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Matters of Principle:
Agency, Practice and Identity in Clinical Bioethics

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ABSTRACT

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This project is an ethnographic investigation of the practices and professional identities of clinical bioethicists working in Canadian and American hospitals. Data collected over a three-year period (September 2000-February 2004) included participant-observation, interviews and the author’s own experience working as a clinical bioethicist. Specifically, the author queries the tropes conventionally utilized by clinical bioethicists to describe their emergent profession. Chapter Two examines the trope of the ethics consultant as the paradigmatic moral agent within health care institutions by conceptualizing clinical bioethics as a form of labor, and its practitioners as subjects situated within particular institutions, political economies, social norms and culturally-marked bodies. Chapter Three examines the trope of the clinical bioethicist as an “ethics facilitator” in the practice of ethics consultation through analysis of the emerging standards in ethics consultation, and the opening statements of actual consults. Chapter Four queries the trope of the clinical bioethicist as “cultural broker” by examining the tension between pluralism and normativity in both the clinical bioethics literature and the discourse of ethics consultations. By documenting and analyzing the work of clinical bioethicists ethnographically, this
project renders a phenomenology of this emergent profession, as well as a meditation on moral agency within institutional contexts.
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Chapter 1: Embodying Ethics

Living in the Body

Body is something you need in order to stay on this planet and you only get one. And no matter which one you get, it will not be satisfactory. It will not be beautiful enough, it will not be fast enough, it will not keep on for days at a time, but will pull you down into a sleepy swamp and demand apples and coffee and chocolate cake.

Body is a thing you have to carry from one day into the next. Always the same eyebrows over the same eyes in the same skin when you look in the mirror, and the same creaky knee when you get up from the floor and the same wrist under the watchband. The changes you can make are small and costly—better to leave it as it is.

Body is a thing that you have to leave eventually. You know that because you have seen others do it, others who were once like you, living inside their pile of bones and flesh, smiling at you, loving you, leaning in the doorway, talking to you for hours and then one day they are gone. No forwarding address.

Joyce Sutphen (Sutphen 2002)
I became a clinical bioethicist because of my religious genealogy. I hail from Saskatchewan, the birthplace of Canada's socialized medical insurance program pioneered by Tommy Douglas, a Baptist-minister-turned-politician. The Baptist church defined my childhood. From birth through adolescence I attended services and events at least three times each week (choir, youth group, Sunday School, etc.). Our church was both theologically conservative and politically leftist: a combination almost anathema in the U.S. but fairly common in Canada. The "social gospel" of Saskatchewan Baptists imprinted me with the belief that a just society is only as strong as its weakest members—thus the poor and the sick deserve special care and support. This religious commitment to helping the sick predisposed me to sympathize with the enterprise of clinical bioethics.

I became an anthropologist because the idea that human experiences, relationships and institutions are grounded in culture—rather than biology or some non-negotiable divine plan—seemed profound to a girl raised as a creationist and Biblical literalist. If humans collectively create structural oppressions, scales of punishment and reward, norms of beauty and morality, cosmologies and rituals, then we are the ingenious architects of our own prisons. I figured the role of anthropologists was to liberate society by mapping these cultural structures and plotting hermeneutic routes to freedom. What could be more a more worthwhile calling (the problem of agency aside)?

I became a clinical bioethicist because when I left the church in my early twenties I felt existentially unmoored. Bioethics offered me a secular morality.
Bioethicists’ methods of reasoning and evidence seemed comfortably familiar; they supported their normative claims regarding right and wrong not with empirical data, but with proof-texts. Only the sources differentiated the bioethics literature from the sermons I’d grown up with: bioethicists appealed to Rawls, Kant, Aristotle or Beauchamp and Childress, instead of Paul, Jesus or Moses. Both genres illustrated their claims using “real life” stories, though the bioethicists called them “cases” and my ministers called them “testimonials.” And like the ministers of my youth, bioethicists’ seemed to have a visceral need to be right—common sense, etiquette or practicality be damned. The familiarity of the rhetorical strategies of (philosophical) bioethics, combined with the almost total absence of God-talk, convinced me I’d found a post-Christian intellectual home.

I became an anthropologist because I was bored by the reliance on texts in my Religious Studies education. I was tired of reading about religion, I wanted to talk to practitioners about what they were doing and why. I wanted to create new knowledge by documenting religious practices and discourses, rather than interpreting scholarly books about religion. Simply put, I was too extroverted for the solitary rigors of exegesis. I craved engagement with living communities, and ethnography—the paradigmatic method of cultural anthropology—seemed to be the answer. I became a clinical bioethicist because I’d wanted a Ph.D. since my first year in university, but I didn’t want to become what my partner lovingly referred to as a “pointy-headed academic.” I wanted to learn something practical, something that would speak to people outside of my subspecialty. Clinical
bioethics seemed not only eminently useful, it also tripled my job prospects, enabling me to seek appointments in my academic discipline, in medical schools or in hospitals.

I became an anthropologist because in 1992, at age 19, I spent two months living in a thatch hut with the Pwo Karen of northwestern Thailand. I was captivated by their colorful woven clothes, their teeth stained red with betel nut, their staccato mode of speech, the way the children followed me on my wanderings in the jungle, coaxed by their parents who were afraid this ignorant giant would step on a snake or be abducted by ghosts. I admired their handiness with a machete, their gentleness with their children, their generosity in the face of the most severe drought conditions in a decade. Now, when people ask what I was doing there, I say I did “literacy training.” What I don’t say is that it was the Bible we taught people to read, and that my sponsoring agency was an evangelical Christian missionary organization. I did manual labor to support Moira, the missionary permanently stationed in the village. Moira specialized in Biblical translation, but the Pwo knew she had a stash of antibiotics and bandages, so sometimes they would come to her looking for medical help. Once a woman from a neighboring village carried her sick son to our hut and laid him on the floor. He was so lethargic he didn’t blink when I palpated his rigid abdomen. I told Moira he needed a doctor; she directed the boy’s mother to the only clinic in the area, 5 miles away. The mother prodded the child onto her back and began the long journey on foot. We could have driven him on our motorbike,
but Moira said she didn’t want to set a precedent, otherwise she’d be so busy playing taxi she’d never finish translating the letters of Paul. Another time I watched a young father remove an intricate grass weaving, intended to protect his family from evil spirits, from the doorway of their hut. I watched the new convert cut protective amulets from the wrists of his coughing baby girl and cast them into the fire on the porch. I remember the flames leaping up as the fibers flared orange then convulsed into ash. I remember the pride in the missionary’s voice as she congratulated the family for forsaking the folly of animism. I remember the stirring of hope in the mother’s eyes when the missionary assured the her that Jesus would prove more responsive to their daughter’s suffering than the spirits of their childhood devotion. The need for redemption from the religious bigotry of my past chased me to anthropology.
I. What’s in a Hyphen?

I, like everyone else in bioethics, have a hyphenated identity that proclaims my disciplinary training: I’m an anthropologist-ethicist. Most of my bioethics colleagues and friends are physician-ethicists and philosopher-ethicists, though I know a smattering of lawyer-ethicists and theologian-bioethicists. The interdisciplinary origins of bioethics (until the late 1990s, there were no degree programs in bioethics per se), necessitates this dual identification.

My anthropology colleagues, on the other hand, call me an oxymoron. It is not that anthropologists do not have their own ethical norms (although they are often loathe to talk about them openly), or do not address ethical issues in their research (they certainly do). But the discipline’s foundational commitment to cultural relativism makes anthropologists queasy about any person or profession that takes a normative approach to questions of right and wrong, abstracted from an analysis of the social norms, politics and institutions that precipitate those situations categorized as “ethical dilemmas.”

I think of myself not as two discrete professionals joined by an amicable hyphen, nor as a contradiction in terms, but as a kind of chimera: a mutant combination of loyalties and obligations, of insights and ineptitude, of intellectual genealogies and modes of labor. Some of my hyphenated colleagues have told me they always feel like a philosopher/physician/lawyer first, and a bioethicist second; whatever discipline they studied in graduate school remains their intellectual ego, animating and directing their work in bioethics. Perhaps because
I became involved in clinical bioethics\(^1\) early in my graduate studies, or perhaps because I experience both clinical bioethics and anthropology as "callings" of a sort, neither designation dominates my thinking. They coexist, sometimes congenially, sometimes through cognitive dissonance, as the rather tangled warp and woof of my professional identity and intellectual orientation.

In my dissertation grant proposals, I described my project as an ethnography of the emergent profession of clinical bioethics in the U.S. and Canada. In the traditional hyperbole of the genre, I proposed a comparative study examining the cultural inflections of the practices and discourses of bioethicists working within health care institutions at four sites, spending a minimum six to eight weeks at a rural and urban hospital within each country. While I found my bioethics colleagues open to being interviewed, the participant-observation component of the project foundered. In some cases the humans subjects research regulations proved logistically insurmountable\(^2\). But even at sites where I did get approval to do participant observation, the work of clinical bioethics is

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\(^1\) There is (as yet) no standard title for bioethicists employed by health care institutions. Some call themselves "clinical ethicists," others are "health care ethics consultants" or "clinical ethics specialists." I have chosen to use the term "clinical bioethicist" to emphasize both the clinical context and content of this labor, as well as its theoretical indebtedness to academic bioethics. "Ethics committee members" are generally employees of the hospital who volunteer for the institution's clinical ethics committee; in some hospitals they participate in ethics consultations, in others their role is more administrative.

\(^2\) Some hospital research ethics committees told me I would have to appoint a hospital employee to be the principal investigator of my study. I told them this would violate my code of ethics as an anthropologist because it would infringe on the confidentiality of my research subjects as the PI—a colleague of my informants—would have access to my interview data and fieldnotes regarding their work. They insisted that the policy was non-negotiable, and that it was necessary to ensure the protection of research subjects. They were unmoved by my observation that their policy would in this case ensure the violation of the rights of my research subjects; the paradox was lost on them. Thus, I did not do participant observation at those hospitals with this requirement.
unpredictable at best. Four hot-button clinical cases may surface in two days, followed by a dry spell of weeks. I did not have the opportunity to observe clinical consultations at three of my sites, although I did attend some educational events and administrative meetings with my informants. As a result, I was unable to conduct my study of ethics consultations at three of the four sites. Thus, this project is not a comparative study across multiple sites, but rather a case study of one site—Research Hospital—augmented by interview data from ethics committee members and clinical bioethicists working in the other sites.

Bioethicists make articulate, engaging interview subjects. They are without exception thoughtful, well read, measured and often passionate about their work. However, whenever I ask them about their practices (what they actually do everyday) I am perpetually disappointed. “I conduct institutional policy review and ethics consultations, and provide bioethics education for health care professionals,” is the standard response. It is recited dutifully in almost exactly those terms, as if they are all reading from the same script (and indeed, as I’ll address later, they are). Further probing yields few concrete details beyond the recitation of mission statements. Alternatively, they resort to stories of particularly difficult cases, recalling the exact words and gestures of this recalcitrant physician or that bullying family member. But they themselves are virtually absent from these case narratives, as if bioethicists are not agents in the drama, but rather the chorus sagely observing the tragic unfolding of fate from the wings.
I almost always leave my interviews with bioethicists empirically disappointed, but also awed by the apparent certainty of their own purpose and utility, and their presumption that their methods are transparent and valid. Their self-assurance grates against my recollections of my own clinical bioethics training, unraveling my feeling of professional kinship with them. Today I remain as confused and skeptical about the enterprise of clinical bioethics as I was at my very first clinical ethics consultation, and I have never been entirely convinced that I did any good (or am any good) as a clinical bioethicist. Again and again I have returned to my memories of encounters with patients and health care professionals at Research hospital where I trained in clinical bioethics for two years. These memories remain almost paralyzing in the ambivalence they evoke.

I have tried to plow through my transcripts, plotting patterns and plucking the juiciest quotes, writing “bioethicists say x and do y,” as if I am not one of them. It is technically possible, but ethically and cognitively impossible. Unable in good conscience to play the part of the objective social scientist scrutinizing her subjects and under the stark glare of social theory, I have chosen to write a book that is more modest in scope, though more theoretically, structurally and personally ambitious than I ever anticipated.

My bioethics colleagues who hoped my project would (finally) provide empirical evidence for the integral role of clinical bioethics in the moral enterprise of healthcare will no doubt be disappointed. My anthropology colleagues who hoped that my study would simply affirm what they already knew (that clinical
bioethics is yet another disciplinary regime, that it internalizes and disarms any critique of biomedical institutions, that it ensures the status quo) will also be dissatisfied. And practicing ethics consultants looking for concrete (if not definitive) data demonstrating the method of consultation that results in the best outcomes will also be left cold by what follows.

The purpose of this project in its current incarnation is not to begin with a definition of clinical bioethics, to empathetically describe the practice, and to conclude with suggestions for process improvement. This project does not aim to lend credence to claims made by various factions within the field that clinical bioethicists should do this or that in order to make their work more effective and relevant. I leave readers to decide for themselves how my experiences compare to their own, and what in my analysis might prove useful in their particular contexts. In my critical but noncommittal orientation, this project is most decisively anthropological.

At the same time this book is not intended to be an endorsement of anthropology as the lone prophetic voice crying out in the wilderness of biomedicine, nor is it yet another irksome and self-interested apology for incorporating more social scientific perspectives into bioethics. Those anthropologists who looked forward to a wry depiction of governmentality in the professional lives of clinical bioethicists, or another highbrow rant against the impersonal malevolence of modern health care institutions and their tyrannical management by indifferent physicians should stop reading now. While there
appears to be an unquenchable thirst for such readings of biomedicine in contemporary medical and cultural anthropology, I cannot oblige. The best I can muster is a reflexive account of the professional identity, discourse and practice of a particular clinical bioethicist in a particular time, place and body. That clinical bioethicist is me.

However, my reflexive analysis of my own training and work as a clinical bioethicist is integrated with (and often challenged by) the formal qualitative research I conducted at Research hospital and at my other sites in Canada and the U.S. Thus, this project is itself a kind of chimera, combining my embodied experience with traditional ethnographic data in a manner that is mutually informing and, at times, discordant. Throughout the project I will reference different domains of knowledge: the personal, the social scientific, the bioethical. My goal in writing up this particular project in this particular way is to contribute a more robust phenomenological account of the work of clinical bioethics than currently exists, and to grapple with the ethical enterprise of ethnographic research and writing as an insider to the community under study.

In this chapter I begin by situating my chimeric identity and the way it informs the evolution of this project. Next I will outline my methods of data collection, with particular attention to the ethical and epistemological challenges posed by this project. Finally, I will outline my theoretical orientation, and the particular strategies I have chosen to deploy in order to expose and interrogate my chimeric identity and its influence on my data analysis.
II. Tales to the Field and Other Silences

At the joint meeting of the American Society for Bioethics and Humanities (ASBH) and the Canadian Bioethics Society (CBS) in Montreal in October 2003, the physician-writer Abraham Verghese delivered a plenary address on narrative, literature and medicine. At one point in his autobiographical talk he lamented: "I decided to become a physician after reading Somerset Maugham’s *Of Human Bondage*. But now my medical students tell me it was *ER* that moved them to become physicians." I disagree with Verghese’s elitist characterization of television as an insufficiently elevated medium for calling young people to the healing profession. However, it struck me that such *narratives of calling* are not stories bioethicists tell to one another, though their sometime characterization as a secular priesthood would seem to warrant it (MacDonald 2003). This absence is particularly strange given that when I tell strangers at parties or in coffee shops that I study bioethics, they often make the connection with a personal ethical issue they have faced. A typical response is: “Wow, bioethics. That sounds fascinating. So you must deal with stuff like when to pull plug and let people die. You know I really could have used you when my mother died. God, the stuff she went through, and they must have known she wasn’t going to make it. But I didn’t know what to do....” Lay people are generally familiar with the word bioethics through the media, and while they sometimes ask me my opinion on human cloning or whatever hot-button issue is in the headlines that week, more often than not the word evokes some personal story of suffering, some lingering moral
doubt. It is thus puzzling to me why bioethicists so rarely disclose, even to one another, the personal roots of their attraction to a field that is indeed fascinating, but also relentlessly morbid.

Every discipline or field has its own particular version of the “tales from the field” genre. Over cocktails and cigarettes at American Anthropological Association meetings, anthropologists compare notes on malarial delirium and highway robbery. War stories of clinical bioethicists take the form of “the interesting case” or “the case from hell.” As Todd Chambers has observed, the vocabulary, structure and rhetorical strategies of these tales are generally modeled after the medical case study (Chambers 1999), and thus provide remarkably little context or personal information about the teller. What seems strangely absent from the bioethics literature is the genre of “tales to the field,” stories about how we came to be engaged in the enterprise of bioethics, and why.3

In my interviews with clinical bioethicists I often ask: “Why did you decide to become a bioethicist?” As Judith Andre also found (Andre 2002), most of my informants provide only perfunctory etiological explanations for their life’s work. “I’m a practical person and I like to do work that has some practical application.” “I hope to do well by doing good.” “Bioethics pays better and there are more funding opportunities.” “There were no jobs in my field, so I took one in

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3 By comparison, I find anthropologists more forthcoming about how they came to anthropology. These stories are generally characterized by disenchantment with conventional understandings of a particular issue or experience (illness, sexuality, religious practice), and/or frustration with the methods or theoretical naivete of other disciplines. As James Faubion once observed, “People come to anthropology limping and bleeding from other disciplines.”
bioethics.” An exception to such pragmatic, philanthropic or economic logic was Audrey⁴, a philosopher-bioethicist who studies disability and consent. She told me: “All the questions [my professor in bioethics] was asking when I was an undergrad—about value-based questions—that was what drew me to bioethics. When I left his classes I felt like I had wings on my heels…. I had an experience working when I was twenty for the summer camp [of a disability advocacy group]. We worked with people who were deaf, blind and disabled, and it had a profound influence on my desire to work for a better health care system for them. My mother has had a disability throughout her adult life, and my friend uses a wheelchair. So I find personal and professional meaning in trying to ameliorate things, and do what I can to make their lives and the system better for them and for us.”

Judith Andre tells me that most philosophers come to bioethics with a theoretical question (personal communication). But surely that original impulse is predicated on others. Why that particular question, and not another? How and when did the question arise? Why use philosophy and bioethics to answer the question? Why not use sociology, religion, astrology, or yoga?

Most of the bioethicists I interviewed reported that they enjoy their work immensely, and many seem to feel that bioethics is more an avocation than a job. Some (particularly feminist bioethicists) have portrayed bioethics as an almost prophetic calling; the bioethicist is one that “speaks truth to power.” In

⁴ All informants are identified by pseudonyms and, where relevant, by the country in which they work (Canada or the U.S.).
addition, clinical bioethicists work in close proximity to human suffering, and are constantly assaulted by the reality of human mortality. In fact, the majority of their ethics consultations involve end of life issues (McGee, Caplan et al. 2001). Even when cases don’t involve severe disability or pain, they are constantly challenged to grapple with family dysfunction, social injustice and acute moral distress. While bioethicists are often paid better than faculty in the humanities or social sciences, there are undoubtedly less emotionally grueling ways to earn a living or to probe interesting questions.

Perhaps tales to the field don’t circulate among bioethicists because they are private. However, physicians—those quintessential professionals—frequently cite personal experiences of illness or death as inspiring them to study medicine. I suspect this narrative lacuna among bioethicists has more to do with the nature of the work they do. While they support patient care, they are not usually directly involved in the provision of care; they do not lay healing hands on patients. In fact, the clinical bioethicists I observed and interviewed tended to articulate their utility as residing in their critical distance from the therapeutic relationships between patients and their doctors and nurses. They depicted themselves as “third-parties” who could mediate disputes and facilitate conflict resolution between various care providers. At Research hospital, ethicists or ethics committee members generally recused themselves from an ethics consultation if they were directly involved in the patient’s care, fearing that their therapeutic relationship with the patient would handicap their ability to weigh the moral
options objectively. Perhaps disclosure of the personal influences on their work would undermine the neutrality of their position.

The philosophical orientation of bioethics might also cause clinical bioethicists to consider their personal genealogies irrelevant. While clinical bioethicists come from a wide range of disciplines, philosophical modes of reasoning continue to dominate. In my experience, “principilism” remains the dominant theoretical model invoked in ethics consultations. Decision-making in clinical bioethics generally involves applying abstract principles (primarily autonomy, beneficence and maleficence) to a particular case through a kind of “common sense” epistemology. Rarely did I see ethics consultants debating the precise meanings of the principles, or the theories that informed them. Feminist bioethics, anthropology and standpoint theory have problematized the disciplinary functions of categories of “reason” and “common sense” by underlining how one’s culture, social capital and history influence moral decision-making. However, bioethicists rarely explore these influences in either their daily practice or their public presentations of cases. The principles of bioethics are invoked by clinical bioethicists as (more or less) universal, timeless and transparently applicable to virtually any ethical conundrum in any context. Under such an elegant, mathematical system, the personal experiences, relationships and motivations of the bioethicist appear irrelevant, onanistic or even contrary to the noble calling of clinical bioethics.

III. Getting In, Getting Lost
I never intended to become an anthropologist. I selected my doctoral program in Religious Studies expressly for its program in Medical Ethics. The program had two distinct, though allegedly related, components. I acquired the requisite theoretical foundation by reading philosophical ethics and the bioethics literature, while my internship with a bioethicist working in a hospital gave me exposure to the clinical setting. Though I'd always gotten top marks in my undergraduate and masters programs in religion, I struggled in my bioethics courses from the outset.

In the first semester of my doctoral program I took a course on clinical bioethics. My first case study was an analysis of a hospital DNR policy. In his comments, my professor summed up my paper as “over-zealous over-reading.” I was mortified. Looking back over the paper now, seven years later, I can see his point. I had spent an entire paragraph dissecting the meaning of the word “those.” But nevertheless, it was a stinging critique coming from a professor of Religious Studies, a discipline whose foundational methodology is (Biblical) exegesis, which is by definition over-zealous over-reading.

The DNR policy I analyzed was a mess, filled with inconsistencies and contradictions. It stated that the hospital’s goals were “sustaining life and conforming with medical, ethical and legal requirements,” even though the purpose of the policy was to delineate procedures for withdrawing and withholding life-sustaining treatments. In addition to pointing out such logical fallacies, my case study hammered the policy for its lack of specificity, and its
reliance on what then seemed like nonsense jargon ("best interests," "medically incompetent," "surrogate"). (Now, through habituation, these terms seem merely descriptive.)

My paper contained more questions than analysis:

"What is meant by best interests of the patient? Is it staying alive as long as possible? Who decides if the patient is not competent? How is a physician supposed to ascertain the desires of the competent patient? What about the desires of the family, where do those fit in? And what do they mean by 'authority' when the policy states: 'If the patient's desires are unknown, the person who has the authority to make the decision should act in the best interest of the patient'? Do they mean the authority of the physician as a medical expert in judging the prognosis of the patient, or the moral authority of the patient's surrogate?

I refused to take anything for granted: not the benevolent sovereignty of the physician, not the self-determination of the patient, not the philosophical argument that there is no ethical distinction between withholding and withdrawing treatment. When at the end of the paper I finally ventured to make a normative claim, it was so specific to that particular case that any cursory attempt at more general application betrayed how arbitrary it really was.

Clearly many of my questions stemmed from my unfamiliarity with clinical realities. I was forever making apple-pie suggestions like, "doctors should listen to patients and include nurses in treatment planning," unaware that the structural organization of medicine made such objectives nigh to impossible. In addition to my obvious ignorance, my early attempts at bioethical analysis reveal an ethnographic sensibility. All of my questions were really about power, context and communication (or as my friends Ann Cook and Helena Hoas put it: "who does
what to whom and how"). I could never make a case simpler, or abstract it from its social milieu. Institutional policies, professional standards, even laws never seemed like sufficient justifications. Norms and values were never extracted from the relationships and practices that shaped and expressed them. Reading my early cases, it is clear that I didn't understand or respect the rules of engagement in bioethics. Lucky for me, ineptitude and dispositional incompatibility with one's chosen course of study are not necessarily barriers to obtaining a doctorate, so I blundered on.

I began my practical training in clinical bioethics in my second year of graduate school (January 1999) as an intern at Research hospital. Six hours each week I followed Lydia, the clinical bio ethicist, to medical rounds in the ICU, to Research Ethics Committee meetings, to policy review committees and to ethics consultations. I was shell-shocked. I'd volunteered at a long-term care facility during my masters program, but here suffering and death dogged us all day long. And as a student at a university where jeans and t-shirts were de riguer, I had trouble adjusting to the dress code. My field journal from January 23, 1999 reads:

I'm not sure what business I have wearing a lab coat. I wouldn't know what to do in a lab if I stumbled into one.... I haven't figured out the white coat code. It seems everyone wears one—doctors, medical students, nurses, nutritionists—except the chaplains, lawyers, patient advocates, clerks and social workers. It seems to demarcate a clear line between the clinical staff and the administrative or patient support staff. But why do we fall on the clinical side? (Lydia told me later that she wears a lab coat so that the physicians will view her as a peer; it's a kind of symbolic compensation for her gender, and the fact that she is not a real doctor, only a Ph.D.)
On in-patient oncology rounds this morning, Dr. K kept introducing me to the patients as “Dr. Frolic,” which I found rather funny. Perhaps he didn’t understand that I am not a post-doc, only a graduate student. Or perhaps he thinks it would be too complicated to explain to patients who I am and why I’m hanging around with him. Patients are used to physicians having an entourage of young medical students, so I blend in on rounds. But don’t patients have a right to know who is witnessing these detailed conversations about their medical conditions?

I attended my first ethics consultation during the inaugural week of my internship. I was excited by the prospect, as I was hungry for direct interaction with patients. I figured ethics consultation was the venue where the clinical bioethicist and the ethics committee would most vocally advocate for patients. When years later I looked back on my notes of that first consult, I was initially confused. I thought I had conflated two different consults in my journal.

[Physician:] The patient is a male in his 40’s with leukemia. He underwent a bone marrow transplant and did well at first, but then had repeated infections and recurrent pneumonia, and was hospitalized in ICU. He came off the ventilator in November, but his wheezing was getting worse. At that time the prognosis was not good, but not futile, as the cancer was responding to treatment. A biopsy of the lungs revealed an inflammatory process (not pneumonia as it was originally thought) that required immuno-suppression. Since the biopsy he has been on a ventilator at extremely high pressures. There is now evidence of bacterial sepsis, kidney failure and blood pressure trouble, and his skin is starting to breakdown due to necrotization. The patient requires very large doses of painkillers and steroids. He has been on the ventilator for 8 weeks. This is the longest ventilation I have ever seen. There is no sign of improvement and there is now no hope of medical rehabilitation. I want to terminally wean the patient from the ventilator, but the family wants everything done for the patient, and they refuse to consider withdrawal. The family is very hostile, angry and accusatory. They have said that the patient never wanted a ventilator and wasn’t told he needed one, which is not true. At the same time they question why he hasn’t recovered, and they want treatment continued. The patient has been non-compliant, repeatedly
altering his own drug dosages. The family’s stress is exacerbated by the patient’s daughter from a previous relationship, who was estranged from her father her whole life, and who now suddenly wants some kind of reconciliation. The wife would like the patient’s pain medication withdrawn so she can talk to the patient about the situation, but that would be medically irresponsible. She is resistant to the notion of the terminal wean because she sees it as “killing him.”

[Wife:] The patient is a loving husband and father. He is a plumber, the sole provider for me and our five-year-old son. He has a daughter from a previous marriage, but he hasn’t seen her since she was a baby. He’s sorry he doesn’t know her better. He wishes things had been different, that he’d figured out how to work something out with her mom, but now he’s sick, and doesn’t know how to start. He really wanted to live, to help me raise his son. He doesn’t want to abandon his second child as he did his first. He found it difficult to cope with the cancer treatment as it interfered with his work. It made him very tired and emotional, and sometimes he would have fits of crying that would come out of nowhere. The medications made him sleepless and achy, he found it difficult to work. He lowered the dosages, just enough so he could put in a good day’s work, and keep bringing home a paycheck while he still could. Sometimes his spleen would feel enlarged, and that’s when he knew it was time to go in for his shot. But one time he got a shot when he didn’t want it. He’d felt fine and his spleen wasn’t swollen. But the doctors didn’t listen to him and they gave him the shot anyway. After that he got sick and started wheezing real bad. He couldn’t catch his breath, and that’s when they had to put him on the “incubator” [sic]. He had one of those living wills. He never wanted to be on an incubator, but now his daughter wants to see him before he passes. He loves his children, he wanted to live for them, and I know he would be willing to keep on the incubator until she comes from Dallas and the rest of the family gathers. I know there is no hope. We were at the funeral home this morning trying to make arrangements. The doctor has no compassion. My husband is all swollen up, and the other day when I asked the doctor if he could do something about it, he said to me, “I’m not going to make him pretty for his casket.” All we want is time, and for this doctor to not interfere with our family good-bye....

[Commentary:] The chair of the ethics committee [not Lydia but a physician-bioethicist who sometimes fills in for her] was obviously sympathetic to the physician’s position—so much so that he escorted the patient’s family out of the room when he decided he’d heard enough, even while they were still talking. The ethics team deemed this a clear case of medical futility. They recommended a terminal wean, but suggested that it be postponed until Friday when the family was expected to gather.
In the rest of the journal entry I express puzzlement over the structure and social organization of the consultation process:

They begin by laying out the ground rules (particularly patient confidentiality), stating the objectives of the consult, and the authority of the ethics team (i.e. they can only make recommendations). Everyone introduces themselves, and after that the attending physician launches in, describing the patient’s medical history. Nursing, social work, chaplaincy, patient advocacy and case management fill-in other data about the background of the patient. Then the patient and surrogate provide their input.

I agree that the clinical data has to come first; you cannot make good ethical recommendations without understanding the medical issues behind the problem. But I wonder about the power dynamics set up by having the attending physician speak first, and the patient speak last. On the one hand, it gives the patient the last word. But on the other hand, the patient’s story becomes so subsumed under medical authority, I wonder if the gravity of their concerns is lost. Why shouldn’t whoever called the consult be allowed to speak first? Why was the room set up so that the medical team was on one side of the table, and the family was on the other? How could the chair so obviously favor the physician’s position when this family’s situation is so tragic? Why wasn’t the family’s distress at least acknowledged? How could the physician accuse the family of being in denial about the patient’s situation, when the wife was the only one who talked openly about his impending death? The physician didn’t say he was dying; he couched it as a “futile situation.” And who am I that I have a right to witness these interactions?

I remember feeling traumatized by that consultation. I remember ranting about it to my spouse for days, wondering why the chair did not attempt to mediate between the two sides, and why he was so rude to this bereaved family. I was incredulous. Surely this consult was an anomaly. Surely the ethics consultation process was about reconciliation. Surely ethicists were obligated to find some way to bridge the competing ontologies of illness brought to the table
by physicians and families. Surely ethics consultation was about giving dignity to the vulnerable and comforting those who suffer.

My frustration with that first consult stemmed from my initial assumptions about the enterprise of bioethics. I thought clinical bioethicists had three primary obligations: (1) to advocate for patients’ needs (medical, spiritual and emotional); 2) to remediate injustice in the health care system so that vulnerable patients are not exploited by or excluded from medicine; (2) to alleviate the existential suffering that comes with difficult health care choices. When I learned about the department of “patient advocacy” at Research hospital, I was confused. Weren’t we patient advocates? Why didn’t we work in their office? Though I was no longer a missionary, I still advocated the option for the poor. Sick people need care; impoverished people need choices; people who are bereaved need hope and comfort. What else could clinical bioethics be about?

So I came to clinical bioethics with questions that were ethnographic, solutions that were logistically untenable, a theoretical orientation that was political-economical, and an activist disposition. Not an auspicious beginning.

And yet... After two semesters as a volunteer intern, I successfully competed to become Lydia’s full-time fellow. I was no longer a mute shadow, a mere graduate student, but an employee of the hospital. Lydia was now my boss, not just my mentor and teacher. My fellowship lasted two years. At first my

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5 I later found out that patient advocacy largely functions as a clearinghouse for patient complaints, mending communication snafus and sorting out scheduling conflicts, ever vigilant to threats of litigation. I was given the impression by other bioethicists that their risk management function is incompatible with the mission of clinical bioethics. As well, most patient advocates have only a high school or college degree, thus associating ourselves with that group would bump us down in the social hierarchy of the hospital.
position was not so different from my internship as I spent most of my time hanging, building credibility with the staff, and working my project through the complex research approval process. About nine months into the fellowship, however, I began to take over some of Lydia’s tasks, including facilitating ethics consultations. By the end of my fellowship I was working as her colleague, with an almost equal degree of autonomy and responsibility.

III. The Madness in My Method

This project is methodologically troubled, to put it mildly. I tried to write that pro forma methods paragraph found in the introductions of most dissertations:

From September 2000 through February 2004 I conducted intensive fieldwork with practicing clinical bioethicists. The primary site of data collection was Research hospital (RH), a 400-bed teaching hospital in a large American city. The research focused on the ethics consultation process at RH. Four distinctive types of data were collected for this study: (1) ethics consultations were audio-recorded and transcribed; (2) extensive fieldnotes were taken in the course of observing the process; (3) quantitative satisfaction surveys and (4) semi-structured interviews were conducted with the ethics committee members, health care professionals, and patients and families who participated in the consultations. Archival research, particularly regarding hospital policies and procedures pertaining to the services of the clinical bioethicists, was also conducted. Interviews and consultations were transcribed according to social scientific conventions. Surveys employed a Likert scale and were analyzed using SPSS under the guidance of a statistician. Adjuvant data, primarily interviews and participant-observation with clinical bioethicists, was collected at three other sites: one urban and one rural community in Canada, and one rural community in the U.S.

I recoil from distilling to such benign jargon the wrenching process of rendering complex social interactions into fixed material objects, of distilling my “field” through the mechanism of pattern recognition and the lens of social theory.
"Field" strikes me as an apt metaphor. It conjures the vision I confront every time I fly over my hometown of Regina, Saskatchewan: fields and fields and fields. They stretch out to infinity in every direction, stitched together by the lattice of gravel roads that make cultivation and inhabitation possible. *Like a patchwork quilt*, says every novelist who tries to capture the prairie landscape. It is a quaint cliché, but the monotonous beige grid that is the breadbasket of Canada hardly compares to the clashes of color, pattern and texture my grandmother pieced together from the old clothes of her children and neighbors. It masks the intrinsic violence of agriculture: the reduction of symbiosis to the logic of monoculture, the subjugation of land teeming with manifold forms of life to the tortuous verbs of harrowing, combining, baling. Canned descriptions of ethnographic methods seem similarly violent in the way they fetishize patterns, asserting a degree of homogeneity in the field that is only attained weeding out exceptions and plowing contradictions underground.

However, I'm also uncomfortable writing a conventional ethnographic methods section because its detached tone presumes a certain degree of distance (more or less) between myself as researcher, and my object of study. I did indeed take notes, conduct interviews, and distribute and collect surveys. But I did so not merely as a scrutinizing spectator of the world of clinical bioethics and an occasional dabbler in its practices. I did so as an apprentice, as a practitioner, and eventually as a leader (of sorts) in my field of study. My informants were also my friends, my workmates, my comrades-in-arms and my
supervisors.

Though Lydia and the ethics committee of Research hospital knew I was studying the institutional roles and practices of clinical bioethicists, and sometimes commented on my compulsive scribbling during meetings, my role as researcher/anthropologist was generally subsumed under my role as bioethics fellow. My informants and I understood that I was at RH in order to become a clinical bioethicist. In the eyes of the institution that paid my salary, I was a clinical bioethicist, and as such my research was expected to support the mission and vision of the hospital. Lydia and I initially hoped my research project would edify the field of clinical bioethics, and the ethics consultation service at RH. In fact, in her annual report, Lydia listed my research protocol as a "process improvement project" for the clinical bioethics service.⁶

In the eyes of my informants, I suspect my anthropologist-researcher identity was either irrelevant, a periodic anomaly, or indistinguishable from my

⁶ The initial design of my research project was predicated on my hunch that patients feel alienated, or at least short-changed, by the bias towards the physician perspective I perceived in the structure of RH’s ethics consultation process. I proposed a study in which I would randomize formal ethics consultations to two arms: a control group and an intervention group. The control group would have a conventional ethics consultation. The intervention would entail meeting with the patient and family before the consultation for a "coaching session." I would help patients and families to clarify their positions and prepare them to present their arguments to the ethics committee. In the analysis I would compare the success of the consultations in each arm of the study. The methodological ignorance betrayed by my original research plan makes me blush. First, I couldn’t be both the researcher and the intervener as it would muddy the data and bias the analysis. Second, I couldn’t measure the relative success of the consultations as there are no practice or outcome standards in clinical bioethics. Third, Lydia only did one or two formal consultations each month, so it would take years to accrue enough consultations to make even a rudimentary comparison feasible. Fourth, if Lydia were facilitating ethics consultations for both cohorts, wouldn’t her behavior in the control group be influenced by what she observed in the intervention group? The physicians on the ethics committee balked, not only because of the sloppiness of my design, but because there was no evidence that there was anything wrong with the consultation process as it stood. So Lydia and I decided to make my project a baseline study of RH’s ethics consultation service, mapping out what happened in ethics consults under the current process, and using that evidence as a springboard to make changes.
clinical bioethics persona. Aside from my obvious note-taking, the only time my anthropologist identity became visible was when Lydia and I decided that an emergent ethics consultation would qualify for my research protocol. I then switched abruptly into research mode. I started documenting what Lydia said and did. I withheld my personal views on the case and how it was being handled, whereas under normal circumstances we freely debated the merits of various strategies, and sought feedback from one another throughout the consultation process. This switch radically changed the content of our interactions, and in some cases might have affected the outcomes of the ethics consultations themselves. During the consultations I studied I would observe silently, monitoring the audio-recorder and numbering surveys for distribution. But in my follow-up interviews with participants, they often asked me what I thought—as a clinical bioethicist—about this or that aspect of the consult, and I sometimes got the feeling that they were telling me things for my professional edification. As soon as the consult was wrapped up and documented in the patient’s chart, Lydia and I would go back to editing a hospital policy together, and commiserating about the sleeping habits of our children. The self-conscious detachment I tried to maintain when I was studying those ethics consultations made both Lydia and me uncomfortable, and there was inevitably some bleeding between my roles, as will become evident in some of the transcripts below.

Not only was my intensive case study of the clinical bioethics service at RH predicated on my identification as a bioethicist-in-training, it was through my
fellowship that I gained access to my other three sites of study when I decided to expand my project. Other established social scientists, with solid publication records, have attempted to study the work of bioethicists or ethics committees, but have been denied access (Bosk and Frader 1998). It was because I was one of them—because I had been initiated into the community of clinical bioethicists and thus understood the complexities and politics of their work—that I got into my additional sites. I met most of my informants at bioethics conferences, kvetching about the irrelevance of the philosophical plenary addresses to the challenges of clinical work, or comparing notes on how to deal with noncompliant patients. I’m sure my informants assumed I was empathetic to their enterprise, that I was on their side, that whatever I produced would further their own aims of professional consolidation. (And they wouldn’t have been wrong.) But I suspect they also consented to my rather impertinent request to watch them at work because I was a student, and because I had no publication record to speak of. (No bioethicist in their right mind would invite Ray Devries or Charles Bosk to hang out with them; their skepticism about the utility and politics of clinical bioethics is already evident in their published articles.) My critical reputation did not precede me, and of course many of us are susceptible to the flattery of having a young apprentice at our heels.

Perhaps I am making too much of my mode of access, since many anthropologists gain entry to their material through relational sleight-of-hand. After all, this is the era of auto-ethnography and practice anthropology and
“studying up”, so what’s all the fuss about? I believe there is something quite distinctive about the research I undertook for my first major ethnographic experiment. Auto-ethnographers generally reach back into their pasts: interviewing family members, studying the political contours of their homelands or religious communities, weaving some sense of identity from their tattered origins. There is also a long tradition of anthropologists apprenticing with shamans or traditional healers or craftsmen to learn more about their rituals, discourses and communities. But this project is different. I did not reach back reflexively into my historical or familial past, or into the religious community of my upbringing. Nor did I go to some distant place, train as a traditional so-and-so and then return home to resume my academic life, writing up my experience for the consumption of other academics. I studied clinical bioethicists while I trained as one. It was not an identity I planned to shed when the project was over and the book published. I would not be leaving the field; in fact, I was striving to become the field. I knew during my fellowship that, given the current job market in anthropology, I had a much better chance of getting a job as a clinical bioethicist than I did as an academic anthropologist. I strove to perform well in my job, knowing that the skills and dispositions I learned in the field would be foundational for my future career. Thus my informants had, both during the data collection phase and the write-up phase, a great deal of power over not only my access to information and behavior in the field (which is not unusual for anthropologists), but also my disposition toward the data. Only when I secured a clinical ethics appointment in
Canada, and I no longer had to rely on my informants for letters of reference, did my writing really take on a life of its own.

To appreciate the power dynamics and conflated relationships between my informants and me, imagine a graduate student studying the work of her own committee for her dissertation project. The tenuous ethics and conflicts of interests are patently obvious in this scenario, and yet my own committee and I were gleeful when I landed the bioethics fellowship because of the opportunity for “unfettered access” it presented. Perhaps this is not what Laura Nader had in mind when she enjoined anthropologists to “study up,” but I doubt I could have done the project without this level of personal investment.

Studying up is a tricky prospect for graduate students. One the one hand, graduate students can gain access to material unavailable to those with more social capital. As a graduate student and fellow I was able to follow bioethicists and health care providers around the hospital, asking obvious and obtuse questions that would have been considered either insulting or incredibly naïve coming from one of their academic peers. And the answers I received often undercut their professional bravado or illuminated contradictions in their practice or discourse.

But at the same time, graduate students are potentially more vulnerable because of their social position, more easily manipulated to empathize with their elite informants, or to reflexively critique them to curry favor with their academic colleagues. And graduate students, because of their inexperience and (often)
inadequate training in research methods and ethics, make mistakes. I was
dogged by fear that my informants—working in litigious medical institutions and
self-conscious of their public images—would sue me for libel. I also feared they
would accuse me of unethical conduct if I published information they found
damning, claiming that they thought their comments to me were off-the-record. At
the very least I was certain they would feel betrayed by a critical portrayal of their
practices (however anonymous), and never speak to me again (which did
happen).

My informants were really “interlocutors.” As both a graduate student and
a clinical bioethics fellow my professional habitus was unstable. I looked to my
interlocutors to help me become a good ethics consultant and land a good job;
they looked to me to stabilize and legitimate their professional practices. We
were complicit in each other’s ambitions. Studying elites, particularly elites who
have a professional investment in a project, may not expose graduate students to
parasitic infections and landslides, but it has its own set of risks: epistemological
seduction, litigation, public denunciation, personal betrayal and intellectual
compromise.

I cannot say now whether I went about my research the right way. Certainly
I would do things differently now, and sometimes I think I shouldn’t have done the
project at all: my divergent loyalties as an anthropologist and a clinical bioethicist
were too incompatible, my relationships in the field too enmeshed. However,
studying bioethics is undoubtedly what has prompted me to expose my position
and scrutinize my methods so explicitly. Undoubtedly somebody with more qualitative research training would have chosen their subjects differently, would have negotiated up front for academic freedom over publishing the results, would have already mastered the art of obtaining and documenting oral consent from informants in the process of participant-observation, and would have juggled their multiple roles with greater dexterity and integrity. But that somebody was not me. And yet I believe my competing investments, my embodied understanding of my informants’ labor, my critique of my own practices as both a clinical bioethicist-in-training and anthropologist-in-training, and my methodological self-consciousness, will render a unique perspective on the hidden but increasingly influential work of clinical bioethicists.

... 

Nadine pressed the back of her head against the cool of the tile wall, fixing her eyes on the toilet flush. She’d heard somewhere that focusing on a single point can help control nausea. Though she stared unmoving, she still felt at sea. Someone rattled the doorknob, wanting to use the restroom. She listened to them listening at the door, straining to detect the sound of running water, some sign that the person within would emerge before their need became emergent. Finally she heard steps padding softly on the industrial carpet retreating to the

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7 In my experience, when anthropologists talk about research ethics it is usually to complain that research ethics committees don’t understand their methods, to decry written informed consent as polluting to rapport, or to assert that ethnographic research poses “no risk” to their informants. Research ethics in anthropology remains alarmingly under-theorized and is rarely taught in graduate schools.
dingy bathroom down the hall. This was the third person she’d barred from answering nature’s call.

She wondered how long she’d been here, and when her secretary would come looking for her. This was her second abrupt departure from the office since she’d arrived this morning. She’d also been sick in the car on the drive to drop Ezra off at daycare. She wondered guiltily if anyone had driven over the plastic bag of vomit she’d knotted and left on the side of the road, unable to tolerate the smell in her car. The mere remembrance gagged her.

From the very beginning of her fellowship, her body had caused her trouble. First it rebelled against her new wardrobe. After the casual luxury of sporting Birkenstocks and tank tops to her graduate seminars, her pantyhose gave her ingrown hairs and her pumps made her feet blister and bleed. Then there was her nose ring. During her first month as the new fellow, she’d accompanied Dr. K on oncology rounds. Later Dr. K called Lydia and told her that the plain silver hoop in Nadine’s nose was “offensive to his patients.” Nadine found this incredible since she’d met several Indo-American doctors in the hospital who sported nose rings. She figured she was simply the wrong color for such and accessory; to Dr. K’s eyes it was not a sign of cultural conformity but of dangerous individuation. Lydia didn’t insist, but Nadine had taken it out anyway. Rapport came before beauty. She touched the side of her nose, now unadorned. The hole had already grown in.
I have got to get back to work, she told herself, and stop being such a suck. There must be dozens, even hundreds of people in this hospital puking at this very moment. I'm lucky. I'm sick for a good cause. I'm not taking poisons that indiscriminately kill every new cell in my body, that wring the life out of my flesh. Most of these patients, they'll feel lousy for months and end up dying anyway. I'm not dying; I'm growing a baby. I'll have something to show for it in the end. And I'll live.

But instead of moving she inspected the cracked grout in the tile floor next to the toilet. This must be one of the original bathrooms, she thought, a vestige from the previous incarnation of this part of the hospital. She remembered what Dr. Schwartz had told her about this hallway. It was the original Intensive Care Unit. That's why the hallway was so wide, and there were plumbing fixtures in odd places. The line of offices on both sides used to be patient rooms. Whenever they had a meeting, Dr. Schwartz would insist that Nadine come to her office. She said she didn't like coming down here. She had done her fellowship here in intensive care and still seemed to suffer post-traumatic stress disorder from it.

She once told Nadine about a patient she'd treated in the very room where Nadine's cubicle resided. The patient's family was from some sort of fundamentalist religious group. Dr. Schwartz thought they were Catholic, but wasn't sure. All she knew was that the family believed that suffering during the passage from this life would reward you in the next. She was sketchy on
theological details, but her memory of the patient's death was still acute years later.

"God, did that old lady suffer! She had lung mets. I knew it wasn't going to be an easy death. She wasn't going to be one of those that just slips quietly into a coma and is gone. And of course I had the luck of coming on service just when she started crashing. We cranked up the oxygen all day until we were giving her 100%. But it wasn't enough. She still wasn't getting good exchange and she started gasping. I mean she was sweating and balling up the sheets in her fists, working so hard you could count every rib with every breath. And her eyes were huge but empty, you know? Eventually they started rolling back in her head. She turned blue, but kept on fighting. She was flopping around like a fish and the nurses had to tie her in so she wouldn't fall out of bed.

"And the family, they were terrified. They couldn't cope. They tried to vigil at the bedside, but most of them couldn't take it and kept darting out of the room. One daughter got hysterical and sat on the floor screaming, 'God, why have you forsaken me?'

"About every half hour the nurses would ask the family about giving her some morphine, but they would just sort of shake their heads and mumble something about God's law. The nurses were ready to revolt, but they couldn't get the family to consent to pain meds. After about two hours of this I couldn't take it anymore. It was the middle of the night and the attending was at home. I didn't say anything to anybody. I went in, hung the bag and titrated the morphine
myself. It didn’t take much. Within a few minutes she laid back, got really still. She started taking these deep, easy breaths. She’d be quiet for a while and then take another one. The family all came back into the room and sat with her. Her daughter combed her hair. Her breathing got more and more sporadic, and within a couple of hours she just stopped. Nobody mentioned the medication, but when they took the body away, every single one of those family members shook my hand and said, ‘Thank you doctor.’ And it was all I could do to not say, ‘Oh, shove it up your ass, you fucking fanatics.’

“I saw a lot of weird stuff happen on that floor where your office is. That place gives me the creeps.”

Hearing the characteristic jangle of her secretary’s keys coming down the hall, Nadine tried to rouse herself from her emetic torpor. She wondered if her morning sickness wasn’t partially psychosomatic. She’d been sick with her previous pregnancies, but this was a whole new level of debilitation. Perhaps her nausea was exacerbated by the constant companionship of sickness and death she felt in the hospital—some form of sympathetic magic. Last fall she’d coughed constantly for two weeks and gone to the doctor, convinced she had lymphoma. The previous week she’d seen a patient, a graduate student, exactly her age, dying of lymphoma. His first symptom had been a persistent cough. When she inquired about getting screened for cancer, her doctor was careful to hold a neutral expression, but his eyes told her he thought she was slightly cracked. “I think we should rule out a bad cold first,” he’d said. “I know you see it every day,
but in reality, lymphoma at your age is about one in half a million." Nadine's
cough had mysteriously vaporized overnight.

She pushed off the floor with her hands, rising to a squatting position.

Gradually she straightened her legs, keeping her head down. She didn't want to
fall over again like she had this morning when she'd gotten out of bed. She
placed her hand against the wall for support. It vibrated slightly—with memory,
with the spirits of the departed, or with the drilling from the remodeling they were
doing upstairs. This place gave her the creeps too.

...
IV. Beyond the Grid: Embodiment, Place, Intersubjectivity

The lived body is not the instrument with which I act: it is my acting. (Gadow 1982, 87)

The person is created through the practices of the place. And the practices of the place maintain and contain the person as well as fabricate the person's subjectivity. (Kaufman 2003, 2255)

...the tendency in bioethics to look to the abstract and the universal is precisely a tendency that is antithetical to the ethical demand that we attend to the concrete and the particular--a feature of ethics that Aristotle emphasized in distinguishing the practical wisdom (phronesis) that lies at the heart of ethics from the theoretical wisdom of science (episteme)...and that Emanuel Levinas takes up, in a different way, in his emphasis on the concrete face-to-face encounter as the proper, indeed the only, place in which the ethical relation can arise. (Malpas 2003, 2347)

A. Bodies...Matter

Anthropology has traditionally taken three approaches to the representation and analysis of the body, according to Thomas Csordas. The first takes the “analytic body” as its locus, attending to the perceptions, practices, parts, processes or products of the body in specific cultural contexts. The second examines the “topical body,” the relation of the body to specific domains of cultural activity, such as the body and religion, the body and gender, etc. The “multiple body” fragments the body by examining the means through which social and political process act on the body, and the attendant consequences for bodily representations and practices (Csordas 1994, 4-6). Only recently have scholars taken seriously the experience of embodiment, and the grounding of culture in the human body, as valuable starting points for thinking about the nature of culture, ethics and our existential situation as cultural beings.
Terence Turner complains that much current social and cultural theory portrays the body as a bounded individual, or as merely an object of social and cultural discourses (Turner 1994, 28). Like Turner, I view the body "in all its aspects, from sexuality and reproductive capacities to sensory powers and physical health, strength and appearance, [as] the fundamental matrix, the material infrastructure, so to speak, of the production of personhood and social identity" (Turner 1994, 28). However, matrix may be too discrete an analogy for embodiment, conveying the image of an identity contained and bracketed within the body. Lyon and Barbelet argue that "bodies are social, and are in a complex of differentiated and simultaneous relationships between distinct aspects of individual bodies, depending on the social relationship or institution in question. We don't have bodies, we are bodies and we make bodies" (Lyon and Barbalet 1994, 50). Christina Toren would seem to concur, emphasizing the intersubjective and emergent nature of embodied identity:

We require humans in order to be human. Human development is a micro-historical process, and an ever-emergent function of the whole person. Identity is the moment-to-moment encounter with the material world and others, mediated by intersubjectivity. There are no received meanings. We make meaning out of meanings that others are making; enmeshed in manifold relations with others, they convey the way the world is. We constantly assimilate other ideas of the world into our own. We see this in relations between infants and caretakers. The world is structured for the child, but that structure doesn't determine how the child internalizes the world. Meaning-making is a process: knowledge is transformed as it is being maintained; it renders each person's perspective unique. (Toren 2003)

Thus the body as the ground of identity is constituted by micro-historical
processes that are organic and material, as well as social.

Lyon and Barbelet further argue that any analysis of agency requires attention to the dynamic interplay between embodiment and social relationships, and the role of emotion as the facilitator of agency: “[E]motion, which is necessarily embodied, functions in social processes as the basis of agency. Emotion has a role in social agency as it significantly guides and prepares the organism for social action through which social relations are generated.... The body cannot be seen merely as subject to external forces; the emotions which move the person through bodily processes must be understood as a source of agency: social actors are embodied” (Lyon and Barbalet 1994, 50). The mechanism for social agency is the evaluating capacity of emotions; they assess internal and external stimuli for their relevance to the embodied self, and this assessment is itself relational.

For example, trust in a physician’s integrity and clinical capabilities are generally deemed essential to ensure patient compliance and positive clinical outcomes. Patients will rarely consult a physician’s publishing (or litigation) record to determine the trustworthiness of her recommendations; instead they will rely on the physician’s demeanor, eye contact, humor, communication skills, or merely the symbolic accoutrements of authority (the white coat, the initials M.D.). These intersubjective evaluations combine with the patient’s own intuitions and experiences to shape the patient’s trust and compliance. According to Lyon and Barbelet, emotion has an ontology that has physical and phenomenological,
as well as social-relational aspects (Lyon and Barbalet 1994, 58). Thus, following Scheler, they argue that emotions are not subjective, but objective as they occur in a social context, and in relationship with the material world (Lyon and Barbalet 1994, 61) Thus emotion lubricates social agency through the body, and is the means whereby human bodies achieve the social ontology through which institutions are created (Lyon and Barbalet 1994, 56).

B. Location, Location, Location

The body as the ground-of-identity is not only intersubjectively and emotionally constituted, it is also shaped by its physical location. If this were not the case, there would be no need for dress codes, uniforms, or that most ubiquitous marker of the relationship between institutions and the bodies that circulate within them: the ID badge. In current theory, a distinction is often made between space and place. According to Malpas, “Space is understood as that universal structure describable in terms of uniform, mathematical principles by means of which all other entities can be located” (Malpas 2003, 2344). He characterizes it as a grid-like imaginary, a concept flowing from Descartes and Galileo (Malpas 2003, 2345), that imagines the universe ordered by principles and universal rules. It is this imaginary that enabled the rise of modern science, and modern moral theory. (This is in contrast to an Aristotelian approach to space that grounds perception and evaluation in particular relations as geographically and socially bounded.)
But, Malpas continues, "spatial modes always have to be 'made flesh,' as it were, by being related back to particular bodies, situations, and places. The 'recalitrance' of place refers to the way in which the spatial must always be 'placed' in this way, even though it often refuses to recognize or acknowledge this" (Malpas 2003, 2348). Malpas characterizes place and space as having a dialectical relationship: "[E]very place encompasses both subjective and objective elements; not merely is space contained 'within' place, but any and every place opens out into broader spaces. If we are to understand the nature of place, then we cannot afford to sever it from space, but equally, if we are to understand space, we also need to understand the way in which it arises in and out of place. There are no pure spaces...every space arises out of certain places and the activities focused around them; every space always has its own places associated with it; every space is grasped and articulated only in and from particular places" (Malpas 2003, 2348).

While place and space may constantly reference one another, they are experienced differently. Malone argues that place is experience-near, characterized by a sense of unity and coherence, while space is more abstract, a conceptualization we are even able to develop only because we first understand ourselves as emplaced. "In this perspective, it is because we are not disembodied subjects set over against a separate background or environment, but persons-in-place, that proximity and distance have relevance in our relations with others" (Malone 2003, 2318). Place is the local, lived articulation of sense,
body, identity, environment, and culture, a person is always in and of place.

Places are both produced by and productive of subjects and subjectivities (Kelly 2003). Place and space are neither neutral nor passive, but rather shaped by embodied and social activities, characterized by tensions and conflicts and power: "In spatial practice, reproduction of social relations is predominant. The reproduction of space, in thrall to both knowledge and power, leaves only the narrowest leeway to representational spaces, which are limited to works, images, and memories whose content...is so far displaced that it barely achieves symbolic force...Within this space...lived experience is crushed, vanquished by what is 'conceived of'" (Lefebvre 1992/1974, 50-51). Here Lefebvre is referencing the circumscription of the experience of persons-in-place within abstract space—the space that characterizes the rationalizing, grid-like logic of modernity. Within institutions like hospitals, abstract space tends to dominate as starkly delineated power relationships drive subjective experiences of embodiment underground.

Professionals represent perhaps most extremely the everyday disembodiment observed by Merleau-Ponty; under normal circumstances, our body disappears from awareness, falling “back into unexperienceable depths” (Merleau-Ponty 1962, 53). In professional, white-collar work, the body is experienced only through its negation, when it hinders performance due to dysfunction, disease or distress (Leder 1990).
The absence of the body is particularly acute (and peculiar) in the work of clinical bioethicists. In their daily practice, clinical bioethicists (like most health care providers) confront the diseased, suffering and dying bodies of patients. However, clinical bioethicists trained as philosophers, lawyers, social workers or social scientists, rarely lay hands on patients or have intimate knowledge of physiological processes. In my experience, even nurse-bioethicists and physician-bioethicists refrain from physically examining the patient in the course of an ethics consultation, relying instead on the patient’s chart and physician testimony to ascertain the patient’s condition. Most of the labor done by bioethicists “at the bedside” is cerebral in nature, involving communication, facilitation and ethical reasoning.

In ethics consultation, the body of the patient is the locus of attention, diverting awareness from the fact that all members of the health care team, including the clinical bioethicist, are embodied and interrelated subjects. That embodied experiences serve as (unarticulated) resources for moral argumentation as well as social action remains unacknowledged. During an ethics consultation 25 people might be crammed into a conference room, but the only body present will be the (absent) body of the patient—a body that is diseased, noncompliant or otherwise troubled. By representing the self (and other healthcare professionals) as disembodied, clinical bioethicists reinforce ontological distinctions between the sick and the well, patients and providers—as if we are not all sick, as if we are not all patients in due time. The sublimation of
embodiment among clinical bioethicists, particularly in the process of analyzing value conflicts in clinical care, also reifies a Cartesian ontology that separates mind from body, emotion from reason, and obscures the intersubjective and emotional nature of moral choices and actions.

Ethicists have what Malone characterizes as a distal relationship to patients (Malone 2003). Not only is their work consciously disassociated from their embodied experience, they are physically distant from the bodies of patients. Their offices are often located in administrative wings of their hospitals, far from patient care areas, and bioethicists who are not clinically trained often have limited contact with patients, even with those patients whose cases they adjudicate in ethics consultation. However, ethicists are constantly negotiating the dialectical relationship between space and place: between the rational, grid-like logic of modern moral theory (particularly principlism), law and institutional policies, and the local relationships and values embedded in particular ethical cases.

Only three types of records usually emerge from an ethics consultation: the ethicist’s (or ethics team’s) recommendation is written in the patient’s chart; standard demographic or categorical information is recorded in a private database for future reference and analysis of trends; and the ethicist may record her thoughts about the case in a personal file. Typically, none of these records will describe the local context of an ethics consultation, the emotional reactions of participants, the embodied and interpersonal dynamics of the interaction. Even
when ethics consultations are written up as cases for teaching or publication, they often follow the spatial and rhetorical structure of a medical case, from which intersubjective and embodied dimensions are omitted (Chambers 1999).

This project attempts to examine ethics consultation—the paradigmatic labor of clinical bioethicists—as an embodied process, and the figure of the bioethicist as an emergent professional whose work remains (despite appeals to standardized methods and moral theories) locally embedded. Embodied specifically refers to my theoretical orientation which favors a moral ontology grounded in the body, comprised of the interplay of physical, spatial and intersubjective elements. This project elucidates the dynamics of ethics consultations as locally embedded by analyzing the dialectic between space (including political regimes) and place (the experience-near micro-structures of the particular institutions in which ethicists work).

I characterize ethics consultation as a process, rather than a practice, because it is still emergent. Ethics consultations are not yet regulated by standards of practice, or performed by credentialed professionals; thus its outcomes and procedures are still (somewhat) unpredictable. While many articles and books in the bioethics literature argue for particular consult models or improvement processes, this project logically precedes such efforts by depicting what is done (by a particular bioethicists at particular institutions), rather than what ought to be done (by all clinical bioethicists everywhere). The relative openness of ethics consultation (unlike the more entrenched practices of
medicine or nursing) makes the process an apt subject for investigating the embodied and embedded dimensions of professional labor. In particular, my project will examine the space-place dialectic through attention to the application of ethical theory to particular localized cases. This analysis will incorporate two strands of discourse on space: phenomenological perspectives which attend to how place grounds our subjective, embodied experience; and critical geographical and historical perspectives which draw attention to the power relationships instantiated in places and spaces, particularly the macro-structures that shape relationships within institutions (Malone 2003, 2318). This will be accomplished through analysis of transcripts of ethics consultations, surveys and interviews with consultation participants, and fieldnotes from my four years of ethnographic research among clinical bioethicists. However, a particularly important resource for my analysis is my "experiencing participation" (Ots 1994), my own training and labor as a clinical bioethicist during my internship and fellowship at Research hospital.

V. The Ethics of Representation/Re-presenting Ethics

Two recent books by bioethicists address the "practices" of bioethicists and ethics consultants: Benjamin Freedman's *Roles and Responsibilities of the Clinical Ethicist* (Freedman and Baylis 2000), and Judith Andre's *Bioethics as Practice* (Andre 2002). Freedman's work is an edited collection of his most difficult and interesting cases over the course of his long career as an ethics
consultant in urban Canadian hospitals. Written in the style and format of the medical case, Freedman describes each patient's medical condition, the options and views articulated by various stakeholders, the ethical merit of each option, and his own recommendations and interventions. However, the conventions of the case genre do not permit reflection on ethics consultation as an embodied, contextual encounter, mediated by institutional space, time and roles. Conflicts are described in categorical terms (non-compliance, informed consent, truth-telling), rather than in intersubjective and embedded terms. Why is the physician taking such a strong stand on this case? Where do her moral intuitions originate? Under what institutional constraints is she laboring (how many other patients is she responsible for anyway)? What is the character of her relationship with the patient: affectionate, distant, manipulative? The physician is depicted as a neutered character in the case study, an invisible hand whose agency is evident only through her management of the patient's physiology. The subjectivity of the patient is also absent, distilled down to a religious belief, family obligation or dying wish.

Strangely, Freedman himself is likewise a disembodied, dislocated presence in these cases. This is peculiar given the title of the book, which suggests an analysis of the agency of the ethicist. However, rather than critically reflecting on the embodied and embedded process of ethics consultation, this collection reads like a curio-cabinet of wonders: a display of the most perplexing cases from a lifetime's work in hospitals. The functions of the book seem to be to
preserve these unique specimens; to provoke fear and awe (what if I got a case like this, what would I do?); to edify the reader by modeling the proper application of ethical algorithms; and to present the bioethicist as an unequivocally heroic character, an indispensable leader within the moral minefield of institutional medical care.

Judith Andre's book takes a different tactic, examining the professional identities of bioethicists in both clinical and academic settings. Her goal is to understand her own transition from academic philosophy to bioethics, and the formation of a new form of professional life (Andre 2002, x). Her book is based on about seventy-five interviews with bioethicists from fifteen centers around the U.S. She does not report observing her interviewees at work, thus her analysis is based solely on what bioethicists say they do, not what they actually do. Andre is not a social scientist, and while she never claims to be doing social science, she has appropriated some of the methods of social science, without its attention to context and representation. Her modes of analysis are opaque; it is not clear how she moves from the raw data of her interviews to her conclusions. She reports that the stories she recounts in the book are altered and disguised, in order to fulfill her promise of confidentiality to her interviewees. Thus the local embeddedness of bioethics drops out (despite her initial attempt to describe her own daily labor) and thus her characterization of the field is one of uniform, universal space, abstracted from particular personal histories, institutions and even disciplinary training.
But Andre makes no claim that the actual practices of bioethicists are unified. While most bioethicists describe their work using the categories of ethics consultation, research and writing, policy analysis and teaching, how each of these activities is carried out varies too widely to be called “practices.” Andre does not use the term practice in the way most social scientists understand it, in the Bourdieusian sense. In fact, she seems disinterested in the work of bioethicists, focusing instead on their collective self-image. Andre takes up Alasdair MacIntyre’s definition of practice as a coherent and complex set of activities, socially constructed, that has distinctive goals and standards of excellence that make the practice what it is, and cannot be fully understood apart from it (Andre 2002, 60). One could argue about whether this notion of practice actually fits bioethics, particularly given the lack of standards of excellence and coherent activities. Even MacIntyre’s definition of practice may be more wistful than accurate in the context of clinical bioethics. However, Andre prefers this concept because it “provides a contemporary way of thinking about virtue” (Andre 2002, 103). Andre’s goal is to bring the broad and fractured field of bioethics under a single banner. She argues that the overarching goal of bioethics is mutual engagement in moral growth.\(^8\) This goal can only be accomplished if bioethicists cultivate certain virtues, including choosing projects well, listening to others, seeking long and wide views on moral issues, tempering one’s need to

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\(^8\) Andre argues that mutual engagement in moral growth is achieved through five activities: (1) keeping moral space open; (2) providing language and skills within the moral space; (3) identifying moral problems and helping create solutions; (4) expanding our understanding of the moral dimensions of health care and biological research; and (5) helping translate these ideals into practice Andre, J. (2002). Bioethics as Practice. Chapel Hill, University of North Carolina Press.
please others, and encouraging colleagues through the founding of “virtuous communities” (Andre 2002, 152). Far from documenting the embedded and embodied practices of bioethicists, Andre’s book serves simultaneously as an apology and allegorical history for the field, and as a homily for its moral edification. Andre is critical of bioethicists’ penchant for choosing projects that are sexy rather than useful, and for abandoning junior faculty. However, her motherhood-and-apple-pie rendering of the goals of bioethics legitimizes the field, without providing any evidence that bioethicists are successful in meeting these goals (how would you measure moral growth anyway?) or that these goals meet the needs of the communities bioethicists are supposed to serve.

Yet Freedman’s and Andre’s books represent some of the most detailed descriptions of the work of bioethicists available. In the bioethics literature, the clinical bioethicist is a ghostly figure: sexless, depoliticized, class-less, race-less (read: white), without psychological baggage or social entanglements. Most strikingly, in case studies clinical bioethicists often present themselves as dislocated figures, extracted from the peculiar qualities their work-places, as if they are unencumbered by institutional demands on their time and attention, as if their moral agency is unconstrained and uncomplicated. Conventional representations of clinical bioethicists are founded on a worldview premised on ontological distinctions between subjects and places, analysis and experience, bodies and their institutional roles. In this view, particularities of person and place
are irrelevant to the function of the individual within their institution: professionals are fundamentally interchangeable.

Unlike Andre, I do not try to represent bioethics as a coherent field in this project. And unlike Freedman, my objective is not to argue that clinical bioethics should be done the way I did it (or will do it). Whenever I publicly present my ethnographic analysis of ethics consultations, a member of the audience will inevitably say, “We don’t do ethics consultations that way.” They think because the ethics consultations in my sample look different from theirs, they aren’t implicated by my critique. However, they are missing the point. The point is that ethics consultation teams and clinical bioethicists do work differently, that local variations in process and position are ubiquitous in the field (in fact variation might be a common characteristic of clinical bioethics). These differences are worth paying attention to, rather than glossing under the category of “professional practice.” The objective of this project is to closely examine how clinical bioethics is done in a particular place; and even more, what it was like to become a bioethicist in a particular institution at a particular time in a particular body. My aim is to take seriously how bodies, places and social relations constitute the work of people who delineate and manage the ethics of the very institutions who employ them.

A different sort of narrative form is required to understand the work of this emergent profession, and ethics consultation as an embodied, as well as socially and culturally located, process. Recently, some bioethicists have begun exploring
reflexive narration. At a recent conference of the American Society for Bioethics and Humanities, Sue Rubin presented her experience participating in an ethics consultation, not in her capacity as a clinical bioethicist, but as a family member struggling with difficult ethical issues after her mother’s diagnosis with Alzheimer’s disease prompted her to question how much clinical bioethicists should reveal about their own perspectives and experiences in the course of their work (Rubin 2003). However, the question of how much personal information is appropriate to reveal already presumes a professional identity that is normatively extracted from embodiment, and presumes a decontextualized spatial orientation to the work.

In this project I aim to take a reflexive turn, presenting a phenomenology of embodied professional practice through the narrative of my own experiences training and laboring as a clinical bioethicist. The goal of this reflexive narrative is both to fill a lacuna in the literature regarding the labor of clinical bioethicists, which Charles Bosk characterizes as a “black box” (Bosk and Frader 1998), and to provide context and contrast for the other components of my analysis. To this end my project contains three distinct voices.

One is the voice of the anthropologist, the “I” of the present who reflects back on my experience “in the field,” and struggles to create an ethnography that is methodologically sound, structurally coherent and theoretically significant, as every good ethnographer should.
Another is the voice of the analyst, that elusive second person, through which I offer my empirical findings, picking out a tune in the cacophony of my raw data.

The third voice is the voice of Nadine. Through Nadine I examine the embodied, intersubjective and contextual dimensions of the labor of clinical bioethics. Nadine is my middle name, but it is a name nobody calls me and nobody recognizes: it is both me and not me. Geib is a surname from my family tree. Using the third person enables me to take a more objective approach to my work as an ethicist. It also highlights the fictional quality of this portrayal. These narratives are not my fieldnotes, they do not represent what "really happened." The artifice of a fictional narrative best enables me to accomplish my theoretical goals for two reasons.

The first is the challenge of representation. I initially tried to document my labor as a bioethicist in the first person. However, I continually stumbled over which "me" was speaking: the me of that present, or the me of this one, two years after leaving Research hospital. I found it impossible to accurately conjure my fellowship through the filters of memory and experience. I don't have access to the "facts" of my work as a clinical bioethics fellow. My reams of fieldnotes document particular aspects of my experience, but in retrospect other dimensions have emerged as even more significant. Fiction allows me to represent how context, time, embodiment and social relations shape the particular practices of the clinical bioethicist. This includes the contested-ness of
the role of the ethicist, and the ways in which overt power relations within the 
institution, and pathways of information, affect her work. Part of this project is to 
document the shifting loyalties and emphases of the ethicist, how these are a 
function of the workplace, as well her own peculiar identity. What does it mean to 
be the human embodiment of ethics for a health care institution? A fictional 
account renders the answer to this question more engaging and compelling, 
allowing the reader not just to intellectually understand the events unfolding 
before them, but to feel them as well. While the stories are based on real 
experiences, the experiential/embodied aspects of these cases and events will 
be the focus: in particular, what I felt, what I thought, what I believed, and how I 
enacted my role. In all of these narratives I judge their success by the extent to 
which they have captured the feelings and events that continue to haunt me.

In addition, a fictional portrayal avoids some of the pitfalls of first-person 
narratives, which are often over-determined or self-aggrandizing. The fictional 
quality of these stories evokes, rather than determines or explains, the work of 
the ethicist, leaving the stories more open to interpretation and debate. In taking 
this reflexive turn, I aim to resist the elision of experience and analysis, and the 
tendency in bioethics to dissolve the personal and contextual into the 
philosophical, the body into categorical norms (DeVries and Conrad 1998). This 
is not only an aesthetic, but also an ethical decision. I believe it is unethical for 
bioethicists to erase their agency and their subjectivity from their case narratives. 
Such erasure dodges responsibility, buries bias and ignores contextual
constraints. The goal of the reflexive component of my work is to present the
work of the clinical ethicist, and the knowledge of the ethicist as situated and
contingent upon context, identity and power, to probe the relations between
place-making and people-making (Gupta & Ferguson, 1997).

As well, a fictional narrative allows me to be specific and detailed, while
still preserving the confidentiality of the patients and colleagues I encountered.
The nature of ethnography often makes it difficult to determine, while in the field,
what are data and what are not. In retrospect, certain casual encounters or
events become emblematic of a theme or theory that emerges through the
process of analysis. The difficulty of determining what counts as data is
particularly problematic in a situation like mine where my job was intrinsic to my
research. Only recently have I come to realize that the richest data I possess
exist in my enactment of my role as a fellow. These data dwell in my memory, in
my relationships, as well as in my body. During some interactions that I now
regard as pivotal, I was acting as a bioethicist, not as an ethnographer (although
everyone at the institution with whom I had regular contact knew that I was
studying ethics consultation and the institutional roles of ethicists). I was
constantly taking notes at meetings and educational events for my edification as
a trainee. I did not at the time get explicit consent to use most of my interactions
on the job as part of my data set. It would be awkward and logistically difficult to
approach those participants now, years later. In addition, these narratives are not
really about the other people I encountered—be they patients or clinicians—or
about Research hospital. They are about me and my experience as a clinical bioethicist.

By using a fictional narrative form I hope to avoid exploiting the trust of patients and colleagues who so generously allowed me to witness some very trying events. While all of the events depicted in Nadine’s narratives are based on my actual experiences, and were often documented in my fieldnotes, all of the characters in the scenes I depict are indeed characters rather than snapshots of real people. Names and genders have been changed, diagnoses have been modified, institutional positions have been fabricated. For example, in all the Nadine narratives, my fellow bioethicist “Lydia” is not a particular individual, but a composite of several bioethicists I have worked with and observed throughout my training and research. And Research hospital is a composite portrayal of two large, urban, American, tertiary care hospitals, where I conducted my formal ethnographic research on their ethics consultation services. While some of my interlocuters may recognize aspects of themselves in what I write, these composite portrayals will enable me to safeguard their sense of privacy and integrity, and their relationships with me.

Nadine’s narratives are organized around the themes of the chapters. Her story does not unfold chronologically, nor does it follow a linear narrative, charting the evolution of the neophyte ethicist into the competent professional. I wish to avoid any such triumphant interpretation of my experience. I remain as confused, as critical and as wary of this emergent profession, as I was at my very
first consultation, but no less fascinated or dedicated to understanding it. Each
narrative is episodic, crafted to interrogate, illustrate or evoke some aspect of the
analytic or theoretical content of the chapter. Each voice is intended to query the
others, in the hopes that through the conversation that emerges, a new
understanding of the work of clinical bioethics is created.
Chapter 2: The Apparatuses of Agency

Nadine said she would buy the bagels herself.

The promise reverberates in her subconscious, dragging her from the pregnant oblivion of sleep. As she breaks the surface of consciousness, her eyelids contract, resisting for a moment the duty of sight. Close to her ear, her clock radio begins to murmur the morning news: allied forces in Afghanistan mistakenly turn a wedding party into a mass grave; African schools close as teachers die of AIDS; the president announces plans to increase prescription drug benefits for Medicare recipients.

After the headlines, Nadine turns her head to read the clock, though she already knows what it will say: 6:02 am. One hour and 58 minutes until her monthly rounds with the oncology nurses. If she gets up this very minute, she can still make it on time. The toddler nestled in her armpit grinds his sweaty head into her ribs, his eyelashes fluttering. Nadine reaches over her son, picks up Lawrence’s arm, leaden with slumber, and tugs gently. Lawrence rolls onto his side, reflexively curling his body around the back of his sleeping son, who instantly relaxes into the embrace. As Nadine rises she is careful to distribute her weight so the mattress doesn’t creak. (She has found through trial and error that tucking her knees and rolling off the bed so that she winds up crouching on the floor creates less turbulence than sitting upright on the edge of the bed, planting her feet and then rising.) She stands under the streaming heat of the shower long
after it has rinsed clean her vanilla conditioner and apricot body scrub. She resists withdrawing from the only solitude she will have all day.

Nadine pours muesli into a bowl, and while the milk softens it, she scours her cavernous refrigerator searching for ingredients for two passable lunches.

“We can’t put off a trip to the grocery store any longer,” she thinks to herself. “I’ll have to plan the menu after supper. Maybe Lawrence can go to the store while I’m putting Ezra to bed tonight.”

She packs the lunches into their respective boxes (blue for Ezra, purple for her) and turns her attention to breakfast. She stands at the counter, settling into a multi-tasking rhythm as she makes Ezra’s peanut butter sandwich.


Nadine dumps the rest of her cereal into the sink, leaving Lawrence to clean up. In Ezra’s room she rummages through drawers for a clean shirt, pants, socks, and a few diapers. She checks the labels to make sure his name is written on each item, then sets them on top of his lunchbox at the front door so they won’t be forgotten.

As she squeezes toothpaste, Lawrence comes in, warm and mellow. He
strips blindly and turns the taps on by feel. He refuses to open his eyes or speak to anyone until after his shower. Nadine carries her toothbrush to her bedroom, sliding back the door of the closet to survey her wardrobe. As she brushes her teeth, she puzzles over the riddle of what to wear. Everyday the algorithm changes. Today, her selection must incorporate the following variables:

(a) it must be clean (strike the pantsuit sitting on the front seat of the car, waiting to be taken to the dry cleaners)

(b) it mustn’t involve showing her legs or armpits, as she’s forgotten to shave for the fourth day in a row (no short skirts or sleeveless blouses)

(c) it must be loose-fitting, as all three pairs of her seamless underwear are currently balled-up at the bottom of the laundry hamper, waiting to be hand-washed (nothing says unprofessional like a visible panty line; this disqualifies her knit grey skirt)

(d) it must match her black oxfords, as the blister caused by her navy pumps is still weeping (forget the navy dress)

(e) it must be suitable to today’s schedule of meetings: nursing rounds are casual (scrubs and trainers); the tissue retrieval policy meeting is populated by administrators (suits and ties only); the orientation of the medical fellows requires a collegial yet authoritative air (business casual); if she meets the family from yesterday’s consult, she must look approachable yet professional…and not too wealthy.

Just a few minutes short of eternity, Nadine settles on khaki dress pants, a
powder blue dress shirt with the sleeves rolled up, a silver locket and plain silver hoop earrings. She'll take her blazer along for the policy meeting.

Nadine checks herself in the mirror, thinking she should be nominated for the Fields medal in mathematics for her stunning combinatorial wardrobe analysis. That's when she sees it: a smear of dried mucus laced with raspberry jam on her right thigh. She flashes back to Friday. That was Ezra's first day back at daycare after two days out with an ear infection (his third in six weeks). The pain had made his sleeping fitful, exacerbating his separation anxiety. Nadine signed him in, handed his prescription to the teacher, put his lunchbox and extra clothes in his cubby, all while balancing Ezra's 30 pounds on her hip as he clung to her neck. At the door she'd squatted down to place him on the floor, cheerfully singing, "Mommy comes back, she always comes back, she always comes back to get you." At that point is crying reached such a pitch that all the other toddlers looked up from their frustrated efforts to establish anarchy. The teacher murmured reassurances as she pried Ezra's arms off Nadine's leg. As soon as she was free Nadine darted out the door, closing it behind her. She turned to wave cheerfully to Ezra as he stood pressed against the window, smearing tears and peanut butter on the glass. She could still hear him wailing as she pulled out of the driveway, weeping herself. Had she really walked around the hospital all that day decorated with baby snot and jam?
Nadine prays today will not be a repeat performance. Wetting the corner of a hand towel in the bathroom, she spot washes her pants, drying it with her hairdryer until only a faint pink splotch is visible. It will have to do.

7:20am. She has to leave RIGHT NOW.

“Lawrence, come help me dress the baby!”

Nadine races down the hall to grab pants, a shirt, a fresh diaper, and sandals for Ezra. When she comes back to her bedroom Ezra is already sitting up in the middle of the bed, blinking heavily, his cheek creased from the corner of the pillow.

“Hungry,” he mumbles.

Nadine sits beside him, kissing his hair, trying to soften the coming assault. The moment she lifts his shirt he arches, flops back on the bed and starts screaming.

“Lawrence, where are you?”

He comes in with a towel wrapped around his waist, a splotch of shaving cream behind his ear. He pulls Ezra onto his lap and talks him through every step, though it’s a bit like soothing a feral cat in a flea bath.

“Hey, little guy, what’s the matter? We are just trying to get you dressed. Okay, here comes the shirt.”

Nadine watches the halo of the neckband widen over his downy curls. She tugs gently when it gets hung up on his ears, and tries to avoid his flailing legs. Lawrence then holds Ezra’s legs down while Nadine quickly changes his diaper
and pulls up his pants before he can flip himself over onto his stomach. After strapping on his sandals (thank God for Velcro), she stands him up.

"There, all done! Now we're ready for school!"

Ezra raises his arms to be picked up and buries his head into her shoulder, bleating sorrowfully.

"Good grief. You'd think we were dressing him in a hairshirt, the way he fights," Lawrence mutters.

Nadine points to the pile of stuff at the door that needs to be carried out to the car: briefcase, purse, two lunch boxes, sippy cup, Ezra's clothes.

"Can you bring these out for me honey?"

While Lawrence pulls on a pair of pants, Nadine grabs the sandwich and carries Ezra to the car. She hands him the sandwich then leans over to buckle him into his carseat. Before she withdraws she cups her hands around his cheeks, wiping his tears with her thumbs, kissing his forehead. He smiles a peanut-butter-and-jelly smile, the insult of dressing already forgotten. Nadine flies out of the driveway.

7:36am.

Late.

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At 8:10am Nadine walks into the nurses' lounge, a bag of warm bagels and cold cream cheese in hand. Eight nurses are seated at the table, stirring whitener into their strong coffee. Most look to be between 40 and 55. Three are
Filipino, one is Vietnamese and two others are Indian. Maureen (the head nurse) and a younger male nurse are white. The only person wearing civilian clothes is Nancy, the social worker. Nadine recognizes some of the nurses from previous rounds, but she knows only Maureen and Nancy by name because they've been in some ethics consultations with her.

Maureen is talking to the Vietnamese nurse across the table. "I've heard some recruiters tell nurses they can't quit working at the hospital that recruited them, or they'll be sent back home. It sometimes takes years for the foreign recruits to understand that they won't get fired if they speak up or ask questions. They just do what the physicians tell them to do, even if it is clearly a mistake. When nurses feel vulnerable like that, they can't advocate for their patients."

"Well, that'll never be a problem on this floor," says a Filipino nurse with long straight hair and round glasses, "the doctors can't get us to shut up."

"Surely the union rep could work with new recruits," ventures Nancy, "to inform them of their rights."

"Oh, this was in the south," Maureen replies, shaking her head, "there was no nurses' union at this hospital. There wasn't a nurses' union in the whole state. Not that some of us didn't try. But truthfully most of the nurses just didn't care. For years there was a bidding war for nurses between the hospitals in the region. Signing bonuses of thousands of dollars. Nurses were getting paid so much they didn't see the point in unionizing. A lot of nurses would work for their initial
contract period, then shop around for a better package down the road. That mobility made organizing hard too.”

Nadine almost says, “I wish I could be exploited like that.” Then she remembers why she is there: they wouldn’t need ethics rounds if nursing weren’t heart-rending, exhausting and frustrating as hell.

“So, what’s been going on in oncology these days? Are there any cases you guys want to talk about?”

A bustling silence follows as the nurses pass around the bag of bagels and rummage for knives and napkins in the drawers beside the sink. Nadine pulls her yellow legal pad out of her briefcase.

“What about Lana?” asks the Vietnamese nurse.

Several others nod vigorously.

“Who’s Lana?” Nadine queries.

Maureen launches in: “Lana is an African-American woman, 24 years old. Diagnosed with Hodgkins lymphoma a year ago in January. She is currently five months pregnant. She started standard chemo in her hometown up north, but when she came to RH she reported that she didn't finish the whole course due to problems with her insurance. She is on Medicaid, so that seems unlikely. She probably didn’t finish because she thought it was a hassle.”

History of non-compliance, insurance issues, pregnant, writes Nadine on her legal pad.

“So how did she come to RH? Has she been here long?” Nadine probes.
“About six weeks,” Maureen continues. “She came in through the ER with pain and stiffness in her neck. They found a lot of nodes around her trachea, so she needed immediate treatment before they grew too large and compromised her airway. The initial plan was to give her radiation. Radiation poses less risk to the fetus, since it’s localized to her neck. But when they tried to simulate her, they couldn’t get a good angle because of pain and immobility in her neck. So the attending decided to give her some chemo that’s milder than standard chemo. It might not be as effective, but they want to be careful with the baby. Unfortunately she didn’t finish that course either. She complained of abdominal cramping; the doctors were afraid the chemo might be triggering premature labor. That’s when she was admitted as an inpatient, about six days ago.”


“It was probably just constipation,” chimes in the male nurse. “Cramping is a pretty common side effect with this chemo. A lot of patients have abdominal symptoms who aren’t pregnant.”

“True,” Maureen says, “but we need to be careful. The OB fellow comes up everyday to evaluate her. She was on a fetal monitor for several hours yesterday, but no contractions were recorded.”

“So what’s the plan now?” Nadine asks.

“I think we are going to watch her for another day or two, and then restart her chemo. They have to get some sort of treatment started soon. She has an open lesion on her neck now and the cancer will continue to progress if left
untreated."

Nadine turns to the rest of the group. "Have any of you been taking care of her? How is she coping with all of this?"

"She's not," pipes up the Filipino nurse with bobbed hair. "I took care of her yesterday. She sleeps all the time. And when she does wake up she's basically uncommunicative, except when she calls for more pain meds. We put her on Methadone, but she prefers IV Dilaudid."

"Before she became inpatient there were concerns that she was selling her medication," says Nancy, the social worker. "She was refilling her prescriptions too often."

_Withdrawn, drug-seeking_, writes Nadine.

"I doubt it. Considering how much she needs to control her pain, I'd say she's taking them all herself," says her Filipino nurse.

_Possible addiction_, writes Nadine.

"Could she be stockpiling them?" asks Nancy.

"You mean to kill herself?" Her nurse takes a slow, thoughtful sip of coffee.

"I doubt it. She has two or three other young kids. The only time I've seen her perk up is when she's talking with them on the phone. She teases them all the time, and gives them heck if they give their granny any trouble. They are in town here, staying with her mom."

_Potentially depressed_, writes Nadine. "Do they come to visit?"

"I think her mom has some mobility problems. I've never seen her up here."
Her kids can't visit because she's immune-compromised. They'd put her at risk of infection. Her poor dentition is a problem that way too. Her teeth are really rotten. But her boyfriend is with her all the time.” (Nadine notices several pairs of eyes roll toward the ceiling.) “He's from her hometown and he sleeps in the room with her. I don't know how long that can go on.”

“Well, at least she has some support,” Nadine says, trying to be optimistic.

“If she stabilizes and the attending decides to discharge her, housing is going to be a problem,” Nancy pipes up. “She can't stay with her mother because her kids are a danger to her health. And it seems like her mom has her hands full as it is. Lana has no money. She hasn't worked since her diagnosis. And her boyfriend quit his job to come be with her, so he's no help. I'll check into the hospitality apartments across the river, but the wait list is several months long.”

*Discharge planning issues*, writes Nadine.

“The OB fellow doesn't want to discharge her,” Maureen adds. “But it's really up to her oncologist. The OB department won't take her unless it looks like she's in labor. The fellow says she should be close by, in case she does go into premature labor. The chemo she's on, its investigational, so they don't know what to expect.”

“Why would they put a pregnant woman on an investigational drug?”

Nadine asks, trying not to sound horrified.

“Well, this drug regimen is supposed to be less toxic,” says Maureen. “The individual drugs themselves have been around for a while; it's really the
combination that's investigational. She didn't start chemo until well after the first trimester, so they aren't so worried about its effects on the baby. But it might impair the functioning of the placenta and that might somehow trigger early labor. They really don't know. I don't think anyone has ever used this regimen on a pregnant patient before. They just have a few animal studies to go on."

"Does the patient understand that the treatment is experimental?" Nadine wonders.

"There's an informed consent form with her signature on it in her chart," says her nurse.

"And really, what's the alternative?" Maureen continues. "Radiation isn't an option, standard chemo isn't an option, and doing nothing isn't an option."


"If I can get a letter from the OB fellow, saying it is medically necessary that Lana be near the hospital, I might be able to get her bumped to the top of the wait list for an apartment," says Nancy.

"He should be by around ten to check on her," Maureen replies.

"So, what's her prognosis?" asks Nadine, determined to try to get a big-picture view on the case before it disintegrates into a thousand details.

"Not good," states Maureen matter-of-factly. "The attending thinks she has refractory disease because she didn't get the full course of chemo initially."

"It's really a shame," says the Vietnamese nurse, shaking her head. "This type of cancer is often curable in young people like this, if caught early and
treated properly. It seems like we’ve been seeing a lot of these cases lately. Patients with curable disease who are non-compliant, and end up with bad outcomes. It’s such a shame.”

“H don’t know what she was thinking, getting pregnant again.” Exclaims one of the Indian nurses. “She was diagnosed just after the birth of her last baby. If she hadn’t gotten pregnant, and she’d finished her initial treatment, it’s possible that she could be in full remission right now. As it is she’ll be lucky if she lives long enough to deliver this baby.”

“Is that what her attending says?” Nadine’s skin starts to prickle as the full horror of the case begins to dawn on her.

“No,” says Maureen. “This attending is not one to come out and say something like that, even if he thinks it. He insists it is cruel to take away a patient’s hope by being so direct. Between you and me, I’ve never seen a patient with nodes like she has around her trachea last more than a few weeks without treatment. And even then…”

Silence blankets the room.

*Poor prognosis?* writes Nadine. The scratch of her pen sounds like an animal clawing at the door.

“Do you think the patient knows how sick she is?” Nadine asks, trying to capture the echoes of the unsaid. “Does she know that she is forgoing treatment for the sake of the baby, and that she might not live long enough to deliver it?”

“I doubt it,” says her Filipino nurse. “For one thing, she doesn’t really seem
that concerned about the baby. She didn’t get any prenatal care at all until she came here. She said it was because the hospital in her hometown doesn’t take Medicaid patients anymore, and the nearest county hospital was over an hour away. She couldn’t manage the trip with her kids. When you ask her about the pregnancy, or about her plans for the baby, she just kind of shrugs. The only thing that seems to motivate her is getting her pain meds.”

“Perhaps she would be willing to consider terminating the pregnancy, if she knew it might save her life and allow her to raise her other children,” Nadine suggests.

Some of the nurses shift in their seats, averting their eyes. “Oh bother,” she thinks. “I forgot which side of the 49th parallel I’m on. God forbid anyone mention the A-word.”

“This attending would never suggest an abortion,” the Indian nurse volunteers. “He’s a strict Catholic. And besides, she’s already pretty far along.”

“But I don’t think the Pope himself would let both this woman and her baby die, if there’s a chance her life could be saved if the pregnancy were terminated,” Nadine counters. The only thing more frustrating to her than religious dogmatism itself is imaginary religious dogmatism. “The Catholic theory of double-effect states you aren’t guilty of murder if, in trying to save the life of one person, you inadvertently but knowingly kill another. So as I understand it, it would be okay to knowingly kill a fetus if it is the only way to save the life of the mother.”

“Yeah, but the Pope is not the attending,” replies the nurse. The group
laughs, joking about who feels more entitled to play God, doctors or the Vatican.

"What about getting a psych consult?" Nadine asks. "She sounds like she might be depressed."

"The attending hasn't ordered one," her Filipino nurse states. "She always perks up when he comes in, and puts on a show of her discomfort to bamboozle more drugs out of him. He's only there for about ten minutes in the morning, when she's most awake. He doesn't see how she sleeps the rest of the day, so I don't think he realizes how lethargic she really is."

"Can you request a psych consult?" Nadine asks Maureen.

"No, but I can talk to the OB about it," says Maureen. "I think he's worried about depression too. He wouldn't order one without the okay of the attending, but he's in a better position to talk him into it than we are."

"I don't think she is drug-seeking," asserts the Filipino nurse with bobbed hair. "I worked a double shift a couple of nights ago and I took care of her. I think she is genuinely in pain. Around three a.m. I came in and she was crying. She didn't say much, but she was agitated and clammy and clearly uncomfortable. She can barely hold up her head so it is tiring for her to sit up. That's why she's always lying down. And that one lesion on her neck is weeping and inflamed. I think she needs the meds."

Nadine uses the ensuing pause to catch up on the twists and turns of the case. Physician objection to abortion (religious). Truth-telling. MATERNAL-FETAL CONFLICT!! she writes.
Nadine wants to get back to the issue of the patient’s prognosis and whether she knows about it, but she doesn’t want to push her own agenda. This is their time after all. The only time they probably have all month to talk about cases together. She is just about to speak when the male nurse pipes up, “What about Mr. J? I came in this morning and he was gone.”

“He started to crash last night so they took him up to the ICU,” Maureen says.

“But he didn’t want any of that,” retorts the male nurse. “He and I had a long talk about it a few days ago. He said he knew he was dying and he didn’t want to be put on life support. He’d watched his dad die in an ICU and he was adamant that he wouldn’t die that way. He just wants to be comfortable and awake enough to visit with his wife.”

“How old is the patient?” Nadine inquires, turning to a fresh sheet in her legal pad.

“56,” says Mr. J’s former nurse.

“Do you think he changed his mind about going to the ICU?” Nadine inquires.

“No way. He’s known all along that he was just buying time with treatment. He’s been sick a long time and he’s tired and ready to go. But I know how these things happen. The attending isn’t around at night, and the night nurse doesn’t know the patient very well because he sleeps most of her shift. He starts to go downhill so they call the code team. And the head of the code team, some fellow
who's never seen the patient before, stands over him with a tube in his hand
asking, 'Do you want help breathing?' Well, what's the patient going to say? He's
lying there gasping. It's not really a fair question, is it? So they tube him and up
he goes to the Factory."

"The Factory?" asks Nadine.

"Yeah, you know, the ICU," says the male nurse. "It's all about input and
output and systems and monitors up there. Those patients are just extensions of
the machines. They're just manufacturing death up there, at least for the
oncology patients." He pauses. "Sorry. I've seen too many of my friends die in
ICUs."

"I don't think he was intubated last night," soothes Maureen. "He had an
arrhythmia, so they took him up to the ICU to watch him. But he's very anorexic
and sooner or later he'll get an infection, and then his airway will be at risk."

"Do you know if his wishes were written down anywhere? Does he have a
living will? Or even better, is he DNR?" Nadine ventures hopefully.

"I know he isn't DNR," says Mr. J's nurse. "This attending never makes
patients DNR unless they specifically ask for it. Very few patients think to do that,
particularly when their physician is always blowing sunshine. I'm sorry, but it's
true."

Nancy interrupts, "Mr. J is a Jehovah's Witness, and I know he had one of
those forms in his chart requesting no blood products. I didn't look at it closely,
but sometimes those forms also address end-of-life issues."
At that moment the door of the lounge swings open. Another Filipino nurse leans in: “Bernie, I need to change Mr. H’s bed linens. Can you come give me a hand? He never tries to bite you.”

“Oh he tries,” says Bernie pushing back his chair. “It’s just that I have longer arms than you do so I can stay out of range.”

The rest of the nurses begin wadding up their napkins, cramming the rest of their bagels into their mouths. The day’s labor has been deferred long enough. They take turns at the sink, rinsing their coffee cups. Nadine looks down at the pad in front of her.

*Living Will?*

*J.W.*

*End-of-life care options? Hospice?*

*Blowing sunshine?*

She crosses out the last line, and looks around at the suddenly empty room. She tries to decipher the words on the coffee cups drying on the counter. They read like the nomenclature of exotic Amazonian insects: Zoloft, Zyban, Zantec, Lamisil, Prozac.

It occurs to Nadine that she’s just spent an hour determining what the nurses already knew: there is an ethical dilemma. More like a morass of ethical dilemmas. All the suggestions she’s offered are either structurally impossible or alienating. She suddenly wonders if these rounds are worthwhile after all. She’s always believed in empowering people to come up with their own solutions by
asking probing questions and facilitating open discussion. But all she’s done this morning is delineate the powerlessness of these capable professionals to really help their patients. Perhaps she should suggest to Maureen that next month they get their bagels from their friendly neighborhood drug rep, and have a simple staff meeting, instead of ethics rounds.

"Thanks Nadine," says Maureen as she comes back in the room to gather her papers. "I’m going to pull the depression checklist from on-line and get the OB fellow to look at it this morning when he comes to round on Lana. Maybe he can cajole the attending into getting a psych consult if he sees her symptoms in black and white. I’ll look into getting her kids up here for a visit. It should be okay if they are gowned and gloved, and we limit it to one child at a time for fifteen minutes. We can enlist the help of the boyfriend to coordinate it. If she gets more engaged in the world again, maybe she’ll become more interested in her pregnancy and her treatment. At any rate, she needs to see her kids before she gets any sicker. She’ll end up in the Factory for sure if those nodes start invading her airway. And they don’t let kids up there ever."

Nadine brightens, making one last plug, "Well, let me know if you want back-up on this one. You can always call a formal ethics consult if you get stuck. You know the doctors on the ethics committee are really committed to truth-telling. They’d argue that the patient should be told her prognosis and treatment options straight up. Getting the attending in a room with some of his colleagues might make him rethink his position."
“We’ll try the backdoor approach first, before we bring out the big gun. But I’ll keep you posted,” Maureen promises.

“Okay. Hey, I was going to go up to the ICU anyway, so I’ll look in on Mr. J. I’ll call you later to let you know what I find out,” says Nadine.

“Great, I wasn’t sure if I’d have time to do that today. We’ve been running at one hundred percent capacity down here, so it’s ‘out of sight, out of mind’ when our patients get transferred out. It’s a shame they moved him, though. He and Bernie had become very close.” Maureen turns to walk toward the nurses’ station. “Thanks again, for coming. And thanks for the bagels!” she calls back.

Nadine stands for a moment on the threshold of the ward. Nurses move from room to room; orderlies maneuver dialysis machines and food carts and mop buckets down the hall; medical students cluster in twos and threes, flipping through charts and debating etiological theories.

“How can so much activity produce so little noise?” she wonders. Anywhere else the bustle would amount to a dull roar; but in these halls, it is merely the muffled drone of modern medicine at work.

Nadine turns toward the main elevators. Other wards branch off left and right: GYN, GI, Transplant, Cardiology. Each has an identical floor plan, identical industrial beige paint with burgundy accents, identical decorative prints of still ponds reflecting lush evergreens. Nadine pushes the down button and looks out the floor-to-ceiling window that faces the elevators. Rush hour is over but traffic around the hospital is always brisk. She imagines what a model of the hospital
might look like: hundreds of 12x12 rooms stacked thirteen stories high; a body in each bed flanked by the accoutrement of illness (IV polls, bedpans, hovering relatives): the architecture of affliction.

Yet the inimitability of each patient's suffering is sealed within their skin, beyond the skill of even the most gifted craftsman.

Nadine leans her forehead against the cool glass, thinking of Lana. How must it feel to be dying with a baby growing inside you? Nadine can't imagine. She knows the opposite. She knows what it feels like to walk the streets, to shop, to talk on the phone, to perform the courtesies of daily life, while carrying a dead baby inside her. That's what she did when her daughter Aria died in utero and she waited two days for the surgeon to deliver her. But how must it feel to be leaving two (or was it three) other children behind, in the uncertain care of a boyfriend and a disabled mother? Who can blame Lana for checking-out early? Maybe her attending is right. Maybe the truth is too cruel to tell. How would it help her now?

And to think her cancer was potentially curable. How could the nurses be so judgmental? Was she really "non-compliant" with her initial treatment? Only the poorest of the poor get Medicaid, so it's unlikely she had a car to get to her appointments. What was she supposed to do with her kids while she was at the hospital getting chemo? If her boyfriend was working, who was around to help take care of her when the drugs made her sick? This woman could be dying from lack of childcare, thinks Nadine, turning from the window, suddenly stricken
herself with vertigo. And here we are worrying about whether she’s hooked on her pain meds, blaming her for getting pregnant again. Maybe her boyfriend asked her to have his child, and she wasn’t in a position to say no. Maybe having babies is just something she enjoys. Maybe she was using birth control, and it failed. If she had to travel an hour for prenatal care, how far would she have had to go to get an abortion if she’d wanted one?

The elevator hums its arrival. The vertical lips part. Nadine steps inside the cavity and is swallowed.

... 

As Nadine passes the ICU waiting room, a dozen eyes scrutinize and release her. No white coat, no stethoscope, no sensible shoes to comfortably stand all day, no trailing medical students: she’s not the one they are looking for. She’s not a doctor. She’s just another cog in the system, another buffer between them and their loved one’s physician, the One they are counting on to heal their sick. Nadine checks her watch. 9:15am. Fifteen minutes until visiting hour starts.

At the double doors she swipes her ID badge through the reader on the wall. The doors swing open toward her, revealing a perfect panopticon. Nine rooms with sliding glass doors are arrayed in a semi-circle around the central workstation. From any point in the nurse’s station you can see into every patient room. If your eyesight is especially good, you can even read the monitor that guards the left shoulder of each patient. Every bed is full, as usual. An obese African-American man lies semi-prone with his head back, jaw slack, saliva
collecting in the hollow of his neck. An elderly white man on a ventilator appears
to sleep while the machine thrusts air into his lungs, his gown gaping, revealing
dark nipples and burns on his chest. A nurse vacuums little red pebbles from the
throat of a young woman whose skin is too yellow to determine her race. A
Hispanic teenager with one leg enclosed in a metal cage from toe to hip, moans
and tosses his head from side to side as two nurses restrain him from pulling out
his lines. A middle-aged white woman serenaded by the whirring, beeping chorus
of a cluster of machines sits frozen, her finger stuck in the corner of her eye, as if
in the act of removing some sleep she’d forgotten how to drop her arm. In Bed
927 sits the skinniest man Nadine has ever seen, his gown too flimsy to conceal
the precipitous angles of his collarbones, the ellipses of his ribs. He looks bored
and irritated as he fiddles with the oxygen mask over his face.

The knot of white coats at Bed 928 tells Nadine morning rounds are still
grinding on. Nadine nudges Lenore, the social worker, and whispers, “Have they
done Jessop yet?”

“No, he’s next.”

Nadine walks over to the narrow desk outside Mr. J’s room and picks up
his chart. She flips open the cover of the legal-size blue binder. DNR orders are
usually placed on top for easy access, but it isn’t there. Under the “advance
directives” tab there is a Jehovah’s Witness living will. It contains the usual
proscription against blood transfusion but it also prohibits aggressive treatment if
the patient’s condition is terminal or irreversible. Nadine scans the rest of the
document; it appears to be properly witnessed and legal.

“Okay,” says Dr. L, wrapping up bed 928, “so he’ll get dialysis today and we’ll wait for his labs to confirm the pseudomonis. I’ll ask neurology how long they need to declare this PVS. Once we have that, we can start preparing the family for the next step.”

The group shifts about five feet to the right. Three med students are in short white jackets, the ICU fellow is in scrubs with a long white coat over top, the nutritionist is in navy scrubs, and the nurse in purple scrubs. Dr. L is immaculate in a white shirt and red tie with a subtle striped texture, white monogrammed coat (M.D. Ph.D) and three pagers on his belt. As Dr. L rolls his chair over in front of the glass doors of room 927 (everyone else is standing), he notices Nadine hovering on the periphery.

“Hello Nadine, should I be alarmed or honored by your presence?” Dr. L is a frequent flyer of the ethics consultation service.

“I got a heads up about this patient from the oncology nurses who’ve been taking care of him for a few weeks. They asked me to come up and look in on him.”

Well, they hadn’t asked exactly, but she’d volunteered, which is almost the same thing.

“Great, welcome.” He turns to the medical students. “This is one of the clinical bioethicists. You’ll undoubtedly be seeing a lot of her on this rotation.”

“Got a few cases coming down the pipe do you?” Nadine asks.
“Oh, always. You know me, the master of the purge,” he jokes. “Purging” is how the ICU doctors describe getting patients off the unit by withdrawing treatment from “futile” patients or moving the chronic cases to other facilities. “We’re expecting some overflow from the Surgical Intensive Care Unit this week.” “Well, you know our number. I’m on call this week, so just page me and I’ll see what I can do to help.”

“All right. Jacob. Give us the story on Mr. J.”

As usual, Nadine only grasps fragments of the student’s display of technical knowledge of human organ systems and their sundry mechanical failures. From what she can gather, the patient was transferred to the ICU last night with shortness of breath. He has been treated for ALL (leukemia) on a research protocol but he’s continued to “progress.” Fatigue and severe anorexia are his most troubling symptoms at the moment, but in his weakened state he is likely to bleed internally. Pneumonia may also be developing on the right side.

Nadine’s attention starts to waver, so she lets her eyes rove around the group. Dr. L’s back is to the patient, and everyone else is either looking at the chart or at the presenting student. Quite by accident, Nadine’s gaze lands on the patient. He is six feet away behind the glass door, frowning at her. Nadine tries to smile but it freezes on her face when his expression doesn’t change. She quickly looks back at the medical student, pretending to be totally absorbed in his explication of saturated whatsits and negative cultures of blah-blah-blah.

“So what do you recommend, Dr. K?” Dr. L asks Jacob.
"I think we should start with some antibiotics, and a transfusion to get his counts back up. And of course, nutrition is a priority. Whatever we can do to keep him from losing any more weight so we can build him back up for another round of chemo."

This was her chance.

"Dr. L," Nadine interrupts. "Some of the nurses downstairs expressed concern about his transfer to the ICU because he told them he didn’t want aggressive treatment to prolong his life. Apparently he’s said this throughout his hospital stay, repeating it again just a few days ago."

"Dr. K, is this true?" asks Dr. L.

"Uh, I haven’t actually spoken with the patient yet," Jacob stammers. "I was just going from his labs and his admission report from last night. I thought I’d meet with him after rounds."

"I checked his chart," Nadine persists, "and he has a living will. It’s not the conventional form, it’s one used by the Jehovah’s Witness community, but it looks legal. It states that he refuses all blood products, as well as aggressive measures if he is deemed terminally ill."

"He didn’t get any blood last night did he?" asks Dr. L., alarmed.

"No sir," Jacob states. "And he was always conscious, so I’m sure he would have stopped us if we’d tried."

"Okay, well this changes the plan significantly then, doesn’t it Dr. K? Now what do you recommend?" asks Dr. L.
“Um, I guess we’ll have to clarify what the patient wants, since he’s likely to require intubation if the pneumonia gets any worse,” Jacob ventures.

“Dr. L, what’s the patient’s prognosis?” Nadine lowers her voice, uncertain how soundproof the glass doors are.

“Very poor,” replies Dr. L at full volume, “but blood might buy him a few weeks. Without blood, it’s probably a matter of a few days. With his platelet count he’s likely to bleed out before the pneumonia gets real serious.”

“Do you think the patient knows this?” Nadine inquires.

“I doubt it. His oncologist is not in the habit of giving bad news. He’ll give patients chemo on the way to the morgue. There’s always one more protocol to enroll in, one more phase one drug to try.” He turns back to the student. “Okay, Dr. K, you and I will talk to the patient after rounds and come up with a plan. Actually, you’ll talk to him and I’ll back you up. You need to learn how to deal with Jehovah’s Witness patients.”

“Remember,” says Nadine, taking in the rest of the group, “that a living will doesn’t come into effect until the patient is declared both terminally ill and incompetent to make medical decisions. Until that point you need to talk with the patient about his wishes, and not just assume he will refuse things because he has an advance directive. He can revoke or alter his living will at any time. Maybe he’s changed his mind, if not about the blood, then maybe about the possibility of intubation.”

As the group moves on to the last bed, Dr. L turns to Nadine and mutters,
“I hate talking to patients. That’s why I went into anesthesiology, so I wouldn’t have to talk to patients. Families, families I can deal with, but it’s so rare that we have a patient who is alert and oriented. It’s not my strong suit."

“Well, you can take the living will out of the chart and use it to structure the conversation,” says Nadine. “That’s really how these documents are most useful, as a springboard for discussion. They are so general, how you implement them entails a lot of negotiation.”

Nadine decides to stay to hear the presentation of the last patient, since there’s a chance she might be hearing about it later in the week. But before the next student begins, Jacob pipes up, “Um, Dr. L. If we can’t intubate him and he starts to experience air hunger, what option do we have?"

Dr. L gestures in the air like he’s turning an invisible doorknob, “Crank up the morphine. It’s not our usual practice. Usually the patient is intubated and we just gradually turn down the volumes until the patient stops breathing. Terminal sedation with morphine makes me a little nervous, I mean legally, especially in this state. It sometimes can take so much morphine that an autopsy shows a morphine overdose as the primary cause of death. But as long as the ethics police says it’s okay, we can do it. We just write ‘titrate for comfort’ in the chart and watch the patient closely.”

Nadine is just about to scold Dr. L for calling her the ethics police in front of his impressionable students, when another young doctor comes up. Nadine recognizes him from a consult a couple of months ago.
“Dr. L, I have a question for you. You’ll like this one too,” he says, nodding at Nadine. “A patient just came in from neurosurgery. They found this really aggressive cancer, deadly. The patient is a physician and he was awake during the surgery. He was all nice and grateful to the surgeon, but as soon as he left, he asked one of the interns to give him a shot of potassium. He said, ‘I know what this is. I know what the cancer is going to do to me. I’ll lose my mind, I’ll be in agony, and I’ll end up a drooling vegetable before the end. Please kill me. I’ve seen it before. I can’t go through that.’"

Dr. L just shakes his head, nonplussed. “It’s just like paraplegics who beg to be euthanized when they are first told that they will never walk again. My suggestion is that you sedate him, give him a good night’s sleep and then bring his family in. Right now he’s in shock. I can guarantee he won’t say anything like that with his wife and kids standing next to him.”

Nadine is about to argue with his analogy. A paraplegic can have an excellent quality of life once he has adjusted to life in a wheelchair. But a man with an incurable brain cancer who faces an excruciating death, that is another matter. Using his family to coerce him into being optimistic seems cruel. But at that moment, Nadine’s PDA alarm goes off, deep in her briefcase. She’d almost forgotten about the tissue-banking meeting. Active euthanasia isn’t legal in this state, so it would be a purely academic discussion anyway.

“I need to go, Dr. L, but let me know if you need a hand up here. I’ll call you later to see how it goes with Mr. J.” She turns to Jacob, who looks a little
pale. "Good luck."

Nadine drops a couple of her business cards at the nursing station on her way out. Through the narrow windows in the double doors she sees a throng of people waiting to be let into the unit. She pushes the release button and as the doors open an anxious tide of spouses, children, friends and neighbors of the sick streams into the Factory. Visiting hours have begun.

...

Nadine makes her way to down to the third floor, over the skybridge, past the cafeteria, where she gets diverted helping a young woman and her grandfather find their way to the GU clinic, then to another bank of elevators and up to the Tower, the suite of administrative offices on the eleventh floor. By the time she arrives she's broken into a sweat.

It seems like dusk in the president's conference room despite the a.m. reading on the wall clock. The room is paneled in dark wood, with burgundy carpeting and a walnut-stained table. The light fixtures use regular bulbs, not fluorescents as in the rest of the hospital. There are about twelve people around the table from a variety of departments: patient admissions, information technology, patient advocacy, the legal office, the office of clinical research, pathology, and Lydia, the director of the clinical bioethics program and Nadine's supervisor.

**Dr. G [Vice President of Research]:** Okay. Hopefully this is the penultimate draft of this thing before we launch January 1. There are a couple of issues with
the form that still have to be worked out, as well as some implementation details. Darrel, why don’t you tell the group what you and I were talking about yesterday?

**Darrel** [hospital legal council]: Sure. As you know, this blanket consent form gives patients the opportunity to consent to the storage and use of their surplus tissues for future research.

**Dr. G** [interrupting]: This only covers research that hasn’t yet been imagined. Any current research on tissues requires its own protocol to go through the IRB. Sorry Darrel, but that’s been a point of confusion.

**Darrel**: Thanks, Gerry. Basically, this will systematize what researchers have been doing informally for years. My understanding is that up to now, tissues have been stored here and there in lab refrigerators, and used at the sole discretion of the researchers. Is that right Dr. M?

**Dr. M** [pathologist]: That’s right. It’s been very ad hoc. So this program will ensure that all tissue samples are banked according to a standardized procedure. They’ll be collected systematically from the operating rooms, stored in a central location and catalogued and tracked through a central database.

**Darrel**: Right. And up to this point patients haven’t given formal consent for the use of their tissues, or their patient information, for research. Now originally this form gave patients a number of options. We first thought we’d give them some choice about what kinds of diseases their tissues could be used to research. So if somebody with diabetes only wanted their tissues used for diabetes research, they could make that known. But then we talked to some of
the bench scientists who pointed out that a lot of their research is so basic—you know, about processes at the level of the cell—it is hard to categorize by disease. So we scrapped that option.

We also gave patients a choice about future contact. Right under the section where it states the patient won’t be entitled to any profits from patented materials derived from their tissues, we ask the question: ‘Do you wish to be recontacted if significant health information is discovered about you through this research?’ They can mark the box ‘Yes’ or ‘No’ and their choice is recorded in the sample database.

Now I have three problems with this. First, what is “significant health information”? I think that’s debatable. Second, if the patient indicates ‘Yes, I do wish to be recontacted,’ does this obligate us to recontact them? I think the logistics of recontacting someone with information about some trait that is discovered maybe years or decades after their original biopsy, could be staggering. A lot of the samples are gathered through screening programs, so these people might not even be patients here or have any significant ties to the institution. So tracking these people down could impose a significant burden for the hospital. Third, if we do discover some genetic trait, couldn’t that have repercussions not just for the patient but for their whole family? As you know, genetic screening poses a lot of difficult ethical challenges, and conveying this information is a very sensitive process. I said to Dr. G that I think this option could be a can of worms that we just aren’t prepared to handle.
Lydia: It might be helpful to know the background of this particular option. The whole push to formalize consent for future tissue research began with a case that was brought to the clinical bioethics service last year. One of our bench researchers called me up, and told me that he had found a genetic anomaly in a sample he was working with. It wasn’t something he was looking for; it literally jumped out at him. This anomaly could have devastating consequences for the patient’s future offspring. After some deliberation with the ethics committee I suggested that he convey the information to the woman’s primary care physician, so that someone she knew and trusted could give her the information. This seemed like a better route than having some random stranger call her up out of the blue to give her the information. As it turned out, this woman didn’t plan to have any children, but she wanted to share the information with her brother, who was planning to get married. So, you are right, it does have implications for the whole family, and we never found out what happened. Some people would think twice about getting married to someone they couldn’t have children with. But based on this case, we decided people should be given the choice up front to be recontacted or not, since as you say genetic information might have ramifications for their health, their insurability, their employability, as well as their family relationships.

Darrel: I understand that, but we could continue to inform people on a case-by-case basis, you know, when urgent issues like that arise, without obligating ourselves to recontact everyone every time a researcher discovers the
gene for hairy ears or dimpled thighs. I think we should drop this option. It's a
blanket consent. Either they agree to let us use their tissues and information for
research, or they don't. That will make it cleaner and easier for everyone
involved.

**Dr. G:** I think that is a good compromise. And it is more manageable given
the resources at our disposal. I think the situation your described Lydia is pretty
rare, and we shouldn't set up a rule that is really for the exceptions. Is everyone
agreed?

**Lydia:** As long as we can deal with the exceptional cases as they come
up, I think it is fine. Just make sure the researchers know they have that option.
And you can refer them to our service.

**Dr. G:** Great. So we'll strike that option from the form and the patient will
just indicate yes, you can use my tissues and information, or no you can't. So
what about the logistics?

**Dave [information technology]:** That streamlines implementation
somewhat. Now as I understand it, the consent will be completed upon
admission to the hospital, or before a screening or out-patient procedure takes
place. The admissions clerk will enter the patient's yes or no into the system at
that point.

**Donna [patient admissions]:** That's right.
Dave: But what happens if a patient changes his mind. Let’s say he has a particularly rare disease or tissue type, and his doctor asks him to reconsider his decision. How does that change get into the system?

Donna: The patient can come back to patient admissions and fill-out a new consent, and then the clerk can change the value in the system from no to yes.

Lydia: Wait a minute. We don’t want a situation where physicians might be tempted to coerce patients into changing their consents.

Dr. M: That’s unlikely since we designed the database so that every sample is assigned a catalogue number and all other identifying information is stripped from the sample. Only the samples with yes values on the consent come up when a researcher enters his request for tissue samples. So if a researcher wants to look at mesothelioma cells, the patients who did not consent to the use of their tissues, their samples will not even be listed. When the researcher comes to the bank to pick up the samples he’s ordered, they are marked with the catalogue number, not the patient number. So it would be impossible for a physician to know from the database or from the samples which of his patients consented and which did not.

Lydia: But the possibility for coercion is still there, isn’t it? Couldn’t the physician look at the written consent on the patient’s chart?

Dr. M: That’s right. But that would require a lot more effort on the part of the researcher.
**Donna:** And having the consent values entered at patient admissions, that also helps to diminish the possibility of coercion because it isn't the physician's research nurse entering the values.

**Dave:** Just to get back to the consent change issue. Could we put a sentence on the bottom of the last page that any changes to the consent should be submitted to patient admissions?

**Donna:** That's fine. I'll make sure the clerks have a few extra forms at their workstations, in case people want to redo them. Why don't you put the Patient Admissions main number down there as well, so people can call me if they have questions. I can always refer them to Dr. G or Dr. M if they have technical questions about the storage and use of the tissues.

**Dr. G:** That's easy enough to do. Is there anything else?

**Nadine:** Yeah. I just have a legal question for you Darrel. It's about the financial disclaimer. Uh, last month you and Lydia did grand rounds to educate the physicians about this new consent form and the tissue cataloguing system. You talked about the financial disclaimer, the statement that patients will not receive any portion of profits made from products derived from their samples. You said this disclaimer is based on the ruling from Moore vs. the Regents of the University of California. In that case, as I understand it, the patient was not given a share of the hundreds of thousands of dollars the researchers made from the cell-line they developed from his tissues. But in your talk, you mentioned that the ruling did not make whole lot of sense, since it basically argues that other people
can treat your body as property and profit from it, but you can’t enjoy those profits yourself. And you also said this was a lower court ruling in another state and therefore didn’t have much authority outside that jurisdiction. So if that is the case, what is the legal basis for the disclaimer, here in this state?

**Darrel:** Moore is really the only precedent we have. A Supreme Court ruling carries the most weight, of course, and certainly federal and state courts carry more weight, but in the absence of any other rulings, even the decision of a lower court in another state can suffice. It might not be a good decision, but it is the only one we have, and it works for us.

**Dr. G:** It’s a good thing we’ve already moved on this issue because from what I hear, the feds are going to make consents for the use of genetic materials in research mandatory in the next few years anyway. And you wouldn’t believe the offers we’ve had from private tissue banking companies. These guys are scooping up all the tissues they can get their hands on, and then they charge researchers for access to the samples. Of course they also take a cut of any profits from patented materials derived from the tissues in their banks, so they get you coming and going. Luckily this hospital has the infrastructure and the space to handle our own storage and collection, so our patients’ tissues stay in house and our own researchers have unfettered access to them, and the profits can go back into our clinical and research programs. Okay, so Lydia, if you can make those few changes to the form and email it around to everybody for a final read over, I think we’ll be ready to go. Dave, we can meet with your group at IT
next week to talk about the readiness of the catalogue and how it will interface
with the patient admissions system. Are there any other issues we need to
address?

Nadine looks down at the legal pad in front of her. The top sheet is
covered with her scrawling notes:

_Significant health information: Is this category really so subjective? Can’t
we live with a little uncertainty to keep this option on the form? This is the only
agency donors get to exercise regarding the use of their tissues, and the only
place where ownership gets problematized. Identifying which patients want to be
told significant health information discovered in the course of research is the
whole reason this consent was put together! What about patient agency? The
original intent was to give patients more power over the use of their tissues and
health information. Now the sole function of the consent seems to be to provide
legal and regulatory cover for the hospital. Not so different from how consent to
treatment is treated._

_Fiduciary duty of researchers: Doesn’t this extend to informing subjects of
significant findings, even on patients’ tissues?_

_What happens to the tissues of patients who don’t consent? Are they
stored anyway, hoping they will change their mind? Are they incinerated? Sold to
one of these tissue banking companies?_

_What happens to all the tissues currently in storage? Are those tissues
grandfathered into the system?_
Isn’t it more coercive to do the consent upon admission to hospital?

Patients coming to the hospital are sick and scared. They have innumerable forms to sign when they first arrive; forms they must sign in order to get treatment. Will they even read this form? Will they understand they really can say no and it won’t affect their treatment?

Why is bad law dictating our policy? Why should the hospital take all the profits from genetic patents? Why are we patenting DNA in the first place?

Dr. G: Okay then. Thanks everyone!

Nadine shoves her legal pad back into her briefcase, thinking of Antoine de Saint-Exupery’s little prince, and his encounter with the businessman who spent all day looking at the ledger on his desk, counting and recounting the stars he owned.

And what good does owning the stars do you? Asked the Little Prince.
It does me the good of being rich. Said the businessman. And what good does it do you to be rich?
It lets me buy other stars, if somebody discovers them. How can someone own the stars?
To whom do they belong? Retorted the businessman grumpily.
I don’t know. To nobody. Then they belong to me, because I thought of them first. And that’s all it takes?
Of course. When you find a diamond that belongs to nobody in particular, then it’s yours. When you find an island that belongs to nobody in particular, it’s yours. When you’re the first person to have an idea, you patent it and it’s yours. Now I own the stars, since no one before me ever thought of owning them.
That’s true enough, the little prince said. And what do you do with them?
I manage them. I count them and then count them again, the businessman said. It’s difficult work. But I’m a serious person!...
That’s amusing, thought the little prince. And even poetic. But not very serious. The little prince had very different ideas about serious things from those of the grown-ups. “I own a flower myself,” he continued, and three volcanoes that I rake out every week. I even rake out the extinct one. You never know. So it’s of some use to my volcanoes, and it’s useful to my flower, that I own them. But you’re not useful to the stars. (Saint-Exupery 2000)

This hospital is the businessman, thinks Nadine, staking its claim on the genetic frontier. Only these stars flow through our veins, bloom in our breasts and metastasize in our brains.

“Darrel!” Nadine catches up with him as he is heading out the door. “Just out of curiosity, how much money has the hospital spent so far on patents for genetic material?”

“I think the figure I saw was almost two million.”

“And how much profit for the hospital has been generated from these patents?”

“None so far, but the science is still so young. It could take years before people even figure out which cell lines are useful. So it’s more of a long term investment.”

“Thanks Darrel. See you at Laura’s birthday party!”

Two million dollars and not a single profitable patent. How many hours of babysitting, how many round-trip taxi rides to the hospital could two million dollars cover for the Lanas of this country? Nadine dismisses this thought. What’s the point? As her sister the MBA likes to say, “That’s a system problem, not an ethical problem.”
It is 11:15 am when Nadine sits down in her cubicle for the first time. Reflexively, she turns on her computer and opens her email.

_Hm. Twenty-two new messages. Oh good, responses from the taskforce on my latest changes to the futility policy. Of course, we aren't supposed to call it the "futility policy." It's proper title is "The Determination of Medically Inappropriate Interventions Policy." Hardly poetic. But the taskforce decided when it first wrote the policy five years back to avoid the word "futile" because it is so controversial and because it is impossible to define. When I asked for clarification on this point, one of the physicians on the ethics committee retorted, "Futility is only determinable at autopsy. Until the moment of death, it is impossible to know whether a given treatment was really futile or not." Okay, fine. So instead of defining futile treatment, the policy takes a procedural approach. When a patient requests a treatment that his physician thinks is inappropriate, a panel of medical experts assembles to render a binding decision on the matter. If the panel agrees that the patient's request is inappropriate, the policy outlines a process for withdrawing those treatments. It's all very tidy and in compliance with state law, of course, to protect physicians from future liability.

The whole endeavor stems from a general feeling at RH that the pendulum has swung too far away from medical paternalism. Some patients, desperate for a cure, seem to feel entitled to demand improper and even harmful treatments. I understand how frustrating it must be for a physician to confront a
family demanding CPR for a patient in the grips of some irreversible disease process. In that case, chest compressions are torturous, as well as pointless. But I worry that “medically inappropriate” is too broad a category. Couldn’t any resistance to a physician’s treatment plan qualify as “medically inappropriate”? What if a patient wanted access to a phase one trial as their last option for treatment? The physician could argue it is medically inappropriate, given that it is unlikely the patient will experience any benefit from the trial. But surely this request doesn’t qualify as “futile” because phase one trials are designed to test toxicity not efficacy. Very few participants receive benefit from those trials but people don’t generally call them futile.

And what if a patient refused a treatment that his physician considered appropriate? Under this policy, could a patient be forced to comply if the panel of experts agrees with the doctor that forgoing treatment is “medically inappropriate”? I stopped taking that anti-nausea drug when I was pregnant because of the side effects, even though my OB insisted it was medically necessary to control my vomiting. Would my demand to switch medications be considered “medically inappropriate”? Nobody else seems concerned about the ambiguity of this language. Not Lydia, not senior members of the ethics committee and not hospital legal counsel. The phrasing was pretty much settled when I took on the task of revising the policy. And my goal in taking on this project was not to argue the linguistic subtleties.
I wanted to make the process more patient-centered. I inserted steps into the procedure to ensure that patients and families are fully consulted and given every possible opportunity to make their case. I even wrote a companion to the policy for patients and families that explains the process and their roles in clear terms. I'm not exactly in a position to challenge the whole enterprise. I don't think Lydia would be too pleased if I asked at our next meeting whether this policy isn't just a way to cover the asses of physicians who didn't know how to communicate with patients, or to discipline patients into compliance without really dealing with their suffering. Better to keep moving around commas and fixing grammatical glitches. More than anything, I want this thing off my desk so I can focus on my own research.

Okay, now to prepare for fellows' orientation. Lydia wants me to open the session with the "Ethics 101" lecture we usually do to introduce people to the clinical bioethics service. For years, Lydia has used the same one-page summary of ethical models. She had arranged it chronologically, starting with casuistry, then utilitarianism, then Beauchamp and Childress' principles of biomedical ethics, and ending with feminist and narrative ethics. It's basically a list of bullet-points with one-line definitions of each ethical model or principle. It doesn't really do justice to how the models differ epistemologically and historically. So I decided to redesign the "Ethics 101" handouts into separate "bioethics cheat sheets." It seemed like a good idea at the time.
The utilitarian model is the easiest to represent visually. I found this clip-art image of an old-fashioned scale tipped to one side. Lydia and I decided to title this sheet “Consequentialism” as utilitarianism seems too loaded. Plus, people in the medical field understand the idea of weighing consequences in terms of benefits and burdens because it’s just like the process of formulating a treatment plan. Whatever treatment yields the greatest benefits and the fewest harms is the one recommended. That’s probably why medical students gravitate toward this model. But maybe the scale is too simplistic an image. If you are making a decision about a particular patient with a particular disease, maybe there are only two sides to weigh. But ethical dilemmas are more complex. Any course of action can have consequences for multiple parties: for the patient, for the family, for the physician, for the institution, for society. Maybe another picture would be better. Maybe something like an abacus, to represent the various stakeholders in the decision, to make the process of weighing appear less black and white. But that’s just another arithmetic image. Ethical decision-making isn’t like accounting, is it? It’s much more nuanced and subtle. Well, I don’t have time to redo it now. I’ll just have to add some questions to the bottom to make them think about the wider consequences of any given decision.

The cheat sheet on ethical principles has been a real pain. I came up with the idea of having a puzzle with a principle emblazoned on each piece. I supplemented the Georgetown mantra (autonomy, beneficence, nonmaleficence
and justice) with principles from more recent trends in bioethics: family integrity, professional ethics, multiculturalism, etc. But it looks so flat.

What I really have in mind is a more complex puzzle than the ones you can buy off the shelf at Walmart. Those puzzles fit together a certain way, to make one, two-dimensional picture. What I’m really after is something more like the puzzles I saw in a magazine whose pieces fit together multiple ways, in two and three dimensions. And they come in an unmarked box, so you couldn’t tell at the outset what the end picture is supposed to look like. I love the idea of blindly trying to fit together the different pieces, groping through trial and error toward a coherent picture. That’s how principlism works. Depending on how you prioritize the different principles the answers you arrive at can be radically different. Most people gravitate to certain principles, particularly autonomy and beneficence, but take for granted that their application is straightforward and unproblematic. Confronting them with the notion that there are multiple ways to configure principles, is appealing. But I don’t have several hundred dollars to spare (those puzzles don’t come cheap) and my spatial perception skills are so poor, I’d never in a million years be able to solve one to demonstrate with. So what I’m left with is a conventional, two-dimensional puzzle that only fits together one way and makes one picture. That contradicts my whole message. Whatever, it will have to do.

I promised Lydia I’d redo the title. My original title for this cheat sheet was “American Principles of Bioethics.” I was trying to make the point that other
societies have other ethical principles, and prioritize principles differently than we
do in American medicine. I’m an anthropologist: cultural relativism is my
disciplinary inheritance. I can’t in good conscience present these principles as if
they are timeless and universal. But when I showed the mock-up to Lydia she
argued that some of these principles surely have cogency in other societies, so
labeling them “American” is misleading. Well, okay. Even Americans can’t
possibly believe they hold sole ownership over ideas like “justice.” So we
compromised. I changed the title to “Principles of Bioethics” and down in the
corner I made a new text box with the title “Other Principles” and listed some of
the values I’ve read about in the international bioethics literature: the golden rule;
community integrity; filial piety, etc. I don’t much like the term “other.” There’s
way too much baggage attached to that term. But Lydia will think I’m neurotic if I
try to explain the problem of labeling other societies as “other.” Best just leave it
alone. I need to prioritize my intellectual battles.

Okay, now for the casuistry cheat sheet. This one was the most fun to
make. Originally I had a grid with pictures of various insects: a fly, a beetle, an
ant, a bee, a praying mantis and a spider. Beneath the pictures I wrote the
caption, “One of these things is not like the other....” I thought, “These people are
scientists. They’ll surely recognize that the spider doesn’t belong; it isn’t an
insect, it is an arachnid.” The whole point is to demonstrate that casuistry is
about taking a paradigm case and comparing it to the case before you, to see if it
can provide an example of either what to do, or what not to do. For example, if
the paradigm case is Jack Kevorkian, and one argues that it is unethical to help people die without considering other options to alleviate their suffering, then you can look at terminal sedation and draw the opposite conclusion. Terminal sedation is ethical because its intent is not to take a life, but to provide comfort to patients experiencing unremitting pain and suffering at the very end of their lives. Kevorkian is the spider; terminal sedation is the insect.

But Lydia thought the insects were confusing. She hadn't known that spiders weren't insects. And she pointed out that there are multiple ways of categorizing the bugs: some have wings while others crawl; some are predators while others are prey; some are social insects while others live in relative isolation from others of their kind. Lydia said there are too many variables to consider. I hadn't thought of it that way, but I loved the unsettledness because the selection of a particular paradigm case is the key to the whole method. It determines how you weigh the merits and demerits of the case in front of you. The paradigm frames the case ontologically and epistemologically. What if you are a pro-lifer and you don't take Jack Kevorkian as the paradigm case, but instead you take Oregon's physician-assisted suicide program, with all its sundry safeguards and reporting structures. If that paradigm case is unethical, even though in that program physician-assisted suicide can be performed only with the written consent of patients who are terminally ill and have no other medical options, then the terminal wean doesn't look so palatable after all. If you believe
in the sacredness of life, without regard to the subjective condition of that life, any action that shortens life is unethical.

Lydia wants something more straightforward for teaching purposes, just to get across the idea of case-based reasoning. Doctors love casuistry because it bears a striking resemblance to the traditional diagnostic method. Consider the infant presenting with developmental delay. Match his cluster of symptoms to the paradigm case of malnourishment, and (ta-dal) you have your diagnosis. Okay, but what if the biomedical paradigm distorts the etiology of disease by focusing on the individual patient, rather than the patient’s environment, causing the physician to miss the diagnosis of lead poisoning. And ethical cases are so distinctive. Each presents its own unique configuration of patient values, family structures and institutional constraints. Depending on whose claims you prioritize—those of the pleading patient, the grieving family, the cash-strapped institution, the risk-averse physician—you can appeal to different paradigms. I like the idea of categorizing the insects under multiple paradigms to reveal the variety of possible modes of comparison and contrast. However, for the sake of simplicity I’ll do what Lydia wants. She suggested that I cut the insects and replace them with geometric forms: a circle and various angular shapes (a square, a trapezoid, a triangle, a hexagon, a rectangle). More mathematical imagery! It is rare that a particular case falls completely outside a paradigm, like a circle in a ring of polygons. And anyway, how do we know the polygon is really the right paradigm? Maybe the circle is correct, but we’ve become so
accustomed to thinking about sides and angles, that curves are too alien for our ethical faculties to grasp. Maybe I should just trash the whole thing and go back to Lydia's old bulleted list. These images are too crude, for all their esthetic appeal.

And anyway, no matter how snazzy I make the visual aids I know they wouldn't help me answer the question people always ask at these Ethics 101 sessions: How do you know which model to apply to any given case? That one I'll dodge by suggesting they try them all out, and see which one seems to make the most sense. I only hope they don't ask the harder question: How do we know any of these models actually work? Most are based on the theories of dead (or aged) elite men. There is no empirical data to support any of them. There isn't any evidence that most people agree with them, or that people even solve ethical dilemmas using this kind of deductive process.

It's like that nurse I interviewed a few months back for my ethics consultation project. This nurse is an old-timer on the ethics committee and has participated in countless consults. She told me that she generally makes up her mind about a case within the first three minutes of listening to the patient's medical history at the start of the consult. She doesn't appeal to any ethical theories at all in her decision-making process. She relies totally on gut instinct, and her knowledge of medicine. That's it. If people make decisions on an emotional and embodied level anyway, what is the point of this whole exercise? Isn't it just window-dressing? An attempt to systemize something that is
ultimately subjective?

Maybe Neil is right. He’s a Catholic bioethicist. He said to me once, “I don’t know how you secular bioethicists do it. How you make decisions, I mean. I’ve studied canon law. I have a pretty good idea of what God’s law says and how we should follow it based on centuries of theological debate. But you, what do you have to base your opinions on? Other people’s opinions?”

I doubt that anybody can really know God’s law, even if there is a God and he has laws that apply to individual human actions. But Neil’s right in that all of these ethical models are just tools, blunt instruments for tracing the intricate contours of ethical dilemmas. Think of the cases I’ve seen just today. Lana and Mr. J. These models seem inadequate to solving the problems that lead to those situations. Where in these models can you consider the ego of the attending physician, the lack of accessibility to adequate prenatal care for poor mothers, the fragmentation of in-patient care, the financial interests of the hospital? Maybe my MBA sister is right (God forbid). Maybe there are no ethical dilemmas; maybe it all comes down to system problems.

3:30pm. Arbitrary or not, I have a presentation to make to twenty new medical fellows in half an hour, and I’m not going to look more dithering than they undoubtedly already imagine bioethicists to be. Better get cracking on these handouts, doubt be damned.

...
At 4:32pm Nadine settles into a front row seat in the small lecture theatre on the tenth floor. Lydia is standing at the front, calling the twenty-odd fellows in white coats to order. Nadine knows they need to make this hour count. Fellows spend the most time on the wards and perform most of the medical procedures, as well as mentoring their medical students and residents. If the attending physician is God, the fellow is the archangel Gabriel. An ethically-attuned fellow can set a positive tone for a whole ward, and provide a model for future physicians.

**Lydia:** Thank you all for coming. It’s a pleasure to be part of your orientation session today. Welcome to Research Hospital. I’m Dr. Lydia Crandell and this is my fellow Nadine Geib. We are from the hospital’s Clinical Bioethics Service. The Bioethics Service provides bioethics education to health care professionals such as yourselves in the RH community. We also provide ethics consultation, review and develop policies for the hospital, and conduct research on bioethical issues. One of our ongoing studies looks at the informed consent process for kidney transplants between family members. Those of you on the transplant service may be involved in that study. But today I want to introduce you to our most visible service at RH, the ethics consultation service, and look at a couple of cases our consult service has encountered.

We have an open ethics consultation service, which means that anyone with a legitimate interest in the care of a patient can call a consult on a case. The majority of our consults come from attending physicians, but nurses, social
workers, patient advocates, translators and sometimes, patients and families themselves call for a consult. So that means this service is also open to you as fellows. Nadine is passing around some pens with our pager number on it, so when those pens of yours from Pfizer run out be sure to put these in your pockets.

When you call the pager the ethicist-on-call will respond as soon as possible, usually within a few minutes. That person could be me or Nadine or a senior member of the ethics committee. There are two kinds of consults that we call informal or formal consults. An informal consult usually involves us talking to you on the phone to answer basic questions. Let’s say you want some clarification of who the patient’s legal surrogate is, or how to help a patient complete a Living Will. We aren’t lawyers, but we are familiar with the advance directive laws of the state, so we can answer those questions pretty quickly. Sometimes people call for an informal consult just because they want some moral support or they want to vent about a particularly difficult case. That’s okay, that’s what we are there for. And after a brief conversation hopefully you’ll feel like you’ve gained some clarity about what needs to be done, and that’s the end of it.

A formal consult usually involves a more complex ethical dilemma, or an issue that is particularly novel. Often there are multiple sides to the issue, or competing claims being made, or the different parties involved are having trouble communicating with each other for whatever reason. In those cases it is
preferable to have a formal gathering of everyone involved in the patient’s care to clarify the medical and ethical aspects of the case. At a formal consult the patient’s physicians and nurses and support staff will get together, along with the patient and the patient’s family, as appropriate. Usually, the consult will begin with the patient’s medical history and current treatment, then the perspectives of the nursing staff and the family will be elicited. Formal consults are usually facilitated by myself or Nadine, but we are supported by an ethics team comprised of a physician, a nurse and another health care professional from the ethics committee. We like to have an interdisciplinary ethics team to make sure all perspectives and angles are considered. At the end of the presentation of the case, the ethics team meets separately to formulate a recommendation that is then placed in the patient’s chart. A recommendation can also be charted for an informal consult if that is desirable, but it carries more weight if it comes from a whole team.

**Fellow 1** [Asian-American woman]: So in your recommendation you tell us whether our treatment plan is ethical or not?

**Lydia** [shaking her head]: No. The opinions of the ethicist and ethics team are advisory only. We can’t make decisions for anybody. We don’t have the authority to do that, nor do we want to usurp the rightful decision-makers. Ultimately, treatment decisions are left up to the attending physician and the patient or family. Often by getting everybody involved in a patient’s care around the table at the same time people can begin to talk freely and come up with new
solutions to the problem. The purpose of the recommendations is to provide
moral reasoning for following a particular option. You guys make ethical
decisions all the time, every day. It's when you get stuck, or when you encounter
a lot of conflict, that's when calling us might help. We can provide a kind of
neutral territory for thinking through the issues and offer some other ways to
frame the problem using ethical analysis. Are there any other questions about the
consult service? Okay. I'm going to let Nadine introduce you to the models of
ethical decision-making we use in our service.

**Nadine** [standing and taking Lydia's place at the podium]: Thanks Lydia. I
guess I should introduce myself. I'm Nadine and I'm a Ph.D. candidate in
anthropology. You might not think anthropology has anything to do with ethics,
but a lot of anthropological research is about the values that undergird the social
structures and cultural systems, like that of biomedicine. And in our multicultural
society, it seems more relevant than ever to include an awareness of the social
and cultural underpinnings of ethics. So one of my jobs today is to introduce you
to three models of ethical reasoning that we use a lot in the consultation service.
You might also find these useful in your daily practice.

The first model is consequentialism. This is the first page of your handout.
The root word of consequentialism is, of course, consequences. This model
weighs the benefits and burdens of a particular course of action. If it has more
benefits than burdens, then it can be considered an ethical option. It's a lot like
weighing the risks and benefits of a medical treatment, which I know you are
familiar with. I'm just going to run through these really quickly so we can get to the cases, so stop me if you have any questions.

The next page represents Prinicipism. This method relies on certain ethical principles to determine the best course of action. I use the image of the puzzle to demonstrate that depending on how you put the pieces together, and which principles you privilege and which ones you leave out, the picture you end up with could be really different. You'll notice that truth-telling is one of the principles listed. That is a very important norm in American society. Here we expect our physicians to tell us the truth about our diagnosis and prognosis, but that is not the case in every culture.

Fellow 1 [interrupting]: In Japan, where my parents are from, you never tell anyone they have cancer. It's considered cruel. You tell them they have a growth or a tumor or something, but you never use the word cancer. You only give the diagnosis to the family, because you are supposed to protect the sick person from the knowledge that they are dying. It's supposed to preserve their sense of hope or something.

Nadine: Exactly. You'll notice that in the right hand corner I've listed some other principles that circulate in other cultures. I did that just so you'd keep in mind that not everyone holds the same values we do in the West. This is particularly important to remember if you are treating international patients.

The last model we use is Casuistry. Again, this will be familiar to you from your medical training. The root of that word is case, and it basically means case-
based reasoning. So you take a paradigm case of something that is clearly right, let's say providing an abortion to a woman whose life is at risk if she tries to carry the pregnancy to term. And then you look at other, more ambiguous cases to determine if providing an abortion would be correct in those cases as well. For example, if a woman’s life isn’t at risk, but the fetus is very deformed and will die soon after birth. Are there any questions about these three models? [Silence. Strange, thinks Nadine.]

In RH’s consult service, we don’t privilege any particular model. Some people are strict consequentialists, and others are strict casuists, but here we combine all three models because they all have different strengths and weaknesses. You sort of have to mix and match depending on the particulars of the case before you. Okay. Well if there aren’t any other questions I’ll turn it back over to Lydia, who will present our first case for discussion.

Lydia [resuming her position at the podium]: Thanks Nadine. Okay, turn to the fourth page in our handout. I’ll read the case and you can follow along.

“A six-year-old Mexican national came to Research Hospital with a diagnosis of osteosarcoma. An initial consult fee of $2,500 was paid. The diagnosis was confirmed and potential treatment options explained. His mother agreed to an initial payment of $40,000 so that the child could be treated at RH. She told the financial counselor that the money would be forthcoming after she sold her dairy farm in Mexico. After one course of chemotherapy administered on a randomized research protocol, the child
developed a pathological fracture of the left femur with intermittent fevers. Since no organism could be identified and since the tumor continued to grow, emergent amputation above the knee was deemed necessary. Even though only $4,300 had been paid to date the surgery was approved by the Chief Operating Officer. The child’s surgery was uneventful and he was stabilized. The attending physician then wanted to begin the standard treatment of chemotherapy (a nine-month course). The financial office refused clearance. An ethics consult was called.”

Okay, so what questions or concerns jump out at you as you read this case?

**Fellow 2 [white woman]:** I was trained in England where we have the National Health Service for everybody. This ethical issue is so big that I would hit a wall. I wouldn’t even know where to begin. I’ve never encountered anything like this. We have plenty of immigrants in London, but I’ve never been asked to not treat one of them because they couldn’t pay.

**Nadine:** When I was in London my son had an asthma attack, but luckily we had travel insurance. We tried to give our insurance information to the hospital but the doctor just told us it would be too much of a hassle, so they treated us and sent us away without asking for any payment at all. It was amazing.

**Fellow 2:** Yeah, that’s my experience too. I think with a cancer like this, once you have started a treatment you can’t really stop or the cancer can
become even more aggressive. I don’t think stopping in midstream would be a good idea.

**Fellow 3** [white male, American]: I don’t think this is an ethical issue at all. It is a financial issue. If people can’t pay for care, they don’t get care.

**Fellow 4** [white female, American]: It happens all the time. If you don’t get paid, the hospital goes broke. And then all the patients would suffer.

**Lydia**: Okay, but this is an ethical issue too. Not only might the cancer become more aggressive if chemo isn’t administered, but this boy came to the hospital with two legs and now he’s leaving with one. He probably got that infection because he was immune-compromised from the chemo. Doesn’t the hospital have an obligation to continue his care?

**Fellow 5** [white male with Australian accent]: Look. The financial office clearly didn’t do their homework. The hospital screwed up by starting this kid’s treatment before they paid for it, so the hospital should suck up the cost of his continued care.

**Fellow 6** [Indo-American female]: It says this child was on a protocol, so it’s not like the hospital wasn’t gaining anything from treating him. They probably weren’t even paying for the chemo drugs. The drug company probably was. This patient suffered an adverse event on a protocol. Shouldn’t the drug company pay for his resulting amputation?

**Lydia**: That’s a good point. It is my understanding that in clinical trials the sponsoring company typically only pays for the drug and for the care directly
related to the protocol. They are not obligated to pay for treatments resulting from adverse events. At least in this specific case they weren't.

**Fellow 3:** Wouldn't it constitute a breach of contract for a physician to abandon a patient's care due to financial issues?

**Lydia:** Good question. A physician can legally divorce a patient for any reason. All it requires is notification of the patient and transfer of the patient's care to a receiving physician. In this case the physician does not want to divorce the patient. He is trying to advocate for the patient and the institution is preventing him from giving what he considers to be appropriate treatment.

**Fellow 1:** So what options does the patient really have?

**Lydia:** Well, according to the physician, the patient could receive standard chemotherapy back home in Mexico through their national health insurance program. He even knew of a few good oncologists near the patient's hometown.

**Fellow 4:** But can the patient really get good care in Mexico? I mean, I doubt it would be the same standard of care as at RH. You can't even get the same standard of care at the county hospital down the street. The mother probably brought the boy here in the first place because they got crappy treatment at home.

**Lydia:** Nadine analyzed this case during her fellowship interview, and she brought up a really great point. If the patient stays here he will be very isolated. It turned out that the dairy farm the mom promised to sell was the family's only source of livelihood, so selling it wouldn't do the family any good. This patient
had several siblings at home, as well as an extended family nearby. Imagine how hard it would be on a six-year-old to spend nine months living here in a little apartment, without being able to go to school or see his friends. Never mind how difficult it would be for the mother, who hardly speaks any English and has no support network here. If you think of the patient’s benefit in a broader context—including his social and emotional well-being and that of his caretaker—sending him home may be the best option, especially if he can get follow-up chemo at home. In the end, that’s what the ethics committee decided. Not for that reason, but they did decide to support the financial block on the patient, and the boy did go home.

**Fellow 1**: So what happened to him?

**Lydia**: We don’t actually know, but the physician did call us six months after that consult to say that the boy was doing well and getting chemo.

**Fellow 1**: And what about the boy’s leg? Did RH provide a prosthetic for him, since we were responsible for the amputation?

**Lydia**: That I don’t know. I don’t think so, but I can’t say for sure. Well. Nadine? I’ll let you get on with the next case.

**Nadine**: Sure. Again, I’ll read the case that’s on page five of your handout and you can follow along. This one also happens to be a cancer case.

“A Vietnamese woman, aged 34, is medically appropriate for a stem cell transplant. She has an eight-year-old daughter who lives with the patient’s sponsor for her immigration to the United States. The patient gave birth to the
daughter while living with the sponsor but moved to another state and has not seen her daughter for six years. The sponsors are now the legal guardians of the child. The sponsor agrees to have the daughter typed and she is the only matched and suitable relative. Informed that the patient needs her daughter’s marrow, the sponsor brings the daughter to the hospital for donation.

The harvest technique used involves the placement of large intravenous needles in each arm and the circulation of the child’s blood through a machine for at least three hours. Upon arrival, when the daughter hears the explanation of the harvest procedure, she refuses due to a fear of needles. The social worker and a child-life worker attempt to work with the child, but after her initial emotional outburst she stubbornly refuses to discuss the procedure. At the guardian’s request she has no contact with her mother during this time. The child’s guardian is ambivalent, feeling responsible for the both the mother and child. The transplant team, however, wants to proceed. An ethics consult is called.”

**Fellow 5:** Once again, it sounds like somebody screwed up. Did they not tell this child in advance what the harvest technique would involve?

**Nadine:** I wasn’t around for this consult either, but from what I understand, they thought they could use a less invasive harvest procedure originally. Then when she got here, they found they couldn’t.

**Fellow 4:** Isn’t there some way to sedate the child for the procedure? Just knock her out before they put the needles in.
Nadine: That would be ideal, but there are pretty substantial risks involved in putting a child under general anesthetic for three hours. And remember, this treatment is not for the benefit of the child. It is for the benefit of her birth mother. So it is harder to justify subjecting her to those risks.

Fellow 4: Yeah, it would be different if this mother had been involved with the child. You know, if they had some kind of relationship. But it sounds like she just abandoned her, so how can you force the child to do something she perceives to be traumatic for somebody who’s already hurt her emotionally?

Nadine [feeling her blood beginning to simmer]: Let’s just step back a moment before we start slagging this patient for being a bad mother. This woman came to America alone and was placed with a sponsor in rural Idaho. Now I’ve talked to people from Idaho, and they say that the Vietnamese population numbers about 3. So imagine how isolated this woman was. Then she gets pregnant. If we want to talk about negligent parents, where is this child’s father? For that matter, who is this child’s father? Is the sponsor the father? Was having a child for the sponsoring couple (who is otherwise childless) part of the bargain for getting her to America? I don’t mean to sound melodramatic here, but we really have no idea about the relationships between these people, or the circumstances in which this child was conceived. It’s important to know that this woman moved away from Idaho in order to take care of her elderly mother, who lives here. It’s also likely she didn’t have many employment opportunities in rural Idaho. Just imagine yourself in her shoes. You don’t know the language, you
don't have any education, you have no job or way to support yourself and your child, and you have an elderly mother in city that offers more social support and employment opportunities. Is leaving such an irresponsible option?

**Fellow 4:** But she at least could have called the child or visited in the last six years.

**Fellow 6:** Maybe the sponsor asked her not to. Maybe she decided to let the child grow up a little before reinserting herself back into her life. I was adopted from India, and I wasn’t allowed to find out anything about the circumstances of my adoption, not even the town my mother lived in, until I was 18. I think there are good reasons for doing that. It’s difficult enough being brown and growing up in a white family.

**Nadine:** Okay, so let’s put aside the issue of whether this patient is a good or bad mother, and whether she deserves her child’s bone marrow, and get back to the ethics of the case.

**Fellow 6:** Not to belabor the point, but this patient has her whole life to be this child’s mother. It will probably be in the child’s best interest to have her undergo the harvest, even if she doesn’t like it, so that she has the opportunity to have a relationship with her mother later on. I mean, how will this child feel if years later she realizes that her mother died because she was scared to undergo a very simple procedure. This woman is her link to her cultural heritage. If she loses that she may have a very difficult time later in life.
**Fellow 5:** But it could also seriously traumatize the child if you have to strap her down to a table for three hours. I still remember screaming for what seemed like forever when I got my first cavity filled, and I was like 5 years old.

**Fellow 6:** Yeah, but nobody was going to die if you didn't get that cavity filled. And maybe later on she'll hate her adoptive parents for not making her go through with it.

**Fellow 2:** It is true that developmentally eight-year-olds don't really have a sense of the permanence of death. That comes later.

**Nadine:** Well, I see that it's already 5:30, so we have to wrap up. Thanks everyone for coming and take the pens with you. Call us if we can ever give you a hand with anything. And good luck with your fellowships.

**Fellow 1:** Wait a minute. Aren't you going to tell us what happened?

**Nadine:** Um, sure. Again, I wasn't involved in this case, but from what I understand, the ethics team agreed with the sponsor not to force the child to undergo the harvest. So the patient didn't get the transplant and she died about three months later.

The room falls silent.

*Oh why did we choose these cases? I mean, we wanted to pick some really juicy cases, but we've made ethics consultation look, profoundly unhelpful. In one case they sent a kid home to a developing country minus one leg, and in another they condemned a woman to certain death because they couldn't see*
the long-term benefits of supporting this child through the harvest. So why would they call us?

**Nadine:** Uh. Thanks again everybody. We’re dismissed.

... 

It’s drizzling when Nadine steps out of the hospital. As usual, she is unprepared. Her umbrella is sitting on the floor of her car, eight blocks away. She is still stymied by weather here. Back home in Saskatchewan you can watch a rainstorm coming for hours. It is an event. You can feel the barometric pressure rising. Then the air suddenly becomes sodden, and the rain comes with fury: light, sound and wind. Always wind. Rain in Saskatchewan is laced with danger. Tornados are common, as is hail. An entire crop can be wiped out in a matter of minutes; a year’s worth of work pummeled into what’s left of the topsoil. But here Nadine hasn’t yet learned to read the cues, and she rarely has time to check the weather report in the morning.

Oblivious to her dampness, when Nadine steps into the classroom, Ezra runs and embraces her knees yelling, “Mommy, mommy!” This is the supreme moment of Nadine’s day. He grabs her hand and takes her to the pile of blocks he’s been working with. At his Montessori school they call the children’s play “work.” To dignify it, the teachers say. It should be the other way around, thinks Nadine. It would be more dignified to call what grown-ups do ten hours a day “play.” At least we could drop the pretense of productivity.

As Nadine drives home, they sing.
Cucaberra sits in the old gum tree,
Merry, merry king of the bush is he.
Laugh, cucaberra,
Laugh, cucaberra,
Gay your life must be.
Ezra shouts the words with gusto.
Waff, bawacuda,
waff, bawacuda
Gay your wife muss beee.
Nadine laughs too, for the first time all day.
By the time they get home the rain has stopped. The sun is out and it is hot. Really hot for a September day.

“Poow, mommy, poow,” Ezra pleads as Nadine lifts him out of the car and sets him on the lawn.

“You want mommy to set up the pool for you? Okay. You can have a little swim while mommy works in the garden. It’s probably the last day you’ll be able to swim until spring. We’ll let daddy cook tonight,” she adds conspiratorially.

Ezra immediately begins to disrobe. Nadine unlocks the front door to dump their lunchboxes and her briefcase inside the hall. When she comes back Ezra is sitting on the grass with his shirt lifted over his head. He managed to wiggle his arms free, but the neckband is tight and he’s tugging at it, trying to maneuver it over his round face. Nadine crouches down beside him and silently
watches him struggle, resisting the impulse to help until he asks for it. He wrenches the shirt blindly for a moment then yells, “Mommy!!!!”

“I’m right here. Are you having trouble? Here, let me help you.”

Nadine pulls on the shirt, almost lifting him off the ground. When his head pops free at last Ezra gasps and smiles.

“That’s a tough one, huh. I think we should put this shirt in the goodwill pile. You’re too big for it now. Come on, you can’t sit out here all naked. Let’s go into the backyard.”

They walk around to the back of the house and Nadine pulls the paddling pool out from under the eaves. Now Ezra is stripping methodically, working his shorts down his legs, sitting down on the grass to pull them over his feet, standing up again to pull off his training pants, sitting down again to take off his socks.

“Ah!” he shrieks as he settles his bare bum onto the grass.

“Does it tickle?”

He nods, standing up to scratch his bottom.

By the time he achieves blissful nudity Nadine has turned on the hose and settled it into the bottom of the pool. The water is almost hot when it first comes out. The sun warms it as it sits in the hose on the lawn. In a few seconds fresh water is flowing up from underground, so cold it almost hurts to hold her hand under it. Ezra doesn’t seem to notice. He’s already walking around the pool, lifting his feet high and splashing them down to create maximum spray. Nadine
watches him for a moment, then runs into the house to strip off her work clothes and pull on her shorts and t-shirt. When she comes back Ezra is sitting in the water, holding the hose, transfixed by its font.

"Mommy, swide!"

"You want me to put your slide into the pool? Okay. Let me clean it off first."

As she grasps the plastic slide to drag it over to the pool, she feels a snail shell crunch under her fingers. She sets the slide down and turns it over. Underneath its lip there are perhaps two-dozen snail shells clinging to the blue plastic. Most are dried out, the empty hulls of snails that probably starved to death on the inorganic terrain. She begins to brush them off, then discovers that one or two still have feelers gracefully searching the air. These she picks off individually and tosses them onto the grass. In the crevasse between the ladder and the platform her fingers find a mass of something gelatinous and sticky. For a moment she thinks it is a gob of semen. (Where on earth did that come from?). Then she looks closer. Thousands, maybe millions, of tiny bubbles: snail eggs. She scoops up the mass in the crook of her finger, carries it to the pile of lawn cuttings in the corner of the yard and wipes it off. After she settles the slide into the pool she watches Ezra fill his mouth from the hose and spit the water out, over and over. Most dribbles down his chin but some spatters onto the lawn, an accomplishment he apparently finds deeply gratifying.
Nadine scans the back of her house. The white siding is grey with snail shells and the droppings of snails. What makes these creatures leave the lushness of the garden to climb onto that wasteland, she wonders. Some have made it all the way to the eaves, two stories up. She moves in close until her nose is almost touching the siding. Then she sees it: a thin scum of mold. A snail’s bonanza. Lawrence has been talking about getting a power washer to wash down the house. Now Nadine thinks better of it. The house is part of the ecosystem of the yard now. One strong rain will remove most of the snail shells. Why destroy their food source?

Nadine grabs the old ice cream tub from the back step and begins to pick tomatoes. They are almost blood red and tiny, the size of grapes and almost as sweet. They don’t have tomatoes like this in Saskatchewan. Back home the growing season is so short. Nadine remembers harvesting tomatoes green and setting them on the windowsill to ripen. Often there was already snow on the ground by the time they got eaten. But here she eats them straight off the vine, warm and dusty.

She grabs the wheelbarrow and rolls it to the bare patch of ground they are preparing for winter. She is just about to dump the load of compost when she notices new shoots already sprouting in the wheelbarrow. Those must be from the cantaloupe seeds I dumped in there a couple of weeks back, she thinks. They had begun their futile germination, unaware that they’d never survive the winter. Nadine picks up a handful of compost. She recognizes only a few pieces
of eggshell. All their carrot peelings, apple cores, melon rinds and dead leaves
have turned into rich loam through the efforts of the hundreds of worms and
millions of bacteria who inhabit the six cubic feet of their compost bin. Here was
death and decay, the pedestal of life.

Nadine looks at her house, now part of this web. It had once belonged to a
woman who died at RH. When the woman’s son put the house up for rent the
market was tight and they found themselves competing with another family for it.
Nadine called her godmother for help. She and her godmother went to the
railroad tracks and found four spikes. They drove them into the ground at the four
corners of the house’s foundation and anointed them with rum. As they drove
away in the gathering dusk, her godmother had said, “Now don’t look back. It’s
yours now.”

“Mommy!” Nadine looks back. Ezra is standing in all his glorious skin, his
arms raised. When Nadine lifts his chill body out of the water he nestles into her
t-shirt. Yes, she thinks, it’s mine. But only for a time.
If the genealogist refuses to extend his faith in metaphysics, if he listens to history, he finds that there is something altogether different behind things: not a timeless essential secret, but the secret that they have no essence or that their essence was fabricated in a piecemeal fashion from alien forms.

Michel Foucault (Foucault 1977, 142)

Clinical bioethics was born from medical ethics, tracing its genealogy back 3000 years to Hippocrates. Medical ethics grew from physicians’ collective obligation to protect the public from harmful “treatments” and financial exploitation by quacks by restricting admittance to the profession to those with the requisite training, knowledge and dispositions. Clinical bioethics aims to fortify and enhance the fiduciary relationship between physicians and their patients by providing institutional structures that uphold medicine’s sacred calling and benevolent identity as a healing profession. Clinical bioethics was born from the exposure of injurious experiments carried out on vulnerable populations, such as prisoners of war in Nazi Germany, and poor African-American men and the mentally disabled in America. Henry Beecher’s whistle-blowing article, published in 1966, demonstrated that sloppy, risky or harmful research was commonly conducted at even the most esteemed academic medical centers, and that researchers’ attempts to obtain the consent of participants were absent at worst and uneven at best (Beecher 1966). Clinical bioethics, through the
regulatory practices of research ethics committees and formal consent, aims to protect research subjects from coercion and harm by ambitious scientists by ensuring the scientific validity of their studies, the minimization of risks, and the informed and free decisions of subjects to participate in research.

Clinical bioethics was born from the rapid advancement of medical science, such that our moral reasoning lags behind our technological capabilities to maintain, enhance and alter human life. Over the course of the twentieth century, medicine expanded its domain by moving the pivotal human events of illness, birth and death from the home to those temples of medical science: hospitals. The work of Elisabeth Kubler-Ross and others demonstrated how the technological imperative to sustain life, and the transformation of illness into a series of mechanical problems, tends to ignore and suppress the emotional and spiritual dimensions of suffering and dying (Kubler-Ross 1969). Clinical bioethics aims to keep moral spaces open in the clinical setting by identifying how medicine contributes to suffering, by evaluating how technologies can be applied to maximize benefits and minimize harms, and by working to restore dignity, choice and humanity to the sick (Andre 2002: 69).

Clinical bioethics was born from landmark legal cases such as Roe v. Wade, Karen Ann Quinlan and Nancy Cruzan which challenged the traditional paternalism of medicine, shifting authority over treatment
decisions from physicians to patients or their surrogates (and to the courts themselves). By enshrining the rights of patients to determine what happens to their bodies, these cases dove-tailed with the cultural movements of the 1960s and 1970s, undergirded by suspicion of authority and an emphasis on personal freedom and privacy. The Quinlan decision specifically recommended that hospitals institute ethics committees to resolve conflicts between physicians and patients or families regarding withdrawal or withholding medical treatments. Clinical bioethics aims to provide expertise in ethical decision-making to safeguard the autonomy of patients and to ensure that the self-interest of medical professionals does not subject patients to unwanted medical interventions.

Clinical bioethics was born from the loss of trust and identification between physicians and their patients. This loss was due to a confluence of social and economic factors. The rise of medical specialties supplanted family physicians. The emergence of medicine as a meritocracy caused patients to choose physicians based on their reputations, rather than their social skills or identification with a particular ethnic community or neighborhood. Increasing geographical mobility curtailed the formation of long-term relationships between physicians and patients. Greater educational demands and sicker patients translated into longer workdays, isolating physicians socially. Health insurance schemes restricted patients’ choices of providers, and regulated the treatment options physicians could offer.
Mass displacement of populations due to wars, civil conflicts and poverty increased the cultural and religious diversity of America through immigration, such that patients and physicians began to come to the clinical encounter with divergent treatment goals and worldviews. Clinical bioethics aims to compensate for the lack of identification between physicians and patients by providing principles for ethical decision-making that are secular, comprehensible, applicable to the clinical setting, and flexible enough to legitimate a wide range of personal and cultural preferences (Rothman 1991).

Clinical bioethics was born from a backlash against the so-called 'God committees:' the notorious Seattle committees of the early 1970s that decided who should receive dialysis (and live) and who should not (and die) when dialysis was a new and scarce medical treatment for renal failure. These committees were widely condemned for using social criteria (such as candidates’ employment history and church attendance) to allocate dialysis. However, they were formed to prevent doctors from abusing their authority (by giving priority to their friends or colleagues), and to protect the physician’s obligation to advocate for his individual patient without having to weigh the needs and merits of other patients. The committee was a symbolic representation of the hope that difficult decisions could be made that were not arbitrary, that were ethical, and that incorporated the perspectives of other health care professionals and
laymen (Rothman 1991: 150). This model also relies on the optimistic assumption that communication has a meliorating influence on behavior. The aim of clinical bioethics is to mitigate power differentials in the medical hierarchy, to knit together the fragmented organization of patient care, to curb discrimination, and to clarify and uphold the societal values that inform ethical clinical decision-making through bureaucratic structures such as policy review panels, ethics committees and ethics consultation.
I. Introduction

The ur-moments of bioethics—the origin myths of this interdisciplinary field which positions itself at the nexus of medicine, technology, social justice and human values—are a staple narrative of course lectures, textbooks, monographs and plenary addresses at bioethics conferences. It is understandable perhaps that a new field (particularly one which some have perceived as an interloper into the sacred relationship between physicians and patients, or as the back-water cousin of academic philosophy) must spill a great deal of ink in the first few decades of its existence to demarcate its unique contributions to the advancement of knowledge and societal good, and to legitimize its claim to resources in an era marked by significant cutbacks in higher education (particularly in the humanities). In training sessions with ethics committees and lectures to my anthropology students I have invoked these origins myths myself, though as an anthropologist I tend to favor explanatory models grounded in cultural and societal shifts, rather than legal decisions or the media. But increasingly I find myself shifting in my seat or skipping ahead during these ritual recitations of the birth narratives of bioethics.

It is not the lack of unity or coherence in these myths that bothers me. The emergence of any novel cultural form will have myriad (even contradictory) originating impulses. Rather it is their polarizing rhetorical strategies that repel. Like sociologist Charles Bosk, I have become increasingly irritated by the "Whiggish" quality of these tales, particularly those written by apologists for the
field, "that makes not only [bioethics'] structural position but also its current intellectual configurations appear as both inevitable and desirable" (Bosk 1999: 49). These narratives are uniformly triumphant in tone, portraying bioethics as revolutionary in terms of its impact on medical practice, particularly its success in "overturning a regime of physician paternalism and replacing it with one that was patient-centered" (Bosk 1999: 50)

Origin myths written by critics of bioethics, on the other hand, depict the field as residing in the "belly of the medical whale" (Rosenberg 1999: 38). Committees and regulations designed to protect patient rights against abuse by impersonal technologies are portrayed as technologies in and of themselves that perpetuate the very system they seeks to reform. What both the apologetic and critical origins myths share, however, is a marked inattention to the actual practices of clinical bioethicists, and the social and institutional contexts in which they labor.

Speaking of the pseudo-scientific literature on ethics consultation produced by the bioethics community, Bosk writes: "It exists to underscore that ethics committees are effective, deserve institutional resources, improve the quality of care, serve physician interests, and threaten no one" (Bosk and Frader 1998: 106). According to Bosk this literature appropriates some of the methods of social science, without the rigor, social theory or reflexivity of contemporary social science, resulting in a "just so" story that masks its underlying commitments and investment in the consolidation of professional authority. Bosk
argues that, rather than using social science to assess policies, to improve bioethical discourse or to produce “better” results from bioethical technologies like ethics consultation, the greatest contribution of social science may be to contextualize bioethics and to make it an object of study.

In a somewhat different vein, philosopher-bioethicist Tod Chambers argues that social scientists have paid undue attention to ethics consultation, while losing focus on bioethics as a form of life, to borrow Wittgenstein’s phrase (Chambers 2004). Chambers takes up Clifford Geertz’s argument for ethnography that does not merely examine a particular technical task, but which takes on a cultural frame, examining particular tasks within the context of a way of life (Geertz 1983: 155). Chambers writes: “Such an intellectual move would entail asking the kind of questions that one would have expected social scientists to ask: What kind of life do these people in medical ethics lead, and in what ways do their social patterns influence how they think?” (Chambers 2004). I take issue with Chambers’ “been there done that” posture toward research on ethics consultation, as seven years since Bosk’s call for a sociological examination of this practice the ethnographic data remain remarkably thin. However, Chambers is correct in emphasizing the impossibility of understanding clinical bioethics as an emergent profession by examining discrete actions, removed from the bodies, spaces and lives of actors.

This project, an ethnography of the emergent practices and identities of clinical bioethicists in the U.S. and Canada, aims to answer Bosk’s call to
describe and analyze “the everyday work of people in the new social role we now call bioethicist” (Bosk 1999: 66). I attempt to answer the call to provide an ethnographic analysis of the work of clinical bioethicists (particularly ethics consultation), by attending not only to their enactment of particular technical tasks, but also by examining the social and cultural conditions of their labor and professional identities. This research makes a conscious turn away from the historicizing rhetorical strategies of critics and advocates of bioethics, and from social scientific endeavors to improve the services of bioethicists. In *Strangers at the Bedside*, David Rothman, ably chronicles the legal and social conditions that led to the emergence of bioethics as a quasi-discipline. My project takes up where he leaves off, by examining the work of one category of strangers at the bedside—clinical bioethicists—and the conditions of their labor within specific hospital and clinical settings.

II. Agency and Its Limits

*Court Jester*

*Watchdog*

*Institutional Conscience*

*Moral Police*

*Ethical Resource*

*Clinical Mediator*

*Moral Arbiter*
These are some of the tropes I have heard clinical bioethicists and ethics committee members, as well as their critics, use to describe the work of clinical bioethics. Agency, specifically the moral agency of the clinical bioethicist \textit{qua} professional, is an undercurrent in all of these tropes. The clinical bioethicist's scope of practice, her rank within the institutional hierarchy, and the limits of her authority, are themes that recur in my observational studies of and interviews with clinical bioethicists. This preoccupation with agency among clinical bioethicists stems from several factors.

In contemporary hospitals, clinical bioethicists are the paradigmatic moral agent\textsuperscript{9}. This station stems from their self-promotion as a resource for those confronting the moral dilemmas that attend the provision of medical care, and from the fact that their job descriptions often depict them as arbiters of moral conflicts. In addition, clinical bioethicists often cast themselves as institutional critics. That is, they believe part of their job is to point out the ethical inconsistencies and failures of their places of employment, specifically as these failures affect patient care and clinical research. At the 2001 Canadian Bioethics Society meeting, a speaker described his role as akin to that of the court jester who is given license to criticize and even mock the decisions of the monarch with impunity. Many clinical bioethicists argue that as ethical counselors to their institutions, they (should) possess greater freedom to speak their minds than

\textsuperscript{9} Throughout the text I strategically do not use “ethics” and “morality” interchangeably as is the fashion in common parlance. I use “ethics” when I am referring to norms and values recognized and validated in a culture or sub-culture, such as that of biomedicine. I use “morals” to refer to the personal rendering of ethical norms and values, based on one’s own commitments and experiences.
most health care workers, with immunity from negative repercussions. However, as Carl Elliot and others have pointed out, it is difficult to imagine an institution that would tolerate, never mind encourage, persistent and vocal criticism from within its ranks (Elliot 2001). Nevertheless, so crucial is moral agency to the professional identity of clinical bioethicists that the Canadian Bioethics Society’s taskforce on working conditions for bioethicists has undertaken the project of drafting a model contract for bioethicists that outlines procedures for dispute resolution between an ethicist and her institution, and safeguards for the ethicist’s freedom of expression. In addition, the relative mobility of clinical bioethicists within the hierarchical structure of the hospital—moving from the boardroom to the bedside and everywhere in between—gives them an air of greater agency than many other hospital workers.

By documenting and analyzing the work of clinical bioethicists ethnographically, this project engages the social theorization of agency. As I write, the scandal of prisoner abuse at Abu Ghraib prison in Iraq under the American occupation continues to unfold. Most of the press coverage and public discourse regarding these events have focused on assigning responsibility. Did

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10 Their propounded agency also stems from the social capital that attends their educational achievements (often J.D., Ph.D. or M.D.). Ethicists with Ph.D.s are socialized through their graduate training to think critically about structures, norms and values (unlike medical training, for example, which discourages the critique of authority). Ethicists trained in the humanities or social sciences are accustomed to an institutional setting that preserves academic freedom through the tenure process. Most clinical bioethicists, however, are not tenured; thus, they confront the possibility of losing their jobs if they vocally oppose decisions made by their hospitals. In fact, in his article, “Where are the heroes of bioethics?” Benjamin Freedman bemoans the fact that (at the time of his writing) no clinical bioethicists had been fired by their hospitals for taking a stand against an institutional policy or decision. Freedman fears that this dearth of heroes (or martyrs) indicates that clinical bioethicists are shirking their sacred duty to critique the hospitals that employ them. Freedman, B. (1996). "Where are the heroes of bioethics?" Journal of Clinical Ethics 7(4): 297-9.
someone give a direct order to torture the prisoners in this way? How far up the military and civilian chain of command do these orders originate? While these are pressing concerns, they also skirt broader theoretical questions regarding the agency of moral actors operating within institutional settings such as the military. While the positions of a clinical bioethicist and a guard in a military prison are hardly analogous, the two scenarios are related in that they both present important questions about agency, its operation and its limitations within hierarchical social structures.

As James Faubion argues, the social sciences and humanities alike tend to depict moral action as swinging between the mutually repellent extremes of decisionism and determinism, recognizable in the familiar oppositions of freedom vs. structure and individual choice vs. societal norm (Faubion 2001). Either the individual is depicted as having total freedom over their actions (as in liberal and neoliberal renderings of the ethical agent), or the individual has an abject relationship to a system (as in Marxist thought). Michel Foucault struggled with the issue of agency, seeking to avoid what he saw as the three classic theorizations of agency: the structuralist school which tends to depict human behavior as rule-governed; the phenomenological school that credits autonomous, transcendental subjects with absolute agency; and the more hermeneutic school that casts social actors as enmeshed in deep structures of which they are only dimly aware (Rabinow 2003: 2). Catherine Bell proposes that Foucault’s understanding of agency is enmeshed with power relations, but he
resists casting humanity in a totally abject relationship to power, such that, at the heart of power relationships "lies an insubordination or resistance, an 'essential obstinacy on the part of the principles of freedom,' which means that there can be 'no relationship of power without the means of escape or possible flight'" (Bell 1992:201).

Moral agency constitutes a dance between subjugation and freedom, between institutional norms and personal conscience. When I reflect on the experience of my clinical bioethics fellowship, my predominant feeling is one of frustration; so often I could identify the "right" course of action, but was powerless to follow through due to institutional and cultural constraints. This feeling of frustration is one shared by all moral agents as we navigate our daily lives. Should I buy those luscious strawberries at the supermarket, knowing the exploitative conditions under which agricultural workers labor? (But how does one make a decent fruit salad without strawberries?) How can I traverse a city designed for automobiles, knowing that my decision to drive a car directly contributes to the air pollution that exacerbates my own child's asthma? Over the course of this book I analytically and narratively, explicitly and tacitly, engage such questions as: How is morality defined in the clinical setting? What resources—philosophical, social, personal—do clinical bioethicists mobilize to define "the good" in particular situations? How is moral agency enacted by clinical bioethicists as professionals? What are its limits and how are these limitations made evident? What are the social and structural conditions under
which moral agency flourishes? How do these paradigmatic moral agents cope with the disjuncture we all feel between knowing the right thing, and facing structural impediments to doing the right thing? In addition to the ethnographic endeavor of documenting the work of clinical bioethicists, this project presents a meditation on moral agency within institutional contexts.

The few empirical studies of clinical bioethics in existence have tended toward a deterministic analysis of their agency. That is, the function of health care ethics consultants and ethics committees is portrayed as a means to preserve physicians’ power by internalizing a critique and thereby disarming it (Kelly, Marshall et al. 1997; McBurney 2001). Robert Zussman, on the other hand, argues in his study of Intensive Care Units that bioethical discourses mediate the competing claims of patient rights and medical authority (Zussman 1992). However, while ethical dilemmas in medicine are often framed by this dichotomy, the clinical bioethicist herself is subject to multiple apparatuses constituting the network of conditions under which she labors. These apparatuses structure the “acceptable options” available in any given situation, and both directly and indirectly delimit the agency of the clinical bioethicist herself. Interestingly, these apparatuses are addressed only obliquely in the bioethics literature as “knowledge areas” essential for competent ethics consultation (see Chapter 3). Alternatively they are framed as “organizational ethical issues,” and are either bracketed entirely, or subsumed under the rubric of ethics consultation. In this chapter, I begin my ethnographic analysis and
meditation on agency by mapping the social, economic and cultural apparatuses of the institutional settings in which clinical bioethicists work.

III. Beyond History: Anthropology and Emergence

As a relatively new cultural form emerging over the past thirty years, clinical bioethics presents multiple theoretical and methodological challenges to the ethnographer. An ethnographic examination of an emergent social phenomenon must grapple with such issues as: the relationship between the novel features of the phenomenon and its historical context; the parameters of a project which purports to examine a field with no center and no margins; and the challenge of producing a coherent analysis of a radically heterogeneous and unstable entity. Paul Rabinow advances the anthropological theorization of emergent social forms in his recent book _Anthropos Today_. Adapting some of the insights of Foucault, Rabinow proposes that such ethnographers undertake an “anthropology of the actual.”

Rabinow offers the anthropology of the actual, or the anthropology of the “near future and recent past,” as a remedy to the perpetual cycle within academia of proposing and countering _generalizable_ solutions to the problem of how to think about things human. Rabinow does not propose a general theory to resolve the incompatibility of previous attempts. Indeed, he staunchly argues that no attempt to define the modes, methods, principles of verification, or forms of narration appropriate to the analysis of human culture and social relations could really succeed in producing an enduring solution. Such a strategy would simply
contribute to the cacophony of dispute (Rabinow 2003: 4).

Instead Rabinow proposes a re-examination of the “interpretive analytics” of Foucault who pieced together an innovative method by tacking between archaeological and genealogical impulses. The power of Foucault’s work lies not in its proposal of another theory of truth, but rather in its heuristic value (3).

In the mid-1970s, Foucault began attending to thinking as a practice, rather than a system: an activity involving a degree of constraint as well as a degree of freedom.

Thought is not what “inhabits” an action and gives it meaning; rather, thought is that which permits a certain distance from a manner of acting or reacting, that which makes it possible to make that manner of acting into an object of reflection and to make it available for analysis of its meanings, its conditions and its goals. Thinking is the freedom one has in relation to what one does, the movement through which one detaches oneself, constitutes oneself as an object and reflects on all of this motion as a problem. (Foucault in Rabinow 2003: 46)

Foucault proposes that in order for actions to be thought about in this reflexive way, certain aspects of those actions or domains first have to lose their familiarity, or become problematic in some way. To any set of uncertainties or questions, multiple responses can be given, often with contradictory objectives, epistemologies or effects. He calls this reflexive process that makes something enter into the play of true and false problematization. The task of the analyst is to ask: What makes various responses to a problem simultaneously possible? How have they come to be? How could they be different? Her task is not to rectify the discord of the sundry responses to the problem.
As Rabinow reads him, Foucault proposes the notion of “apparatus” as one conceptual tool to focus an analysis of problematization. Most broadly, an apparatus is a set of devices whose purpose is control and management (50). An apparatus is a strategic conglomeration of discourses, institutions, policies, laws, administrative measures, etc., that function to define and to regulate problematic domains. Apparatuses are political responses to historical crises or problems; thus they are enmeshed in the play of power. Examples of apparatuses include the emergence of the prison industrial complex as a response to the problems of urban policing, or the appearance of HMOs as a response to the explosion of health care costs in the latter half of the twentieth century. Apparatuses may have unanticipated and unplanned effects, such as symbiotic relationship between minimum sentencing laws and the growth of for-profit prisons, or the diminished autonomy of the medical profession due to the regulation of medical care by third-party payers. And an apparatus may not “work” in the sense of achieving its explicit goals, but it may “work” by strengthening the (seeming) rationality of order and power relationships (54).

However, Rabinow’s “anthropology of the actual” takes as its primary object of study not apparatuses, but those secondary matrices from which apparatuses emerge: “assemblages.” “Assemblages stand in a dependent but contingent and unpredicatable relationship to the grander problematizations” (56). Unlike apparatuses, assemblages are not yet a system in which controlled variation can be produced, measured and observed. They function differently, as
an experimental matrix of heterogenous elements, techniques and concepts. They are also comparatively effervescent. Either a structured apparatus emerges from an assemblage, or it dissipates altogether. The task of the anthropologist of the actual is to identify emergent assemblages and to contextualize their relationships to apparatuses and to examine the play of power within them.

There are several problems with Rabinow's conceptualization and operationalization of the anthropology of the actual. The first is its name. Assemblages are by nature embryonic, decentralized and unstable; they are not fully actualized apparatuses, thus characterizing their analysis as anthropology of the actual would seem to be a misnomer.

Secondly, Rabinow offers no methodological tools (never mind a program) for enacting anthropological analyses of assemblages. While he lays out a clear and convincing theoretical argument regarding the need for such analysis in the opening chapters of *Anthropos Today*, his own enactment of it in subsequent chapters tacks between the idiosyncratic and the incoherent. He draws on a variety of sources to make his arguments, but all of his sources are historical; none are contemporary, which is a peculiar method for someone touting a turn away from historicizing analyses of human culture.¹¹

His own book enacts one possible stumbling block for anthropologists of the actual, though he doesn't address it directly; this is the issue of

¹¹ This points to a rather obvious flaw in his proposal, which is that an anthropology of the actual runs the risk of de-historicizing cultural phenomena, though his own example indicates that this is less of a risk than one might presume as it is virtually impossible to address the actual without encompassing its historical precedents.
representation. The emergent nature of assemblages makes it difficult to make
decisions about what counts as data. When analyzing a cultural phenomenon
with no orthodoxy, how does one discriminate between and prioritize available
resources? Without defined boundaries or center, the potential pool of data
bleeds out to the horizon.

I have encountered this problem in my study of clinical bioethics. This field
is a heterogeneous complex of discourses and techniques that have emerged
over the past four decades. It demarcates ethical relations in clinical research
and medical practice as an important intellectual and social endeavor. While
ethics (even medical ethics) might be considered a long-standing
problematization in Western societies, *clinical bioethics*, with its goal of wedding
philosophical and medical reasoning at the bedsides of patients and in the
boardrooms of hospitals, remains an assemblage. As of this writing, there are no
standards of practice, no credentialing processes, and no educational
requirements for those laying claim to the title of “clinical bioethicist” or “health
care ethics consultant.”¹² Thus, I have been faced with the problem of selecting
what to include and exclude in my analysis. Every social scientist confronts this
problem to some degree, however, it is even more acute when addressing a
social phenomenon that is emergent.

For example, clinical bioethicists are perpetually publishing analyses of
their own ethics consultation services and cases. How do I weigh these
idiosyncratic accounts, and the testimonies of my obscure interviewees, against

¹² Throughout the book I will use these terms interchangeably.
the statements of professional taskforces, or the publications of acknowledged giants in the field (such as John Fletcher and Al Jonsen) whose methods and theories of ethics consultation are equally idiosyncratic, though more widely cited by clinical bioethicists? Without any guidelines to distinguish center from margin in an anthropology of the actual, projects risk dissolving into mere anecdote (not unlike medical cases), or expanding almost infinitely to include even the voices of cranks and minor prophets. For example, the pro-life movement has been instrumental in crafting the “futility” legislation in Texas. Must I include this movement in my analysis of their practices and discourses, although most clinical bioethicists disdain the movement and its ethical platform?

Third, most cultural forms are engaged in a perpetual process of emergence. Change constitutes the very basis of human evolution and social institutions. Even ancient and highly structured institutions, such as the Catholic Church, continually evaluate and modify their thinking and practices. Rabinow distinguishes apparatuses from assemblages based on the longevity and stability of the former, and the relative novelty and instability of the latter. Apart from these criteria (temporality and stability), Rabinow does not provide further guidance regarding how to distinguish apparatuses and assemblages, or how to identify an emergent assemblage as a potential object of study. At what point does an assemblage become an apparatus? Are temporality and stability operationalized as defining characteristics in purely relative terms, or are there particular milestones an assemblage must meet in order to cross over to an
apparatus? Certainly there is no bright line demarcating an apparatus from an assemblage (or an assemblage from mere coincidence, for that matter). While change and emergence are inherent in most social institutions, I agree with Rabinow that temporality and stability remain important distinguishing factors. It is a matter of degree. Certainly new social forms can and do erupt in human cultures, followed by periods of steady evolution before another eruption.

Finally, it is difficult to imagine how one can further the theorization of the actual without resorting to the very generalizations that Rabinow adamantly seeks to avoid. His strategy for dealing with the practical problem of avoiding generalization, while still sustaining an argument, is to adopt the strategy of chronicling emergence, rather than resorting to method or theory. Rabinow suggests that most conventional approaches to history demand narrative coherence, integrity, fullness and closure; they impose a beginning, middle and end that can only be imaginary (78). An anthropology of the actual that examines assemblages, on the other hand, should reflect the instability of its object by experimenting with structures that lack closure (79).

Despite the inconsistencies and gaps in Rabinow’s proposal, I find the concept of assemblages to be eminently applicable to my own field of study. I would argue that clinical bioethics is a unique cultural eruption, though it remains to be seen whether it will stabilize into an evolving apparatus like law or medicine. I thus consider this project not an anthropology of the actual, but an anthropology of the emergent. And while I continue to wrestle with the
appropriate strategies and methods for enacting such a project, I find Rabinow’s fragmentary narrative form apt to my own materials and purposes. In this chapter, two narrative strands complement and evoke one another to weave together a portrait of the clinical bioethicist at work. In what I call the “analytic” strand, I map the network of apparatuses in which clinical bioethicists operate using historical and sociological resources, as well as my own fieldnotes and experiences from my fellowship in clinical bioethics. Nadine’s narrative illustrates how these apparatuses inform and structure the discourses, practices and positions of clinical bioethicists. Her day at the office furthers Chambers’ project of depicting bioethics as a form of life, while also raising the question of whether bioethics is a form of life, or a rather a multiplicity of forms contingent upon on the life history, position, neuroses and moral commitments of particular clinical bioethicists in particular spaces and bodies.

In addition, I appreciate Rabinow’s reticence to compose generalizing theories to explain an emergent bricolage like clinical bioethics. I characterize my investigation of moral agency through an analysis of the labor of clinical bioethicists as a meditation, rather than a theoretical enterprise. The issue of moral agency is a long-standing problematization in Western philosophy, and it would be convenient to evoke Marx, Mill, Kant or sundry other thinkers who have contemplated this problem in greater depth than I propose to do here. However,

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13 Of course designating these two strands “analytic” and “narrative” is somewhat misleading as both inevitably contain narrative and analytic elements. Clearly I was analytical in choosing particular events from my fieldnotes to fictionalize in Nadine’s narrative, and vice versa. However, it is their different styles of argumentation—one denotes, the other evokes—that I wish to highlight.
my intention in this and subsequent chapters is to evoke and contextualize moral agency and its relationship to professional practice and power structures through an ethnographic examination of clinical bioethics, rather than attempting to distill it into generalizable claims about human action and its limits. Through my fragmentary analysis and narration of Nadine’s experiences, I aim to provide a raw, yet concrete rendering of moral agency that future analysts can mine to add to the theoretical cacophony regarding the interplay of freedom and constraint in society.

The apparatuses that structure and inform the work of clinical bioethicists fall into six broad domains of problematization, each of which includes multiple institutions, symbols and discourses: (1) academic bioethics; (2) the biomedical enterprise and the organization of medicine; (3) clinical research; (4) the health insurance system; (5) patient rights and patient safety; and (6) the emergent professional norms of clinical bioethics.
IV. Academic Bioethics

It is impossible to draw a bright line between academic and clinical bioethics. In both Canada, and (more recently) the U.S., clinical bioethicists and academic bioethicists are encompassed by a single professional association (the Canadian Bioethics Society and the American Society for Bioethics and Humanities) and attend the same annual meetings. There are only a couple of journals dedicated specifically to clinical bioethics (the Journal of Clinical Ethics and HEC Forum), while academic bioethics journals have proliferated over the past twenty years. At RH, the Clinical Bioethics Service subscribed to many academic bioethics journals (the Hastings Center Report, the Journal of Medicine and Philosophy, IRB, and several others), and most clinical bioethicists I interviewed read several such academic journals on a regular basis. Thus clinical and academic bioethicists access the same articles and books, and hear many of the same talks at their national meetings. Many academic bioethicists situated in philosophy, theology or law departments, in medical schools or in centers of bioethics within universities, also serve on hospital ethics committees, and occasionally perform ethics consultations at the bedside. Both academic and clinical bioethicists conduct research and publish. Both have teaching responsibilities and administrative duties such as institutional policy development and review. There is undoubtedly a great deal of traffic between the two sub-groups within bioethics, but there are also tensions between them, and significant differences in the kind of work they do.
Judith Andre ably depicts the lives and ethical challenges of academic bioethicists in her recent book, *Bioethics as Practice* (Andre 2002). What strikes me as I read her account of her own work in an university center for bioethics, and the challenges faced by her academic colleagues to juggle grant-writing, teaching and writing, and to survive departmental politics, is the distinctiveness of clinical bioethics as a practice and as a *job*. Based on my fellowship experience and my interviews with clinical bioethicists, I argue that variations between the two subfields stem from their distinctive positions within their institutions, their different temporal paces, and the dissimilar teleologies of their endeavors.

Academic bioethicists generally represent the elite of the field of bioethics. And while the field espouses to be interdisciplinary, a Ph.D. in philosophy remains the standard, so that philosophical modes of analysis and argument dominate bioethics journals and national meetings. The clinical bioethicists I interviewed generally had comparable credentials to those of academic bioethicists (usually a Ph.D. in philosophy or an M.D.). However, academic bioethicists usually have tenured, or tenure-track, positions in universities, while most clinical bioethicists are employed by hospitals or health care organizations. Clinical bioethicists are usually classified as members of the hospital staff, and thus rarely are afforded the job security of tenure. This leads clinical bioethics to experience perpetual anxiety regarding their job performance and job security, which sometimes causes them to second-guess their actions and to curb their critical faculties. Tenure allows academic bioethicists a certain degree of freedom
to not only critique their institutions, but also to neglect them in pursuit of their own research. The personal research interests of clinical bioethicists, however, must always take a backseat to their primary responsibility, which is to support the patient care mission of their hospitals.

In addition, academic bioethicists are members of departments and thus have (for good or ill) colleagues with whom to collaborate and share responsibilities. As noted above, many hospitals employ only one or two clinical bioethicists. In addition, clinical bioethicists must maintain relatively neutral relationships with various constituencies within the hospital in order to appear approachable to all; thus, clinical bioethicists are often both spatially and socially isolated within their institutions.\(^\text{14}\) While they strive to support the clinical staff in their efforts to provide ethical patient care, clinical bioethicists are not (and cannot be) full members of the healthcare team. As Nadine’s narrative illustrates, clinical bioethicists lead relatively atomized existences in their workplaces, often relying on the collegiality of clinical bioethicists at other hospitals for support.

Academic and clinical bioethics are also differentiated by the distinctive temporal paces of their home institutions. Clinical bioethicists often wear pagers so that they can respond to an ethics consult immediately. While most clinical bioethicists prefer to practice preventative ethics by conducting rounds with various medical services on a regular basis, many of the ethical dilemmas they confront at the bedside are urgent. They require some sort of resolution within

\(^{14}\) This is particularly true for clinical bioethicists with training in the social sciences, theology or humanities. Physician-bioethicists and nurse-bioethicists may enjoy greater camaraderie with their clinical colleagues.
days, if not hours. In the clinical setting, where physicians and nurses often care for dozens of gravely ill patients over the course of a single day, time is treated as a precious and coveted resource. In hospitals, time literally is money, as the time spent with each patient is strictly allotted in order to maximize efficiency and the profits of the hospital. Even for non-clinical staff, and the pace of life is faster in hospitals than it is in academic settings. Though academic bioethicists undoubtedly work very hard under enormous pressures to publish or perish, they also have more unstructured time to read, reflect and contemplate than their clinical colleagues. While many academic bioethicists address the ethical implications of clinical issues in their writing, most do it from a distance, rather in the hallway of a hospital, or at the bedside of a patient.

The temporal differences between clinical and academic bioethicists, as well as their different institutional settings and proximity to patient care, inform the various purposes of the two subfields. Both academic bioethicists and clinical bioethicists teach; however, their audiences are significantly different. Academics teach undergraduates, graduates and/or medical students, while clinical bioethicists tend to aim their educational endeavors at practicing health care professionals. While academic bioethicists may have relationships with a consistent group of students over a period of months and years, clinical bioethicists often do not have students as such. Rather their teaching responsibilities are largely comprised of one-off encounters or informal case discussions, like the nursing and fellow orientation sessions described above.
Thus, clinical bioethicists have neither the satisfaction nor the aggravation of guiding students through a process of mutual exploration of set texts. Rather, their presentations are structured to present their audience with practical tools for addressing ethical dilemmas in clinical care.

Similarly, while both clinical and academic bioethicists generally conduct research, the former often publish in medical or nursing journals with the aim of influencing medical practice (or the practices of other clinical bioethicists or ethics committees), while academic bioethicists often prefer to publish in academic journals, with the intention of getting tenure or advancing their reputation in the field as original thinkers. The different teleologies of their research leads to a great deal of griping at national meetings. Academic bioethicists accuse clinical bioethicists of lacking intellectual rigor, while clinical bioethicists accuse their academic colleagues of doing research that is irrelevant to the problems they encounter in the clinical setting. This mutual suspicion and disdain is of course not unique to bioethics; it is fairly typical of any academic discipline (including anthropology) with both applied and theoretical aspirations.

In my own practice as a fellow, and in my multi-sited research, I found that although clinical bioethicists are generally familiar with the theoretical trends in academic bioethics, they very rarely reference it in their daily work, and when they do they deploy theoretical concepts strategically. For example, in our “didactic” sessions with medical students, fellows and nurses, Lydia and I utilized visual aids that distilled key concepts in moral philosophy into practical tools. As
illustrated in Nadine’s description of composing her “bioethics cheat sheets,” this process of distillation generally strips these concepts of their historical context and controversies, and whitewashes their inconsistencies and inadequacies, a move many academic ethicists are loathe to take.

In addition, clinical bioethicists generally reference only a handful of the philosophical theories that circulate within academic bioethics. Principlism is the bioethical “theory” most frequently cited by clinical bioethicists, followed by utilitarianism and casuistry. This is undoubtedly because these theories are most palatable to harried healthcare professionals as they are compatible with current models of medical practice and education. Casuistry is akin to case-based analysis; utilitarianism is essentially identical to medical risk-benefit analysis; and principlism is enshrined in the practice of informed consent (autonomy) and the Hippocratic oath (beneficence/nonmaleficence). Theories of power (such as Foucauldian or feminist ethics) were rarely only rarely in the educational sessions of clinical bioethicists I observed. These theories are perhaps more difficult to distill into one-line definitions, in part because they challenge the hierarchical social structure and the epistemological claims of medicine.

The practice of clinical bioethics is aimed at solving practical problems in clinical care, problems of some urgency that cannot be deferred pending reflection and further investigation. In addition, clinical bioethicists socially as well as intellectually isolated within their institutions. Few health care professionals will share their philosophical training, their penchant for thinking critically about
broad moral questions, or their contemplative yearnings. One of my interviewees put it this way: "If you find an angry physician, talking about Kant isn't going to get you anywhere. It's more effective to say, 'Let's have coffee,' and you finally get to the case."

Thus, even when clinical bioethicists recognize the philosophical or social complexity of a given dilemma, the practical orientation of their audience often compels them to forgo subtle theoretical homilies in favor of offering immediate and accessible solutions. In all of the dozens of ethics consultations I have observed and facilitated, I have only witnessed two occasions where a clinical bioethicist directly referenced the literature of academic bioethics. Due to the teleological, temporal and situational differences between the two subfields, it might be said that the relationship between clinical bioethics and academic bioethics resides primarily in the person of the clinical bioethicist, rather than in her daily practice.

However, academic bioethics does affect the moral agency of clinical bioethicists in their professional practice. First, as Nadine's narrative evokes, the predominance of philosophical theories and discourses in academic bioethics can cause clinical bioethicists with other training to subsume their unique disciplinary insights under the hegemony of moral philosophy\(^5\). Second, while clinical bioethicists may possess extensive knowledge of the bioethics literature, their inability to utilize this knowledge due to the temporal and practical

\(^5\) A notable exception to this rule seems to be theologians working in religiously-affiliated hospitals who are empowered by the mission of their institutions to draw upon theological modes of reasoning in their adjudication of ethical dilemmas.
constraints imposed by their professional practice, may cause them to be more acutely aware of the way in which their moral agency is constrained by the various apparatuses of contemporary clinical medicine.

V. The Biomedical Enterprise and the Organization of Medicine

Clinical bioethics emerged and thrives within a particular subculture, that of biomedicine, most often within the milieu of the teaching hospital. The teleology and ontology of biomedicine, as well as the organization of academic medicine, structures the labor of clinical bioethicists and their professional identities, and delimits their moral agency.

The primary objective of biomedicine is the cure of disease. That an ever-expanding array of human experience and variation falls under the purview of biomedicine (shortness, low self-esteem, impotence, etc.), and that relatively few diseases are in fact cured, but rather are chronically managed with varying degrees of pain and disability, only serve to embolden the curative project of biomedicine. This enterprise is undergirded by three key assumptions: (1) a profound dualism that takes the secularized patient body as its object; (2) a reliance on technological solutions; (3) the perception that death is a failure.

The curative teleology of biomedicine lends itself to a dualistic conceptualization of persons. However, unlike Descartes’ rendering, it is the body that has greater ontological status in biomedicine than the “soul” which inhabits it. The ethics consultations I observed almost invariably began with a lengthy description of the patient’s medical history and current treatment regimen
delivered by the attending physician. This was not only because medical "facts" are the foundation for decision-making in ethics consultations, but also because this data is ontologically primary in the clinical context. When attention did turn to who the patient is outside the context of the hospital—her values and significant relationships—this information was generally provided by the social worker, chaplain, nurse or patient advocate. This division of labor demonstrates that knowing the patient as a person (rather than as a collection of deviant organ systems) is not generally the responsibility of the physician.

In the pursuit of cure, people are transformed into medical objects. As Daniel Chambliss observes in his ethnographic study of hospital nurses, medical treatment is a process of profanation, a process of secularizing the flesh that patients normally experience as sacred (Chambliss 1996: 26). In the hospital modesty is banished and gross violations of bodily integrity are consented to with the goal of saving life or mitigating suffering. In this ontological landscape the "real" is the body: a body defined by the (mal)functions of its various organ systems. Thus the body is experienced both by the patient herself and by medical staff as an "other." At times of acute or severe illness, the body-self that used to be a source of pleasure and agency becomes largely passive as patients willingly (and in many cases, unconsciously) subject their bodies to the ministrations of the high priests of the modern medical center. The designation "patient" creates a rift between patients and staff: patients are sick, the staff are well; patients are objects, the staff are agents. They comprise different orders of
humanity. In addition, Chambliss argues that the hospital is a place where terrible things become ordinary through the repeatability of operations, treatments, processes and death (24). For health care professionals, routinization of the extraordinary through repetition leads to a certain casualness, even boredom, with the abnormal.

Another characteristic of biomedicine that frames the work of clinical bioethicists is its technological orientation. Physicians spend years of training learning technical mastery of complex procedures and machines. Not to utilize this training, even on a marginal case, both makes the case uninteresting to them and seems like a "waste" of their capabilities. One of my interlocutors told me the story of a woman who was given less than a ten percent chance of survival by her physicians. The family wanted to stop treatment, but the physicians weren't ready to withdraw the aggressive interventions they had initiated: "I wasn't sure if [her physicians] didn't want to stop because they really believed she could make it, or because they had spent so much time and energy working on this interesting case." In addition to the intellectual challenge technologies present to health care professionals, high-tech treatment programs (such as transplant and intensive care) tend to carry more prestige and attract more lavish funding compared to low-tech specialties like internal medicine and pediatrics.

Andrew Jameton summarizes the technological orientation of biomedicine this way:

If health professionals were mainly concerned with doing the most obvious and immediate good for patients, they would emphasize skills in caring for
and comforting the sick, that is, palliation of symptoms and relief of pain, since most diseases are still either incurable or self-limiting. If bedside care were in fact the most honored specialty, the prestige of the health professions would likely be the reverse of its present standing. The most valued forms of competence currently tend to reflect scientific and technological interests—what people consider intellectually difficult, exciting, and challenging—rather than what is most directly related to patient good or to public health (quoted in Chambliss 1996: 102-013).

The curative teleology, and the technological imperative embedded in biomedicine, as well as a general denial of death in American culture at large, leads to aggressive treatment of even the sickest and most “hopeless” cases. A major frustration faced by the clinical bioethicists I observed was the reluctance on the part of physicians to declare a patient terminally ill. In a retrospective review of fifty randomly-selected patient charts from the oncology department, I found that on average physicians only documented a patient’s terminal prognosis eight days before their deaths. There are a number of reasons for this prognostic reticence. First, patients and families themselves often resist receiving bad news. Second, physicians, particularly clinical researchers, are both personally and professionally invested in the search for curative therapies. As one physician said in an ethics consultation: “I designed the protocol you will be treated with. If you die [while on this protocol], it will look bad for me.” One important measure of the efficacy of a therapy is how long patients survive on the therapy. This creates an incentive for physician-researchers to continue treating patients very aggressively while they are enrolled in a clinical trial. Third, a terminal diagnosis often leads to the severing of the patient-physician relationship. At Research Hospital, once a patient was determined to be terminally ill and ineligible for
active treatment, the patient’s case manager immediately began to seek another, less costly placement for the patient (usually in a nursing home or hospice). Many patients resisted the transition to palliative care not only because it meant that death was imminent, but also because they would have to leave behind the relationships (however tenuous) they had established with care-givers at the hospital. Fourth, as Nicholas Christakis, Mary-Jo DelVecchio Good and others have found, many physicians (particularly oncologists) resist prognosticating because they believe that telling a patient they are terminally ill will somehow hasten the patient’s death by robbing them of hope (Good 1995; Christakis 1999).

Another feature of biomedicine that frames the work of clinical bioethicists is the organization of labor within hospital settings. Ruth Malone astutely observes in her spatial analysis of nursing that contemporary medicine is increasingly “distal” in its organization. The recent increase in medical litigation (or at least the recent increase in the perceived risk of litigation among health care providers) transformed the medical chart from an essentially private means of communication among doctors to a public piece of evidence that documents what the doctor tells, and hears from, the patient. Written documentation has largely replaced word-of-mouth orders in American and Canadian hospitals. Medical staff now spend less time gathering first-hand information from patients, relying instead on technologies such as the medical chart, x-rays, monitor print-outs and blood tests to indicate how patients are doing. Whereas nurses used to
give patients nighttime backrubs which created an opportunity for close physical contact and intimate discussions between patients and their caregivers, this ritual has been replaced by the ritual of completing daily flow sheets and other institutionally-mandated paperwork (Malone 2003).

In addition to this distal quality, contemporary biomedicine is organized in a strictly regulated hierarchy. At the top of the hierarchy is the "attending physician", or "the physician or record" (cf. Zussman). The attending physician acts as "the captain of the ship," to use an oft-repeated metaphor. He or she writes the orders for particular procedures or tests, requests consultations from other specialists, and determines the patient's overall treatment plan. The attending physician is legally responsible for a patient's care. Attending physicians, however, spend relatively little time with patients. The skyrocketing cost of hospital care has caused health insurance companies and hospitals to steadily raise the threshold for hospital admission. Lengths of stay have been reduced and more conditions are treated on an out-patient basis. Thus inpatients are more seriously ill and attending physicians wind up scrambling from crisis to crisis. In an average ward at RH, an attending physician would be responsible for the care of upwards of twenty patients at any given time, many of whom were either in a medical crisis, or on the verge of one.

Most of the orders of attending physicians are carried out by others such as nurses, therapists, fellows, residents and medical students. As one medical fellow at RH observed: "If you ask a patient who their physician is, they will
usually name the resident. The resident is the one who goes into their room ten
times a day, doing things, or forgetting to do things and going back in. Most
patients don’t know who their attending is." Fellows, residents and medical
students (in descending order of experience and authority) are present in the
hospital to provide patient care, and to learn the art of medicine. Medical
education remains largely heuristic: see one, do one, teach one. The procedures
fellows, residents and students perform are intended to be beneficial to the
patient and to their future patients as they hone their skills.

Another contributor to the distal relationship between attending physicians
and patients is the rotation schedule. Attending physicians are expected to be
on-call for their in-patients twenty-four hours a day. Fellows and residents
routinely page them after hours to update them on their patients’ changing
conditions. In order to avoid physician burn-out and provide physicians adequate
time to attend to their out-patients and to their research and teaching
commitments, physicians are often responsible for in-patients on a rotating basis.
These rotation schedules may be as short as one week, or as long as one
month. While rotation may increase the productivity of the hospital and benefit
the physicians, it deals a major blow to “continuity of care” for patients. An
attending physician often meets an in-patient for the first time when they are
already very sick or even unconscious. Having no prior relationship with the
patient, physicians need to catch-up on the patient’s medical history and course
of treatment at the outset of their rotation. While this information can often be
gleaned from the chart, more challenging is the process of building trust with patients and their families. Patients and families may be reluctant to trust physicians who have limited time to get to know them personally. In addition, the rotation schedule can lead to a “pass the buck” mentality among the physicians themselves. As a clinical bioethicist I frequently observed physicians deferring difficult decisions, such as making a terminal prognosis or writing a do-not-resuscitate order, until the next attending physician came on rotation. Such avoidance can lead to weeks of unnecessary aggressive treatment for a dying patient. The ethics committee at Research Hospital repeatedly fingered the rotation schedule as an etiological factor in ethical dilemmas precisely because it erodes patient-physician relationships and the moral responsibility of physicians to “do the right thing” (i.e. withhold or withdraw futile treatments).

Specialists are often consulted by the attending physician to provide assessments of a patient’s particular organ functions: the psychiatrist treats the patient’s depression; the nephrologist monitors his kidney function; the cardiologist treats the patient’s heart disease; the intensivist oversees the patient’s care in the ICU, etc. So fragmented is the patient’s care, and so susceptible to misunderstanding, that many clinical bioethicists report that the primary function of ethics consultation is to bring everybody around the same table at the same time to facilitate communication. However, the attending physician remains the gatekeeper of all major medical decisions. This is reflected in RH’s ethics consultation policy that states the attending physician must attend
the consult. If she refuses, her supervisor will be asked to attend in her stead—a strategy intended to secure her attendance. (Consults were also planned at a time convenient to the attending physician; other participants had to adjust their schedules accordingly.) Although trainees and nurses provide the majority of care to patients and may understand the patient’s condition in a more tangible way, it is the attending physician who generally presents the patient’s medical history in a consultation.

Of all health care professionals, nurses arguably spend the most time with individual patients. Chambliss observes that the nurse is distinctive in her characterization as simultaneously (1) a caring individual (“nurses care, doctors cure”; caring means treating the patient as more than a biological organism; caring means having open-ended duties and requires personal commitment); (2) a professional (nurses have special skills, and they are paid to care); and (3) a relatively subordinate member of the organization (Chambliss 1996). The subordination of nurses relative to physicians is often attributed to their less technical skills. However, their lower status is compounded by the fact that they remain a largely female workforce, and increasingly in America, nurses are immigrant and minority women recruited from the developing world. As Chambliss argues, nursing ethics is distinctive: “Nursing ethics...is the ethics of powerless people; the ethics of witnesses, not decision-makers; the ethics of implementers, not choosers; the ethics of those whose work goes unnoticed. Perhaps, too, as its practitioners are predominantly women, it is the ethics of
more personal relationships" (Chambliss 1996: 87-88). Nursing’s ethical problems are systematic and widespread, transcending individual actors. Their problems are practical, not individual dilemmas. According to Chambliss, bioethics aims to answer the question, “What should be done?” This is a question for powerful people who make decisions, not the powerless who carry them out. Instead, nurses often have to ask themselves, “How should one act when one isn’t powerful? (5). Nurses experience frequent conflicts with physicians, often because of their different professional teleologies (care vs. cure). As Chambliss argues, ethical problems in hospitals are often a symptom of occupational group conflicts that become labeled as moral conflicts: “Ethical issues are not a mere competition of ideas; they are a competition of people, who have their various goals and methods” (118).

There are myriad other healthcare professionals occupying roughly the same position in the hospital hierarchy as nurses. Each has a specialized task: the social worker provides emotional support and social services to patients and their families; the chaplain ministers to the spiritual needs of the patient; the occupational therapist prepares disabled patients to adjust to life outside the hospital; child-life specialists prepare children for the death of a parent; pharmacists manage medications; case managers monitor the patient’s insurance cap and plan the patient’s discharge from hospital by arranging for home health or nursing home placement. There are literally dozens of such “second tier” health care professionals in contemporary hospitals. Each lays
claim to a particular piece of the patient. While the various medical specialties
divide and apportion a patient's body into different organ systems, these health
care professions address the patient's various personal and social needs. It
remains an open question whether such fragmentation leads to patient care that
is more than the sum of its parts.

A third tier in the organization of medicine is "administration." This is a broad
category, ranging from the CEO (at the top) to the executive assistants of various
middle managers (at the bottom). Administration is the umbrella term for those
responsible for the sundry bureaucratic processes that enable patient care. (Most
clinical bioethicists would fall into this category, unless they also practice
medicine or nursing.) Sometimes a high-level administrator (such as a Vice-
President) is himself a physician by training and exercises authority over the
hospital's physicians as a collective body. However, if a physician's treatment
plan for a patient is disputed, the administrator will not generally override the
decision of the attending physician, citing legitimate variances in "clinical
judgment." However, administration imposes restrictions on clinical care through
bureaucratic structures, for example, by imposing policies about DNR orders,
billing procedures, access to patient records, etc. Health care professionals often
express frustration with administrators whom they accuse of not understanding
"life in the trenches," and creating bureaucratic red tape that removes nurses and
physicians from close contact with their patients.

However, there is another group of hospital workers that remains largely
below the radar of clinical bioethics. This group, often captured in the language of “operations,” includes those whose labor and expertise maintain the physical environment and infrastructure of the hospital, and who provide non-clinical services. This includes plumbers, switchboard operators, housekeepers, engineers, cooks, cashiers, parking valets and “sitters” (those who literally sit in the rooms of patients who cannot be left alone). In the two years I worked at Research Hospital, I can’t recall having a conversation with any operations personnel aside from the woman who cleaned my office. While technically the ethics consultation service at RH (and probably most hospitals) was available to operations personnel, I cannot recall a single consultation being called from this group of workers, nor were any ethics education sessions organized for them. While their labor and skills may be valued in a general way for operationally supporting patient care, their concerns (whatever they may be) are considered peripheral to clinical bioethics. This is despite the fact that many operations personnel have significantly more contact with patients than I had as a clinical bioethicist, particularly housekeepers who daily clean the same cluster of patient rooms, and food delivery staff who bring meals to patients three times a day. When the ethics committee at RH was revamping its recruitment process, I suggested to “Lydia” that we try to broaden the membership to include operational staff. At the time the committee was comprised of equal numbers of physicians, nurses and other health care professionals (including a couple of administrators). However, my suggestion was rejected because the ethics
committee policy at the time stipulated that membership was only open to health
care "professionals" or community members from outside the hospital. I never
really understood why Lydia used the policy as a shield to dodge the issue.
Perhaps she sensed a danger in truly democratizing the ethics committee. As
well, Lydia perhaps understood that operations personnel would bring to the
committee a sensitivity to ethical issues stemming from the structural
organization of the hospital (i.e. labor conditions and their impact on patient
care), and the potential this perspective had to upend the tendency of health care
"professionals" to individualize ethical dilemmas by focusing on discrete cases.

I do not imagine the hierarchical organization of labor in hospitals in the
form of a pyramid with physicians at the top and operations personnel at the
bottom. Rather, I think of it more as a web, with physicians in the center, and the
other layers of labor (students, nurses, other health care professionals,
administrators, operations staff) fanning out concentrically to support that
center. Clinical bioethicists move with comparative freedom between the
different layers of the hospital; they must in order to establish networks of support
for their work since they rarely have many colleagues of their own. The flip-side
of this social mobility is of course marginality. Clinical bioethicists, while often
technically administrators, strategically try to maintain a neutral relationship with
the various factions in the hospital's organizational structure. This is reflected in

16 As Chambliss has observed, the complexity of hospital organization means that confusion of
responsible is easily incurred, causing patients to get dumped or passed on or simply ignored
(Chamblis 111).
17 Most of the clinical bioethicists I interviewed worked alone; the lucky ones had one or two
others in their department.
the spatial location of their offices. Most of the clinical bioethicists I interviewed
and visited have offices isolated in obscure hallways, physically distant from
patient care areas or hospital wards. It is also reflected in their titles.

RH reorganized its clinical bioethics service during my fellowship. When
senior members of the ethics committee observed that Lydia’s new ID badge
designated her as a member of the Critical Care department, they balked. Below
is an excerpt from my fieldnotes of an ethics committee meeting.

Lydia: My badge says "Critical Care" and there has been some
discussion about whether my office should relocate to be in their office
suite.

Ethics committee doctor: I just want to know why Critical Care?
Ethics committee nurse: The Critical Care appointment may lead to
the perception that you are not as objective. The ethics service should be
independent, not seen as allied with one service.

Lydia: We don’t want it to look like we are owned by Critical Care.
This creates a political problem.

Doctor: I’m wary of having ethics under the hegemony of a [clinical]
department, particularly Critical Care. We selected a non-physician ethicist
to avoid bias, to make the ethicist more objective and more autonomous.
I’m concerned that you not be poached by another program. Ethics is its
own entity. It needs its own structure and identity.

Nurse: I agree. If you get tacked onto another department it
diminishes your integrity to the whole institution.

Nadine: In fact a large portion of our ethics consults stem from
disagreements between the primary team and the ICU team. You don’t
want to be seen as taking sides because of this affiliation.

Nurse: There could be ulterior motives from Critical Care. They may
have expectations of having you there in that department.

Lydia: Yes, I’m expected to attend their faculty meetings.

Nurse: Then you will be privy to the information and team dynamics
of that department.

Lydia: I’m concerned that I not be perceived as the police for
Critical Care.

Doctor: But how will it look to a family if you have to facilitate an
[ethics consultation] wearing a badge that says Critical Care?

Nurse: Even in teaching fellows you may be perceived as biased if
they see your badge says Critical Care.
This exchange clearly illustrates that clinical bioethicists must remain open to all but allied with none. Lydia later expressed to me her frustration with the ethics committee, saying that the charge of bias through affiliation with a particular department could be extended to affiliation with the hospital in general. "It could be argued," she said, "that we are inherently biased because we are employed by the hospital, and that patients and families shouldn't trust us to make fair recommendations. The only way to get around this would be to work as an independent consultant." In the end, Lydia kept her appointment in Critical Care but had her ID badge altered to read simply "Clinical Bioethics." This gesture maintained a veneer of neutrality.

However, this emphasis on neutrality denies the practical importance of the social network to the work of clinical bioethicists. When I was a fellow, the vast majority of RH's ethics consults were initiated by physicians and nurses who had some sort of personal connection to the ethics committee. For example, fifty percent (check stats) of all consultations originated from the hematology department. Lydia and the ethics committee hypothesized that this was because hematology patients usually have very poor prognoses. However, the same could be said for other services, such as neurology or the GI cancer clinic, yet physicians in these departments rarely called the ethics consultation service. The more likely explanation for the high utilization by the hematology service was that several physicians and nurses in this department had served on RH's ethics

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18 Less than five percent of ethics consultations were initiated by patients and families even though a pamphlet about the service was included in their admissions package when they arrive at RH.
committee. They knew Lydia personally, and were comfortable with the processes and procedures of ethics consultation.

The significance of personal relationships and social networks was illustrated by a presentation I saw at a bioethics conference. A panel of clinical bioethicists presented statistics detailing the utilization of their hospital's ethics consultation service over the past ten years. When one of the panelists got to a slide depicting the annual number of consultations, she noted that the graph depicted a steady increase in consultations from the inception of the service, then a sudden and significant decline for one year, followed again by a steady increase in consultations. Pointing to the dip in the graph she said, "We haven't quite figured out what caused this drop in utilization of the consultation service. However, it happens to coincide with the departure of the ethicist who founded the service, and the arrival of a new ethicist" (Smith, Pentz et al. 2003). While the audience laughed at the insinuation that the new ethicist caused this drop, I would argue that this coincidence graphically depicts the centrality of social relationships to the work of the clinical bioethicist. The services of the clinical bioethicist—particularly ethics consultations that arising in the midst of moral and medical crises—are requested primarily by those who know and trust the bioethicist; that individual must prove to their colleagues through face-to-face encounters or word-of-mouth accounts that they are worthy of trust.

At the same time, it remains essential for the clinical bioethicist to maintain her veneer of neutrality in order to preserve her social mobility within the
institution. Being too closely allied with a particular department, or with any particular layer within the hierarchy of the institution, could diminish the ethicist’s access to other departments and workforces within the hospital, restricting her social network and opportunities to provide services to the staff. As mentioned above, this mobility presumably boosts the agency of the clinical bioethicist, as her commitment is to the institution at large, rather than to a particular echelon or clinical department that may be competing for resources with other departments. However, the clinical bioethicist’s agency is delimited by the power structure within the hospital as there are certain norms, such as deference to the attending physician, even she must abide by. Her commitment to the institution, and her social network within the hospital undoubtedly affects her moral agency in another way. It induces her to identify with the needs and values of the hospital staff with whom she interacts on a daily basis (and whose clientage she relies on for her livelihood), rather than the needs and values of the transient population of patients, all of whom eventually leave the hospital, one way or the other.

VI. Clinical Research

Contemporary teaching hospitals serve double duty: not only are they sites of medical treatment, they are also sites of medical research. Medical or clinical research employs a variety of methods and serves a variety of ends, depending on its context, disciplinary orientation and funding source. Research conducted at teaching hospitals may include basic or “bench” research, for example, studying the molecular structure of asbestos embedded in the lungs of vermiculite miners.
It may include animal studies of new treatments. Basic and animal research is
governed by its own set of federal regulations and institutional structures (such
as an Animal Care Review Committee), and clinical bioethicists generally have
little interface with these researchers.¹⁹ Research involving human subjects
include phase one, two and three clinical trials to measure the toxicity and
efficacy of drugs, devices or surgeries. Behavioral studies measure patients’
subjective experiences of their illnesses and treatments, while epidemiological
research tracks general trends in health and disease. Both clinical and behavioral
research is reviewed and approved by Institutional Review Boards (IRBs or
Research Ethics Boards in Canada). Clinical bioethicists often serve on IRBs,
contributing specifically to the structure and content of informed consent forms
for participants. For some clinical bioethicists I interviewed, research review
comprises the bulk of their work within their hospitals. However, in addition to this
specific task, the clinical research milieu informs the types of ethical dilemmas
they are asked to adjudicate, and the limits the range of moral options available.

At a managers’ meeting I attended during my fellowship at Research Hospital,
the Vice President announced the hospital’s strategic goal for the next five years:
to have fifty percent of all patients enrolled in clinical trials. Nurses and
physicians I spoke with reported that eligibility for a research protocol was

¹⁹ An exception to this rule occurred at RH when I was an intern. A clinical researcher had
designed a study of a new biological agent that involved administering the agent to patients
diagnosed as brain dead, and then extracting tissue samples from these patients for analysis. His
research team, comprised of PhDs in biology and organic chemistry with little clinical experience,
revolted. They were morally repelled by the prospect of performing basic research on patients
who were in the throes of death. Lydia was consulted by the principal investigator and
subsequently held an educational seminar with the research team to clarify their concerns and
educate them about bioethics’ emergent theorization of research on “the nearly dead.”
already used as a criterion for admission by many departments of the hospital. In pediatrics, for example, 100% of patients were enrolled in research protocols. Such tacit policies might be considered discriminatory against those who are too sick to be enrolled in a research trial or who simply have very "ordinary" diseases. It might even seem exploitative of sick people desperate to receive care. However, research is integral to the contemporary teaching hospital. One of the tabs in RH's in-patient charts was labeled "Consents." It was a rare for me to pick up a patient's chart that did not have at least one consent form for a research protocol under that tab.

Not only was eligibility for research trials used as a criterion for admission to RH's clinical programs, but also certain physicians were rumored to keep patients alive long after the point of no return in order to improve the mortality statistics of their protocols. I was told privately by junior faculty in one department that a senior physician continued recruiting patients to a protocol even though three relatively young (though gravely ill) patients had died suddenly in the course of the trial. In the departmental Morbidity and Mortality meeting, however, no one brought it up. Such suspicions are difficult to confirm, particularly as physicians vary widely in the levels of aggressiveness with which they treat patients, and many patients and families themselves want "extraordinary measures" up to the point of death. It might be impossible to trace the death of a patient with a pre-existing severe and complex illness to a particular drug regimen. And ironically, the research approval process also keeps such
suspicions under wraps. While the IRB and its bureaucratic procedures for reviewing protocols for safety and ethical acceptability is widely recognized as imperfect, approved protocols are legitimized through it. If one researcher's integrity is called into question, the politics of the hospital are such that the whole department could be tainted by the allegation. Researchers know that if they accuse one of their colleagues of conflict of interest, they could open up the entire enterprise of clinical research to scrutiny. It is not important whether these rumors were in fact true (though it would be important to the families of the patients who died); the mere possibility for such conflicts to exist is significant.

David Rothman, in his seminal legal and regulatory history of bioethics, quotes James Shannon, the director of the National Institutes of Health in 1996 when Henry Beecher published his expose of research abuses: "[T]he bedrock principle of medical ethics—that the physician acted only to promote the well-being of the patient—did not hold in the laboratory.... The doctor-patient relationship could no longer serve as the model for the investigator-subject relationship" (quoted in Rothman 1991: 89). As Rothman further observes, with the dawn of clinical research, the patient's good was eclipsed by the need to develop new knowledge and new therapies. In a teaching and research hospital, the physician is no longer in the same relationship to patients that he is in the conventional medical setting. Doctors who let monetary concerns guide their actions by making treatment decisions in order to increase their incomes are immediately recognized as patently unethical. However, ethics become
obfuscated in a system of promotions that emphasizes grant getting and publications. The physician who lines his pockets at his patients' expense is condemned, whereas the researcher who produces new findings by disregarding the rights of his subjects might well win tenure and scientific prizes (10). This environment calls into question the notion that the interests of patient-subjects and physician-researchers are identical.

Clinical research is funded through a range of agencies. The hospital may provide small grants to its own researchers, but more commonly physician-scientists will apply for grants from federal funding agencies such as NIH or NSF, from private foundations, and from pharmaceutical or biotechnology companies. It is well known that the pharmaceutical industry courts physicians to do trials of their drugs, providing substantial consulting fees and stock options to the principal investigators, as well as funds for specific trials. During my fellowship, Research Hospital formed a Conflicts of Interest Committee (COIC) to review the relationships between clinical faculty and outside agencies. The COIC created a "voluntary mandatory" review process. Physicians were expected to disclose to the COIC financial involvement in or relationships with external organizations related to their clinical expertise. This included consultancies with pharmaceutical or biotech companies, honoraria for speaking engagements, stock options or stocks invested in biotech or drug companies, particularly those producing drugs or devices that researchers use in medical practice or clinical protocols.

The COIC was limited in scope, however. It did not have the authority to
police the practices of clinical researchers or to discover undisclosed conflicts of interest. They also were not empowered to enforce policies that restricted use of hospital resources for personal gain. RH's conflicts of interest policy allowed clinical faculty 240 hours per year of administrative leave for continuing education, travel to conferences, speaking engagements and consultancies with external companies. This was equivalent to roughly six weeks of paid leave.\footnote{In comparison, RH allowed clinical faculty and staff twelve weeks of \textit{unpaid} leave per year to care for a newborn or sick family member.}

Principal investigators were allowed to receive up to $10,000 in consultation fees per year from a company whose drug or device they were testing in a clinical trial. The COIC policy also allowed faculty members to receive up to $10,000 per year from companies sponsoring research in a laboratory overseen by the physician. The chair of the COIC explained it was generally believed that for a clinical researcher with an annual income of well over $100,000, $10,000 would not unduly influence the investigator's clinical judgment. (In fact, the $10,000 ceiling was borrowed from federal regulations, and was not based on any empirical studies of how monetary incentives influence clinical judgment.)

The purposes of the COIC, as I observed it, were threefold. First, through review of these relationships, the committee attempted to ensure that researchers' primary commitment was to the care of patients, and the mission and vision of the hospital. Second, the review process attempted to safeguard the scientific integrity of the clinical trials conducted at the hospital. In this way, the COIC acted as a custodian of the reputation of the hospital from allegations
of misappropriation of hospital resources or misconduct of researchers. It is difficult to judge how effective the COIC was at achieving its goals. At the COIC meeting I attended as a fellow, one member pointed out that the hospital seemed to be giving mixed messages to the faculty. On the one hand, they were supposed to be vigilant about avoiding conflicts of interest. On the other hand, a hospital executive had sent an email to all clinical faculty recently, asking those with ideas for new companies and new drugs and devices to contact the institution’s development office which had created a new venture capital program to bring their ideas to fruition [fieldnotes]. The chair of the COIC also noted at that meeting that the majority of clinical faculty had not submitted their “voluntary mandatory” disclosure forms to the COIC, although the policy had come into effect more than a year before.

Lydia served on this committee as a non-voting member. Throughout the discussion of the failures of the voluntary mandatory system she remained silent. She later disclosed to me that as a non-voting member she was uncertain how her input would be received, thus she kept her disagreement with significant aspects of the system to herself. The COIC’s voting membership was comprised entirely of RH faculty and administrators, including at least one hospital lawyer; there were no community or public representatives on the committee.

In the handful of IRB and REB meetings I observed in the US and Canada, the protection of patients from exploitation and harm by sponsoring agencies was an important theme. Reviewers of the proposed studies generally trusted the
integrity of the investigators, thus there was relatively little debate about the scientific merits of the protocols. Sometimes reviewers (even physicians) would admit to being unable to judge the validity of a trial due to its specificity. Reviewers were concerned, however, to shield subjects from a sponsoring agency's over-zealous attempts at risk management and the attending erosion of patient rights. One reviewer, a lawyer from the community, was particularly perturbed at the language of some consent forms that stated research participants who suffer an unforeseeable, non-negligent injury resulting from the research would not be entitled to receive compensation from the sponsor. He argued that an injured participant should be compensated by the sponsor, even if the investigator conducted the research appropriately: "After all it is the patient that bears the risk. First of all for the benefit of humanity, second for the benefit of the drug company, and maybe, if they are lucky, for their own benefit. What if the participant suffers an unforeseeable brain injury as a result of the customary conduct of the research? Who will compensate him for that?" [fieldnotes].

Another issue that surfaced repeatedly in the course of reviewing protocols was the criteria for listing particular risks on the consent form. Individual IRBs and REBs largely determine their own threshold for what constitutes a significant risk to participants, and this caused a great deal of controversy among committee members.

One member delivered a report from a pharmaceutical company regarding an adverse event involving a drug currently used in trials at the hospital. ...This adverse event involved a patient who developed a rash following the administration of this drug, then very rapidly deteriorated and within a
day or two sloughed his skin and died. ... Another physician asked which drug company it was that sent the report. It turned out to be a company he had had some dealings with before. He had tested another drug this company produces and published an article showing that the doses recommended by the company were fifty percent to a third higher than they should be for acceptable toxicity. The company did not change its recommended dosage, nor did it share his article with the physicians to whom they were promoting the drug. Eventually, however, the FDA had them scale back to the dosage recommended by this physician. This doctor thought that if the company was notifying people about an adverse event, they were doing so under duress, so this information should definitely be told to potential research participants. The chair put an end to this lengthy discussion, saying, "It is our job to ensure the patients are informed of all possible risks. It's up to the patient to decide whether to participate knowing these risks." [fieldnotes]

Reviewers balked at another protocol that attempted to monopolize control over information about the trial, even going so far as to censor patients from talking about the trial, and to prevent investigators from reporting their findings. The protocol stipulated that by signing the consent, the participant agreed not to discuss the study with anyone.

There has been criticism in the literature of gag-orders placed on researchers, particularly if the results of their studies are negative. However, sponsors are now trying to extend this silence to participants themselves. This is not for the protection of the participants, but for the protection of the sponsor. As one REB member put it, "it is good business practice." There was some concern among committee members that even though a consent form is not a contract, contractual language was being introduced into the document through this stipulation. Another member asked, "Could a patient be held liable if they discussed their participation in the study, even with their family or primary physician?" The committee recommended that this language be taken out of the consent. [fieldnotes]

Another issue that surfaced in research review committees on both sides of the border was concern over how to curb the extractive endeavors of pharmaceutical companies to procure DNA samples from participants for their
own private “gene banks.” In several protocols, sponsors inserted a paragraph or an additional page into the consent form, explaining that additional blood samples would be taken from participants and stored anonymously at the sponsor’s facilities for use in future research. The consents implied, either tacitly or explicitly, that the patient would not benefit financially or therapeutically from this future research. IRB/REB members objected to such tactics for two reasons:

First they were concerned that the samples would not be anonymous as the company claimed because demographic info was being collected, as well as blood types. One doctor was concerned that genetic information could be leaked to health insurance companies or employers. Second, some members were skeptical about the scientific validity of this alleged future research. One said, “This is essentially a ‘fishing expedition’ for the pharma company. There is no hypothesis they are testing using this material. This IRB would not approve the collection of tissues if the study had no scientific validity. If we approve this, we are bending our own rules.” He convinced the IRB to not approve the protocol unless they received a letter from the CEO of the company insisting that the samples would be kept anonymous. As there was a vanishingly small chance that any CEO would make such a promise, this maneuver effectively killed the protocol. [fieldnotes]²¹

Patient care at teaching hospitals is influenced by clinical research in several ways. First, it provides incentives to individual researchers and institutions to enroll patients in trials. Second, it creates the possibility for conflicts of interest as physicians juggle the roles of doctor, scientist, consultant and investor. Third,

²¹ These examples illustrate how the interests of global companies are now embedded in and intertwined with the therapeutic relationship between patients and physicians at teaching hospitals. The broader questions surrounding such genetic prospecting were not addressed in the IRB and REB meetings I observed. Do participants want their samples anonymized? Doesn’t this “protection” cause them to forfeit any claim to profits or therapeutic benefits from the research? Might there be a fiduciary duty to notify the patient if important health information is discovered in the process of analyzing their DNA? While a DNA sample itself may be destroyed, does that mean that the digitized genetic information it contains will be destroyed? One clinical bioethicist at a community hospital noted that drug companies seemed to be focusing on recruiting smaller hospitals to run their trials as they often have less stringent research review processes.
research may pose additional risks to patients, ranging from the risk of breach of confidentiality, to the risk of injury, to the risk of loss of insurance, to the risk of additional health care costs. As one bioethicist I interviewed put it, research is an extractive industry: subjects are mined for their healthcare information, for their behaviors, and for their genetic materials. This extraction may be beneficial to research participants if the research is therapeutic, but participants also incur risk of harm. Even therapeutic research is designed primarily for the benefit of future patients, rather than its participants. Under the apparatus of clinical research, physicians become brokers, mediating between the agencies and companies that fund research, and the patients who provide the raw materials and data in the form of their bodies, tissues and information. Though the review processes of the COIC and IRB or REB are intended to safeguard the scientific validity of research and minimize risks to participants, these committees have neither the mandate nor the infrastructure to oversee the actual conduct of research. At one REB meeting the committee acknowledged that they had no idea what happened once the protocol was approved: “How is informed consent actually carried out? How much time are people given to make the decision to participate in a trial? How much of the content of the consents they sign to they actually understand? Do they make decisions based on a rational assessment of the risks and benefits, or based on their faith in their physician-researcher? Nobody knows. Ultimately the committee has to rely on the virtue of the researchers” [fielnotes]. The “extractive industry” of clinical research, however, is only possible
through appropriation of the symbols of the fiduciary relationship between physician and patient. As Rebecca Dresser points out, the therapeutic misconception—the assumption that research serves the patient’s best interests—is perpetuated precognitively through the informed consent process and structure of clinical trials (Dresser 2002). The researcher-physician appears in the patient’s room in a white coat or scrubs, wearing a stethoscope and other symbolic accoutrements of the contemporary healer. The patient is told about the research in a therapeutic setting (a physician’s office or hospital room). Even the same term—“informed consent”—is used to refer to both to consent for treatment and consent for research, and the forms are similarly structured (denoting the risks, benefits and alternatives of the treatment/research).

In one REB meeting a member raised the issue of whether it isn’t coercive for physicians to request consent for research from their own patients, especially if patients have waited months to see this specialist or surgeon. In IRB/REB conversations, as well as in some of the written protocols, there was constant slippage between the terms "patient" and "participant," as well as "study doctor" and "physician." This slippage is ubiquitous in casual conversations at RH, demonstrating that the current structure of clinical research makes the distinction between “sick people getting treatment” and “sick people getting studied” blurry at best. The preoccupation of REBs/IRBs with safeguarding patients against the “shenanigans” of pharmaceutical companies also indicates the extent to which the interests of third parties have penetrated and imperiled the fiduciary duty of
physicians to their patients.

As Nadine’s narrative demonstrates, the research agenda of contemporary teaching hospitals, and its system of incentives for investigators, can curtail the moral agency of the clinical bioethicist. While Nadine personally reviles the extraction of genetic materials from patients, both she and Lydia are relatively powerless to curb the hospital’s ambition to harvest these materials and to bank the future profits. Ironically, they were unwitting founders of this extractive system as it was Lydia who brought the issue to the attention of the administration, based on an ethics consultation she’d had two years previous. In addition, the potential for conflicts of interest inherent in the dual roles of physician and researcher make it very difficult for clinical bioethicists to discern the motivations of physicians who propose particular treatment options for their patients. The uncertainty of the moral ground of claims made by physicians-researchers further problematizes the adjudication of ethical dilemmas within the hospital setting.

VII. Health Insurance

The health insurance system is another apparatus that structures the practices of clinical bioethics. Although the US is typically categorized as a “two-tier” health insurance system, in teaching hospitals like RH there are often four tiers of patients, grouped according to the source of payment for health care. These four tiers are listed below in order from the most desirable to the least desirable, in terms of their economic benefit to the hospital.
Cash Cows

The cash cow is a category that includes a broad range of patients: VIPs (such as celebrities or foreign royalty); wealthy citizens who are able to pay for treatment out-of-pocket; and middle-class non-citizens whose governments pay the hospital for treatments unavailable in their home countries. What they all have in common is the capital they generate for the hospital because they pay the “retail” price for treatment rather than the discounted fees third-party payers (such as insurance companies) often negotiate for their patients. At one meeting I attended as a fellow, a Vice-President of RH indicated that he hoped in the next five years to increase international patients (who comprise a substantial proportion of cash cows) to ten percent of the hospital’s total patient population. (At the same meeting it was projected that uninsured patients would drop to five percent of RH’s patient population.)

Cash cows represent a source of revenue for the hospital, but as such they may also be vulnerable to exploitation, as illustrated in this story from my fieldnotes:

Following up on the case of Mr. Y today, I went down to the rehabilitation floor. I ran into Lani, the case manager, who was talking to Dr. A. ‘I told you that by the time I came back from vacation today I wanted Mr. Y [a poor patient with no insurance] and Mr. X [a wealthy Eastern European businessman paying cash for his treatment] discharged. What happened?’ ‘Well [replied Dr. A], we couldn’t find anywhere to place Mr. Y outside the hospital. So we kept Mr. X in hospital as well, to subsidize the care of Mr. Y.’ (Dr. B laughed. Lani scowled.)

While cash cows are not customarily used to subsidize the care of indigent patients so directly, the desirability of these patients, and the lengths to which
hospitals will go to recruit them can hardly be overstated. In order to attract cash cows, RH, like many hospitals in the community, designed a floor called pejoratively by the ethics committee “the VIP floor.” This wing of the hospital was renovated to look more like a hotel than a hospital. The patient rooms were converted into suites with elegant furniture and decorative touches. Amenities included 24-hour valet and room service. When I toured the VIP floor, I literally tripped on its threshold as the flooring changed from industrial tile to hardwood. A room on the VIP floor costs roughly twice that of a regular patient room. Its patient population is comprised primarily of wealthy American and international patients.22

After September 11, 2001, the international patient census at RH sharply decreased. This was due in part to fear of further attacks in the United States, and in part to the difficulty patients from the Middle East had procuring visitor visas. This situation was considered so dire for the economic health of the hospital that any endeavor, however well-intentioned, that might discourage international patients from seeking treatment at RH died on the table. For example, after several ethics consultations involving international patients who were not informed of their diagnoses and prognosis, ethics committee members

22 The opening of the VIP floor provoked a furor among ethics committee members. Senior members familiar with the institution’s original mission to treat all state residents, regardless of their ability to pay, were particularly incensed. They feared that VIP patients could buy better care than ordinary patients, creating a two-tier system in the hospital. More circumspect members argued the opposite: it was unethical to create such a floor as VIP patients would undoubtedly get poorer medical treatment because it was a general medical floor, housing patients with a wide range of diseases. Regular patients were thought to get safer and better treatment because they were housed in dedicated wards, under the care of specialists and nurses familiar with their particular diseases.
met with the director of the hospital’s international patient office to address the issue. The ethics committee recommended that the literature sent to potential international patients state explicitly that it is customary in American hospitals to inform patients of their diagnoses and prognoses, and to involve patients in medical decision-making. The director of the center refused to comply, stating that she was having enough trouble recruiting patients as it was; she didn’t want to risk scaring off patients who may not agree with this custom.

Private Insurance Patients

These patients procure health insurance through their employers or independently. Hospitals can generally negotiate profitable rates with insurance companies. However, experimental treatments are often not covered by insurance. Sometimes an insurance company can be coaxed into paying for all or part of a new or experimental therapy. If not, the cost may be paid for by the patient or absorbed by the hospital. Private insurance policies often carry large deductibles or they limit the amount the company will pay for the treatment of a particular illness in a policy year. As a fellow I observed the case of one patient who languished in the intensive care unit of RH for over six months. His insurance capped out but hoping for a miraculous recovery, his wife sold their family business and their house in order to pay for his continued treatment. By the time the patient died his wife was left homeless, without a source of income, and totally dependent on their children [fieldnotes].

Public Insurance Patients
Public insurance through federal programs is available to the very poor (in the form of Medicaid) and the elderly (in the form of Medicare). While I was unable to procure exact figures for the reimbursement rates of Medicaid/Medicare, many physicians at RH complained that these agencies paid for only a fraction of the real cost of treatment. These agencies are also loath to provide reimbursement for experimental treatments, and there is often a delay between when a new treatment is proven effective, and when these agencies approve reimbursement for it. At an ethics committee meeting during my fellowship, the chair of the committee cited lost revenue from the low compensation rates of these federal agencies as among the most urgent ethical problems facing the hospital.

**Uninsured Patients**

In 2003, the medically uninsured or medically “indigent” population in the US soared to over 40 million, with perhaps tens of millions more underinsured. The uninsured span an increasing range of classes and social stations; from the homeless, to the working poor, to the middle-class unemployed, to the underemployed, to students, and all others not poor enough or old enough to qualify for Medicaid or Medicare, but not wealthy enough to purchase their own insurance. Many new and illegal immigrants are uninsured, as they are often ineligible for the federal insurance programs.

While the original charter of Research Hospital committed the institution to the moral mission of providing treatment to state residents without regard for their
ability to pay, the proportion of indigent patients at RH visibly diminished throughout the late 1990s. This drop was due in part to partnerships RH established with county (public) hospitals. These partnerships enabled RH physicians to treat indigent patients in county facilities.\(^{23}\) RH absorbed most of the cost of treating uninsured patients, though this cost was somewhat mitigated through state grants. While I heard of many cases of patients being refused care (aside from emergency treatment) because of their inability to pay, indigent patients did sometimes gain access to treatment at RH hospital if they qualified for a research protocol, or presented with a particularly intriguing medical problem. For example, one patient arrived at the emergency center of RH with just five dollars in his pocket. He had traveled from West Africa to RH because he wanted “American doctors” to treat the large tumor growing on his abdomen. His surgeon described this tumor as the largest he’d ever seen, “roughly the size of a turkey platter.” This patient’s treatment was approved by the hospital administration under an informal program that allows for the treatment of four or five particularly “interesting” indigent patients each year. Thus, indigent patients were perhaps most likely to get treatment if the physicians at RH felt that the patient provided an opportunity to gain knowledge and experience.

Canada, by contrast, has a single-tier health insurance system known in common parlance as “Medicare.” The core values of the Canadian health care

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\(^{23}\) The stated goal of this endeavor was to enable public hospital patients to benefit from the expertise of RH physicians, and for these physicians to mentor their colleagues at the county hospitals. However, members of the ethics committee believed that patients receiving treatment at the public hospitals would not receive equal care because many of RH’s services and specialties were unavailable at the cash-strapped county hospitals.
system are contained in the guiding principles of the Canada Health Act. Health
care is paid for through general tax revenues that are then transferred to the
provinces and territories that are responsible for administering health care to their
residents. To obtain the full federal contribution to health care funding, provincial
and territorial health care plans must provide coverage that is universal,
comprehensive, accessible, portable, and publicly administered (Baylis, Downie
et al. 1995: 73). New immigrants are generally covered by Medicare, although
visitors to Canada and undocumented workers are not24. Medicare does not
cover the costs of drugs, though Canadians pay less for drugs than do
Americans because the federal government negotiates with pharmaceutical
companies for lower prices. Nevertheless, the high cost of medications is of
serious public concern, and this presents a barrier to effective treatment for
Canadians who cannot afford supplementary insurance. The Medicare system is
structured similar to that of most HMOs in the US. Access to specialists is
generally procured only through one’s family physician. Canadians perpetually
complain of long waits to see specialists and to have elective surgeries such as
joint replacements. However, most Canadians still prefer the single-tier system
as it provides basic health care to all residents, and it affords patients greater

24 I asked one Canadian bioethicist what happens if a visitor or undocumented worker needs
medical treatment that they cannot pay for. She said she’d seen this exact case just a few weeks
before. A physician called to tell her that he had a patient who had come to Canada to visit
relatives and fallen ill. This patient had no insurance. The physician was being pressured by the
hospital administration to withhold treatment. The bioethicist told the physician: “This person is
your patient and you have a duty to treat that patient like any other patient.” The physician
thanked the bioethicist for affirming what she felt was morally right and continued the patient’s
treatment [fieldnotes]. I cannot verify how common this scenario is, or how frequently Canadian
hospitals continue treatment for uninsured patients.
autonomy over the selection of their care providers.

I was surprised to find that the ethics committees and clinical bioethicists I interviewed in Canada consistently named “resource allocation” as the most important ethical issue facing their hospitals. This was in sharp contrast to the American bioethicists I studied, who generally named end-of-life issues as their most pressing and frequent ethical dilemmas. I had anticipated that the American bioethicists would be much more concerned with resource allocation, given that the US health insurance system is so fragmented, and the medically indigent and underinsured comprise such a large portion of the population. I hypothesize that the sensitivity of Canadian bioethicists to resource allocation is due to the fact that in Canada health care is overtly rationed, while in America it is tacitly rationed. In addition, Canadian bioethicists are personally invested in the public health care system as they interact with it in their daily work and benefit from it as patients. Most American bioethicists, on the other hand, are wealthy enough to have access to private health insurance and thus have limited personal experience with the challenges of being medically indigent.

In both countries, the apparatus of the health insurance system is a frequent undercurrent in the ethical dilemmas clinical bioethicists encounter. And as Nadine’s narrative demonstrates, the limitations and inequities of the system often limit the range of options available to resolve these dilemmas. Particularly in America, clinical bioethicists are routinely frustrated by the unfairness of the four-tiered health insurance system that denies adequate treatment to those who
often need it most. This was illustrated by one of my interviewees when he responded to my question, “What aspects of your work do you enjoy the least?”:

I became frustrated, like everyone else, when problems became insoluble. One of the unfortunate aspects, is the labeling of situations that were really not ethical problems, so much as they were systemic problems. I see an ethics problem as a messy problem that no one else knows what to do about. You know, often you would be the last resort; they had already called everyone else to try to solve it. So by the time it comes to you, it’s already insoluble. One example is the Russian sailor who dove off a ship trying to seek asylum in the U.S. He was shot by the police, and had brain damage. He had absolutely no status in this healthcare system or under the law, but he ended up staying in [my] hospital for six months. The Russian consulate wanted to take him back, only to prosecute him. He couldn’t speak English and was probably permanently disabled. Or there is the more typical example of the migrant worker who needs dialysis [but who is medically indigent]. That’s a horrible problem, but it is a ... statewide problem. Often when I realized that was the situation, I would have to tell people, “I really don’t think I can help you much, except to let you know that you aren’t alone, and to help you in your role. This is not an issue of ethics, it is an awful social problem to which there is no easy solution, but I’m happy to talk about less awful alternatives with you.” [transcript]

Clinical bioethicists are employed to manage and enlighten the micro-ethics of clinical research and patient care within individual medical institutions. Because hospitals of 10,000 or more employees often employ a single ethicist, their daily responsibilities often leave little time or energy to engage in political action to address the macro-ethics of federal or state health care policies. It is perhaps human nature to focus one’s efforts on ameliorating one’s immediate environment and community, rather than laboring for the benefit of the abstract citizenry. But the health insurance system itself provides a rationale for clinical bioethicists to remain focused on micro-ethics. Clinical bioethicists do not generally bill third-party payers for their services and they generate no revenue
for their institutions (though some speculate that a clinical bioethics service may reduce the frequency of litigation against a hospital). In Canada, clinical bioethics services are usually paid for through an administrative decision to allocate a portion of the finite funds given to the hospital by its provincial health authority. In America, however, cash cows and privately-insured patients indirectly pay for clinical bioethics services through the profits they generate for the hospital. Thus, lobbying for equitable and rational healthcare resource allocation may well run counter to the personal interests of American clinical bioethicists.

VIII. Patient Safety and Patient Rights

"In effect: one more aspect of modern life has become contractual, prescribed and uniform. One more encounter of a primary sort now tends to be disinterested, neutral, and remote" (Rothman 1991: 261). This is how David Rothman describes the contemporary physician-patient relationship. What was in the first half of the twentieth century a relationship based on neighborhood, ethnic identity and personal rapport, became at the close of the twentieth century a relationship based on consumption. Doctors are now "health care providers" and patients are now "clients." This shift occurred not merely due to the structural changes that caused the practice of medicine to be physically less proximate and more distal, as outlined above. The consumer model of medicine also grew from a social and historical phenomenon Rothman characterizes as "bringing rules to medicine."
Medicine has traditionally relied on the heuristic of the case study. Even in the face of evidence-based medicine, the clinical anecdote or the miracle case remains an important epistemological and rhetorical resource for physicians struggling to decide on a course of treatment for a patient presenting with a unique set of symptoms and circumstances. As Rothman observes: “It is as though their ability to resolve the incident at hand absolves them of the need to formulate or respect general principles” (7). However, medicine has become increasingly subject to rules from a variety of quarters and toward a variety of ends. These rules are usually pressed upon medicine by “outsiders” (non-physicians). Physicians often initially refute these rules, then begrudgingly accept them, then defensive wield them. In both Canada and the US, contemporary hospital care and its attending ethical dilemmas are not only structured by the organization of biomedicine, clinical research and the health insurance system, but also by these rules, loosely captured by the umbrella term “the patient rights movement.” This movement and its rules are manifest in hospitals through four apparatuses: (1) civil litigation; (2) legislation; (3) hospital accreditation; and (4) hospital policies.

Civil Litigation

Previous to the 1970s, the courts interfaced with medicine primarily through malpractice litigation. This entailed determining whether negligence or malfeasance had contributed to the injury or death of a patient. However, the courts became proactive in the 1970s (Rothman 1991: 232), laying the
groundwork for the legislation and hospital policies that would come to shape the practices and discourses of clinical bioethics. Many scholars identify the Quinlan case of 1976 as the turning point. In 1975 Karen Ann Quinlan, aged twenty-two, fell into a coma, the etiology of which was never explained, and from which she never recovered. After several months, recognizing that she would not recover, her parents asked her physicians to remove her respirator and allow her to die. Her physicians refused and the case eventually went to the New Jersey Supreme Court. Rothman argues that while there were many ethical, theological and legal issues at play in the case, the fundamental conflict came down to the question, “Who rules at the bedside, physicians or patients and their legal advocates?” The Quinlans’ argument relied heavily on the constitutional right to privacy, and by extension, the right for patients to determine their own medical care.

The court rejected the distinction made by the hospital’s physician between withholding treatment and withdrawing treatment from hopelessly ill patients (the former he argued was morally sanctioned, the latter was not.) The court felt it was fear of civil or criminal legal action that prevented Quinlan’s physician from discontinuing treatment, and took up the challenge of finding “a way to free physicians, in their pursuit of their healing vocation, from possible contamination by self-interest or self-protection” (quoted in Rothman 1991: 227). The court appropriated Karen Teel’s recently published recommendation that hospitals form “ethics committees” (Teel 1975). (The court, however, viewed the ethics committee as a forum to determine the prognosis of patients, rather than
weigh the ethical issues of a case.) Such a committee would allow physicians to share this grave responsibility, and to free themselves from worries about litigation. It would also free judges from having to review decisions to terminate treatment.²⁵ In other words, the goals of these committees were to protect physicians both from the temptation to use their expertise capriciously and from their own fear of being sued.²⁶ Only by liberating physicians from their conflicts of interest could patients be ensured the right to privacy and to full participation in their own treatment decisions. Given that the New Jersey Supreme Court expanded its traditional range of activities by taking up a case proactively and refuting the physician's opinion, it is ironic that they argued this innovation would make physicians less worried about litigation.²⁷

Physicians rarely cite fear of litigation as the primary motivation for calling a clinical bioethicist, although in many cases it is undoubtedly an undercurrent. Their belief that an ethics consult will protect them from malpractice is erroneous as the decisions of ethics consultations are not legally binding, and a few ethics

²⁵ "The committee was a symbolic representation of the hope that decisions could be made that were not arbitrary and that were ethical" (Rothman 151).
²⁶ As Zussman and others have found, physicians often over-estimate the risk of lawsuit, though the reasons for their near-pathological fear of lawsuit remain unclear. From my observation, it arises from a mixture of anxiety at the prospect of having their practices exposed to their colleagues and to public scrutiny, recognition of their own fallibility, and the considerable time litigation takes away from their research and clinical endeavors.
²⁷ In clinical bioethics, landmark cases such as Roe v. Wade and Quinlan are often used to illustrate the swing from medical paternalism to patient autonomy in clinical decision-making in the latter 20th century. Other landmark cases emphasizing social justice, including those of the civil rights movement, are rarely quoted in the bioethics literature. This may be, as Rothman argues, because autonomy appeals to everyone—the haves, and the have-nots—because everyone is a potential patient. Of course, as many of the ethics consultations I observed illustrated, the haves of society are much better able to wield their autonomy as patients because of the wider range of choices available to them.
committees and clinical bioethicists have been named in suits. However, having a note in the patient’s chart from an “ethicist” supporting a physician’s controversial treatment decision might enable the physician to “share” some of the responsibility in case of a suit. And a clinical bioethicist could make a compelling witness on the physician’s behalf, should the case go to court.

**Legislation**

During my fellowship, the Clinical Bioethics Service participated in monthly orientation sessions for new nurses at Research Hospital. In our one-hour presentation, either Lydia or I would introduce the nurses to our services and outline the ethics consultation process. The bulk of the hour, however, was spent educating the nurses about out-of-hospital and in-hospital DNR orders and advance directives, and discussing two cases about surrogate decision-making for medically incompetent patients. Toward the end of my fellowship, Lydia became concerned about the conflation of legal and ethical perspectives this session might create in the minds of nurses, and reorganized the session so that she co-presented the material with a hospital lawyer. While some clinical bioethicists have legal training, most do not, and even those who do take pains to distinguish their role from that of hospital counsel. Clinical bioethicists often state that the law and ethics are not necessarily in accord, and that at times it may be ethically necessary to contravene the law. However, I’ve never seen a clinical bioethicist recommend this course of action. On the contrary, many informal ethics consultations are “resolved” when the clinical bioethicist explains to the
caller the current legislation relevant to the case.

The law most often invoked in ethics consultations at RH was known colloquially as the “advance directive act.” This state law governs: (1) the designation of surrogate decision-makers for medically incompetent patients; (2) the legal requirements for valid advance directives (living will, medical power-of-attorney or out-of-hospital DNR order); and (3) a la Quinlan, defines a process for resolving disagreements between physicians and patients/families regarding the provision of life-sustaining treatments. Though as a fellow I took pains to explain to callers that they should talk to the legal office if they had a concern about risk management, often the issue could be settled by answering some basic questions with reference to this legislation: Who is legally in a position to make decisions for this patient? Is the patient’s living will properly executed? Does the patient meet the requirements for the living will to take effect (is the patient terminally or irreversibly ill and medically incompetent)? The clinical bioethicists’ rudimentary understanding of the law is often sufficient to quell the need for more involved discussion.

Hospital Policies

In addition to appealing to state legislation or case law in their deliberations about particular cases, clinical bioethicists also frequently reference hospital policies. Some policies are directly modeled on state or federal legislation. This was the case for RH’s “Advance Directives” and “Determination of Medically Inappropriate Interventions” (abbreviated to “futility”) policies.
However, because legislation is usually short on details about how its general guidelines should be enacted, hospitals must create their own policies and procedures to specify how legal requirements should be met in the context of a particular institution. Most hospital policies, however, do not reference particular laws or statues, but instead are intended to direct the daily activities of the staff, and to regulate their comportment and practices.

A clinical bioethicist can usually identify which particular policy or policies are relevant to any specific case. For example, at RH, if a family demanded resuscitation for a hopelessly ill patient and the physician argued that this was not in the patient’s best interests, Lydia often referenced the hospital’s DNR policy (which happened to state that DNR is a medical order and does not require the consent of patients or their surrogates, although they must be informed when a DNR order is written). Other policies frequently cited by the clinical bioethicists at RH included: the Minor Donor policy (for children donating organs or tissues to sick relatives); the Withdrawal or Withholding of Treatment policy (regulating how dying patients were removed from life-sustaining treatments); the Refusal of Blood and Blood Products policy (crafted for Jehovah’s Witness patients); the Staff Request policy (detailing the rights of professionals to refuse to provide treatments they find morally compromising, such as abortions); and the Informed Consent policy.

Most of these policies enshrined either the patient’s right to self-determination or the rights of physicians to limit treatment based on their medical
judgment. In Rothman's terms, most of these policies stipulated who was in charge at the bedside—the patient/family or the physician—and what the limitations on their authority might be in a given situation. While hospital policies are not as compelling as laws in that the repercussions for not following them are not as severe, clinical bioethicists do wield hospital policies to great rhetorical effect in ethics consultations. Policies may even be cited in the recommendations clinical bioethicists place in the patient's chart in order to bolster their suggestions for resolving a particular dilemma.

Clinical bioethicists not only utilize hospital policies in their daily practice, they are customarily involved in the authorship of policies. During my fellowship, policy review was initiated for three reasons: (1) by the institution's routine review process that required policies to be updated every three years; (2) by new legislative initiatives or accreditation requirements; (3) by ethics consultations that highlighted particular gaps or inconsistencies in the hospital's policies. When policies were referred to the ethics committee for review, a subcommittee of volunteers was generally created. Subcommittee members had a great deal of influence on the shape of the policy, and the fundamental principles it articulated. For example, after witnessing an ethics consultation during which a decision was made by the physicians (backed by the ethics committee) to withdraw treatment from a patient in a persistent vegetative state, I felt the relevant policy should be revised to ensure that the process encouraged more participation from patients and families. I undertook the revision of this policy and successfully advocated
for what I felt was a more inclusive procedure.

However, in addition to being relatively idiosyncratic, I saw the policy review process flounder when a policy attempted to address broader structural issues that had no foundation in case law or legislation. RH’s ethics committee undertook to revise the hospital’s resource allocation policy. After months of debate and research into how patient care was actually paid for, the original policy underwent only minor revision. It essentially rested on the principle of medical utilitarianism: the hospital’s resources should be allocated to those who can most benefit from them. This principle was intended to discourage physicians from expending resources on “hopeless cases.” The policy did not, and probably could not, grapple with the question of RH’s moral obligation to treat the thousands of uninsured people in the community, and how to balance this obligation with the institution’s commitment to clinical research. While hospital policies are often useful for resolving ethical dilemmas at the individual level, they are not well adapted to tackling the structural roots of these dilemmas. The last formal ethics consultation I performed as a fellow (which I describe in detail in Chapter 5) involved the question of whether the hospital should provide treatment to a medically indigent patient. At no point in the consultation process—which spanned two weeks—did I reference this Resource Allocation policy. Its model of medical utilitarianism was simply inadequate to the structural complexities of the case.

Hospital Accreditation
In the early 1970s, the National Welfare Rights Organization (NWRO) attempted to inject a rights model into hospital practices through the policies of the Joint Commission on the Accreditation of Hospitals (later the Joint Commission on the Accreditation of Healthcare Organizations, called "Jayco") and the American Hospital Association. The NWRO was dedicated to instilling the concept of entitlement into relief and welfare policies, such that "no person should be denied impartial access to treatment...on the basis of...race, color, creed, national origin, or the nature of the source of payment." (JCAH, 1970, quoted in Rothman 145). The JCAH adopted many NWRO proposals in its preamble, however, it primarily emphasized the right of patients to receive adequate information concerning their medial problems, treatment options and prognoses.\textsuperscript{28} The principles of informed consent and privacy became the cornerstones of the AHA's Patient Bill of Rights,\textsuperscript{29} though the AHA strategically dropped those NWRO's proposals that argued for access to health care as a human right. Thus, the patient rights movement, which grew from the broader movement for social justice and civil rights in the mid-twentieth century, came to reiterate the status quo regarding obvious inequities in the American health care

\textsuperscript{28} Rothman reports one physician's assessment of informed consent from the 1970s: "It is no longer enough that we let the terminal patient know that his prognosis is grave; he must know that it is utterly hopeless, and he must completely agree with us. If we allow him a slim thread of hope, if he persists in his natural denial of death, he must spend his last moments with someone pounding on his chest 60 times a minute" (151?).

\textsuperscript{29} As Daniel Chambliss observes, the Patient's Bill of Rights posted in hospital cafeterias and elevators all over the nation carry with them "the faint odor of guilt" as if to say "we will never do these things which we didn't really do in the first place" (Chambliss 145). However, they also give the impression that these rights are merely a gesture of good will, that they can be revoked at any time. By underscoring patient's inherent vulnerability to exploitation and to breaches of their privacy, these documents may not in fact embolden patients, but only heighten their sense of powerlessness.
system.

The JCAHO currently accredits hospitals to receive federal funding. The organization sends a team of auditors to hospitals every three years to observe its practices, with a particular emphasis on patient safety and quality of care. In 1992 the JCAHO revised its regulations to mandate that every health care organization provide a mechanism for resolving ethical issues in patient care. An ethics committee or clinical bioethicist often helps the hospital to fulfill this requirement for accreditation (1992).

The JCAHO has also mandated procedures to ensure patient safety, such as no-fault reporting structures to document and analyze medical errors, which claims the lives of 44,000 to 98,000 Americans each year—three times the number of people who die in car accidents (Kohn, Corrigan et al. 1999; Baker, Norton et al. 2004). However, it remains an open question whether these regulations actually curb medical paternalism and prevent medical errors. Ann Cook and Helena Hoas, in their qualitative case studies of medical error with rural health care practitioners, have found that most hospital employees only recognize mistakes made by nurses. Mistakes made my physicians are not categorized as errors but as “differential diagnosis,” or the legitimate exercise of professional judgment by doctors (Cook and Hoas 2003).

In addition, in order for a “sentinel event” to be considered a mistake, it must be categorized as a “system error” under the no-fault reporting structure recommended by the JCAHO. As a fellow I was consulted about a case that I felt
involved a clear mistake: the physician had violated the expressed wishes of a terminally-ill patient to avoid aggressive treatment by keeping the patient "full-code," meaning that the patient would be given CPR and transferred to the ICU if he suffered a cardiac arrest. I met with a representative of the office that investigates medical errors and outlined the case. I was told that because the case involved a decision made by a single physician—rather than a structural problem—that office would not perform a root-cause analysis on the case. Although physicians and their decisions are integral to the structure of hospital treatment, their authority within the organization of medicine, and the latitude given to them as privileged professionals, makes it difficult to categorize their actions as errors.

The multiple apparatuses of the patient rights movement inform the assemblage of clinical bioethics in various ways. Many hospitals began hiring clinical bioethicists and organizing Institutional Ethics Committees after the JCAHO made a mechanism for resolving ethical conflicts in the clinical setting mandatory for hospital accreditation. Thus, the JCAHO regulations may provide justification for institutional investment in clinical bioethics services, as accreditation is essential to the fiscal well-being (and reputation) of the hospital.

While the employment of clinical bioethicists may be staked (directly or indirectly) on hospital accreditation regulations, litigation paranoia may bring in business for clinical bioethicists, as evidenced by one interviewee who reported: "More than once I was told [by a physician], 'I want to cover my ass from
malpractice, I don’t care much about ethics, just tell me if I’m doing something egregiously wrong.’ And I’d say, ‘Well, I’m not a lawyer, but okay; I’ll let you know if you’ve done something egregious.’”

At the same time, however, case law and federal or state legislation may significantly curtail opportunities for ethical reflection and analysis. As stated above, many ethical dilemmas “disappear” when the legal aspects of the case are clarified. Because of the time pressures of academic medicine—and a general perception that laws are absolute, unalterable and usually ethical—most people calling for an ethics consultation have little patience for academic discussions about the ethical grounds of a particular legal decision or law, or how this specific case might challenge the law. And as Nadine’s observation of the tissue banking policy meeting illustrates, case law can be utilized selectively and strategically to further the aims of the institution, even if the decision itself is ethically suspect.

Hospital policies are authored by, and directed at, hospital staff. At RH, patients did not have access to hospital policies. In fact, the Clinical Bioethics Service had links to several ethics-related hospital policies on its public website, but a hospital lawyer advised Lydia to disable this portion of the website, citing a desire to limit public access to institutional policies. Like laws, hospital policies often function as a means to delimit the range of acceptable options in any given clinical situation; unlike laws, hospital employees and clinical bioethicists have a direct hand in their creation. However, hospital policies are created exclusively by
institutional insiders; aside from the occasional IEC community member, lay persons and patients were never represented on the policy taskforces I observed. Thus, the people with the most at stake—the patients whose care would be governed by these policies—were not given a voice in their formation. For example, a Jehovah’s Witness was never invited to advise the taskforce reviewing RH’s policy on blood transfusion, even though this policy was primarily directed at this constituency. In addition, these taskforces tended to be populated largely by administrators, lawyers and physicians, with minimal representation of bedside nurses or other health care professionals. Thus, the hospital policies generally upheld the interests of the institution and its physicians. As a result, many of RH’s policies had the effect of mitigating patients’ rights in order to preserve the power and professional autonomy of physicians. An example of this is RH’s DNR policy that stipulates that physicians do not need to obtain consent from patients/surrogates in order to make a patient DNR.

While clinical bioethicists often have a hand in authoring institutional policies, and thus have more moral agency than most hospital staff, they are one lone voice in group that is generally preoccupied with preserving the professional autonomy of physicians and the institutional integrity of the hospital. Again, the social context of the work of clinical bioethicists—their personal identification with their hospital and their dependence on the good graces of their colleague—significantly curtails their ability to address neglected moral issues.
IX. The (Emergent) Professional Norms of Clinical Bioethics

These norms and their structural inflection of the work of clinical bioethicists are analyzed in depth in the following chapter.

Conclusion

My project has two primary goals: to present a phenomenology of clinical bioethics as labor, and a phenomenology of moral agency within institutional settings. Paul Rabinow's notion of cultural "assemblages" (a heterogeneous and unstable web of symbols, discourses and institutions constituting a novel social form) is a useful tool for depicting clinical bioethics as an emergent profession. The tropes conventionally utilized to describe clinical bioethicists highlight their unique professional agency as institutional critiques and moral arbiters. It might even be said that clinical bioethicists are purported to embody the ethical principle of autonomy they so frequently cite in their ethics consultations and educational seminars with health care professionals. The above analysis of the apparatuses that structure the assemblage of clinical bioethics—namely, the biomedical enterprise and the organization of medicine; clinical research; the health insurance system; the patient rights and patient safety movement; and academic bioethics—queries this depiction of clinical bioethicists as the paradigmatic moral agent within their institutions. However, this examination of the multitudinous ways in which the autonomy or agency of the clinical bioethicist is curtailed (spatially, temporally, socially and politically) brings to mind another
trophe to describe the position of the clinical bioethicist within her hospital: that of the oracle.

This trope was offered to me by a health care professional I worked with as a fellow. When we first met each other at the hospital, he was totally unfamiliar with clinical bioethics and asked me: “So what are you, some kind of ethical oracle?” At the time I laughed off his suggestion and instead offered him a more conventional trope, such as conflict mediator. But the image has stuck with me, all these years later, and the more I have reflected on my fellowship and my observation of other clinical bioethicists, the more it rings true.

An oracle is blessed with the gift of insight. She has access to knowledge that social convention strives to keep hidden. She may even be able to predict the future based on what she sees (and what she’s seen before). However, while oracles see all, they are generally powerless to affect or alter the events they observe unfolding in their crystal balls or their scattered bones. Similarly, the social mobility of clinical bioethicists enables them to know and see the inner workings of their hospitals. They are often perceptive observers of institutional behavior and the power dynamics of medicine. However, the apparatuses they rely on to support and inform their professional practice often prevents them from being able to do what they believe to be right, both as moral agents, and as “experts” in the ethics of clinical medicine and research.