclusion,”<sup>19</sup> or “compassion and repression.”<sup>20</sup> The ends of the spectrum are well thought out, but the middle—where one might find a hard, pragmatic, imperfect, but potentially reasonable solution satisfying a variety of parties—remains elusive to characterize.

These stories also struggle between multiple seemingly incommensurate frames of reference. Does the dilemma result from federal policy, from our economic sensibilities, or from our sense of moral responsibility? As physicians or citizens? During the adult ethics committee’s discussion of A.’s case, the frame was one of economic loss and personal irresponsibility. The story of another recent patient was told by a hospital administrator on whose desk these difficult dilemmas often land:

We had one woman from Mexico who was here in the hospital for a year getting dialysis. No outpatient facility would accept her because she was an illegal immigrant and had no insurance and no money. So she lived on a hospital floor for a year, and we spent more than a million dollars on her. We asked whether she had relatives or anyone who would help pay or take responsibility for her, but she said no. We came up with plans to send her home to Mexico, but she said she wanted to stay, and we couldn’t do anything about it. Finally, we convinced her to go, on condition that we would pay for her to be transported and reintegrated into the community at home in Mexico, where her dialysis would be covered by the country’s national health insurance. When she got to the airport, there were a dozen family members and others cheerfully waiting for her.<sup>21</sup>

But the denial of treatment is not always in society’s best financial interests. The *Times* story highlights this problem of political norms creating an economic inefficiency:

So when his younger brother volunteered to donate a kidney to restore him to normal life, they encountered a health care paradox: the government would pay for a lifetime of dialysis, costing \$75,000 a year, but not for the \$100,000 transplant that would make it [dialysis] unnecessary.<sup>22</sup>



This extra cost was a direct result of the norm that noncitizens are ineligible for transplantation reimbursement. Programs can elect to transplant noncitizens, though at the risk of financial loss and potentially of audit by the transplantation center licensing body.<sup>23</sup>

In the article, the focus shifted from the man's plight to the cost of keeping him alive; the debate assumes a familiar tone of decrying waste. Inefficiency is not an injustice, per se, but it does exacerbate injustices by making resources even more scarce, which is disproportionately burdensome on the poor.<sup>24</sup> The story also highlights an injustice in the organ allocation system, which tends to disfavor making immigrants recipients while accepting them disproportionately as donors.

The financial frame of reference is omnipresent in our healthcare discourse on policy, in patient care, and even in bioethics. It is easy to interpret a noncitizen's plight as a mere financial liability in a healthcare system where cost savings has become a core value of reform. For example, the chief executive of an Alabama hospital described his optimism surrounding the passing of his state's strict 2010 immigration law:

I certainly think [a decrease in healthcare costs as a result of the healthcare law] has the opportunity to occur across the state [because] the majority of illegal immigrants have no health insurance. [...]

Bad debt and charitable care are one of the biggest challenges both locally and across the nation given the economic climate. There is certainly the possibility for both of those to decline given this new law.<sup>25</sup>

What is most remarkable about this statement is how it relates utilization of charity care to mere financial loss, without much regard for the social value of this care. No spending,

however small, will be considered valuable, reasonable, or even tolerable when seen through a narrow lens where charity is synonymous with waste.

By contrast, the story can be told in words amounting to a humane appeal to professional responsibility. During the ethics committee's meeting, after this patient had already been approved for chemotherapy, a pediatrician and committee member posed the following question: is there any patient in the world who is more vulnerable to us than a minor, experiencing mental status changes undermining her agency and ability to speak for herself, lacking any ability to speak English, who has no money nor access to reimbursement through public or private insurance, and who is suffering an extremely quickly-progressing, expensive-to-treat, and yet highly curable disease? Hearing this formulation from my colleague threw the problem of an illegal immigrant wanting treatment into another frame altogether: the problem of a person, and a child at that, who needs care we are technically able to provide. Simply reframing this issue as one of moral responsibility and not economics or politics opened a new kind of conversation, and with it a new feeling about the case and the persons involved.

Unfortunately, this shift split the problem in a new way, which was equally oversimplified. It unfairly characterized physicians as advocates and administrators as impediments to this advocacy. In truth, there were no immoral actors in this play; just a lot of people—a whole institution, even—who were unprepared to make a quick, difficult decision based on, and simultaneously challenging our idealizations of, the principle of justice.

#### 4. CENTRAL QUESTIONS AND METHODS

Reflecting on A.'s case, a number of questions jump out with a kind of social and moral electricity. What exactly makes a *person* illegal, and—more to the point in the case—were we absolutely sure this patient's residency was illegal? What evidence did we have? It is not too easy for the term to catch onto a person, like a virus, whether or not their immigration status agrees?<sup>26</sup> If they are truly "illegal" in the way our nation's laws define it, what responsibilities should a physician, another clinician, a hospital administrator, a hospital have to reinforce these laws, at the expense of treating the ill? Should noncitizens without access to money or insurance be considered distinct from citizens who do not have such resources, for the purposes of allocating healthcare resources? What larger responsibilities to a public, whose goals include taking care of its own, are relevant when an "outsider" breaks its ranks?

I intend to address many of these concerns by way of analyzing the central question in A.'s case: *what is our obligation to patients who travel to this country explicitly for the purpose of receiving expensive, life-preserving treatment such as cancer care, organ transplantation, or dialysis?* By looking at this less proximate (compared with citizens or longtime residents) moral claim on a community's resources I hope to illuminate various norms and dynamics comprising this debate, while providing specific guidance to institutions facing a range of similar dilemmas, and suggestions of how to fairly and reasonably operationalize and govern these cases.

In order to do so, I will begin in Chapter II by documenting the ambivalent ethos of charity present in the American medical profession's professional ethics and in

changes in the form of healthcare delivery throughout the past century. Then, I will turn to Yale's own history to articulate the competing interpretations of what a hospital is—moral community, fiscal one, community organization, private business, and so on. Finally, I will review recent American healthcare policy affecting reimbursement for hospital care of noncitizens, as well as the status of these individuals in recent health reform, and the status of health in recent state-level immigration reform.

In chapter III, I will focus on the ethics of the clinical problem of allocating presumably scarce resources to noncitizen patients requiring expensive hospital care. By deconstructing a set of common positions, I aim to show how complex the notion of belonging to a community is, and offer my take on which principles should be followed in performing these microallocation decisions. I will subsequently present a draft policy aimed to guide governance of this issue from within the hospital, including a statement of need, a set of essential principles (meant to be a practical distillation of chapter III), and a proposed process for making these difficult, imperfect microallocation decisions in real time. This process will incorporate substantial scrutiny of how these principles are operationalized and governed within the complicated moral community of the hospital, where power can so easily alter one's experience of life and death.

I will conclude with a discussion of some inherent flaws in this pragmatic approach, and a recommendation for how this case may be more justly framed and governed in public policy.

In order to address these complex issues, I will employ evidence from history, politics, law, and public health in order to objectively explore this issue from all sides. In

my ethical analysis, I will contend with a variety of positions which lead me to the original hospital policy found in Chapter IV. My research has spring from a previous draft of a possible policy for “extraordinary treatment,” as well as extensive debate on this topic conducted by members of the adult and pediatric ethics committees at Yale, but this hospital policy has not been seen, discussed, approved, or used by Yale in any respects. It is my own original work, intended as a work of scholarship and as one suggestion for how a place like Yale-New Haven Hospital may strategize its use of charity funds in these increasingly common cases. Since the charity funds possessed by Yale have diminished in recent years (see Table I) while the population of uninsured persons and noncitizens living here grows, I believe the hospital has a duty to judiciously plan out its approach to the problem of noncitizens—both newly-arrived and well-established ones—who need expensive, often life-preserving, care, in order to minimize confusion and injustice.

## II. CHARITY CARE AND THE NONCITIZEN: HISTORICAL AND POLITICAL ROOTS IN AMERICAN MEDICINE

### 1. CHARITY AND NONCITIZENSHIP IN PROFESSIONAL ETHICS

#### *American Medicine's Founding Ethos*

The 1847 document “Medical Ethics of the American Medical Association,” published in the year of the guild’s formation, has been used by commentators as evidence of how the notions of charity, beneficence, and equity are present at the roots of American medicine. Hoffman (2006) cites references to “eleemosynary [charitable] services”; to the idea of caring for “indigent” patients; and to providing services with “gratitude, thusly accorded.”<sup>27</sup> In her essay, as in the public imagination, the American medical profession has at its origin a strong ethos of service, an ethos which has been gradually corrupted by exclusionary federal policy, by the rise of biomedical technology with its focus on research and progress, and by managed care with its emphasis on economic efficiency—each at the cost of human values within the profession.<sup>28</sup>

However, a close reading of the 1847 Code of Ethics shows that the obligation to care for the underserved is articulated in strong tension with various other factors, such as the “dignity of the profession” and the notion of justice. All in all, the duty to care for those in need is articulated as a limited one wherever it occurs in the text. For example, the 1847 Code says:

There is no profession, by the members of which, eleemosynary [charitable] services are more liberally dispensed, than the medical, but justice requires that some limits should be placed to the performance of such good offices.<sup>29</sup>

Charity is not presented as a moral duty, but simply a fact of the profession, not worth pushing as a guideline.<sup>30</sup> Furthermore, the passage continues by acknowledging—in the very same sentence, without a full stop to separate these ideas of obligation and boundaries—that limits should be recognized as inherent to the idea of charity.

This statement may contain a variety of moral suggestions, among these that fairness to the profession means fair remuneration. This stance would help the AMA secure the economic and social status of the profession for many decades to come.<sup>31</sup> Furthermore, by acknowledging that “some limits must be placed,” even members of a profession which is known above all others for its commitment to helping those in need, are not positioned to alleviate all the suffering around them, nor can the profession be expected to solve all the injustices in the world. A provider should not be expected to dedicate his whole practice to volunteerism, lest it be utterly unsustainable, forcing him to abandon those to whom he dedicated himself in the beginning. In other words, charity should not overwhelm the profession’s viability.

And nor should it tarnish its character. In “Duties for the Support of Professional Character,” the 1847 code states: “It is derogatory to the dignity of the profession [for a physician to be seen] publicly offering advice and medicine to the poor gratis.”<sup>32</sup> This prohibition suggests a way of doing charity care that occurs under the table:

Neither institutions endowed by the public or by rich individuals, societies for mutual benefit, for the insurance of lives or for analogous purposes, nor any profession or occupation, can be admitted to possess [...] valid claims for gratuitous services.”<sup>33</sup>

One possible interpretation is that the practice of providing free care to those in need was so common in mid-19th century medicine that the code needn’t make a point of

physicians' responsibility to provide this service. But charity is also presented as a threat to medicine's status and security, something worth hiding and downgrading, an inconvenience in the rise of political, scientific, and moral status of the profession. There is a fear, moreover, that "rich individuals" and the companies offering "insurance of lives or for analogous purposes" will by default avoid sharing the responsibility to care for the underserved of the day.<sup>34</sup> There is even a danger that the virtue of beneficence will be capitalized upon by the wealthy: the AMA advises that physicians who should "should not give advice gratis to the affluent; because his doing so is an injury to his professional brethren."<sup>35</sup>

All in all, the code articulates a physician's duty as limited with respect to his deserving patients, and to the society at large wherein he operates:

The office of a physician can never be supported as an exclusively beneficent one; and it is defrauding, in some degree, the common funds for its support, when fees are dispensed with, which might justly be claimed.<sup>36</sup>

Of note, a physician's duty to the "welfare" and "benefit of the community" is frequently mentioned,<sup>37</sup> but nowhere is there any discussion of who exactly qualifies for this right. Nor to the status of immigrants, refugees, noncitizens, or other persons of need whose social class would disqualify them from the social programs of the time.

The 1847 statement articulates a clear ambivalence about charity: it is one of medicine's core values, but it is potentially an economic and political hazard and a temptation to veer from realistic practice, which in 1847, as today, involved economic sustainability.



*Professional Codes Today*

Current professional codes articulate the same kind of ambivalence expressed in the 1847 document. The AMA's Principles of Medical Ethics, first adopted in 1957, does declare that "a physician shall support access to medical care for all people."<sup>38</sup> However, this notion was prioritized at the very bottom of the document as the ninth principle of nine. Similarly, the more extensive "Code of Medical Ethics" of the AMA states that "all physicians should work to ensure that the needs of the poor in their communities are met. Caring for the poor should be a regular part of the physician's practice schedule."<sup>39</sup> But this incitement is filed deep within the code in Opinion 9.065, below entire sections on "Fees and Charges," "Continuing Medical Education," and "Free Choice," which states that "free choice of physicians is the right of every individual."<sup>40</sup> Nevertheless, physicians should accept "a part of the responsibility for the medical care of those who cannot afford essential health care."<sup>41</sup> Similarly, The American College of Physicians (ACP) Ethics Manual (2012) states, in its section on "Financial Arrangements," that "Each individual physician is obliged to do his or her fair share [...] to provide services for uninsured and underinsured persons" based on "their professional obligation to care for the poor."<sup>42</sup>

Other professional statements do go somewhat further than the AMA's does in recognizing the duty to perform charitable practice. American Association of Family Physicians engages directly with the political realm, specifically opposing laws requiring physicians to report unauthorized immigrants or criminalizing the care of these persons.<sup>43</sup>

## 2. HOSPITAL CHARITY IN AMERICAN MEDICAL HISTORY

### *Early Hospital Charity*

From its roots in the hospitals and medical schools founded more than a century ago, American medicine has been organized around the notion of charity, meaning providing care to those who can not afford it. Yet the very same institutions displayed sharp boundaries around who deserved such care, what it would entail, and where and when it would be provided. By examining the recent development of healthcare policy affecting both authorized and unauthorized noncitizens living in the United States, I aim to illustrate how this ambivalence about the virtue of beneficence has carried through in the modern healthcare system, thereby framing the social dynamics and financial pressures shaping medical practice today.

Around the time of the 1910 Flexner Report, American academic hospitals usually incorporated charity into their educational offering and clinical services.<sup>44</sup> The impulse may not have been entirely altruistic. In his history of the American medical profession, Starr (1982) writes that the notion of charity was wrapped tightly in social status, as well as in a moral agenda. He describes how the “wealthy transformed charity dollars into social status; by participating in the social good, they could also push a social agenda.”<sup>45</sup> At the same time, these charity institutions began to transform in their essential quality. What was really happening to the hospital at the turn of the 20th century, Starr argues, was its “reorganization [...] along the lines of a business rather than a charity.”<sup>46</sup>

Does a for-profit hospital, ostensibly focused more on business than charity, have different measurable behaviors as a result of its primary mission? One study of 17 private

non-profit hospitals bought and converted to for-profit entities between 1980 and 1992 showed that three years after the change to private status, a hospital's ratio of unreimbursed care to total expenditures did not change significantly. Most remarkably, though, was that unreimbursed care was less than 3% for each type.<sup>47</sup> This poverty of services was also found in a study of Californian not-for-profit hospitals, where in 20% failed to provide "community dividends" in accord with of the tax subsidies they receive.<sup>48</sup> Another study factored in a wide range of expenditures and losses consistent with the notion of "community benefit," and found that 43% of these expenditures were on discounts for private insurers. "This raises the question of why nonprofit hospitals use the community's funds for activities that transfer money within the community rather than on activities that make the community as a whole better off," the authors concluded.<sup>49</sup>

### *A Local History at Yale*

Burrow (2002) reports that Yale's medical school and hospitals continually "struggled" with their relationship to the community, and in general with the notion of what he calls "social responsibility."<sup>50</sup> It was true that "local influences played an important role in shaping the medical school," but these relationships were complex from their very origin.

In 1810, the Connecticut Medical Society and Yale College collaborated to start the Medical Institute of Yale College, which later became Yale School of Medicine. Subsequently, a local state hospital was founded by local physicians and Yale faculty, but

only one of its ten founding corporators, William Leffingwell, was a layperson who represented the community more than the profession.<sup>51</sup> Because of doubts they maintained about the proposed hospital's commitment to New Haven and Connecticut at large, the state legislature resisted funding this hospital as legislatures had done in Massachusetts, Pennsylvania, and New York. In response, the New Haven Medical Association formed a committee which declared that "the hospital shall be a charitable institution and no physician or surgeon shall receive any compensation for his services." This encouraged the legislature to supply \$5,000 to the fund in 1826, thereby making New Haven Hospital the nation's fourth voluntary hospital, along with the Pennsylvania, New York Hospital, and Massachusetts General Hospitals, each of which had similar origins.<sup>52</sup>

The intention was to create a charitable institution, and the social norms underlying selection of worthy recipients of charity were largely determined by those contributing the funds. For example, during New Haven's 1833 cholera epidemic, "the Board of Health wanted the new hospital to treat cholera patients. But the hospital directors claimed that [the patients'] character forbade admissions of patient with communicable diseases."<sup>53</sup> This was common practice at the time:

Persons who were contagious, vagrant, or morally suspect were not welcome in most voluntary [what has become non-profit or charity] hospitals. The mentally ill and chronically ill were also not admitted. Rather, most voluntary hospitals were for the "deserving poor," the citizens who could not recover in their usual residencies (servants in fashionable homes, for example).<sup>54</sup>

The early charter at New Haven Hospital was no different.<sup>55</sup> According to Burrow's history, the community reacted strongly to their own being turned away during the

cholera epidemic, which "slowed popular acceptance of the hospital."<sup>56</sup> Physician groups, for a variety of reasons, became estranged from the medical school and from New Haven Hospital, leading to the founding of two more institutions—St. Raphael's and Grace Hospital.<sup>57</sup>

Early on, Yale College was the intellectual and financial center of the University, while the medical school suffered from "chronic underfunding" and "the recurrent threat of medical-school extinction."<sup>58</sup> This trend persisted until the technological transformation which led to medicine's ascendance in society occurred. In the 1960's the medical school began to produce its own revenue, largely corresponding to the emphasis on research, not clinical care.<sup>59</sup> At the same time, after World War II, the hospital declared itself not responsible for community members who were unable to pay. According to Burrow, Yale's Director of Medical Affairs at the time "concluded that in reality the patients—and appropriate third parties—were actually responsible for the cost of their illness."<sup>60</sup>

Now, Yale-New Haven is the largest distributor of charity care in the state of Connecticut (see Table I). These charity dollars are largely spent as unreimbursed expenditures from its Free Care fund, which is available to anyone, including undocumented immigrants, who have been denied public benefits. The hospital has also gone outside of its own walls to purchase equipment and services on a noncitizen patient's behalf, such as funding outpatient palliative care services for a pediatric oncology patient and undocumented immigrant whose family preferred her to die at home.<sup>61</sup> The hospital could have chosen to keep her in house to merely lose the operating

costs rather than paying for these services from another vendor, but they saw the immense social value in granting this family their wishes during the final weeks of life for their child.

These acts of charity have not come without considerable strife. The Free Care program was created out of a scandal involving not an undocumented person but a longtime New Haven resident. In 2003, a story ran on the front page of the *Wall Street Journal* describing how a man named Quinton White, a 77-year-old former dry cleaner from New Haven with kidney failure and heart disease, was being pursued by debt collectors who were contracted by Yale-New Haven Hospital.<sup>62</sup> He had owed \$18,740 after his wife, who was diseased at the time of the collection efforts, had been treated there in 1982. Subsequently, the hospital's debt collectors engaged in a decades-long pursuit of Mr. White employing what the article calls "relentless collection techniques." Mr. White's home was subject of a lien despite his paying off \$16,000 of the debt, which by that time had grown to in excess of \$50,000.<sup>63</sup> At the same time, a series of class-action lawsuits involving individuals who were treated unfairly because they had no access to the lower fee structure used by public and private insurers.<sup>64</sup>

### 3. AMERICAN HEALTHCARE POLICY ON CHARITY AND NONCITIZEN HEALTHCARE

#### *Obligations to Benefit the Community*

In 2008, Senator Charles Grassley began an investigation into the perceived "evolution" of non-profit hospitals into businesslike entities in order to "hold nonprofit hospitals more accountable for the billions of dollars in annual tax exemptions they

enjoy.”<sup>65</sup> Grassley’s investigation into the tax-exempt status of non-profit hospitals comes long after a set of changes in the nature of how law defines a hospital’s duty to its community, beginning with with “charitable care standard” which was written into the tax code in 1956. This standard explicitly mandated that “the hospital must be operated so that services are provided, to the extent of its financial ability, to those who are not able to pay and not exclusively to those who are able and expected to pay.” In 1969, this was replaced by current “community benefit standard.” It requires only that a non-profit hospital must house an emergency room, unless one is already present in the community.<sup>66</sup>

Grassley’s efforts, like the lawsuit filed in 2003 against Yale by the State of Connecticut, rest on legislation which has come to be known as The Hill-Burton Act of 1946, which authorized funds for hospital construction to as much as half of the nation’s hospitals between the law’s inception in and the last year of funding, 1996.<sup>67</sup> Each hospital that received funds was obligated in turn to provide what was initially described as a “reasonable” amount of charity to those without access to services, and to those living in the community where the hospital makes its home.<sup>68</sup> These obligations are known, respectively, as the “uncompensated care obligation” and the “community obligation.”

### *EMTALA*

The Emergency Medical Treatment and Active Labor Act of 1986 (EMTALA) protects a rudimentary set of hospital services for any person who needs them, regardless

of citizenship status or ability to pay. This legislation was written to prevent cases such as the one which resulted in *Guerrero v. Copper Queen* (1975). In that case, the Arizona Supreme Court ruled in favor of a parent of two young children who had been forced to drive 18 miles to a county hospital from the private Copper Queen Hospital in the border city of Bisbee, Arizona to receive care for severe burns they had endured in a kitchen explosion at their home in Sonora, Mexico.<sup>69</sup> The court found that the lack of citizenship was not enough to deny these individuals emergency care, based explicitly on the fact that the legislature had not defined whether legal citizenship or residency should be a factor into the decision. The legislature and the courts both failed to articulate any moral norm, and they ignored whether the patient's legal status as minors should factor into the decision, or into any just policy.

In order to protect patients from what had happened to the Guerreros, EMTALA was passed by the U.S. Congress as part of Omnibus Budget Reconciliation Act of 1986.<sup>70</sup> It established a limited right to treatment for any person requiring emergency care or labor and delivery services, regardless of citizenship status, insurance status, and ability to pay. As one co-sponsor of the bill said, "the practice of rejecting indigent patients in life threatening situations for economic reasons alone is unconscionable."<sup>71</sup> EMTALA was a marked shift from most states' legal precedents which held that hospitals had no duty to care for such patients.<sup>72</sup>

Under EMTALA, any hospital taking Medicare funding—nearly all of American facilities—must fulfill two obligations for all patients with “emergency medical



conditions” and women in active labor: provide appropriate medical screening examination<sup>73</sup> and stabilize a patient enough to enable transfer or discharge.<sup>74</sup>

Diekema (1995) commends EMTALA’s specific objective (“to establish in law a right to emergency care”) as well as its underlying norm (promoting the “equal treatment of all individuals requiring care”).<sup>75</sup> However, for him the law contains two major problems which merit review because these insufficiencies illustrate the significant social pressures facing hospitals and noncitizen patients today.

Firstly, the law’s vagueness may subvert its intent to provide a common level of care to all patients, regardless of social status. Because of “widespread confusion” about actions specified by the law—what constitutes presence inside a healthcare facility, exactly who performs the screening examination, and what is meant by an “emergency medical condition”—there remains significant potential for separate, unequal, but legally sufficient processes of screening, stabilization, treatment, and transfer for different patients. For example, case law has found that being hooked up to telemetry devices monitored by hospital personnel has been found insufficient to constitute “presence” by courts, but driving onto a hospital parking area in a private ambulance does.<sup>76</sup> This vagueness speaks to the difficulty of determining exactly when a patient enters into a hospital which may need to assume responsibility for their care.

Secondly, EMTALA did not support the norm it establishes with any financial strength, and subsequent sources of funding have been insufficient, time-limited, and subject to inclusion criteria that exclude a considerable segment of the population of noncitizens.<sup>77</sup> For example, one key reimbursement mechanism, known as “Emergency

Medicaid,” was authorized as part of the Immigrant Responsibility and Control Act of 1986.<sup>78</sup> The program authorized temporary extension of benefits to individuals requiring emergency care who meet individual states’ Medicaid criteria, which today largely exclude all undocumented immigrant adults as well as legal noncitizens who have yet to reside (and in some cases, to be legally employed) in the sponsoring state for a period of five years.<sup>79</sup> These barriers were strengthened by the Personal Responsibility and Work Opportunity Act of 1996, also known as the “Welfare Reform Act,” which cut the funding for health services benefitting noncitizens. The bill “took away all federally funded preventative preventative health care for illegal immigrations, while providing access only for emergency services and treatment for communicable diseases.”<sup>80</sup>

#### *PPACA, Medicaid, and its Financing*

During public debate of the federal healthcare reform acts of the 111th congressional session which culminated in H.R. 3590, the “Patient Protection and Affordable Care Act” (PPACA), the White House was criticized for supporting immigrants’ rights to healthcare. Specifically, they were said to support unauthorized aliens’ participation in insurance exchanges, in the failed public option, and in the expanded public insurance programs—in all the features of reform aimed to increase access and decrease costs. The president himself carefully denounced claims that the white house was going to cover “illegals.”<sup>81</sup>

The resulting legislation provides for a marked expansion of public insurance as well as the creation of health insurance exchanges, but neither will benefit noncitizens.

Since the Omnibus Budget Reconciliation Act (OBRA) of 1986, Medicaid eligibility criteria has excluded all unauthorized immigrants; after the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996, states were awarded the right to experiment with eligibility requirements, resulting in the additional exclusion of many legal residents who have not met durational requirements.<sup>82</sup> Furthermore, by barring immigrants from participating in state health insurance exchanges, they limit these persons from a major solution to the dual problems of access to care and cost control. (PPACA also provides for the creation of a contested individual mandate for coverage which may apply to noncitizens.)

In general, PPACA solidifies federal policies systematically excluding undocumented immigrants and many legal noncitizens from public insurance and insurance incentives. Furthermore, as the dominant legislation package addressing issues of access to care and financial concerns within the American healthcare system, PPACA has made other inclusive federal solutions all but political impossible. This includes the reauthorization of funds such as those contributed by the budget authorizations made in 1997 and 2003, intended to supplement Emergency Medicaid as a way for willing hospitals to cover the provision of extensive services to noncitizens.<sup>83</sup>

### *Recent State Policies*

In 1994, 59% of California voters elected to bar illegal immigrants from Medical and to institute a variety of measures discouraging these individuals from seeking healthcare and other social services, some of which recruited healthcare professionals to

aid in their enforcement.<sup>84</sup> Despite passing by a comfortable margin, the law was blocked by the California Supreme Court, based on the fact that immigration is the administrative responsibility of the federal government.

However, immigration is often the *financial* responsibility of more local communities, including counties and states. In 1996, one political leader acknowledged the contradiction embodied by EMTALA, where federal mandates can come without attention to their funding. In this case, non-enforcement of immigration laws was interpreted to be a “mandate” to tolerate noncitizens in communities. “How can any Member walk on this floor, deny the citizens of California the right to implement proposition 187, without expecting California to come right back here and ask for \$3 billion from the Federal Government annually to pay California for the cost of a Federal failure?”<sup>85</sup> His solution, like many critics of laws protecting illegal aliens’ rights to some kind of care, was to side with the voters of California, at the time mired in recession, to eliminate such legal rights for illegal people.

Commenting on Proposition 187 in the *New England Journal of Medicine*, Ziv and Lo (1995) argued that the law endangers the public health, denies care to persons in need, and violates patient confidentiality in unprecedented ways.<sup>86</sup> They also report how the deaths of two individuals which occurred in the period between when the law passed and when it was declared unconstitutional in California Supreme Court, appeared to be the result of unauthorized aliens delaying the act of seeking treatment because of fears of identification and deportation.<sup>87</sup>

Today, similarly strict state immigration policies have begun to be instituted in Arizona, Alabama, and Georgia where legislatures have made it a crime for nonresidents not to carry authorized papers.<sup>88</sup> These laws were opposed by educators, doctors, and others on the grounds that they turned their professions into auxiliary support for the government's efforts to control the migration of persons.

### *Conclusion*

Healthcare policy has affected the coverage of noncitizen patients in a few key ways. Firstly, it has met increasing financial and social pressures with insufficient economic resources, shifting the financial responsibility onto hospitals and localities and thereby exacerbating bias against immigrants. Partially countering this strategy is the EMTALA legislation which guarantees what might be considered minimally humane treatment for these individuals, avoiding the moral catastrophes such as what happened to the Guerreros and to countless women who feared that seeking hospital services at the time of birth would put them at risk for identification and deportation.

Secondly, federal and state public insurance policies have articulated an insufficient set of norms defining what it means to be part of the American community. Legal residence remains the only factor represented in the law, despite the millions of immigrants who remain here undocumented, and who may contribute significantly to American communities through employment and in other capacities.

Finally, state policies such as the now-overturned Proposition 187 in California and the 2011 laws in Arizona, Georgia, and Alabama which require the policing of public

institutions have allowed the state's interests in controlling the migration of persons to become a core public value, and one that is meant to be shared, despite considerable objection from physicians, teachers, and law enforcement, by the public servants and professionals working in these communities, and by courts reviewing early legal challenges to these legislations.

### III. ETHICS OF HOSPITAL CHARITY CARE ALLOCATION

#### 1. MEDICAL CARE IS NOT AN UNLIMITED RESOURCE

The history of Burkitt's lymphoma is a compelling example of modern medicine's power to improve the lives of human beings. Between 1957—when Denis Burkitt originally described a series of 38 Ugandan patients suffering from what appeared to be a tumor of the jaw—and the present day, advances in chemotherapy and molecular oncology have produced at least a fourfold improvement in survival.<sup>89</sup> New proposed treatments such as those using a monoclonal antibody—a potent symbol of recent medical progress—provide even more hope.<sup>90</sup> At the same time, those living in resource-poor countries suffer a greatly increased risk of developing the disease and of dying from it.<sup>91</sup> These risks stem not only from viral and immunological factors (such as Epstein Barr Virus infection and Acquired Immune Deficiency Syndrome) but from socioeconomic ones as well.<sup>92</sup>

Pellegrino and Thomasma declare that “the existence of a genuine medical need constitutes a moral claim on those equipped to help.”<sup>93</sup> *Those equipped to help* includes the medical professionals who possess the knowledge and skills to cure or palliate illness, and it includes members of the public at large, who must take some interest in one another's well-being, and especially in the well-being of those least empowered to help themselves. In this sense, *those equipped to help* form a considerable number in the United States country alone, where only one ten-thousandth of the population—just 14,000 families—acquire enough wealth every week to fund an entire course of

chemotherapy and hematopoietic stem cell transplant (an efficacious treatment for recurrent disease) for a child such as A.<sup>94</sup>

But Burkitt's is only one type of disease, and a relatively uncommon one. It is reasonable to think that our wealth might be used to provide for basic comprehensive healthcare for all persons present in the United States—legal citizen or otherwise—but it would be impossible to cover the entire population of the Americas, much less the entire world's population.<sup>95</sup> Indeed, for however compelling each genuine medical need appears to physicians and others in the helping professions, there exists a point at which the ability to address these needs is circumscribed by resource limitations. At this point, the moral claims of individuals begin to conflict.<sup>96</sup> Any community operating under the condition of limited resources makes decisions, intentionally or by default, about how its resources will be distributed.

### *Concerns About the Nature of Money*

Two criticisms of this formulation of financial scarcity are worth mentioning. First, one can question whether financial resources are truly limited in the way that organs or devices such as the mechanical ventilator or extracorporeal membrane oxygen machine. Is money a reliable enough foundation for life-or-death decisions? Can it be redistributed effectively? Unlike the physical substance of vital organs, which can be cooled, transported to another county or state, and then given whole hog to another person, money is symbolic and changeable, and potentially unreliable. Routine phlebotomy may cost someone paying with cash twice what it costs an third party who



has pre-negotiated their rates with a laboratory, though these procedures are identical in terms of time, equipment, and expertise required to perform the job.<sup>97</sup> And that is not to mention the social and emotional issues which make money seem to be an unreliable substance on which to build a system striving to achieve moral clarity.

Secondly, distributive justice is *most just* when applied to large populations and a wide range of problems.<sup>98</sup> Even if the allocation process is confined to the hospital level, it would be practically impossible to adjudicate every request for treatment which plays into the hospital's unreimbursed expenditures. Confining the task to only the free bed fund dollars enforces clear boundaries of the system, and makes the task practical. But it also further separates the problem from its root—inequities in the system at large—and it involves a kind of selection bias for only the most expensive cases, which tend to involve the sickest individuals. These individuals might be penalized for the severity of their illness, when this can also be seen as a moral claim to be treated.<sup>99</sup>

These two claims contribute to a practical problem: if a policy were to be devised for “expensive” charity care, what should be threshold which activates it? Is it reasonable to set a quantitative trigger for such a policy, knowing that healthcare prices will probably inflate, and a hospital's ability to pay will also change over time? Is \$50,000 of treatment worth the same to a 90-year-old as it is to a 5-year-old? Is contributing that for them worth the same to us, as a public?

Furthermore, what about the costs of not treating a person with expensive curative treatment or surgery? It stands to reason that if a fair procedure were to be put in place, its very success may result in a tragic death, however justified the death may appear to, or

amy actually, be. To avoid making this situation truly inhumane, the hospital should provide palliative care for patients for whom there are no charity funds. But the costs of this care are significant: by one estimate, about \$40,000 per patient with a terminal illness, averaged over a variety of end-of-life scenarios.<sup>100</sup> A person could never be reasonably denied a \$50,000 treatment with a reasonable chance of cure for a \$40,000 course of palliative care with zero chance of survival. But there *is* some difference in money which may reasonably justify this alternative.

However appealing these arguments are, it is key to point out that money—and all its associated irrationalities and injustices—can not be simply set aside. A hospital must operate in the financial realm in order to justify its beneficent mission, despite the compelling myth of Asclepius, which illustrated how we hope for care and coin to be separate.<sup>101</sup> Additionally, the comparison with organs is illuminating. For however concrete organs may seem compared with money, the supply of transplantable organs is still thoroughly dependent on social values and public policy.<sup>102</sup>

Ultimately, neither concern addresses what should be done with an individual patient presenting to a hospital which possesses a limited quantity of charity funds. Does the symbolic nature of money obligate us to care for a patient like A.? Do the inequities in our society? These lines of thinking reflect important work yet to be done within the healthcare system, but they distract from the problem of what to do with A. given what inequalities and absurdities of pricing exist within the hospital and in society at large. These problems may indeed be at the root of her dilemma, but they can not be solved quickly enough to prevent the tumor from consuming her.<sup>103</sup>

## 2. A POLICY IS NECESSARY TO MAKE ALLOCATION REASONABLY FAIR

A key worry about allocation is that whoever writes the policy will be able to fix the odds in their favor, or set the social agenda underlying it. As discussed in Chapter II, physicians and hospital administrators have historically used their power to control the allocation of resources, as well as the notion of charity itself, to push social agendas unrelated to the health of the population at large.<sup>104</sup>

To address this fear, it is crucial that a policy be grounded in the philosophical principle of *justice*. Specifically, it needs to promote *equity* (all persons having equal opportunity to obtain a minimum set of resources, no matter what their social standing) as well as *efficiency* (judicious use of resources in order to maximize their impact across the population, especially for those of least means). These principles are critical because health or healthcare is not just another good; health has special moral importance, such that *inequities* in income and other financial resources can lead directly to *injustices*.<sup>105</sup> A process should be governed in a way that promotes transparency and consensus in order to maximize accountability within the process, and accord with the values various constituencies that comprise the public.<sup>106</sup> It should also involve well thought out processes of self-regulation or external review, and public accessibility.<sup>107</sup>

## 3. CARE SHOULD NOT BE WITHHELD BASED SOLELY ON IMMIGRATION STATUS

A situation of limited resources necessitates a fair allocation mechanism to ensure

that justice is maximized when balancing the individual rights of each member of a public. But how does one define a public? Do the rights of non-citizens always represent less of a moral claim than those of individuals who possess citizenship, either by birth or naturalization? What about legal immigrants or permanent residents, who are largely ineligible for public insurance despite being in bounds of the law?

It is my contention that immigration status does not reflect the value of a person in a community, nor does it honor the dignity of the medical profession's way of apprehending individual persons. The use of a legal and political norm to allocate healthcare resources constitutes a threat to professional dignity and a violation of professional ethics. Illegal immigrants should not be excluded from healthcare merely because they are "illegal," because doing so would mistake the state's interest in controlling the migration of persons with the profession's aims to support the health of patients and public at large, truly denigrating the ethos of the profession and its ability to assess and to care for those in need.

#### *Citizens' obligations to the public*

A key counterargument to this position is based in the responsibility that members of a citizenship—including doctors and other professionals—have to that community's integrity. Like doctors, citizens have obligations to the public, including to its laws. Proponents of society can say that the nation has a moral duty to keep its boundaries intact. If members of a public are suffering because of inequity, the moral claims brought by noncitizens may be seen as an honest threat to mutual care within the group.

This “nationalist” argument fails because medical professionals have *special relationships* with those for whom they care.<sup>108</sup> Furthermore, it disguises how citizens and noncitizens both may be valuable residents of a place. As Dwyer (2004) points out, “the narrow framework of the debate pits poor citizens against illegal aliens in a battle for health care resources.”<sup>109</sup> In some cases, treating some noncitizens may even produce benefits for public, including the prevention of advanced disease (with its associated costs) and control of infectious diseases.<sup>110</sup>

However, a patient such as A., however, suffering from a non-infectious disease which is already advanced, does not fit this public health benefit scheme. Therefore, a justification for this treatment or withholding thereof must come from a source other than the utility to society of treating these persons, such as their vulnerability or their inherent value as human beings.

Another counterargument involves the nature of the national public from which these patients are excluded. If individuals comprise the citizenry, and the government is simply the representation of these individuals, then what is the moral discrepancy between a medical profession and a government which administers to this public? Both, in theory, are working in the best interests of the public; why need physicians dedicate themselves against this nation’s immigration policy?

I contend that the public (whose health is a concern primarily of doctors) and the state (whose integrity is a primary concern of immigration authorities and lawmakers) are similar but that their differences in ethos and duty are critical in the noncitizen dilemma. These differences are illustrated by the way that meaning is made in each domain. In law,

“undocumented immigrant” signifies illegitimate legal status as a resident, a simple breach of the law. However, in medicine, the identity of “undocumented immigrant” is a risk factor for structural violence and lack of access to care, and a proxy for poverty and all the health risks that condition brings. Furthermore, enforcing anti-immigrant norms might compromise a physician’s ability to protect patient privacy—a small breach of dignity—and it could potentially cause outcomes as disastrous as in capital punishment, regardless of whether the physician was actively or passively causing death. All of these problems accompany the mistake of confusing the state’s interest in controlling the migration of persons for any reasonable goals of the medical profession.

Yet another argument for the nationalist position is that it is an arbitrary but convenient way to distinguish people when some distinction must be made.<sup>111</sup> Unfortunately, this does not acknowledge the profound vulnerability of these persons, nor does it attempt to minimize bias which endangers just allocation.

### *Screening Citizenship as a System of Distributive Justice*

Finally, some justify the use of characteristics such as legal citizenship status not as binary moral judgment but as a way to define the public—in short, as a theory of distributive justice. (The difference between these two may seem small, but it is the difference between a law and a philosophic norm.) In this sense, it is clear that the use of citizenship status fails as a matter of social science. By using citizenship to define what is meant by the idea of community membership, we flatten a complex and age-old social phenomenon of human migration into a simple binary class: are you or are you not one of

us? The reality is much more complex: noncitizens contribute to the tax base, they contribute to the workforce, and they endow a community with cultural goods. They may even use fewer resources of social welfare compared with equals from a citizenship class, and overall, citizens who are uninsured or underinsured present even greater financial burdens to American hospitals.<sup>112</sup> It is clear that the nationalist position, as Dwyer writes, “focuses too narrowly on what we owe people based on legal rules and formal citizenship.”<sup>113</sup>

#### 4. Alternatives to Citizenship: Contribution, Attachments, Age, and Vulnerability

If citizenship status is too vague and politically-charged for use in healthcare allocation, what criteria would be fair enough to use? By way of finding a middle ground, some have proposed that noncitizens should be allocated healthcare benefits based on their contribution to society through *work*.<sup>114</sup> This formulation is sociologically honest; it recognizes that immigration is an ancient human phenomenon and that its regulation is new and difficult to fully enforce. Furthermore, this formulation reflects how undocumented immigrants may contribute significantly to the public in a number of ways which deserve to be rewarded, including through taxes (especially local sales and use taxes) and also through *work*. Often this work is that which few citizens will perform, contributing labor on which entire industries may rest.

One striking example of the real contribution to the nation’s economy made by undocumented immigrant workers occurred subsequent to the passing of the strict state immigration laws in Alabama, Georgia, and Alabama during 2010. These strict policies

created a severe labor shortage which some have called a “man-made disaster.”<sup>115</sup> For example, a North Carolina farmer who runs one state’s oldest and most successful vegetable growers is at risk of losing his business because the laborers he now has access to is limited to the more costly H-2A Temporary Agricultural Work Program program:

What too many politicians and people in the general public don’t seem to understand is that these migrant workers aren’t taking jobs from American citizens. I’d love to hire local labor, but they simply aren’t available.<sup>116</sup>

Importantly, this farm owner argues that it is not the way they contribute tax dollars to the community that define them as contributing members of society, but the way that they form a crucial underclass on which the “real” members of society depend:

The migrant laborer who comes to work on our farm doesn’t pay taxes, but doesn’t utilize tax-paid services either. But most importantly, what too many people don’t seem to understand is that these migrant workers allow folks like me stay in business and pay taxes.

All in all, the agricultural shortage illustrates one way in which immigrants do contribute to a society, given that the key economic sector of an entire region was threatened by a tightening of immigration policy. Perhaps most interestingly for a problem about borders and boundaries, the shortages and subsequent economic impacts thereof were not confined to the states in which these laws were passed: the entire region of the South, from Florida to Virginia, has experienced these workers’ absence as an economic detriment.<sup>117</sup>

Like immigration status, work should not be used as a simple binary factor, but instead as one element in a rich description of how a person has spent their life, what roles they occupy in society, and what attachments they have to people and places. To



create a thicker description of contribution, Dwyer suggests formulating a taxonomy of kinds of work and its diverse moral claims:

There may be important ethical distinctions, for example, among the following groups: U.S. citizens who lack health insurance, undocumented workers who lack health insurance in spite of working full time, medical visitors who fly to the United States as tourists in order to obtain care at public hospitals, foreign citizens who work abroad for subcontractors of American firms, and foreign citizens who live in impoverished countries. I believe that we—U.S. citizens—have ethical duties in all of these situations, but I see important differences in what these duties demand and how they are to be explained.<sup>118</sup>

He does not elaborate on a system which takes these distinctions into account. Instead, he advocates for awarding healthcare benefits to noncitizens based on their contribution to society as employees. Putting value on employment effectively debunks the notion that noncitizens are by definition not part of a functioning society because they contribute so critically to the labor base. However, it is only *one* way to define how persons may belong to a society, and as a general definition of public membership employment has several critical flaws.

#### *Problems with Employment Status as a Factor for Allocation*

Firstly, the employment-insurance connection has received considerable criticism because people may change jobs frequently, and because employers small and large suffer from these costs.<sup>119</sup> Secondly, many important contributors lack official status of employment. Of course, there are those working hard under the table, but what about the stay-at-home mother, or the great aunt who performs daily childcare for three children under the age of four? What about a person who can not find a job, but instead spends

more than twenty-five hours a week volunteering at a community organization, such as a soup kitchen, a parenting support network, or a library?

More importantly, using work as a way to determine who deserves benefits would exclude from analysis those who can not or should not work, such as children, persons with significant physical or cognitive disability, or persons with disabling mental illness. While these persons may not be highly valued in the law which establishes American immigration priorities, those who have already migrated to the U.S. present challenges to policy because of their vulnerability and dependence. Many of these individuals, such as children and some disabled adults, probably had no active role in the decision to immigrate, so why should they be held accountable for the “crime” committed by those on whom they depend?<sup>120</sup>

But just how to conceptualize children as members of a public outside of their family unit, given their slowly-diminishing dependence on that unit, is opaque and largely unexplored in bioethics.<sup>121</sup> Outside their family membership, children do not, and should not, work. Their vocation is playing, learning, developing their capacities as individuals and members of groups. Every child, therefore, represents the possibility of contributing goods—economic, social, and cultural—in the hopes, dreams, and potential contributions their futures hold. (They also represent all of the detriments eventually suffered at the hands of people).

Because of these uncertainties, I advocate a policy that avoids denying care to children and other dependent persons by default, based on their vulnerability. However, there may be a time when competing requests for care may need to be adjudicated. Does

a child whose parents work have a greater moral claim on life-sustaining treatment than one who does not? What about a child who was brought to Connecticut to receive care, versus one who has been living here for three years? What about a six-year-old child, versus an adult whose intellectual capacity is assessed to be around the age of six? These difficult questions make up the hardest work of any person or community attempting to define the norms of allocation. To borrow from the approach used by Daniels and Sabin (2002), we will largely focus on making a reasonable process—getting the right hands on deck—and allow those participating in the process to help refine the set of applicable norms.

#### 5. Preference May be Given for Geographical and Historical Proximity

Thus far, we have framed the dilemma as a problem of competing moral claims, and distributive justice and competing moral claims. There appears to be a conflict between citizens and non-citizens, but the tension is actually shared amongst members of a society who contribute in a variety of ways which go unrecognized in their legal immigration status. Two further elements in the story and background deserve attention, related to the ethical appeal to proximity.<sup>122</sup>

Legal precedents may not define what is the most morally satisfying formulation of belonging, but they reflect a fairly broad range of interpretations of what it means to establish residence in a community. The Hill-Burton legislation, which obligates any hospital receiving reconstruction funds, defines membership in a community by whether a person has been “(1) living there with the intention of remaining permanently or for an

indefinite period of time; (2) living there for purposes of employment; or, (3) living with a family member who lives in the service area.<sup>123</sup> By contrast, the state-based durational requirements of medicaid mostly bar even legal immigrants from public benefits for five years.<sup>124</sup>

### *Physical and geographical proximity*

The moral relevance of proximity is typically thought of as a result of physical proximity, as in Levinas' appeal to the ethical primacy of a face-to-face encounter.<sup>125</sup> This situation translates into a way to judge between competing requests within a system of allocation, when two patients differ only in their history of place. For example, A. came to us directly from her home country for treatment, whereas a similar patient—let's call her B.—may have lived here for 6 years, attending school in a nearby town, before falling ill. She may have done this through a process of legal citizenship, while C. overstayed a work visa to become an undocumented resident.

Physical proximity in this community does seem to present a kind of claim useful for competing requests, but it should not be an exclusionary criteria because of how interconnected the world is, despite the norm articulated by strict exclusionary criteria for public benefits.<sup>126</sup> Upon posing more questions—such as whether patients from countries that share borders with the U.S. have a bigger claim than those merely from within the Americas? Would a Malaysian person, or an Australian person, be less deserving than a Venezuelan, or a Argentinian?—the arbitrariness of distance becomes evident. All in all, we may say that the world is indeed flat, but the attachments people make continue to be

of strong importance, as are principles such as caring for the vulnerable—since those with no roots anywhere may present a unique moral appeal to care.

As a matter of hospital policy, the institution's approach to deportation can follow along these lines, valuing genuine attachments to a place over administrative or legal descriptions of belonging.<sup>127</sup> Companies specializing in medical deportations may be used only with care and oversight in order to ensure the patient's safety and access to treatment in their home country.

### *Spending Versus Saving: Proximity of Time*

A second issue of proximity involves a classic ethical problem of balancing the needs of one real, present person against many theoretical, or future persons.<sup>128</sup> Free bed funds have operated as endowments, generating interest which can be sustainably applied to their cause. But it is fair to keep this money for future persons?

In 2003, Attorney General Richard Blumenthal sued Yale-New Haven Hospital for failing to honor its commitment to charity by “hoarding” the funds earmarked for the poor.<sup>129</sup> At that time, Yale had been spending around two percent of its free bed funds, which totaled nearly \$26 million at the time of the lawsuit (see Table 1). By comparison, this was significantly below the state averages of that period, which were 2.8-7.8% in the three years preceding the lawsuit.<sup>130</sup> (In FY 2001, all but one hospital spent in the range of zero to 31%; Griffin Hospital was the only one on record to spend 100% of its free bed funds, or \$251,190, on charity care.) Importantly, these hospitals were also usually

eligible for reimbursement of these funds, shifting free bed funds to their general funds pool via these reimbursement mechanisms and thereby “bypassing donors wishes.”<sup>131</sup>

There are several reasons by spending should be favored over saving. First, market gains are uncertain. Secondly, healthcare is a special resource, and money should be spent to maximize the health of those living today. Thirdly, spending funds may make them scarcer, but spending has the potential to increase awareness of the need for charity funds, and potentially encourage donors to benefit the funds at Yale, given the need for continual donation. Finally, to justify withholding of therapy in the name of allocation, money must be truly scarce, and not theoretically or potentially so.

#### 6. Physicians Should Participate in Allocation Decisions, but Patients’ Own Physicians Should Be Advocates and Consultants

Physicians resist the notion of distributing healthcare because it threatens their notion of being advocates only for their patients’ best interests and, in general, of doing good in the world. One popular formulation of this argument is that “we should recognize no limits, in principle, to the sacrifice that morality can demand of us in promoting the overall good.”<sup>132</sup> Similarly, the oaths endorsed today by many graduating medical students tend to endorse this humanist norm with zero interference from competing interests: “the health and dignity of my patients will be my first concern.”<sup>133</sup>

This position has a variety of benefits: it is simple; it focuses on individual dignity, a universal value and the foundation of most systems of ethics; it ignores social biases that threaten equity and justice; it is satisfying for clinicians to know that their job

is untarnished by other obligations, such as to their employers, guilds, communities, systems, or to their own idea of what a patient's best interests are; it satisfies patients who can feel that their best interests are being faithfully represented; and it preserves the function of advocacy for physicians, whose myriad responsibilities have made advocacy an increasingly difficult task.

Writing in a 2005 editorial in the *Journal of Trauma*, a head trauma surgeon at one of the biggest public hospitals in Arizona, a state historically at the center of immigrant hospital policy conflicts, appeals to his colleagues about the humanistic duty to care:

I believe it is our duty to recognize the vulnerability of all injured patients in our care and to continually advocate for the provision of excellent treatment. Although JC was an illegal worker in relationship to our state and federal governments, he should be viewed as a legal member of our community. Our moral responsibility is to assure that trauma care is available to all individuals and that a person's immigration status, the color of his skin, or the foundation of his religious beliefs does not diminish that responsibility.<sup>134</sup>

This is the ideal that a physician's chief goal should be to honor the individual relationship between themselves and their patient. To maintain this covenant, a physician must detach the "ethical" or "professional" issues from the "administrative," "political" or "economic" ones, writes this surgeon-administrator:

Indeed, for society, what seems on the surface as an economic issue based on access and payment of health care truly is an ethical problem based on social justice and societal responsibility.<sup>135</sup>

His statement balances duty to individual patients with duty to society by adopting positions of advocacy in both domains. This is a very appealing position, but one that

involves, paradoxically, a distancing of the clinician from his case, because there are already financially-based decisions affecting many aspects of the case.

Despite this idealization, physicians do occupy a complicated seat in between individual and public responsibilities, and in some scholars' findings, they are already participating in significant allocation decisions whether or not they think they are.<sup>136</sup> The contradiction is illustrated in two professional guidelines from the American College of Physicians. In 2004, a working group on managed care ethics wrote definitively that "Resource allocation policy should not be made at the bedside," while a 2012 guideline on treatment decisions encouraged physicians to make "parsimonious" choices, in order to minimize wasteful spending and maximize justice in the system at large.

All in all, I believe that physicians as a group should participate in the allocation of resources because not doing so would be to decline to sit at the table where these decisions are already being made. In general, physicians may bring to the process a perspective of moral cognition that is rooted in close proximity to suffering. This very bias has been grounds for criticism of physicians' ability to balance the needs of a patient with that of the overall good. However, another way of thinking about this "bias" is that physicians' values and reasoning are rooted deeply in their relationships of care.<sup>137</sup> While less "rationalistic," including this perspective may ensure that the vulnerable patient is being represented fairly at the table.<sup>138</sup>

Ultimately, a patient's own physician, such as the oncologist for A., should not make the actual decision any more than he should sit on the ethics committee when they are discussing a conflict in end of life care for one of his patients. It is a conflict of



interest, a violation of the patient's confidence, and of the consultants' independent authority. Furthermore, physicians *should* be emotionally entwined with their patients in a way that would be devastating if they should have to make a reasonable decision not to offer one a life-saving, but expensive and unreimbursed, treatment. It is possible that serving this dual role would make the least ethical physician (in terms of their allocation duties) the most attuned to their patient's needs, and thus the best advocate.<sup>139</sup>

Ultimately, the consensus of his colleagues, of his hospital, and of the profession at large—through professional guidelines that should be established—should unburden a physician from actively playing this dual role, even if it occupies her somewhat in her heart.<sup>140</sup>

#### IV. A POLICY FOR THE ALLOCATION OF COSTLY CHARITY CARE AT YALE-NEW HAVEN HOSPITAL

##### 1. STATEMENT OF NEED

Key missions of Yale-New Haven Hospital include providing health care services to all patients regardless of ability to pay, and to provide support, services, and access to care within the community at large.<sup>141</sup> This mission is consistent with one of the aims of the medical profession, which is to support the health of the public and to promote equity in healthcare. Some of these services (such as those specified by the Emergency Medical Treatment and Active Labor Act of 1986) are mandated by federal law and reimbursed in part by federal and state budget provisions, but much of these services have historically been awarded at the discretion of the Hospital through its charity funds—both donations made explicitly to cover care for those in need as well as resources that the hospital is morally and legally obligated to benefit the underserved and the community at large.

Because even a relatively resource-rich hospital such as Yale-New Haven does not have the financial ability to provide all available services to all patients in need, there is a need for 1) a clearly articulated set of principles of allocation of charity care within the Hospital and the community it serves, and 2) a transparent process to operationalize these principles into practice which governs charity care allocation decisions within the hospital.

##### 2. PRINCIPLES AND AIMS

- a. *Balancing Responsibilities.* The process of resource allocation aims to balance the hospital's obligations to individual patients with its obligation to the community in which it makes its home. Individual physicians share this balance of interests, though they are primarily advocates for their patients' best interests.
- b. *Requirement for True Scarcity.* The hospital must transparently and publicly report its charity funds in order to prove the conditions of scarcity that would justify any tragic outcomes associated with this policy. Physicians participating in the allocation process need to know the details of the hospital's charity finances, just as an oncologist needs to know survival rates to accurately inform patients about possible plans of care, or the ethics committee making a futility determination needs to know expected efficacy of treatments potentially being withheld, since these statistics are largely the moral justification for these serious actions.
- c. *Vulnerability and Prejudice.* Intolerance has no place in the mission of the hospital or the profession of medicine at large. Patients fitting these criteria (i.e. those without access to resources or insurance) must be recognized, above all else, to be a severely vulnerable and deserving group. Criteria such as race, gender, religious belief, and personal values will not qualify nor disqualify any patient from consideration (though an investigation of the patient's social history shall be performed in order to assess for their attachments and plans with respect to the community served by this hospital).
- d. *Federal Immigration Status is an Insufficient Criteria.* Immigration status is a poor proxy for membership in the community to which this hospital devotes its charity mission. Simply denying care to immigrants regardless of their membership in this

community would reinforce the state's interest in controlling the migration of persons, and not the goals of the medical profession which include supporting public and individual health. Immigration status should be inquired about in the process of identifying potential benefits, but it should not play a decisive role in allocation decisions, and under no circumstances should this information be used to enhance enforcement of immigration laws.

e. *Diversity of "Public Belonging."* There is no one definitive definition of "deserving," of "community member," or even of "resident" which will satisfy all cases brought under this policy. Instead, this policy will establish a case-based approach aimed to achieve consensus amongst diverse members of the hospital's constituency charged with determining the allocation of charity funds. By employing a thorough biopsychosocial formulation of the person's medical condition, social situation, existing and potential attachments, benefit to the public (i.e. in the case of infectious diseases), and consideration of the circumstances that brought the patient to the system, cases will be considered individually and comprehensively.

f. *Preventing Delays in Care.* If patients are already admitted to Yale-New Haven Hospital, providers should initiate treatment (i.e. with an initial course of chemotherapy, dialysis, or stabilizing treatment in advance of surgery) while this process is being carried out in order to minimize risks associated with waiting to deliberate. However, patients should not be transferred from other tertiary care hospitals to begin treatment under this policy without approval. Beginning treatment does not preclude discontinuation should the criteria of this policy be met.

- g. Valuing Spending over Saving.* The aims of charity are to help improve the world as we know it, not to save up for another world worth improving. The hospital should err drastically toward spending charity funds in order to benefit existing patients rather than theoretical future ones, even if it is possible in economic or philosophical theory to produce more benefit at a later date, since 1) these calculations depend on a not-insignificant degree of uncertainty in investment return, and 2) the moral claim of actual patients outweighs that of future ones.
- h. Patient Responsibilities.* All patients should partner with the hospital to accurately represent their ability to pay for services. Information used in this proceeding will not be provided to federal immigration authorities. However, a payment agreement will not be necessary for treatment initiation, should treatment be authorized.
- i. Physician participation.* The committee is required to have in its constituency at least one hospital physician-leader and one physician from each of up to two departments, preferably departments involved in the care of the patient (though not clinicians with direct care responsibilities). Furthermore, the primary physician responsible for the patient being considered for treatment is encouraged to join the proceedings as a consultant and patient advocate.
- j. Addressing Competing Requests.* Competing requests should be prioritized based on expected benefit, projected cost, and deservingness with respect to the public directly served by the hospital (i.e. long-time residents over those who immigrated for treatment). In absence of these criteria, competing requests may be prioritized based on a first-in-line method, or expected medical benefit.

- k. Treating Children and other Dependents.* Minors and other dependent and incapacitated persons should be treated by default. These conditions may not be used to potential recipients from one another based on such concepts as innate deservingness, societal worth, or utility.
- l. Nonabandonment.* Should proposed treatment be withheld, alternatives may be considered, and humane alternatives such as palliative care, itself no small expense, are always required if none of these should be decided upon.
- m. Against Policing the Population.* The hospital will always oppose regulation requiring reporting of any undocumented immigrants to municipal, state, or federal authorities for any punitive purpose. The hospital should not provide patient records, nor records of these proceedings, to immigration authorities for the purpose of enforcing immigration laws.
- n. International Transfer May be Reasonable.* It may be reasonable and parsimonious to offer international transfer home (or to a country of citizenship) where a roughly equivalent treatment is available, so long as a patient or his or her surrogate who request or will agree to this service. If no agreement is reached, the hospital will not transport patients out of the country against their will unless it is clearly established through the procedure outlined in this policy that the patient's sole attachments in this country are the hospital. If no approximately equivalent treatment is available in a home country, patients will receive care at YNHH.
- o. An Imperfect, Necessary Solution.* The problem of uninsured and underinsured immigrant persons and citizens without any insurance is not a Hospital problem at its

root, but rather a regional, national, and international problem; a political problem; and a problem of economics and financing. Nevertheless, the hospital must make clear its strategy in navigating these difficult yet inevitable microallocation decisions.

### 3. ALLOCATION PROCESS

- a. A consultation with a charity care subcommittee (defined below) is triggered either by initiating an **endorsement process** or crossing a **financial threshold**.
  - i. An **endorsement process** is reserved for patients in need of services such as non-emergent surgeries, transplantation, courses of chemotherapy, or stem cell transplantation. Two persons affiliated with the hospital, or one affiliate and one member of the public, must endorse a patient for consideration of charity fund support for either in-house or—in rare circumstances—outpatient services.
  - ii. The **financial threshold** is relevant for patients utilizing, or expecting to utilize ongoing services such as dialysis or long-term ventilator therapy who are unable to find suitable alternatives to hospital care. All care above \$100,000 may be scrutinized for appropriateness based on the criteria outlined above.
- b. A thorough **biopsychosocial assessment** is required for consideration, in order to minimize misapprehension of the facts, and to uncover a patient's attachments in the community. The assessment will be performed by the patient's primary clinician, by any mental health professional (social worker, psychologist, psychiatrist), or by a hospital ethics consultant. It should include a comprehensive history including the following elements: history of present illness, including

history before being admitted (or considered for admission) at Yale, and hospital course; social history, including family history back at least one full generation, with special attention to places lived and worked; educational and work history; and any other relevant data, even if these data are difficult to obtain with high reliability.

c. The charity care committee will be made up of members from hospital leadership, hospital ethics committee, and patient services or care coordination.

*i. Hospital representation.* The committee must include at least 4 representatives of different hospital constituencies, including: 1) Care coordination or finance (1 member); 2) clinician leadership (1 member); 3) clinicians, preferably of different departments (2 members).

*ii. Patient representation* (1 member). Because of these patients' vulnerability, it is critical that they have proper representation with minimal conflict of interests. This role may be filled preferably by a lawyer working pro bono or a member of a law school immigration law clinic; or, should the patient or her representative prefer, by an immigration rights advocate' or a community advocate or representative from community, city, or regional leadership.

*iii. Community Members* (0-2 members). Preferably representing constituencies not accounted for otherwise (e.g. racial, geographic, and/or socioeconomic diversity).

*iv. Physician Clinician(s).* Participation in the case presentation by a patient's primary clinician is encouraged, but not required. A physician serving any



direct clinical capacity for the patient in question may participate as an advocate, but should not be present for the committee's discussions or decisions.

v. *Family*: Family members may choose to address the committee directly, but they should observe the aforementioned boundaries outlined for clinicians.

vi. *Consensus*: Committees must reach a unanimous decision to withhold treatment based on the principles discussed above.

vii. *Appeal*: A patient, family member, or clinician may appeal the committee's decision to the hospital chief-of-staff or his representative.

viii. *Transfer*: At any point in the process, including after a decision has been made, a patient may request transfer to another institution, anywhere in the world. If transfer is accepted by the receiving institution, reasonable expenses will be shared by both institutions.

#### 4. OTHER REQUIREMENTS

a. *Records keeping*. The hospital will keep detailed records of all cases deliberated in this manner, as well as all charity expenditures during the active fiscal year (previous years are already on file with DHS) for use by committee members.

b. *Public Engagement*. The committee must prepare an annual report with financial statistics and the year's entire history of brief masked case histories for distribution to state and federal representatives serving this region of Connecticut, as well as the director of Connecticut's Department of Public Health and Medicaid/Title IXX

Programs. The purpose of this communication will be to attempt to bridge the profound gap between the actuality of these microallocation decisions as they exist in the hospital and as they are represented and insufficiently addressed at the level of state and federal reimbursement policy.

## V. CONCLUSION

### 1. AN IMPERFECT BUT NECESSARY SOLUTION

Ultimately, a charity care allocation policy is not an inspiring moral document in the way that the positions of duty articulated by those such as Pellegrino and Thomasma are. *“The existence of a genuine medical need constitutes a moral claim on those equipped to help”* inspires; the notion that some people may die because the hospital (and we as a public) can’t afford to pay for effective, otherwise available treatment, is utterly depressing. It is tempting to focus instead on advocacy in the public domain, or in the community at large, the way that some Yale physicians have.<sup>142</sup> Why not drop all this ratiocination and dedicate oneself to increase the resources on hand by lobbying in Congress, or addressing other barriers to care?<sup>143</sup>

The likely truth—admittedly lacking hard evidence to prove that this is the case—is that these decisions are being and will continue to need to be made, but that they are made in quiet.<sup>144</sup> Calabresi (1978) has argued that this is so because revealing these deliberations to the public gaze would be morally intolerable.<sup>145</sup> This feeling was evident in the response to the public allocation of renal dialysis performed by the so-called “God Squad” in the earliest phase of these treatments’ existence.<sup>146</sup> Even though the committee included non-clinicians such as “a lawyer, a minister and a homemaker” in its ranks,<sup>147</sup> its use of questionable notions of social justice such as “good citizenship” was seen as an affront to medicine’s ethos, and the value that the public placed on an impartial healthcare profession.<sup>148</sup> No consensus, this historical situation would seem to signify, could

reasonably stand for the consent of each and every different individual to submit to the squad's formulae.<sup>149</sup>

Without returning to the social judgements of the God squad, it is possible to adopt a process such as the one I have articulated which will 1) promote transparency of resource availability, in order to justify its serious aim; 2) specify and operationalize the concept of justice as equity, in order to promote respect for all persons, and especially for those with few means and other vulnerable groups; and 3) allow these decisions to be made in view of the profession and of the public at large, in order to promote an honest sense of the problem. These aims, I believe, are reasonably satisfied by the process set out in Chapter IV. But they are not satisfied perfectly, and the process' flaws are critical to foresee lest this work be used—unintentionally or otherwise—to exacerbate inequity and justify bias against noncitizens requiring expensive hospital-based care.

#### *Major Flaws of this Solution*

In general, the policy presented here makes it very difficult by default to decline to treat anyone based on a simple notion of membership in the community served by the public, even the global community at large. The discussion in chapter III regarding the insufficiencies of various legal or administrative ways to define belonging is intended to lead readers to the conclusion that there are many ways to belong, or many ways for a community to justify wrapping its arms around a person in desperate need—independent of their citizenship status, local tax contributions, employment history, and so on. But as the shortage of charity dollars decreases (as it is tending to do at Yale and in many places,

based on the policy changes described late in Chapter II, and the data illustrated in Appendix I), there will be pressure to adjudicate more and more competing moral demands on a limited set of resources. This will lead to two major flaws inherent in this practical, hospital-based solution I have proposed.

One major problem surrounds the complexity inherent in the notion of citizenship, and the pragmatic goals of a hospital policy— major points in tension within this work. To adjudicate between competing demands—a situation likely to be more prevalent as funds run out (see Appendix I, as well as Chapter II)—a committee may need to use aspects of the comprehensive biopsychosocial formulation presented in this policy (see Chapter IV, item 3b), since it is unlikely that these difficult decisions will be able to be made entirely on expected medical benefits or other ways of measuring the non-social value of treatment. These psychosocial data were intended to be generated to protect these persons from prejudice and misunderstanding; however, they could become tools of care denial. Indeed, this would even be more just, based on the reasoning in Chapter III, than a simple determination of legal citizenship status or accounting for taxes contributed to the locality. While it would be grossly unethical to apply such criteria as race, gender, or socioeconomic status in an allocation scheme,<sup>150</sup> some measure of citizenship—not legal citizenship, but some way to formulate real citizenship—may be warranted as a marker of who belongs to the public which shares some basic responsibility for its members well-being. Can a complex notion of citizenship be reasonably formulated in this process? If it does, will it satisfy providers' sense of moral distress at the need to make these difficult decisions? Moreover, who would agree to

these assessments if they know that they would be used to deny them care? Would a person's consent be valid if they were told that they would only be considered for treatment if they spell out their life history? Would psychiatrists and other psychosocial professionals generating these formulations be willing to do so, for the express purpose of allocation?<sup>151</sup>

### *Confusing the Locus of Responsibility*

A second flaw is that this work attempts to strike a pragmatic balance between the moral and economic frames of reference, as well as between the individual and public responsibilities that physicians, hospitals, and others in scenario all share. It is true that these clinical cases are too easily seen as purely economic or legal disagreements, and not as moral dilemmas (see pp. 10-12). By taking for granted the conditions of economic scarcity which both create the need for and justify the process of allocation, this troubling economic frame has been justified somewhat. The key danger is that a fair policy will obviate the need to address the root problem here, of economic injustice.

Similarly, the hospital policy solution mistakes an international problem for one that can be addressed by a hospital alone. But, working at the level of the hospital may allow for the kind of nuanced moral reasoning that is simply impossible to perform at the level of our national political debates. The kind of nuance that regards the circumstances of a person's immigration as important without fitting these circumstances into rigid criteria for or against inclusion in a public insurance plan, as much a barrier to access and fairness as the durational requirements of Medicaid have become.

These significant problems are probably chief amongst the proposal's flaws.

There are several checkpoints in the system that allow reasonable members of the hospital constituency to affect the process. For example, whoever writes the psychosocial formulation must agree to do so in good professional conscience; consensus must be reached unanimously for care to be denied; and this process can not take the place of comprehensive care coordination to find other resources in this country and beyond to provide the patient with appropriate care.

## 2. WHO SHOULD PAY?

The foregoing flaws of this policy's limited scope are accompanied by one major problem: who might bear the costs of this treatment, or even more importantly, who *should* pay for these individuals' care.

Without a sustainable source of funding from the federal governments or from private donors, the situation of scarcity will only worsen, and there will be more social pressure to exclude noncitizens from healthcare, when everyone is suffering. This may further threaten the ability of a hospital to embody the moral norms of the profession of medicine rather than of the society at large.

The most direct solution would be to promote federal and state policy that rewards hospitals for providing charity care. This would be politically preferable compared with allocating public benefits to noncitizens, because it would place the moral compass in the hands of the hospital itself, who can then define what it means by belonging to the public it serves.

However, in absence of these funds—or if the funds were secured but applied inconsistently throughout localities or between states, leaving some noncitizens more vulnerable to political conscience than others—a mechanism could be used to promote allocation between localities within a regional or national network. The comparison to the mechanism employed by UNOS is useful here. As a public, non-governmental body, UNOS has a national mandate, a broad consensus, and yet some degree of insulation from national politics. It has developed a formula to adjudicate between competing demands based on time waiting, medical need, and expected utility of the therapy, but also uses psychosocial criteria such as ability to cope with and care for the transplant, as well as citizenship status itself, in the name of the greater good.<sup>152</sup>

A UNOS-like system of information sharing that preserves the local relevance of these problems while promoting a centralized mechanism to connect persons requiring various expensive treatments could help to account for hospitals' charity care expenditures and to coordinate for care when a particular locality is unable to meet all its constituents' needs. Free medication programs currently offered by pharmaceutical companies could be coordinated through this gateway, along with free treatments associated with research protocols and with charitable care.<sup>153</sup> This solution would not provide sufficient funding for this care—that would have to come from other federal and state legislation, from hospitals' own duties to care for the indigent in their community, and from charitable donations from individuals and from corporations—but it would provide a way to reach more people and to account for the actual needs of this population. By accounting for charitable donations from a variety of constituencies in



healthcare the burden of free care could be spread widely not just geographically but in the healthcare marketplace.

*Truth or Consequences: Neither Justifies Inaction*

It is possible that firm limits at the level of the hospital may actually change the public debate substantially. Currently, it is easy for public policy to assume that a hospital will take responsibility for these patients based on the moral duty of the profession. The idea that limits can fairly be set may lead, at some point, to a tragic consequence, but it may also start a conversation about how to avoid further tragedy that could not exist whilst this problem is obscured. My hope is that loss will not be a gross injustice but one that has resulted from a reasonable process that, and furthermore, that this loss may inspire people to see this issue as one that presents a moral claim to all of us in the broader community, to address this issue by taking the notion of charity seriously, and seeing to it that limitations are minimized, and all types of deserving persons are cared for.

However, if this optimism is not justified in reality, this clear, rational process will provide members of the hospital constituency a chance to act collectively in these matters of injustice. Even without funding support from the federal government, the notion of charity is too deeply grounded in medicine and in society at large—even if it is based in a strong ambivalence—for no one to at least attempt to fill these gaps through charitable donation, or collaboration between providers and institutions in the way I have suggested in my analogy to the UNOS system. Bringing these problems to light may indeed cause

positive or negative consequences in public policy, but that sphere is less likely to reflect the kind of nuanced, social solution to the problem that may be reached locally, however in tension these efforts are with federal policy and immigration law.

APPENDIX I. CONNECTICUT FREE BED FUNDS

YNHH	Free Bed Funds	Expenditures	Total CT expend	of total CT	DSH Payments	Yale Exp <sup>^</sup>	State avg. <sup>^</sup>
FY 2001	36,676,957	680,210	3,319,782	20.5%	28,006,587	1.9%	2.8%
FY 2002	23,524,093	571,215	5,279,746	10.8%	31,009,553	2.4%	5.5%
FY 2003*	25,897,318	541,550	7,900,494	6.9%	23,805,540	2.1%	7.8%
FY 2004	25,977,098	2,622,182	13,043,185	20.1%	24,629,764	10.1%	11.1%
FY 2005	25,977,098	4,721,870	10,933,759	43.2%	17,207,806	18.2%	9.4%
FY 2006	20,187,870	6,893,000	13,492,854	51.1%	26,248,183	34.1%	8.2%
FY 2007	—	—	—	—	—	—	—
FY 2008	16,208,569	3,901,514	—	—	—	24.1%	—
FY 2009	11,321,005	813,615	—	—	—	7.2%	—
FY 2010	9,993,532	834,500	—	—	—	8.4%	—

\* Year of Quinton White controversy and AG Blumenthal's charity fund misuse lawsuit was filed in 2003.

<sup>^</sup> Hartford Hospital, Connecticut's second largest charity care provider, which combined with Yale provide more than 70% of the average annual charity care, spends, by comparison, between 2.5 and 10.7% of its funds on a yearly basis, without the upward trend seen in Yale's figures.

(Sources: Connecticut Health Policy Project; Office of Health Care Access, Connecticut Department of Public Health)

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- (7) For data from Arizona, see Scheer, N. J. 2003. Keeping the Promise: Financing EMTALA's Guarantee of Emergency Medical Care for Undocumented Aliens in Arizona. 35 *Ariz. St. L.J.* 1413: 1419f; as well as Petersen, S. R. 2005. Patients Crossing Our Borders: An Ethical or Economic Conundrum? *Journal of Trauma* 59: 1037-1041. For Florida, see Siddharthan, K., Alal Sundaram, S. 1993. Undocumented Aliens and Uncompensated Care: Whose Responsibility? *American Journal of Public Health* 83: 410-412.

(8) This split between the “nationalist” perspective and “humanist” one forms the basis for a moderate argument in Dwyer, J. 2004. *Illegal Immigrants, Health Care and Social Responsibility*. Hastings Center Report 34: 34-41.

(9) Deuteronomy 10:19, New American Standard Bible.

(10) “Justice.” In Beauchamp, T. L., Childress, J. 2001. *Principles of Biomedical Ethics*, 5th Edition. New York: Oxford University Press, pp. 226-229.

(11) Identifying information, including medical details, have been masked to protect the privacy of the patient and family. However, clinicians and hospital staff may be identifiable because of the fact that this was indeed a pediatric oncology case at my training hospital. One reason why I have chosen to tell this story without obscuring these aspects of the case was that it would lose the power lent by concrete details, and by my particular involvement in it, should I make it more of an abstract philosophical example. Furthermore, I believe strongly that no one person is liable for A.’s delay in getting treatment. The problem was a lack of preparation for the situation, and that is why a clear procedure needs to be in place to help guide these decisions. This appears to be the norm amongst all the hospitals with whom we have conferred about this subject (Mercurio, M. 2012, Feb 1. Personal Communication).

(12) Event-free survival in Burkitt’s lymphoma patients with CNS involvement is 60% at five years, compared with 81% for CNS-negative tumors. Salzburg, J., Burkhardt, B., Zimmermann, M., et al. 2007. Prevalence, clinical pattern, and outcome of CNS involvement in childhood and adolescent non-Hodgkin’s lymphoma differ by non-Hodgkin’s lymphoma subtype: a Berlin-Frankfurt-Munster Group Report. *Journal of Clinical Oncology* 25, pp. 3915-22; and there is a 30% response rate to bone marrow transplant after disease recurrence. Gross, T. G., Hale, G. A., He, W., et al. 2010. Hematopoietic stem cell transplantation for refractory or recurrent non-Hodgkin lymphoma in children and adolescents. *Biology of Blood Marrow Transplant* 16: 223-30.

(13) What is, or who are, “the hospital?” I take it to be a diverse moral community, a business community, a social community, and a professional community, with its own distinct culture and ethos compared with the community, but with many connections and responsibilities to the community at large.

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- (28) In each case, a powerful social force was a “third party” which proved to be somewhat conflictual for the doctor patient relationship—the notion of science and its conflicts around research and progress, and then the 3rd party payer and the public’s money.
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- (31) Starr, P. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- (32) AMA (1847), p. 98.
- (33) *Ibid.*, pp. 105-106.
- (34) *Ibid.*, p. 104. (“A wealthy physician should not give advice gratis to the affluent; because his doing so is an injury to his professional brethren. The office of a physician can never be supported as an exclusively beneficent one; and it is defrauding, in some degree, the common funds for its support, when fees are dispensed with, which might justly be claimed.”)
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- (42) Snyder, L., and the ACP Ethics, Professionalism, and Human Rights Committee. 2012. “Financial Arrangements.” In *American College of Physicians Ethics Manual*, 6th Edition. *Annals of Internal Medicine* 156: 73-104.
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- (44) Quoted in AMA Code, 9.065. Note that there is no no real mention of immigrant status, or any other political controversies that characterize problems in caring for the most politically, and often medically, vulnerable persons.

(45) Starr (1982), p. 153.

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(51) *Ibid.*, p. 257.

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(53) *Ibid.*

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(55) Burrow (2002), p. 257-8.

(56) *Ibid.*, p. 258. Now, community advocates speak out for the rights of immigrants to receive charity care, but they remark that many residents believe these persons receive privilege over un- or under-insured New Haven Residents, and feel much less sympathetic (Rev. Bonita Grubbs, Symposium on "Access to Hospital Care for Foreign Patients in the U.S." Yale Medical School Program for Biomedical Ethics, September 22, 2011).

(57) *Ibid.*, p. 3.

(58) *Ibid.*, p. 2.

(59) *Ibid.*, p. 5.

(60) *Ibid.*, p. 253.

(61) Personal communication with Ms. Ginny Szondy, Care Coordinator for Pediatric Oncology, Yale-New Haven Children's Hospital.

(62) Lagnado, L. March 13, 2003. Twenty years and still paying—Jeanette White Is Long Dead But Her Hospital Bill Lives On; Interest Charges, Legal Fees. *Wall St J.*, at B1.

(63) Cohen, B. 2006. The Controversy Over Hospital Charges to the Uninsured—No Villains, No Heroes. *51 Vill. L. Rev.*: 95-151.

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(65) Carreyrou, J., Martinez, B. December 18, 2008. Grassley Targets Nonprofit Hospitals on Charity Care. Wall Street Journal, page A5; Kane, N. M. 2006-07. Tax-Exempt Hospitals: What Is Their Charitable Responsibility and How Should It Be Defined and Reported. 51 St. Louis U. L.J. 459, and Folkerts, L. L. 2009. Do Nonprofit Hospitals Provide Community Benefit? A Critique of the Standards for Proving Deservedness of Federal Tax Exemptions. The Journal of Corporation Law 34: 612-640.

(66) Folkerts (2009), p. 615.

(67) Loue, S. 1992. Access to health care and the undocumented alien. Journal of Legal Medicine, 13: 281-286.

(68) 42 U.S.C. § 291c(e) (1988), quoted in Loue (1992), p. 281 fn70: “[T]he Surgeon General . . . shall by general regulation prescribe . . . (f) That the state plan shall provide for adequate hospital facilities for . . . persons unable to pay therefor. Such regulation may require that before approval of any application for a hospital or addition to a hospital is recommended by a state agency, assurance shall be received by the State from the applicant that . . . (2) there will be made available in each such hospital or addition to a hospital a reasonable volume of hospital services to persons unable to pay therefor, but an exception shall be made if such requirement is not feasible from a financial standpoint.”

(69) Guerrero v. Copper Queen. 1975. Hospital Arizona Supreme Court 112 Ariz. 104 (1975) 537 P.2d 1329 (Discussed in Hoffman (2006), p. 241).

(70) Emergency Medical Treatment and Active Labor Act of 1986, 42 U.S.C. § 1395dd (2000); Krugh, T. D. 1991. The Federal Anti-Dumping Act after five years: a critical analysis of medical COBRA. Leg Med: 287-335.

(71) Quoted in Sheer (2003).

(72) Ibid, p. 1416-17.

(73) EMTALA (1986).

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(75) Diekema, D. S. 1995. Unwinding the COBRA: New perspectives on EMTALA. Pediatric Emergency Care 11: 243-248.

(76) Ibid., p. 243. These distinctions will reemerge in a different form when considering the moral claim of proximity (see Chapter III).

(77) This financial conflict hardly began with EMTALA. In her review of judicial precedents to EMTALA, Hoffman (2006) also cites a court case from 1982 which was filed not with a patient as plaintiff but by a local private hospital which sued a county hospital for reimbursement when the county hospital refused to receive the transfer of a patient.

(78) Immigrant Responsibility and Control Act of 1986. See Sheer (2003), p. 1422.

(79) The other source of funding has largely been through specific authorization for hospitals to receive reimbursement not for individual patients seen but in proportion to the proportion of unauthorized immigrants in the community. In 1997, Congress authorized \$25 million a year for 1998-2001 to be distributed amongst the twelve states with the largest populations of unauthorized immigrants, and in 2003, \$250 million was provided annually for 2005-2008. individuals” (Section 1011 of the Medicare Modernization Act (P.L. 108-173).

A final source of money is funds specifically targets by the Refugee Act of 1980 for healthcare costs for applicants for the status of political asylum, originally for the duration of three years after immigration but subsequently shortened to four months in January 1990). (Siddharthan and Alalasundaram (1993), p. 411.) Hospitals and municipalities have sued the federal government many times over unreimbursed care thought to be a result of non-enforcement of immigration laws, as reported in Fallek (1996-97).

(80) 104th Congress (1995-1996). H.R. 3734. Park, S. 2004. Substantial Barriers to Health Care for Illegal Immigrants. 18 *Geo. Immigr. L.J.*: 569.

(81) Rector, R. November 23, 2009. Providing Health Care for Illegal Immigrants: Understanding the House Health Care Bill. Heritage Foundation Backgrounder 2345. [http://www.heritage.org/research/reports/2009/11/providing-health-care-for-illegal-immigrants-understanding-the-house-health-care-bill#\\_ftn1](http://www.heritage.org/research/reports/2009/11/providing-health-care-for-illegal-immigrants-understanding-the-house-health-care-bill#_ftn1) (accessed 11 January 2012).

(82) Luo (1992), p. 288; see also Donohue, D. A. 1998. 72 *St. John's L. Rev.* 72: 451-484; Siskin, A., Lunder, E. K. 2009. Treatment of Noncitizens in H.R. 3200. Congressional Research Service, pp. 6-8.

(83) The key notion that these other budget allocations are in danger in the wake of PPACA comes from Burt, R. A. Personal Communication, 13 February 2012. For an overview of the budgetary wrangling affecting immigrant coverage in Massachusetts after its universal health reform and during the financial crisis, see Tavis, A. C. 2010. Healthcare for All: Ensuring States Comply with the Equal Protection Rights of Legal Immigrants. *B.C. L. Rev* 51: pp. 1627-1629.

(84) California Health and Safety Code, Part I, Division 1, Chapter 1.3, Section 130 (a)-(d).

(85) Haberman, M. November 28, 2011. Newt Gingrich's embrace of Pete Wilsonism. <http://www.politico.com/news/stories/1111/69211.html> (accessed 11 January 2012).

(86) Ziv, T. A., Lo, B. 1995. Denial of care to illegal immigrants. *New Eng J Med* 332: 1095–109.

(87) *Ibid.*, p. 1095.

(88) Arizona S.B. 1070, Alabama H.B. 56, and Georgia H.B. 87.

(89) In the 1960's, about 20% survived long after treatment with high-dose alkylating agents (Ziegler, J. L. 1981. Burkitt's Lymphoma. *New England Journal of Medicine* 305: 735-45). Now these numbers are 80-90% with earlier stage disease and 60% after recurrence of CNS-involved disease (Salzburg, J., Burkhardt B, Zimmermann M, et al. 2007. Prevalence, clinical pattern, and outcome of CNS involvement in childhood and adolescent non-Hodgkin's lymphoma differ by non-Hodgkin's lymphoma subtype: a Berlin-Frankfurt-Munster Group Report. *Journal of Clinical Oncology.* 25: 3915-22).

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(91) Incidence and survival abroad: Hartge P, Wang SS, Bracci PM, et al. 2006. Non-Hodgkin lymphoma. In: Schottenfeld D, Fraumeni JF Jr, eds. *Cancer Epidemiology and Prevention*. New York: Oxford University Press; 2006: 898- 918; Ogwang, M. D., Bhatia, K., Biggar, R. J., Mbulaiteye, S. M. 2008. Incidence and geographic distribution of endemic Burkitt lymphoma in northern Uganda revisited. *International Journal of Cancer* 123: 2658–2663. For comparison to U.S. incidence, Mbulaiteye, S. M., Biggar, R. J., Bhatia, K. 2009. Sporadic childhood Burkitt lymphoma incidence in the United States during 1992–2005. *Pediatric Blood & Cancer*, 53: 366–370.

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(93) Pellegrino, E. and Thomasma, D. C. 1995. *Medicine as a moral community*. In: Pellegrino ED, Thomasma DC. *The virtues in medical practice*. New York: Oxford University Press, p. 36 (Quoted in Ziv, T. L. and Lo, B. 1995. *New England Journal of Medicine* 332, p. 1097).

(94) This comparison was suggested to me by Stephen Bezruchka, Seattle Pediatric Bioethics Conference, July 2011.

(95) This clear example of the potential power and limitations of wealth comes from Mark Mercurio (personal communication, 1 February 2012). Hall (1997) makes a rough calculation to show how U.S. wealth being insufficient to cover all available services for all people (Hall, M. A. 1997. *Making Medical Spending Decisions: The Law, Ethics, and Economics of Rationing Mechanisms*. New York: Oxford University Press, pp. 3-5 and fn 1, p. 11.)

(96) This is only one way to break down the public into groups, and, as I hope to show, a poor one at that.

(97) There is even evidence that medications have been priced not based on supply and demand, but on what "inherent value" they have in extending life as measured by quality-adjusted life year cost, employing a cost-effectiveness measure not for the overall efficiency of the system but in order to justify a staggering price point based on our collective attitude about extending life. See Brock, D. W. 2006. How Much Is More Life Worth? *Hastings Center Report* 36, pp. 17-19.

(98) Daniels, N. 1979. Daniels (2001).

(99) For example, UNOS factors a range of norms into its distribution mechanism, including the norm thought of as urgency of need.

(100) Morrison, R. S., Dietrich, J., Ladwig, S., Quill, T., Sacco, J., Tangeman, J., & Meier, D. E. (2011). Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries. *Health Affairs*, 30(3), 454–463. doi:10.1377/hlthaff.2010.0929

(101) "When Zeus was informed that Asclepius, the founder of medicine, was "bribed with gold" to bring the dead back to life, Zeus struck him dead with a thunderbolt." Kane, N. M. 2006-07. *Tax Exempt Hospitals*. 51 *St. Louis U. L.J.*: p. 459.

(102) Lock, M. 2001. *Twice Dead: Organ Transplants and the Reinvention of Death*. University of California Press.

(103) Daniels and Sabin (2002) make a claim for reasonableness as a key feature of a just allocation scheme that lacks the systematic quality of a true theory of justice. (Daniels, N., Sabin, J. E. 2002. *Setting Limits Fairly: Can We Learn to Share Medical Resources?* New York: Oxford University Press (Especially Ch. 4, “Accountability for Reasonableness”).

(104) See Ch. II of the present work, including the brief description on New Haven’s 1833 cholera outbreak.

(105) Daniels, N. 2008. *Just Health: Meeting Health Needs Fairly*. New York: Cambridge University Press, pp. 29-102. This idea clarified for me by Mark Mercurio (Personal Communication, February 1, 2012).

(106) A Rawlsian might argue that the policy should be designed under the veil of ignorance, by members of the community unaware of what roles they occupy as stakeholders in the process. However, this is impossible in practice, as our roles as students, physicians, social workers, administrators, and so on are well defined and known beforehand.

(107) Daniels, N., Sabin, J. E. 2002. “Accountability for Reasonableness” in *Setting Limits Fairly: Can We Learn to Share Medical Resources?* New York: Oxford University Press.

(108) Mark Mercurio, February 1. Personal communication, February 1, 2012.

(109) Dwyer (2004).

(110) (Park (2004), p. 570, Fallek (1997); Kenworthy, N. 2012. *The Psychiatric Hospital as Safe House? Strange Asylum for Undocumented Immigrants with Mental Health Needs*. Access Denied. <http://accessdeniedblog.wordpress.com/2012/01/04/the-psychiatric-hospital-as-safe-house-strange-asylum-for-undocumented-immigrants-with-mental-health-needs-nora-kenworthy/> (accessed 2 February 2012).

(111) Kaldjian, L. 2011. Talk from symposium on “Access to Hospital Care for Foreign Patients in the U.S.” Yale Medical School Program for Biomedical Ethics, September 22, 2011). Rawls: “It does not follow from the fact that boundaries are historically arbitrary that their role in the Law of Peoples can not be justified. On the contrary, to fix on their arbitrariness is to fix on the wrong thing. In the absence of a world state, there must be boundaries of some kind, which when viewed in isolation will seem arbitrary, and depend to some degree on historical circumstances.” Rawls, J. 1999. *The Law of Peoples*. Cambridge, Mass.: Harvard University Press, p. 39; Quoted in Dwyer (2004).

(112) This argument was first used in Blum, R. Seattle Pediatric Bioethics Conference, July 2011.

(113) Dwyer (2004).

(114) Dwyer (2004).

(115) <http://southeastfarmpress.com/orchard-crops/alabamageorgia-laws-impact-florida-labor>

(116) <http://southeastfarmpress.com/vegetables/farm-labor-laws-crippling-carolina-fruit-vegetable-operations>. Other industries affected include healthcare (<http://kuow.org/program.php?id=25541>). Also <http://newamericamedia.org/2012/01/future-of-anti-immigrant-state-laws-on-the-line-for-2012.php>.

- (117) \$5.5 billion agriculture industry in Alabama alone. <http://southeastfarmpress.com/orchard-crops/alabamageorgia-laws-impact-florida-labor>
- (118) Dwyer (2004), p. 34.
- (119) Blumenthal, D. 2006. Employer-Sponsored Health Insurance in the United States — Origins and Implications *N Engl J Med* 355: 82-88.
- (120) Chang, C. 2005. Health Care for Undocumented Immigrant Children: Special Members of an Underclass; 83 *Wash. U. L. Q.*: 1271.
- (121) Blacksher E. 2008. Children's health inequalities: Ethical and political challenges to seeking social justice. *Hastings Center Report* 38: 28-35.
- (122) Importance of proximity as a guiding principle comes from Mark Mercurio (Personal Communication, 1 February 2011).
- (123) Loue (2002), p. 285.
- (124) Donohue DA. 1998. Penalizing the Poor: Durational Residency Requirements for Welfare Benefits. 72 *St. John's Law Review*: 451; Siddharthan and Alalasundaram (1993), p. 411.
- (125) Levinas, E. 1969. *Totality and Infinity: An Essay on Exteriority*. Trans. by Alphonso Lingis. Pittsburgh: Duquesne University Press, 307 pp.
- (126) Donohue DA. 1998. Penalizing the Poor: Durational Residency Requirements for Welfare Benefits. 72 *St. John's Law Review*: 451.
- (127) Nijhawan, Michael. 2005. Deportability, Medicine, and the Law. *Anthropology & Medicine* 12 (3):271-285. Petersen (2005) finds that deportation was the most reasonable and humane discharge: "The best concentration of resources (clinical, financial, and social) was in Guatemala, where JC had the social support of his family and the medical treatment necessary for his recovery." See also Dwyer, J. 2009. When The Discharge Plan is Deportation: Hospitals, Immigrants, and Social Responsibility. *American Journal of Bioethics* 23: ii-iv. as well as news such as Diamond, M. 2012. Quadriplegic Undocumented Immigrant Dies In Mexico After Being Deported From His Hospital Bed. *Think Progress Blog*, January 6, 2012. Available at <http://thinkprogress.org/justice/2012/01/06/398022/quadriplegic-undocumented-immigrant-dies-in-mexico-after-being-deported-from-his-hospital-bed/?mobile=nc> (accessed 10 February 2012); which illustrates how these deportation procedures may lack oversight and may neglect patients such as Quelino Jimenez, a 21-year-old man who became quadriplegic after a construction accident and who died in a "unequipped" facility in Mexico, and who was deported by a Chicago hospital.
- (128) McKie, J., Richardson, J. 2003. The Rule of Rescue. *Social Science & Medicine* 56: 2407-2419; Daniels, N. 2012. Reasonable Disagreement about Identified vs. Statistical Victims *Hastings Center Report* 42: 35-45.
- (129) Leibenluft, J. February 21, 2003. Hospital sued for \$37m bed fund. *Yale Daily News*. See the complaint itself, *Blumenthal v. Yale-New Haven Hospital, Inc.* Hartford Superior Court, 25 March 2003. [http://www.ct.gov/ag/lib/ag/press\\_releases/2003/health/ynh.pdf](http://www.ct.gov/ag/lib/ag/press_releases/2003/health/ynh.pdf) (accessed 14 Feb 2012).

(130) CT Health Policy Project Briefs on “CT Hospital Free Bed Funds,” 2002-06 and “Connecticut hospital funds for the uninsured, 2006,” available at <http://www.cthealthpolicy.org/pubs/default.htm> (accessed 26 January 2012). Also reports at OHCA, CT DHS. Notably, in the bill resulting from his 2007 investigation, Sen. Grassley aimed to have nonprofit hospitals spend 5% of their revenue on charity care.

(131) CT Health Policy Project Briefs on “CT Hospital Free Bed Funds — FY 2001” Policymakers Issue Briefs No. 6, Feb 2003. Available at [www.cthealthpolicy.org/briefs/issue\\_6\\_hosp\\_table.htm](http://www.cthealthpolicy.org/briefs/issue_6_hosp_table.htm) (Accessed 26 January, 2012).

(132) Kagan, S. 1989. *The Limits of Morality*. Oxford: Clarendon Press, p. 1-2, 402-3; quoted in Beauchamp & Childress (2001), p. 214.

(133) “A Yale Physician’s Oath” from 2004 Commencement Ceremony Program. <http://info.med.yale.edu/education/osa/milestones/commencement04/program.pdf> (Accessed 16 January 2012). Note the difference between this oath and the ethics of the AMA going back to 1847, and between the medical school’s graduating ethos and the ambivalent attitude towards charity that the Yale medical community has manifested throughout its history (see Chapter II).

(134) Petersen (2005)

(135) Ibid.

(136) Ubel (1999)

(137) Gilligan, C. 1993. *Psychological Theory and Women's Development*. Cambridge: Harvard Univ. Press, 216 pp.

(138) This characterization is highly contestable. Veatch (2001) suggestively reports how it seems that physicians can harbor secret desires to undermine their patients’ best interests: “The United Network for Organ Sharing (UNOS) Ethics Committee, when it was debating the principles for allocating organs, discovered that the physicians were the defenders of utility maximization and the nonphysicians were defenders of equity. Only by a law requiring both does society get protected from physicians whose natural inclination is to be utility maximizers.”

(139) Veatch (2001).

(140) I became convinced of the value of unburdening in conversation with Mark Mercurio (Personal Communication, 1 February 2011).

(141) “Our Mission.” Yale-New Haven Hospital Online. Available at [www.ynhh.org/about-us/mission.aspx](http://www.ynhh.org/about-us/mission.aspx) (accessed 31 January 2012).

(142) New Haven Register. August 17, 2011. Project Access marks its first year. <http://www.nhregister.com/articles/2011/08/17/opinion/doc4e4addf9497d9975134923.txt> (Accessed 3 February 2012).

(143) This is a question I ask repeatedly of myself personally, and the direct action resulting in this case was strong evidence for why this discourse is important for the patients sake, and also in augmenting the model of the physician-patient relationship with a real sense of limits, and with the responsibilities owed to the public, the system, the profession, and various other notions of the “third” party, which can be obliterated when the physician-patient bond is the only one acknowledged. In psychotherapy, this is a real danger to developmental progress in the dyad (see Searles, H. 1979. The “Dedicated Physician” in the Field of Psychotherapy and Psychoanalysis. In *Countertransference and Related Subjects: Selected Papers*. New York: International Universities Press, pp. 71-88; and Muller, J. P. 2007. A View from Riggs: Treatment Resistance and Patient Authority IV: Why the Pair Needs the Third. *J Am Acad Psychoanal Dyn Psychiatry* 35: 21-41).

Furthermore, bioethics began as and continues to exist primarily as a field of advocacy, even though some argue that it can itself be conflicted with regard to medicine’s powerful forces of progress in the domains of science and finance (see Elliott, C. 2002. Throwing a bone to the watchdog: Conflicts of interest and bioethics. *Hastings Center Report* 3: 9 and Lessons in Conflict of Interest: The Construction of the Martyrdom of David Healy and The Dilemma of Bioethics. *The American Journal of Bioethics* 5 :W3; or that the field has too little academic coherence to be truly unique viewpoint; see Fox, R. C., Swazey, J. P. 2008. *Observing Bioethics*. New York: Oxford Univ. Press, 400 pp.) Nevertheless, I believe that bioethics, and more specifically, the ethics of the medical profession, has important power to frame this conversation in a mixture of medical and social norms. Moreover, it has a clinical power—it has bought its seat at the table, in many circumstances—to effect change from within the institutions, rather than within academic journals or the press alone. This is the value of my moderate argument as well as of clinical ethics as a whole: it helps arrive at consensus fueled by moral norms.

(144) My own personal experience as a patient, student, and in more than three years of ethics consultation on two committees is that judgments about deservingness, social utility, and good citizenship are not uncommon in clinical dilemmas, including but not limited to pre-listing transplantation assessment and intensive care resource allocation.

(145) Calabresi, G. 1978. *Tragic Choices*. New York: W. W. Norton, 256 pp. This crucial reference, and the “God squad” discussion, come directly from suggestions made by Burt, R. Personal Communication, 14 February 2012.

(146) Jonson, A. R. 2007. The God Squad and the Origins of Transplantation Ethics and Policy. *The Journal of Law, Medicine & Ethics* 35: 238-240; Schneiderman, L. J., Jecker, N. S. 1996. Should a criminal receive a heart transplant? Medical Justice vs. Societal Justice. *Theoretical Medicine* 17: 33-44.

(147) Lerner, B. H. 2006. Choosing a ‘God Squad,’ When the Mind Has Faded. *New York Times*. August 28, 2006.

(148) Schniederman and Jecker (1996).

(149) For more on consent to allocation decisions, see Hall, M. A. 1997. “Informed Consent to Rationing.” In *Making Medical Spending Decisions: The Law, Ethics, and Economics of Rationing Mechanisms*. New York: Oxford University Press, pp. 193-224.

(150) Criteria such as age and cognitive capacity may be less obvious to sort through.

(151) An alternative to using any social criteria would seem to be to exclude all social criteria in those making an allocation decision, as if constituents of this process can possibly reside behind a veil of ignorance. (See Freeman, S. 2012. "Original Position." In *The Stanford Encyclopedia of Philosophy*, Spring 2012 Edition. Edward N. Zalta, Ed. Available at <http://plato.stanford.edu/archives/spr2012/entries/original-position/> (accessed February 19, 2012); and Rawls, J. 1999 [1971]. *A Theory of Justice*, Revised Edition. Cambridge, MA: Harvard University Press.) However, even a decision of distributive justice constructed in fidelity with Rawls' intent would need to determine who belongs to a public deserving of minimum securities, and what those are. The veil of ignorance, therefore, would apply to those making the rules, which is impossible for this individual writer or any small team of writers given our stake in the profession and public at large, and in our own lives; but it could be an empirical exercise worth performing.

(152) Unfortunately, UNOS employs a quota on transplantation for noncitizens—a quota few centers utilize, even as they employ noncitizens disproportionately as organ donors; see Gupta 2008.

(153) For example, Genentech Access Solutions. Available at <http://www.genentechaccessolutions.com/portal/site/AS/> (accessed 16 February 2012).